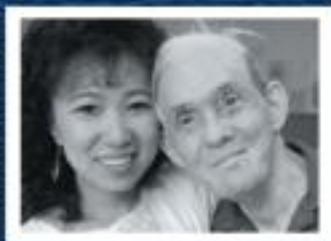


Building Capacity and Coordinating Support for Family Caregivers and the Direct Service Workforce

White Paper



**Common Goals and Policy Recommendations Emerging
from the CMS Leadership Summit on the Direct Service
Workforce and Family Caregivers**

Held in Washington, DC—September 16 & 17, 2010

*Report prepared by the National Direct Service Workforce Resource
Center*

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Executive Summary

*“Caregivers can provide better care when their own needs are met.”
– Summit Participant*

In the world of long-term services and supports policies and programs, caregiving tends to be thought of as a dichotomy of family care vs. paid careⁱ, with little coordination across programs and public policies affecting family caregivers and professional (paid) caregivers. However, both family caregivers and paid caregivers are vital to ensuring access to quality services and supports for people of all ages with disability/illness, and both groups experience similar rewards as well as challenges.

To explore potential options and benefits of a more coordinated approach, the Centers for Medicare and Medicaid Services (CMS) convened the Leadership Summit on *Building Capacity and Coordinating Support for Family Caregivers and the Direct Service Workforce* in September 2010. The event brought together leaders in the field of caregiving to identify areas of policy intersections and develop recommendations for action for working together to address cross-cutting issues. Invited participants included national leaders in the fields of family caregiving, direct service workforce development, policy makers, consumers of long-term services and supports, caregivers, workers, and advocates. A focus group/think tank model was used to help participants make connections, find commonalities and differences, and establish a set of agreed upon goals. This white paper presents the common goals and policy recommendations emerging from the Summit discussions.

From these discussions, consensus emerged that a high degree of commonality exists across caregivers in terms of their contribution to and significance in the lives of people with disabilities and their needs. Furthermore, discussions showed that the needs and interests of caregivers cannot fully be separated from the needs and interests of the people they support. To the extent that public policies support the interests of people with disabilities, caregivers benefit, and to the extent that caregivers are supported, people with disabilities benefit.

The leaders in attendance at the Summit ultimately articulated 12 common goals, each with specific policy recommendations. These are presented here in two general categories: 1) common goals for broad systems change that would improve the entire system of long-term services and supports, and thus benefit family caregivers and the direct service workforce, and 2) common goals that are more specific to family caregiver and workforce policy. Across these areas, diverse participants agreed that taking more coordinated action in these areas would improve conditions for all caregivers and people with disabilities.

ⁱ In this paper, the terms “paid caregiver,” “direct service worker,” and “direct support worker” are used interchangeably. When the term “paid caregiver” is used, “care” is meant to encompass more than medical care and protection of safety, but also support services to promote full integration in the community.

Twelve Common Goals	
Broad Systems Change	Specific Goals for Family Caregivers and Direct Service Workforce
1. Improve Coordination and Collaboration	7. Improve Recruitment, Selection, and Retention
2. Improve Long-Term Services and Supports Navigation and Access	8. Increase Economic Security of Paid and Family Caregivers and People with Disabilities
3. Promote Community Living, Inclusion, Employment, and Quality of Life for People with Disabilities	9. Raise Awareness of the Importance of Home and Community Based Direct Service Workers and Family Caregivers
4. Strengthen Public and Private Financing for Long-Term Services and Supports	10. Integrate Caregivers in Team-Based Approaches
5. Expand Participant Direction	11. Expand Peer Support
6. Focus on Quality of Care and Protection from Abuse / Neglect in Home and Community Based Settings	12. Invest in Training for Paid and Family Caregivers and for Consumers as Employers

More time was devoted to training than other topics at the Summit (see [Appendix B](#), Agenda). From these discussions, the group identified recommendations for meeting the training needs of paid and family caregivers. Participants noted that training opportunities for family caregivers should be expanded, recognizing that family caregiver training should be: flexible, optional, accessible, “just in time”, self-paced, and customized to meet the needs of individual caregivers and individuals receiving supports. Meanwhile, participants generally agreed that training and credential requirements for paid caregivers supporting people of all ages and types of disabilities should be expanded beyond current minimum standards in most public programs to reflect the basic skills needed to provide high quality services; these should include skills beyond basic health and safety, such as communication, advocacy, and problem solving. Summit participants also discussed the importance of expanding training opportunities for individuals who are directing their own services.

Summit participants identified five immediate next steps for participants to take together to follow-up on the discussions, including the need to continue working together to identify and advocate for common goals, share information across sectors, and reach agreement on core competencies.

- 1. Continue/expand stakeholder discussions to share information and build consensus** on priorities issues for raising awareness and seeking systems change. Emerging from all group discussions was a common recommendation that this discussion needs to be continued and expanded to include additional stakeholders.
- 2. Reach out to CMS Center for Innovation and other Patient Protection and Affordable Care Act (ACA) implementation workgroups**, to recommend that the challenges and

needs of direct service workers and family caregivers be considered in ACA demonstration projects. Specific suggestions for the Center for Innovation to consider as they develop future demonstration programs and consider innovative models included:

- ▶ Seek out and promote innovations in delivery of caregiver support services
- ▶ Promote innovative team-based approaches that include individuals and family members as equal partners on care teams, such as a hospice type model
- ▶ Pilot new approaches to reimbursement for teams-based approaches
- ▶ Consider new approaches to fund ongoing competency-based training, and ensure that increased wages are associated with greater levels of competence

3. Support ongoing compilation and dissemination of information on the caregiving workforce and broader home- and community-based services (HCBS) issues.

Specifically, participants discussed the need for: 1) best practices/effective models across populations and across caregiver types (paid, unpaid, agency, participant directed), 2) information about what state and federal agencies and other stakeholders are currently doing, and 3) research on outcomes and cost impacts of interventions, to help make the case for investing in caregivers and HCBS.

4. Develop a roadmap, or crosswalk to describe and compare currently available competencies and clarify the core competency domains for caregivers, building on the Direct Service Workforce Resource Center analysis, and other work by the Department of Labor (DOL), the Health Resources and Services Administration (HRSA), and CMS.

5. Convene stakeholders across populations to reach consensus on a common set of core competencies, and additional competencies beyond the core set depending on the needs of the person they support and types of services they provide, to guide the development of training materials for paid and family caregivers. To guide the development of training materials, participants agreed on the approach of identifying a common set of competencies that all community-based caregivers (paid and unpaid) need (e.g., how to support people to live independently in the community, how to advocate, and how to help people achieve personal goals). Participants also agreed on the need to identify additional competencies workers may need beyond the core set, depending on the needs of the person or people they support and the types of services they provide.

I. Purpose of Summit—Why Coordination Matters

In the world of long-term services and supports policies and programs, caregiving tends to be thought of as a dichotomy of family care vs. paid care,¹ with little coordination across programs and public policies affecting family caregivers and professional caregivers (i.e., those caregiving as an occupation). Although they play somewhat different roles in the lives of the people they serve, informal (unpaid family members and friends) and formal (paid) caregivers provide similar types of supports and people with disabilities often receive services from both types of caregivers simultaneously. Both groups are vital to ensuring access to quality services and supports for people of all ages with disability/illness, and both groups experience similar rewards as well as challenges.

Many professional caregivers entered the field because of a personal desire to help people with disabilities and have altruistic motivations for doing this work. Stories abound of direct service workers who develop close relationships with the people they support and who voluntarily provide additional help beyond their paid work to ensure that needed services are provided. However, these workers are also pursuing a career path and trying to earn a living. Similarly, family caregivers often describe the sense of personal satisfaction they experience helping a loved one, but many struggle to balance the demands of caregiving with their own economic security and life goals. Providing care for a family member often involves a significant change in the relationship as illustrated by comments frequently heard from caregivers such as, “When did I stop being a wife and start being a caregiver?” There are ethical considerations and societal expectations involved in family caregiving. For example, how does one “fire” a relative from their caregiving role and conversely, how does a relative “quit” being a caregiver?

Neither formal or informal caregivers are highly visible, the importance of the services they provide is rarely acknowledged in public society, the demands of their work are not widely recognized, and the financial compensation they receive is typically low relative to other types of work (or non-existent). Neither group could be described as highly unified or organized, but both groups have associations, interest groups, and advocates working on their behalf to improve their quality of life and working conditions – some working in the realm of family caregiver support and others in the world of labor laws and workforce development.

Particularly in participant-directed long-term services and supports programs, through which individuals may direct and control their support services and the caregivers who provide them, the lines between formal and informal caregivers blur. Many individuals in participant-directed programs choose to hire a friend or family member, turning once informal caregivers into formal members of the direct service workforce. Some professional workers started out as family caregivers and transitioned to providing paid services for other individuals. In addition, some professional caregivers provide informal care for members of their own families “after hours” in addition to their paid caregiving duties.

¹ In this paper, the terms “paid caregiver,” “direct service worker,” and “direct support worker” are used interchangeably. When the term “paid caregiver” is used, “care” is meant to encompass more than medical care and protection of safety, but also support services to promote inclusive lives in the community.

To explore potential options and benefits of a more coordinated approach, the Centers for Medicare and Medicaid Services (CMS) convened the Leadership Summit on *Building Capacity and Coordinating Support for Family Caregivers and the Direct Service Workforce* in September 2010. The event brought together leaders in the field of caregiving to identify areas of policy intersections and to develop recommendations for action for working together to build capacity for all support providers to ensure access to quality services and supports for consumers. The Summit was part of the federal *Community Living Initiative*, launched in June 2009, with the goal of strengthening collaboration and coordination among federal agencies, to improve services for people with disabilities and older adults who rely on HHS services to support community living.²

Members of the *Community Living Initiative Workforce Workgroup* and staff at the Direct Service Workforce (DSW) Resource Center, a Technical Assistance Center working for CMS to improve the strength and stability of the paid direct service workforce, began talking about the idea for the Summit in early 2010. We wondered whether a more coordinated approach to caregiver supports and workforce development might be possible. Would policy makers be willing to consider the needs of both groups of caregivers together? Would a more coordinated approach to caregiver supports make it less likely that new policy might adversely impact one group while trying to assist another? Would caregiver and workforce advocates think that joining together to work for their shared interests is a good idea? Could it raise overall visibility and public acknowledgment of the importance of the work? Do consumer and disability advocates think that a coordinated approach to caregiver and workforce supports might improve quality of services? Could coordination of supports improve the stability of the workforce? Would transitions between settings and between caregivers happen more smoothly?

The one and a half day national Summit brought together invited national leaders in the fields of family caregiving and direct service workforce development to discuss and begin to answer these questions. Attendees included policy-makers at the local, state and federal levels representing civilian and military agencies, consumers, consumer advocates, caregivers, caregiver advocates, employers, paid and unpaid caregivers. The group included individuals representing the diverse populations of people who receive long-term services and supports, including older adults, working age adults and children with physical disabilities, intellectual /developmental disabilities, cognitive impairment, mental illnesses and substance abuse problems, chronic illnesses, traumatic brain injury, and other conditions. More information about attendees is included in *Appendix A*.

This white paper will be used to help refine the agenda of the *Community Living Initiative Workforce Workgroup* in these areas and serve as a “menu of ideas” for policy makers, advocates, consumers, and other stakeholders in thinking about how they might collaborate to address the needs of the direct service workforce and family caregivers.

² HHS, Office on Disability, “Our Commitment to Community Integration,” <http://www.hhs.gov/od/topics/community/olmstead.html>

II. Common Goals and Policy Recommendations

On the first day of the Summit, participants were presented with a suggested initial list of five areas of policy intersections identified by the DSW Resource Center and CMS. Participants confirmed these as important areas of concern for family caregivers and the direct service workforce as well as potential areas of common ground. These five topics served as the basis for further discussion in small and large groups (see *Appendix B* for Summit agenda).

- ▶ Raising visibility
- ▶ Economic security
- ▶ Participant direction
- ▶ Team-based approaches to service delivery
- ▶ Training

From these discussions, a strong consensus emerged that a high degree of commonality exists across caregivers in terms of their contribution to and significance in the lives of people with disabilities, and their needs. Furthermore, discussions showed that the needs and interests of caregivers cannot fully be separated from the needs and interests of the people they support. To the extent that public policies support the interests of people with disabilities, caregivers benefit, and to the extent that caregivers are supported, people with disabilities benefit.

Building from the five initial discussion themes listed above, twelve common goals emerged from the discussions each with specific policy recommendations. These are outlined briefly below. Participants did not rank these goals or assign to them any kind of priority order. They are organized here in two general categories: 1) common goals for broad systems change that would improve the entire system of long-term services and supports, and thus benefit family caregivers and the direct service workforce, and 2) common goals that are more specific to family caregiver and workforce policy. Across these areas, diverse participants agreed that taking more coordinated action in these areas would improve conditions for all caregivers and people with disabilities.

Twelve Common Goals and Policy Recommendations

Common Goals	Policy Recommendations
Broad Systems Change Goals	
1. Improve Coordination and Collaboration	<p>Improve coordination across systems, agencies, programs, and populations and civilian and military government agencies; increase collaboration among caregiver stakeholders; break down silos.</p> <p>Improve coordination across Federal benefit programs (e.g., Medicaid and Medicare).</p> <p>Address differences in terminology used across settings and groups (e.g. caregivers, support provider, workers, informal/formal, unpaid/paid, consumers, program acronyms, job titles).</p>

Common Goals	Policy Recommendations
Broad Systems Change Goals	
2. Improve Long-Term Services and Supports System Navigation and Access	<p>Provide information, training, and assistance to help people with disabilities and the caregivers supporting them, to navigate the system.</p> <p>Assist all caregivers to access training and supports available to them as caregivers.</p>
3. Strengthen Public and Private Financing for Long-Term Services and Supports	<p>Increase public financing for long-term services and supports, and increase awareness of the need for planning for long-term services and supports costs, to improve access to affordable services and supports for people with disabilities.</p>
4. Promote Community Living, Inclusion, Employment, and Quality of Life for People with Disabilities	<p>Promote community living, community inclusion, employment, and a good quality of life for people with disabilities. The more people with disabilities and their caregivers are visible and part of every day life, the more they will be recognized and valued.</p> <p>Improve access to employment for people with disabilities in federal, state, and local government agencies and in service providing organizations.</p> <p>Better support people with disabilities to make decisions and choices about the things that matter most to them.</p>
5. Expand Participant Direction	<p>Promote more person-centered, family-centered, and culturally competent policies and supports for people with disabilities and caregivers.</p> <p>Ensure participant direction models are flexible enough to meet the needs of diverse groups of participants and families.</p> <p>Extend reimbursement for participant direction in public long-term services and support programs to all populations, particularly for people with mental illness.</p> <p>Ensure flexibility to allow participants and their family members/representatives to review and adjust their caregiving arrangements as wanted, needed, and appropriate.</p>
6. Focus on Quality of Care and Protection from Abuse / Neglect in Home and Community Based Settings	<p>People with disabilities and both groups of caregivers would benefit from raised awareness about the issue of care and the importance of protecting people with disabilities from abuse or neglect.</p>

Common Goals	Policy Recommendations
Specific Goals for Family Caregivers and Direct Service Workforce	
7. Improve Recruitment, Selection, and Retention of Caregivers	<p>In preparation for the increased demand and reduced pool of paid and unpaid caregivers, improve recruitment, selection, and retention strategies for paid caregivers to strengthen and stabilize the paid workforce, improve quality of services for people with disabilities, address unmet need, and relieve the growing burden on family caregivers. Support supervisors—including individuals with disabilities, family members, and agency staff—to increase their competence to implement evidence-based best practices.</p>
8. Increase Economic Security of Paid and Family Caregivers and People with Disabilities	<p>Address common economic and support needs of family and paid caregivers and people with disabilities together.</p> <ul style="list-style-type: none"> ▶ Address common economic and support needs of family and paid caregivers together, through 1) expanded opportunities to earn Social Security credits for caregiving work, 2) financial literacy education/counseling and savings opportunities, 3) access to the Earned Income Tax Credit and other tax credits, 4) access to training, and 5) assistance hotlines that provider caregiver coaching and counseling about social services and supports. ▶ Improve wages and access to health insurance and other benefits for paid caregivers (related and unrelated to person receiving services). ▶ Provide incentives to promote the development of credentialing programs, apprenticeship programs, and other career leader options to support the development and retention of the direct service workforce by tying wages to skills/competencies or quality. ▶ Expand support programs, tax laws, and workplace policies to improve economic security of family caregivers (e.g., flexi-time, job sharing, professional development opportunities, tax benefits/stipends, Family Medical Leave Act, health insurance). ▶ Improve benefits and employment programs for people with disabilities, to enable them to improve the economic security for their caregivers. ▶ Take actions to align the interests of people with disabilities and direct service workers, so they can advocate in unison for improving wages for workers while maintaining access to services.
9. Raise Awareness of the Importance of Home and Community Based Direct Service Workers and Family Caregivers	<p>Increase acknowledgement and recognition of the value of the job being performed by paid and family caregivers by policy-makers, in private workplace settings, and in the media.</p>
10. Integrate Caregivers in Team-Based Approaches	<p>Promote person-centered and flexible team-based approaches. Promote coordination across funding streams and flexible reimbursement policies to enable team members such as direct service workers to fully participate.</p> <p>Individuals with disabilities, direct service workers, family members, and support brokers should be included as integral members of service planning processes, care coordination interventions, and interdisciplinary teams. People receiving services and those closest to them have the most experience to</p>

Common Goals	Policy Recommendations
	contribute and are the best positioned to make these types of interventions successful.
11. Expand Peer Support	Expand access to peer support, most commonly used for people with mental illnesses, to all populations, by expanding reimbursement for peer support services and recruiting more peer support providers. Offer opportunities for paid and family caregivers to support each other with issues they face as caregivers.
12. Invest in Training for Paid and Family Caregivers and for Consumers as Employers	See <i>Training Recommendations</i> below.

More time was devoted to the topic of training than other topics at the Summit (see [Appendix B](#), Summit Agenda), in recognition of the keen interest among Summit organizers and participants in identifying similarities and differences in training needs, existing training systems, and training requirements and policies currently affecting formal and informal caregivers. From these discussions, both in small and large groups stretching over both days of the Summit, the group reached consensus that training is critically important for both groups and several common recommendations emerged. The group also identified key differences in what training should include and how it should be approached for paid/professional workers, family caregivers, and consumers as employers.

Training Recommendations

Training Recommendations for All Caregivers
<p>Involve individuals with disabilities and family caregivers, including parents of children with disabilities, in providing and/or directing training for all types of caregivers.</p> <p>Training /educational supports for all caregivers should be more widely available in a variety of formats, modes, and settings to meet individual circumstances and needs (e.g. internet-based, classroom, video, on-the-job learning).</p> <p>Establish a code of ethics for the direct service workforce across populations and settings.</p> <p>Caregivers need additional support to be able to attend trainings (e.g. respite care arranged, transportation provided, compensation provided for missed work).</p> <p>All training should be offered by qualified and experienced trainers using evidence-based training methods.</p> <p>Options for funding training in public programs should be expanded and barriers to funding training eliminated.</p> <p>Increase overall investment in training to support training infrastructure development.</p>

Recommendations for Family Caregiver Training	Recommendations for Paid/Professional Worker Training
<p>Expand training opportunities for family caregivers, recognizing that they have different training needs than professional direct service workers.</p> <p>Training for family caregivers should be:</p> <ul style="list-style-type: none"> ▶ Flexible ▶ Optional ▶ Accessible ▶ “Just in time” ▶ Self-paced ▶ Customized to meet the needs of individual caregivers and people receiving services 	<p>Training requirements for paid caregivers should be expanded beyond current minimum standards in most public programs to align more with the real skills required to perform the work.</p> <p>Basic training for paid caregivers should cover the competencies required to support people of any age or disability type and should include “soft skills” like communication, advocacy, and problem solving. Basic training should address topics other than health and safety. Efforts should focus on expanding dissemination of existing best practice training programs.</p> <p>Paid caregivers should get training on how to support individuals to live independently in the community, how to find and maintain employment, how to advocate, how to work in participant-directed settings, and how to help individuals achieve personal goals.</p>
<p>Recommendations for Training Consumers as Employers</p>	
<p>Assist people with disabilities and family caregivers in accessing training and supports to assist them in employing, training, and managing their workers.</p>	

More detailed discussion of the twelve common goals with examples of participants’ comments is presented in [Section III](#) of this report. See [Appendix C](#) for details about how the discussions were organized and the methodology used to identify common themes and prepare this paper. Additional resources on the direct service workforce and family caregiving are provided in [Appendix D](#), and example programs and initiatives mentioned by Summit participants at the event are listed in [Appendix E](#).

III. Detailed Discussion of Twelve Common Goals and Participant Comments

1. Improve Coordination and Collaboration

- ▶ **Break down funding stream silos and improve coordination across systems, agencies, and programs** and increase collaboration across stakeholders. Participants noted federal and state examples of a few efforts to improve coordination and blend funding streams and suggested that more incentives for coordination were needed. For example, the Community Living Initiative fosters collaboration across federal agencies to further the implementation of the U.S. Supreme Court’s *Olmstead* decision, which held that the unjustified isolation of people with disabilities in institutions is a form of unlawful

discrimination under the Americans with Disabilities Act.³ Throughout the Summit, a frequently mentioned issue was fragmentation of long-term services and supports funding sources and programs, which was seen as a significant barrier to raising awareness across sectors, providing effective, affordable services, and bringing about other needed reforms. Participants noted that a barrier to coordination is the tension regarding whether the philosophy of care will be guided by the medical model (focused on medical health and safety), the long-term rehabilitation model (focused on improving physical functioning), or the philosophy of helping people to live lives of inclusion. Lifespan Respite Programs, while limited to provision of respite services specifically, demonstrates that successful collaboration across state agencies and through state respite coalitions can be very effective in maximizing resources, building respite capacity, and recruiting and training respite workers.

- ▶ **Address differences in terminology.** Participants stressed that “nomenclature is important” and suggested using common terminology to avoid confusion. Henry Claypool, Director of HHS’s Office on Disability, noted that many people consider the terms “care” or “caregiving” paternalistic, as these terms reflect the medical model of services, and prefer other terms such as “personal assistance.” However, he added that people use the term “care” differently, and what is more important is to focus on the values that undergird the terminology (e.g., the values of care or love). Mr. Claypool noted that service recipients often have deep personal relationships with the people who support them. To help in finding common understanding, John Morris, with the Annapolis Coalition on the Behavioral Health Workforce, in his presentation suggested that if someone uses language that is different from the term we would have used that participants “make the translation in our heads.”

2. Improve Long-Term Services and Support System Navigation and Access

- ▶ **Provide assistance with navigating the system and accessing services.** Several groups noted the challenges, confusion, and lack of coordination in the system of long-term services and supports and suggested that individuals, workers, and family caregivers need better information/resource centers to help them navigate the system. Several participants noted that Aging and Disability Resource Centers and single-entry-point models, such as those utilized in some Lifespan Respite Care Programs, could help with this, and that these could also be used to educate and empower caregivers.

³ HHS, Office on Disability, “Our Commitment to Community Integration,” <http://www.hhs.gov/od/topics/community/olmstead.html>

COMMENT: Instead of trying to solve the problem of silos themselves, might it be an easier solution to educate frontline staff to be able to navigate silos and make the process more seamless for consumers?

3. Strengthen Public and Private Financing of Long-Term Services and Supports

▶ **Strengthen public and private financing of long-term services and supports.**

Participants noted that a major concern of caregivers is to increase financing for long-term services and supports to ensure access to affordable services for the people with disabilities. Such an increase would benefit the individual receiving services as well as their family members and other support workers. Medicaid and VA programs and private insurance policies sometimes do not cover needed long-term services and supports. One suggestion to improve affordability was to find strategies to bundle multiple sources of funding so funding streams are not so fragmented, as in the example of the unified long-term care budget being developed in Ohio or Global Budgeting in New Jersey (see [Appendix E](#)). Others suggested helping people to plan ahead and raise awareness among younger people, at a national level, about options for long term services and supports for their loved ones and themselves. Participants discussed how several provisions in the new health reform bill might improve financing for long-term services and supports such as the CLASS Act and funding for community care transitions. However, another concern was maintaining existing funding levels in the face of threatened reductions due to struggling state budgets. Raising awareness of the cost-effectiveness of home and community based services was recommended as a strategy to support the case for maintaining and increasing funding for home and community based services.

4. Promote Community Living, Inclusion, Employment, and Quality of Life for People with Disabilities

▶ **Promote community living, community inclusion, employment, and a good quality of life.** Several participants noted that promoting community living and inclusion in the community would improve the quality of life for people with disabilities and their service and support providers. The more people with disabilities are integrated into the community, the more accepted and the more visible and respected their service and support providers will be.

COMMENT: "If I am in the shadow of a person who is invisible, what do I look like?" – DSP quote cited by participant.

5. Expand Participant Direction

▶ **Provide more person-centered, family-centered, and culturally competent services** for people with disabilities and caregivers. In large group sessions,

participants agreed on the goal of transforming systems to be more person-centered, family-centered, and culturally competent. Discussion about participant direction, a specific model of long-term supports and service delivery, focused on building a better infrastructure to support this model and supporting the needs of both career members of the workforce and family/friends/peers who serve as providers in participant-directed programs. Overall, participants agreed that the long-term services and supports system is still overly medicalized, paternalistic, and provider-driven and should be more participant-directed. The challenge identified is how to move to a more person-centered and family-centered system.

COMMENT: The needs of the person need to drive the system, not the needs of the organization or system.

COMMENT: We should always use the filter of person and family centered care and not "staff-centered care."

COMMENT: "Nothing about us without us."

- ▶ **Ensure participant-directed programs are flexible to meet needs of diverse groups.** Summit participants discussed that involvement of family members varies based on cultural differences, people's personal situations, family dynamics, and sometimes the age of the person with disability. For example, among younger people with substance abuse problems, families are very often at the forefront. Participants noted that family caregiving changes the role of a person with disability within their family, and some people with disabilities are opposed to all family caregiving for this reason.

COMMENT: A lot of older people don't want to depend on kids, but a lot of immigrants want their kids to take care of them.

- ▶ **Extend reimbursement for participant direction** in public long-term services and support programs to all populations, particularly for people with mental illness. Participants in several groups recommended expanding publicly funded participant direction programs to cover more people across all populations of service recipients, particularly people with mental illness.

COMMENT: People are learning to take responsibility for their own care and support. People want to direct their supports, care, treatment... Create greater availability for self-directed services for populations who do not currently have it.

- ▶ **Ensure flexibility to allow individuals, and their family members/representatives as needed, to review and adjust caregiving arrangements as wanted, needed, and appropriate.** Caregiving arrangements are often made in a crisis and not revisited or adjusted later when things settle

down. Therefore caregiving plans should be flexible to allow individuals, and their family members/representatives as needed, to periodically review and adjust caregiving arrangements as wanted, needed, and appropriate. People need more options other than firing their caregiver when things are not working out, e.g., reducing hours, hiring additional caregivers, etc. Negotiation should not be a one-time thing.

COMMENT: Firing your worker, or quitting the caregiving job is an even bigger issue in the case of family caregiving – fiscal intermediaries can help, or having a "pre-nuptial" type agreement.... Agreement should be formalized and revisited.

6. Focus on Quality of Care and Protection from Abuse / Neglect in Home and Community Based Settings
 - ▶ **Raise awareness about ensuring quality of care and protecting people with disabilities from abuse or neglect in home and community-based settings.** In home and community based settings, feedback loops for quality control are inadequate, and the public often assumes that high quality services are provided. The absence of accurate data contributes to lack of awareness of the need for reform, particularly for services delivered in the home and community. Gretchen Alkema of The SCAN Foundation noted that the health reform law included provisions to improve the quality of long-term services and supports, including the Elder Justice Act and new requirements for nursing home transparency and improvement, however, those initiatives do not address the need for quality monitoring in home and community settings. Participants also discussed the need to address the fact that most abuse occurs at home by family members, who are often engaged in providing the bulk of care without needed supports, such as early and frequent respite care.
7. Improve Recruitment, Selection, and Retention
 - ▶ **Improve DSW recruitment, selection, and retention strategies, building on strategies and interventions that are proven effective.** Participants emphasized the need to recruit and retain more workers to meet the growing demand for home and community based services by increasing the use of effective strategies for DSW recruitment, selection, and retention. Hiring entities, whether individual, families, or organizations, need training on how to effectively recruit, choose, and retain workers who are a good match for the job. This includes effective techniques to improve selection and reduce turnover, such as structured behavioral interviewing and realistic job previews. For recruitment, participants suggested targeting recruitment of people with disabilities, older workers, college students, and family caregivers. Participants also suggested getting involved with the Careers that Matter Most initiative (see [Appendix E](#)). Several suggested the strategy of using worker registries to help people find workers; registries could also be used to offer access to training, self assessments

for training needs, and tracking of training completed. Participants also discussed the need for criminal background checks and better screening processes. Additionally, several participants mentioned the importance of having a professional code of ethics guiding the field, and discussion ensued over whether there was a way to look at ethics in screening caregivers.

8. Increase Economic Security for Family and Paid Caregivers and People with Disabilities

- ▶ **Address the common economic and support needs of family and paid caregivers together.** Participants agreed on several common challenges and solutions regarding low wages, lack of benefits, and economic insecurity for both paid and family caregivers. For professional caregivers, the challenges include low wages and lack of benefits, which leave many direct service workers living in poverty and relying on public benefits. Economic challenges faced by many family caregivers include reduced wages and benefits when they leave work to provide care, difficulty returning to work after spending time out of the workforce, and limited incomes of the persons receiving care. Common needs of family and professional caregivers could be addressed more fully through: 1) increased opportunity to earn Social Security credits; 2) financial literacy education, financial counseling, financial planning education, and savings opportunities; 3) improved access to the Earned Income Tax Credit and other tax credits; 4) improved access to training; and 5) assistance hotlines that provide caregiver coaching and counseling about social services and supports.
- ▶ Economic security is a struggle, because caregivers need payment to survive, but people who need services also have limited funds. A significant discussion arose regarding the issue of some service users and paid caregivers being in conflict over the need for increased worker wages and benefits, because of consumers' fear that any increase in wages for workers would result in a reduction of service hours. In this time of budget constraint, this is a sensitive issue and also influences the debate over Fair Labor Standards Act overtime protections for home care workers. Summit participants recommended taking actions to align their interests so that they can advocate in unison.

COMMENT: To earn credit for Social Security, a worker must earn \$1,700 a year from one employer. Because they often work multiple jobs for low pay, many DSWs do not qualify. Also, family caregivers do not earn Social Security for the unpaid caregiving they provide.

- ▶ **Improve wages and benefits for paid workers.** Participants noted several times that a high proportion of direct service workers rely on Medicaid or other public benefits for low-income workers; if they had higher wages and private health insurance, these numbers would be reduced. A recommendation was to look holistically at packages of compensation, so that workers do not completely lose benefits such as subsidized housing or public health care due to small increases in wages. A key barrier to economic security and professionalization of the

direct service workforce is the “medical model,” which model was associated with inadequately valuing direct service work and inadequately addressing the lifelong habilitation needs of people with disabilities. Another challenge was societal devaluing of family caregiving, with the common belief that family members should provide care for free. One recommendation was to recognize the value of caregiving work in economic security policy by making the Fair Labor Standards Act applicable to all direct service workers and addressing Family and Medical Leave Act and other job protections for these workers.

COMMENT: If a person works full-time in direct care they still earn less than poverty level wages.

- ▶ **Enhance career path/lattice opportunities for direct service workers that tie wages to skills/competencies or quality.** Participants recognized the need to base pay on skills/ competencies irrespective of whether the person is a family caregiver or direct service worker. Several participants recommended that Medicaid provide for pay increases based on training or quality of practice. One suggested approach was to use credentialing models to demonstrate competency and build wage structures on credentials. Ohio was mentioned as an example of a state that is developing a tiered competency and wage program for direct service workers in Medicaid reimbursed programs across populations (see [Appendix E](#)). Also noted, however, was that in participant direction, paid caregivers who are family members and friends of the person receiving services may not want to attend classes or receive certifications and any training requirements could reduce the pool of participant-directed service workers.
- ▶ **Expand programs and policies to support family caregivers.** Employment policies that would improve income and benefits for family caregivers include workplace flexibility, flex-time, job sharing, and opportunities for professional development during a leave of absence to help people stay connected to their fields and make it easier to return. Government could provide better tax benefits and/or stipends for caregivers. Participants commented that, while the Family Medical Leave Act provides some job protection for family caregivers, and the health reform law will help caregivers get affordable health insurance, more was needed.
- ▶ Participants noted that the Administration on Aging National Family Caregiver Support Program (Title III-E of the Older Americans Act) provides some respite, support groups, counseling, and other support services for family caregivers, but this program is limited in scope and size and does not address all the need – particularly for parents caring for children with disabilities. The Lifespan Respite Program, also administered by the Administration on Aging, is extremely limited, but has the potential to help states more efficiently use existing resources to leverage additional funding. The program addresses worker and volunteer training and recruitment; capacity building; and

improving respite service delivery, access, and coordination across the lifespan and for all conditions.

Kathy Kelly of the Family Caregiver Alliance noted that high levels of prolonged elevated stress from family caregiving is associated with health risks, particularly if the individual receiving care has a cognitive impairment. Those who are caregivers for a longer period of time face an estimated shortened life span from the physical strain and stress. Many family caregivers do not take breaks or vacations because of lack of other family members to provide care, lack of money to buy respite care services, or inability to relinquish care. The Veterans Administration tackles this by providing respite for vacations – two weeks of rest. The new VA benefit also covers mental health services, recognizing that depression can be a problem for family as well as paid caregivers.

Heather Mahoney-Gleason, National Caregiver Support Program Manager with the Veterans Health Administration, presented information to Summit participants about new caregiver support provisions passed as part of the Caregivers and Veterans Omnibus Health Services Act of 2010 (Public Law 111-163, Title 1, Section 101-104). The program will support caregivers of eligible veterans who were seriously injured in the line of duty on or after 9-11 (September 11, 2001). New benefits for primary caregivers include: a caregiver stipend (with formalized training program, certification of competencies, and ongoing monitoring); health care coverage; mental health services; and travel, lodging, subsistence, and respite to attend training and for staying at the hospital with the veteran.

COMMENT: Caregivers can provide better care when their own needs are met.

COMMENT: Family caregivers have no income if they leave their job, no Social Security, less retirement benefits. Caregiving is an impoverishing experience.

► **Improve benefits and employment programs for people with disabilities.**

Participants in several discussion groups suggested that changing policies to improve the financial position of people with disabilities would enable them to improve the economic security of their caregivers because they would have more income to support themselves and families and pay their workers.

Although participants mentioned a number of existing initiatives to support employment of people with disabilities (e.g., Medicaid buy-in programs, DOL employment programs, the Senior Community Employment Services program, and work incentives in Social Security benefit programs) some were concerned that these initiatives might be too restrictive, too limited, or too complicated. Many individuals do not have assistance from family members and manage their own needs without any assistance. Participants noted that direct service workers in community-settings need effective training on how to support employment for the people they support.

9. Raising Awareness of the Importance of Home and Community Based Direct Service Workers and Family Caregivers

- ▶ **Increase acknowledgement and recognition about the importance and value of the job being performed by direct service workers and caregivers** by policy-makers, in workplace settings, and among the general public. Participants commented on the importance of increasing awareness that most direct service is provided by paid and unpaid direct service providers, not doctors and nurses. Without a qualified direct service workforce to meet the growing need, we cannot support people to be in, and part of, their communities and people risk falling back on institutional services. Several participants discussed raising awareness of the challenges of recruitment and selection, particularly in home and community-based settings, and the importance of better valuing caregivers in organizational cultures, professionalizing the direct service workforce, and getting medical professionals to recognize the importance of direct service work. Participants suggested that questions about whether the person provides care and potential caregiving stressors be added to health screenings, and at intake for acute and long-term services and supports, to identify and increase caregivers' awareness of their own needs and available resources.

10. Integrate Caregivers in Team-Based Approaches

- ▶ **Promote person-centered and flexible team-based approaches.** Participants agreed that team-based approaches need to be flexible enough to meet individual needs. Policy-makers must be careful that these programs remain flexible as they are implemented. The siloed nature and reimbursement restrictions of funding streams prevent team members such as direct service workers from fully participating. For example, Medicaid payment rules reportedly prevent two people from billing for work performed in the same room at the same time. The Patient Centered Alignment Team, Green House, and hospice models were mentioned as examples of coordinated approaches between direct service workers and family caregivers on teams.

COMMENT: How can we make sure LTC delivery is team-based, culturally competent, and family-centered?

- ▶ **Include people with disabilities, paid caregivers, family caregivers, and support brokers as integral team-members.** Participants discussed team-based approaches to service and care coordination and how to include people with disabilities, direct service workers, and family caregivers more in these approaches. One set of challenges identified relate to the view that the team concept, having originated with the medical model, revolves around case managers and medical professionals and does not always recognize the value of including direct service workers, family caregivers, and participants on teams. Teams should not be limited to medical or social service professionals, but should be expanded to include people receiving services, direct service workers, and family members. Expansion will require funding and training to support their participation. In participant direction, support brokers are often used to

provide service coordination and case management. Team-based approaches can also minimize potential for abuse as they provide a community for caregivers, and more importantly also provide the necessary checks and balances to help ensure a person's well-being.

11. Expand Peer Support

- ▶ **Expand access to peer support.** Peer support, a model most commonly used in the behavioral and mental health services sector, could be expanded to all populations, by expanding reimbursement for peer support services and recruiting and training more peer support providers. Individuals with personal experience living with a disability make excellent services and support providers for others. In large and small group sessions, participants also mentioned expanding opportunities for family caregivers to support and mentor one another with issues they face as caregivers. Another suggestion was that family caregivers create peer networks to support each other.

12. Invest in Training

- ▶ **Involve individuals with disabilities and family caregivers in providing/directing training.** Several groups discussed the need for greater recognition of the role that people receiving services can play in providing training or determining the type/amount of training needed for the people supporting them.

COMMENT: People with disabilities are the experts. Training and curriculum out of hospitals/universities get more credit than the consumer's training, but the consumer can train too because they know their own needs.

COMMENT: How much training is regulatory driven? Is there a disconnect between policies and skills needed?

- ▶ **Provide training that aligns with skills required to perform the work.** A common perception among participants is that current training is too heavily focused on health care and assistance with activities of daily living. Participants noted that too little attention is paid to other skills needed to effectively support people with disabilities living in the community such as self-advocacy, problem-solving, social integration, and behavioral supports. Overall, participants thought that training is too often "cookie cutter" or "regulatory driven." Several suggested that parallel training programs should also be provided for supervisors, trainers, medical professionals, and case managers, and other staff from entities involved in long-term services and supports. Participants agreed that many good curricula are available and that efforts should focus on making training more widely available, rather than developing new training programs.

- ▶ Participants suggested **core skills that should be addressed in training** for caregivers, but often are not addressed, and these include:
 - *leadership*
 - *advocacy*
 - *respect*
 - *participant-driven supports*
 - *human development*
 - *listening/empathy*
 - *problem-solving*
 - *communication*
 - *stress management*
 - *family dynamics*
 - *basics of mental health*
 - *preventing abuse*
 - *mitigating occupational injuries*
 - *adjusting practice to the needs of the individual*
 - *navigating the LTSS system*
 - *working on interdisciplinary teams*
 - *understanding care transitions/skills in the “hand-off” between settings*

COMMENT: We invest much, for instance, in training workers how to perform CPR. Is it really the most critical caregiving skill?

- ▶ **Make training/support available in a variety of formats and on-the-job.** Participants recommended increasing the use of evidence based or “adult learning” models and online training, and creating an online community of practice. Experiential training can be most effective for adult learners and can be offered through models such as coaching, apprenticeships, and mentoring. In terms of training mode, group participants suggested that policy-makers should consider distance learning including internet-based training, in addition to classroom/college-based, especially in rural areas.

COMMENT: Ways to get the training out there? Libraries, one stops, vocational training centers, community colleges. Rural areas are challenging. So many solutions are internet-based – traveling mobile vans. Post office – everyone goes there – use that infrastructure! Make information available at YMCAs, 4H, churches and other faith-based organizations.

- ▶ **Expand training opportunities for family caregivers.** Family caregivers and paid caregivers may have different experiences and different needs, but both still need training on some core competencies. Participants recommended helping family caregivers learn about resources and training that have been developed. While many family caregivers become skilled in the needs of the individuals receiving care through their first-hand knowledge and experience, some caregivers may at times appreciate the opportunity to access outside information and training resources.
- ▶ Kathy Kelly of the Family Caregiver Alliance noted that the training components needed by family and paid caregivers are similar because they essentially perform the same tasks, and many of the skills needed by paid caregivers are also needed by unpaid caregivers (communication skills, care coordination, etc.). The difference is how tailored the training is for the specific

tasks at hand and whether they can be updated when conditions change. Among Summit participants, the general consensus was that training for family caregivers should be voluntary.

- ▶ **Training for family caregivers should be flexible, “just in time”, and customized to meet the needs of caregivers and individuals receiving care.** Participants emphasized that training for family caregivers should be made available at the right time and in accessible format. In several groups, participants indicated that flexibility in training in terms of mode of delivery, timing, and content was considered important for both professional caregivers and family caregivers, but particularly for family caregivers. Participants suggested a modular curriculum, with courses available for caregivers to take when they need them. A frequent suggestion was to assess what caregivers already know and what they need to know, to determine training needs. Much conversation centered on the theme of person-centered training – both the content of training featuring person-centered services, and also the concept of person-centered *training* that is responsive to the needs of caregivers.

COMMENT: Let’s ask caregivers, “What do you know? What do you need to know?” Then let’s build on that.

- ▶ **Increase reimbursement and infrastructure support for training.** Participants discussed the lack of reimbursement for training, including training on the use of technology/telehealth, mentoring/coaching/on-the job support and supervision/making relationships work, and training in participant direction. Workforce Investment Boards (WIBs) were mentioned as a potential source of training funds.
- ▶ **Use evidence-based training methods.** Although participants supported continued innovation in caregiver training, they expressed frustration at how many different training curricula are being created all the time, rather than relying on what is known to work. Participants emphasized that training should be based on sound “adult learning” practices and trainers should be well-qualified and understand effective training techniques.
- ▶ **Provide training and assistance to support participant direction.** Three related suggestions were made regarding training to support participant direction: 1) expand training opportunities for individuals directing their own services, 2) expand training for family caregivers supporting them, and 3) clarify and increase consistency of state Nurse Practice Acts. Participants agreed that more training should be offered to individuals directing their own services on topics related to being an effective employer, such as hiring, managing, firing, supervising, and managing relationships. Training in the area of participant-direction is also critical for family caregivers, as it can be difficult to manage the multiple roles they may have. The concern was that these relationships can be complex and fraught with tension, boundary issues, and inappropriate

expectations, and individuals receiving care do not always have a clear place to safely raise issues or receive advice. State Nurse Practice Acts vary in what they allow family members and unrelated caregivers to do, and Summit participants thought more clarification and uniformity in this area would help enhance flexibility around service delivery.

IV. Next Steps and Action Items

In addition to the common goals and policy recommendations listed above, Summit participants identified five immediate next steps to take as a follow-up to the Summit. These included steps to continue working together to identify and advocate for common goals, share information across sectors, and reach agreement on core competencies.

- 1. Continue/expand stakeholder discussions to share information and build consensus** on priorities for raising awareness and seeking systems change. Emerging from all group discussions was a common recommendation that this discussion needs to be continued. Although the Summit participants represented diverse stakeholders representing civilian and military federal and state government agencies, academics/researchers, direct service workers and trainers, family caregivers, individuals receiving services, and employers (*Appendix A*), several suggestions were made to expand the discussion to include additional stakeholders. Various meeting formats were suggested, including a Web 2.0 environment to allow participants to interact and collaborate using the web, a meeting modeled after the White House Conference on Aging, Policy Academies, a meeting modeled after New York State’s listening sessions, or more meetings like this Summit. Participants emphasized that the conversations should focus on shared values and on reaching consensus among the cross-sector coalition of stakeholders, in order to speak with a “unified voice” in advocating for systems change.

COMMENT: We need to:

- Define systems change and what we are trying to raise awareness about.*
- Identify and prioritize the most pressing needs in HCBS and facility-based LTC services and supports*
- Develop common strategies and take action to address common areas of concern across disability and aging communities.*

- 2. Reach out to CMS Center for Innovation and other ACA implementation workgroups,** to recommend that the challenges and needs of direct service workers and family caregivers be considered in ACA demonstration projects. For example, as part of the CLASS program created by the ACA, HHS is establishing a Personal Care Attendants Advisory Panel. HRSA has awarded grants to six states through the Personal and Home Care Aide State Training Program (PHCAST), which was created as part of the Affordable Care Act. Also under the ACA, the Administration for Children and Families is awarding grants for Health Profession Opportunity Grants to Serve TANF Recipients and Other Low-Income Individuals (see *Appendix D* for information on ACA activities). Specific suggestions for the CMS Center for Innovation to consider as they develop future demonstration programs and consider innovative models included:

- ▶ Seek out and promote innovations in delivery of caregiver support services
- ▶ Promote innovative team-based approaches that include individuals and family members as equal partners on care teams, such as a hospice type model
- ▶ Pilot new approaches to reimbursement for teams-based approaches
- ▶ Consider new approaches to fund ongoing competency-based training, and ensure that increased wages are associated with greater levels of competence

3. Compile and disseminate the evidence base on the caregiving workforce and broader HCBS issues. Specifically, participants discussed the need for: 1) information on best practices/effective models, 2) information about what state and federal agencies and other stakeholders are currently doing, and 3) research on outcomes and cost impacts of interventions, to help make the case for investing in caregivers and HCBS. Several discussion groups also emphasized the need to compile research and information on best practices in a usable form for dissemination across diverse aging and disability stakeholder groups, so that they can learn from each other. Suggested avenues for dissemination included meetings, building on existing work in this area including work by the DSW Resource Center, and using technology to share resources.

COMMENT: We should be assigning an economic value to services rendered in the home care environment. We should document the money and the "talent" that are lost because people are not in the workplace.

4. Develop a roadmap, or crosswalk, to describe and compare currently available competencies and clarify the core competency domains for caregivers, building on the DSW Resource Center analysis, and other work by the Department of Labor (DOL), the Health Resources and Services Administration (HRSA), and CMS.

COMMENT: A meta-analysis of existing sets of competencies needs to be completed in a legitimate process. The DSW Resource Center is collecting and reconciling core competencies – Iowa, Nebraska, Alaska, Ohio, etc. are involved in the efforts. The Annapolis Coalition just released a cross-walk for key competencies.

5. Convene stakeholders across populations to reach consensus on a common set of core competencies and additional competencies beyond the core set depending on the needs of the person they support and the types of services they provide, to guide the development of training and credentialing materials for paid and family caregivers. Overall, participants agreed on the approach of establishing core competencies (e.g., how to support people to live independently in the community, how to advocate, and how to help people achieve personal goals) and identifying additional sector specific competencies from there. A repeated recommendation was for the different sectors to work collaboratively to develop core competencies and additional sector specific competencies as needed, depending on the needs of the person they support and the types of services they provide. Basing training programs on identified competencies will support retention by allowing workers to move between sectors and maintain wage scales and credentials.

Appendix A: Summit Participants

Participants included representatives from the following groups, some of whom also had personal experience as caregivers or as individuals receiving long-term services and supports:

- ▶ **Representatives from 11 federal agencies/offices:** 1) HHS Office on Disability; 2) Centers for Medicare and Medicaid Services (CMS), Disabled and Elderly Health Programs Group; 3) Substance Abuse and Mental Health Services Administration (SAMHSA); 4) Assistant Secretary for Planning and Evaluation (ASPE); 5) Administration on Aging (AoA); 6) Health Resources and Services Administration (HRSA); 7) National Center for Health Statistics, Centers for Disease Control and Prevention (NCHS/CDC); 8) Department of Labor (DOL) Employment and Training Administration (ETA); 9) DOL Office of Disability Employment Policy (ODEP); 10) Department of Veterans Affairs (VA) Veterans Health Administration (VHA); 11) National Institute of Disability and Rehabilitation Research, Department of Education (NIDRR)
- ▶ **Representatives from state and local government:** Ohio Department of Aging; Texas Department of Disability and Aging; Louisiana Office for Citizens with Developmental Disabilities; Aging Resources of Central Iowa, Family Caregiver Specialists; Asian Community Center of Sacramento Valley; and National Association of State Directors of Developmental Disabilities; National Association of Area Agencies on Aging
- ▶ **Academics and researchers:** The Lewin Group; PHI; Institute for the Future of Aging Services; University of Minnesota, Research and Training Center on Community Living; Annapolis Coalition on the Behavioral Health Workforce; The Westchester Consulting Group; University of California, San Francisco; University of Wisconsin at Milwaukee, Center on Aging and the Community; Appalachian Consulting Group; The SCAN Foundation
- ▶ **Professional (paid) caregivers and education/training providers:** College of Direct Support; New York Consortium of Geriatric Education Centers, Mount Sinai School of Medicine; Direct Care Alliance; National Alliance for Direct Support Professionals
- ▶ **Employers / service provider representatives:** American Network of Community Options and Resources (ANCOR); Long-Term Care Alliance; ARCH National Respite Network and Resource Center; OptumHealth
- ▶ **Family caregivers and individuals receiving long-term services and supports:** Family Caregiver Alliance; Rosalynn Carter Institute for Caregiving; Wounded Warrior Project; Consumer Directed Services Network; National Association of Peer Specialists; Michigan Disability Rights Coalition; National Council on Independent Living (NCIL); AARP Public Policy Institute

Appendix B: Overview and Detailed Agenda

The first day of the Summit combined three types of sessions: 1) presentations and Q&A/discussion on big picture background information, followed by 2) small group breakout discussions on issues and recommendations on five topics, and finally 3) large group discussion on setting priorities for collaborating on direct service workforce and family caregiver issues. The second day was a half-day meeting on the topic of training and competencies for both career members of the workforce and family members/friends/peers who serve as providers. A DSW Resource Center team member took notes at each small and large group session while also participating in the conversations. The discussions served as “high power focus groups,” to make connections and better understand commonalities and differences.

Thursday, September 16

8:30 – 9:00

Welcoming Remarks

Henry Claypool, Director, DHHS Office on Disability

9:00 – 9:15

Key Objectives and Desired Outcomes

Kate King, Centers for Medicare & Medicaid Services

9:15 – 10:45

Policy Intersections and Common Ground

Brief presentations will define the scope of today’s conversation, outline opportunities of new legislation, and identify key policy issues and trends.

Steve Edelstein, PHI

John Morris, Annapolis Coalition for the Behavioral Health Workforce

Gretchen Alkema, The SCAN Foundation

Heather Mahoney-Gleason, Veterans Health Administration

Carrie Blakeway, The Lewin Group

Kathleen Kelly, Family Caregiver Alliance

Questions and answers and facilitated discussion with all participants.

Amy Hewitt, University of Minnesota Research and Training Center on Community Living

11:00 – 2:30

Small Work Groups – Rounds 1-3

Participants are invited to discuss one area of policy intersection in small work groups at their tables. Instructions for small work groups will be provided at the beginning of Round 1. Areas of policy intersection include:

- *Raising awareness*
- *Economic security*
- *Participant direction*
- *Training and mentoring*
- *Team-based approaches to service delivery*
- *Other topics added as necessary*

2:45 – 4:00

Setting Priorities – Large Group Discussion

*Amy Hewitt, University of Minnesota Research and Training Center on
Community Living*

4:00 – 4:30

Next Steps

Michelle Washko, Administration on Aging

Friday, September 17

8:30 – 9:00

Follow-Up and Review of Key Outcomes from Day One

*Kate King, Centers for Medicare & Medicaid Services
Carrie Blakeway, The Lewin Group*

9:00 – 10:00

**Current Competency Development and Caregiver and DSW Training Initiatives
—A National Perspective**

*All participants are invited to share about initiatives they work on or are
involved with related to core competency development, training, credentialing,
apprenticeship and identify training needs or challenges.*

10:15 – 11:15

**Small Work Groups - Core Competencies and Training Activities: Intersections
and Differences**

Participants are invited to work in small groups to:

- *Identify how needs for training across caregivers and support workers are similar and how they are different, considering needed competencies and context.*
- *Identify ways that different programs and initiatives might be extended to address the common needs of all caregivers and support workers.*
- *Identify programs, initiatives, strategies that work well for one group but not all.*

11:15 – 12:00

Identifying Common Strands and Concluding Remarks

Facilitated wrap-up discussion with all participants.

*Carrie Blakeway, The Lewin Group
Kate King, Centers for Medicare & Medicaid Services*

Appendix C: Discussion Topics, Group Discussion Process, and Methodology for Drafting White Paper

On the first day of the Summit, each attendee had the opportunity to discuss three of five main topics in small workgroups over the course of the day. Altogether, 28 small workgroups were held over the two days, focusing on five topics of policy intersections for family caregivers and the direct service workforce:

- ▶ **Raising awareness** about caregiving and direct service providers and the needs of all caregivers (5 groups)
- ▶ **Economic security** – wages and benefits for paid and unpaid, family and professional caregivers (4 groups)
- ▶ **Participant direction** – building better infrastructure for this model of service delivery, refining and realigning programs to support the needs of both career members of the workforce and family/friends/peers who serve as providers (6 groups)
- ▶ **Team-based approaches** to service delivery and care coordination that include DSWs and family caregivers (5 groups).
- ▶ **Training and mentoring** for paid and unpaid caregivers, career members of the workforce and family/friends (3 groups on day one, and five small groups on day two)

On the second day, participants met for a large group discussion to discuss initiatives related to competencies/training/credentialing. Participants later broke into five small groups to discuss core competencies and training and then met again as a large group to identify common strands.

In many cases, the same barrier or recommendation theme emerged in several different topic areas (e.g., Training, Raising Awareness, Participant Direction), in small and large group sessions, and on both days of the Summit.

A DSW Resource Center team member took notes at each table during the small group discussions while also participating in the discussion. The Lewin Group coded and analyzed the notes (using QSR NVivo 8 qualitative data analysis software). Then the draft paper was circulated to the DSW Resource Center team, CMS, and Summit participants to ensure that comments were captured accurately, get details about programs/resources mentioned, clarify comments, and obtain overall comments on the draft white paper.

Appendix D: Additional Resources on the Direct Service Workforce and Family Caregiving

Background on Direct Service Workers and Family Caregivers

Rosalynn Carter Institute for Caregiving, *Averting the Caregiving Crisis: Why We Must Act Now*, Americus, GA, author: October 2010.

http://www.rosalynncarter.org/UserFiles/File/RCI_Position_Paper100310_Final.pdf

CMS National Direct Service Workforce Resource Center. "2008 Symposium on Strengthening the HCBS Direct Service Workforce Summary of Small Group Discussion Themes."

http://www.dswresourcecenter.org/tiki-index.php?page=DSW_Symposium

CMS National Direct Service Workforce Resource Center, Research and Training Center on Community Living/ Institute on Community Integration/ University of Minnesota, PHI, and The Annapolis Coalition on the Behavioral Health Workforce November 2008. *A synthesis of direct service workforce demographics and challenges across intellectual/developmental disabilities, aging, physical disabilities and behavioral health*. Washington, DC: The Lewin Group.

http://www.dswresourcecenter.org/tiki-download_file.php?fileId=372

Hewitt, A.S. & Larson, S.A. (2007). The Direct Support Workforce in Community Supports to Individuals with Developmental Disabilities: Issues, Implications and Promising Practices. *Mental Retardation and Developmental Disabilities Research Reviews*, 13, 178-187.

PHI. February 2011. "The direct-care worker at a glance (2009)."

<http://phinational.org/policy/about-the-workforce/at-a-glance/>

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Appendix E: Example Programs and Initiatives

Below are example programs and initiatives mentioned during Summit discussions.

Training / Credentialing / Skills Development / Mentoring and Retreats

The **College of Direct Support** (CDS) is a national internet based comprehensive, interactive multimedia training program primarily for direct support professionals and their supervisors and managers. The CDS is also used by family members of people with intellectual/developmental disabilities (IDD) to train staff and in some cases individuals with IDD who are self-directing their supports to use CDS to help train their staff. Website:

<http://info.collegeofdirectsupport.com>

Active Support trains teams of direct support workers to provide people with disabilities more opportunities to participate in daily activities in their homes and communities. The training and technical assistance model includes classroom training and problem solving, two hours on-the-job, one-on-one mentored instruction with a master trainer for each staff member, and ongoing support for implementing the approach across individuals, activities, and environments.

Researchers in Europe and Australia have found that when staff receive training in Active Support, the people they support spend more time participating in tasks they enjoy and find interesting and less time sitting around with nothing to do. Website:

<http://www.arcuk.org.uk/1000437/en/training+products+%26+services+%28draft%29.html>

A randomized controlled trial of Active Support is currently underway at the University of Minnesota: <http://ici.umn.edu/index.php?projects/view/37>

The **Wounded Warrior Project (WWP)** holds caregiver retreats, which provide caregivers a chance to unwind and improve their coping skills. Website:

<http://www.woundedwarriorproject.org/content/view/1129>

Other retreats are listed at: <http://www.aw2.army.mil/supporters/recreation.html>

“Respect” trainings, developed by consultant Joel Slack, are DVD-based trainings for people with mental health issues and their caregivers. Website: <http://respectinternational.org>

As part of their Money Follows the Person grant, Ohio convened a Workforce Development Workgroup to identify issues, develop recommendations, and design processes and protocols related to workforce development. The workgroup recommends that Ohio implement a **DSW career lattice model** based on core competencies used in the Nurse Career Lattice model developed by the Council on Adult Education and Learning (CAEL). This program combines the Registered Apprenticeship training model for the CNA and LPN with online instruction and clinical training for the Associate Degree in Nursing (ADN). The Ohio Workforce Development Workgroup recommends that this model be customized for Ohio and specifically incorporate skill sets suited for DSWs who work with individuals with intellectual and developmental disabilities. Website:

http://jfs.ohio.gov/OHP/infodata/MFPGGrant/meetings/wfd_recommendations.pdf

Department of Labor (DOL) Registered Apprenticeship is a successful training and employment model that is used in a variety of industries to train highly skilled workers. Materials from a January, 2011, Direct Service Workforce Resource Center webinar on DOL Registered Apprenticeship are available at: <http://www.dswresourcecenter.org/tiki-index.php?page=Webinars/Calls>

The Administration on Aging is developing **core competencies for Aging Network professionals**.

Stakeholder Workgroups / Partnerships

The **White House Conference on Aging** hosts approximately 1,200 selected delegates, who make recommendations to the President and Congress to help guide national aging policies for the next ten years and beyond. Website: <http://www.whcoa.gov/>

The Health Resources and Services Administration's (HRSA's) Homeless Policy Academies brought together 10-12 leaders across departments for 3-4 days in a nice environment to build a plan, follow up with technical assistance, and help participants stay focused.

The New York State Office for the Aging (NYSOFA) and the State Society on Aging of New York (SSA) released joint final report, providing information, strategies, and suggestions obtained from a series of eight **Listening Sessions held across New York State** between 2006 and 2007 that brought together older adults, faculty and educators, planning and service personnel, state and local government representatives, and advocacy groups to focus attention on the critical issues facing the state in workforce training and education in order to successfully prepare New York State's diverse workforce to interact and work with older adults and their families. Report: Rosenbaum, J., Heiser, D., Brownell, P., Horowitz, B., Maiden, R., Howe, J., and Krout, J. (2008). *Working with Older Adults: Charting the Future of Workforce Training and Education in New York – Listening Sessions: Summary and Next Steps*. New York State Office for the Aging: Albany, New York. <http://www.aging.ny.gov/ReportsAndData/Index.cfm>

Ohio has brought together experts/researchers and stakeholders advocating for systems change through the **Ohio Money Follows the Person Demonstration and the Ohio Department of Aging Unified Long-term Care Systems and Supports Workgroup**. Website: <http://aging.ohio.gov/information/ultcb/>

Summit participants suggested that funding programs should require partnerships, like recent AoA funding for Aging and Disability Resource Centers. <http://www.adrc-tae.org>

Financing LTC

The **Long-Term Care Partnership Program**-active in 40 states, is a partnership between private long-term care insurance companies and Medicaid to increase access to long-term care financing by allowing purchasers of long-term care insurance to “buy in” to Medicaid. Website: <http://www.dehpg.net/lcpartnership/map.aspx>

Ohio is developing a unified LTC budget, in a recent program with which they've made progress. Website: <http://aging.ohio.gov/information/ultcb/>

Philadelphia Insurance was mentioned as an example of a private insurance company that has developed a good LTC insurance package (with Aflac).

Community-Based Services and Supports Models

Assertive Community Treatment (ACT) was mentioned as a program that helps preserve a person's ability to stay in the home of their choosing in a community. The Assertive Community Treatment Association defines ACT as "a team treatment approach designed to provide comprehensive, community-based psychiatric treatment, rehabilitation, and support to persons with serious and persistent mental illness such as schizophrenia." Website: <http://www.actassociation.org/>

The **Veterans Directed HCBS** program provides participating veterans a budget to purchase goods and services to help them stay at home. <http://www.adrc-tae.org>

Medicaid Infrastructure Grants have supported deinstitutionalization. Authorized by Section 203 of the Ticket to Work and Work Incentives Improvement Act of 1999, the grants help states to develop infrastructures to support working individuals with disabilities. For eligibility under this grant program, a state must offer personal assistance services statewide within and outside the home to the extent necessary to enable individuals to be engaged in full-time competitive employment. As of 2011, 42 states and the District of Columbia are participating in this program. http://www.cms.gov/CommunityServices/45_Employment.asp

Lifespan Respite Care Program, administrated by the U.S. Administration on Aging, provides competitive grants to states to build statewide systems of community-based respite services for family caregivers of adults and children. States must use funds to build or enhance coordinated systems of respite, provide planned and emergency respite, recruit and train respite workers and volunteers, and assist family caregivers in accessing respite services and payment sources. Website: http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/LRCP/index.aspx

The **hospice** model of end-of-life care was also mentioned by several participants.

The Green House Project is working to transform institutional nursing facility care by creating viable small homes that spread the Green House vision of powerful and meaningful lives, work, and relationships. Website: <http://www.thegreenhouseproject.org/>

Program of All-Inclusive Care for the Elderly (PACE) is a program authorized by the Balanced Budget Act of 1997 (BBA) that features a comprehensive service delivery system and integrated Medicare and Medicaid financing.

Peer Support

North Carolina's **Peer Support Specialist Program**, at the University of North Carolina School of Social Work, provides a peer support training program and is developing a curriculum for peer support supervisors. Website: <http://pss-sowo.unc.edu/pss>

Recruitment, Selection, and Retention

ANCOR Foundation's **Careers that Matter Most** initiative: <http://www.ancor.org>

Find, Choose and Keep Great Direct Support Professionals: The Illinois Direct Support Professional Workforce Initiative created two versions (family and individual) of this toolkit, which provides easy-to-use tips and strategies to help people find, choose, and keep high quality Direct Support Professionals (2007).

Toolkit for people with disabilities:

<http://www.ildspinitiative.com/docs/ToolkitforPeoplewithDisabilites.pdf>

Toolkit for families: <http://www.ildspinitiative.com/docs/ToolkitforFamilies.pdf>

The National Association for Direct Support Professionals' (NADSP) Moving Mountains Award has been highlighting one to two organizations per year for more than ten years. The NADSP and the Research and Training Center (RTC) at the University of Minnesota's Institute on Community Integration sponsor an annual competition to identify promising practices and organizations using best practices in direct support staff workforce development that result in improved outcomes for the people being supported. The website contains profiles and contact information for the winners since 2001. Website: <http://www.nadsp.org/mountains/index.asp>

Best Buddies matches people with intellectual and developmental disabilities with supportive friends who help them succeed in middle school, high school, college, jobs, and the community. Website: <http://www.bestbuddies.org/our-programs>

PHI's matching service web pages tracks the development of publicly supported matching registries across the country. Website: <http://phinational.org/policy/the-phi-matching-services-project/>

Private matching registries (e.g., Care.com). Care.com and other private, for-profit websites require fees to access listings of independent providers of services including senior care and other services.

Navigating the System and Accessing Information and Services

Aging and Disability Resource Centers (ADRCs), a collaborative effort of the Administration on Aging and Centers for Medicare & Medicaid Services, serve as single points of entry into the long-term services and supports system for older adults and people with disabilities. Website: www.adrc-tae.org

For example, **Iowa's ADRC, Lifelong Links** connects services for older adults, people with disabilities, children with disabilities, and 211. Website: <http://www.lifelonglinks.org/>

The Department of Defense National Resource Directory (NRD) was observed to be very useful even though it, too, has limitations. The NRD is a website for wounded, ill, and injured service members and veterans and their families. It provides access to national, state, and local services and resources to support recovery, rehabilitation, and community reintegration. Website: <http://www.nationalresourcedirectory.gov/>