



## **Administration for Community Living Office of Performance and Evaluation**

# **Interim Learning Agenda Fiscal Years 2020–2022**

*September 2020*

## Table of Contents

Background	1
ACL’s Learning Agenda Development Process	2
ACL’s Priority Question and Sub-question	3
ACL Learning Activities	4
ACL Learning Products	6
Challenges and Mitigation Strategies	6
Appendix A–ACL Caregiver Support Program Descriptions	8
Appendix B – Existing Evidence Presented by Evidence Type	11
References	16

## Abbreviations

ABI	Acquired Brain Injury
ACL	Administration for Community Living
ADA	Americans with Disabilities Act
ADL	Activities of Daily Living
AGID	Aging, Independence, and Disability Program Data Portal
AT	Assistive technology
CIL	Center for Independent Living
CPE	Center for Policy and Evaluation
CoP	Community of Practice
CRO	Center for Regional Operations
HCBS	Home- and community-based services
HHS	U.S. Department of Health and Human Services
LTSS	Long-term services and supports
MIPPA	Medicare Improvement for Patients and Providers Act
NASDDDS	National Association of State Directors of Developmental Disabilities Services
NFCSP	National Family Caregiver Support Program
NIDILRR	National Institute on Disability, Independent Living, and Rehabilitation Research
NSOAAP	National Survey of Older Americans Act Participants
OAA	Older Americans Act
OIG	Office of the Inspector General
OMB	Office of Management and Budget
OPE	Office of Performance and Evaluation
PPR	Program Performance Report
RA	Regional Administrator
RAISE	Recognize, Assist, Include, Support, and Engage
SCI	Spinal Cord Injury
SHIP	State Health Insurance Program
SMP	Senior Medicare Patrol
UCEDDs	University Centers for Excellence in Developmental Disabilities Education, Research, and Service

## Background

*“The Administration for Community Living was created around the fundamental principle that older adults and people of all ages with disabilities should be able to live where they choose, with the people they choose, and with the ability to participate fully in their communities.”<sup>1</sup>*

### What is the Administration for Community Living?

The U.S. Department of Health and Human Services (HHS) created the Administration for Community Living (ACL) in 2012. ACL serves as the federal agency responsible for increasing access to community supports while focusing attention and resources on the unique needs of older adults and people with disabilities across the lifespan. ACL’s mission is to enhance the independence, well-being, and health of older adults, people with disabilities, and their families and caregivers. By funding services, maximizing support programs provided by networks of community-based organizations, and investing in research, education, and innovation, ACL helps make this mission a reality for millions of Americans.

### Why Develop a Learning Agenda?

ACL developed this learning agenda in adherence to guidance from the Office of Management and Budget in M-19-23 that each CFO Act agency should immediately start the process of developing and implementing a multi-year learning agenda and that operational divisions within CFO Act agencies are strongly encouraged to implement a learning agenda<sup>2</sup>. Learning agendas, also known as evidence-building plans, are the driving force for several of the requirements of the Foundations for Evidence-Based Policymaking Act of 2018.<sup>3</sup> They are a systematic way to identify the data agencies will collect, use, or acquire, as well as the methods and analytical approaches to facilitate the use of evidence in policy making. They encourage the use of data to improve agency operational and programmatic outcomes and develop appropriate policies and regulations supporting successful mission accomplishment.

By promoting deliberate planning of evidence-building activities, including prioritizing limited resources and addressing potential information gaps, ACL’s learning agenda will:

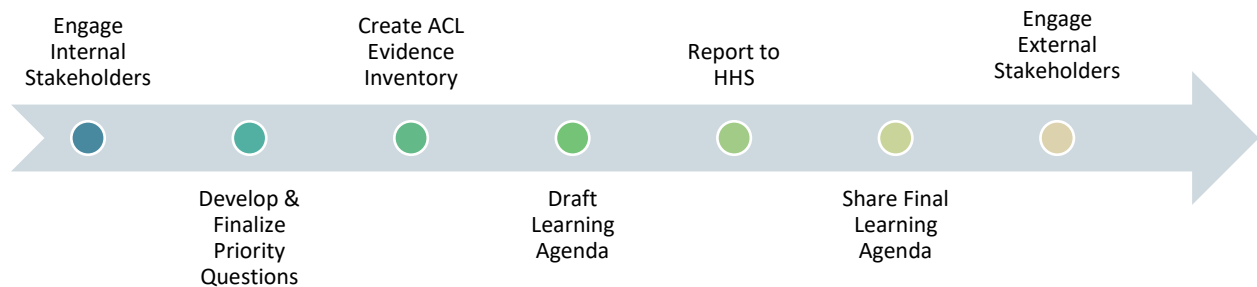
- **Support ACL budget requests and justifications:** As the Office of Management and Budget increasingly requests evidence to justify budget requests, the data ACL compiles to answer its priority questions will support ACL’s provision of concrete, empirically based responses.
- **Allow for more substantive participation in the HHS strategic planning process:** The learning agenda process invites cross-ACL participation in determining how best to advance ACL priorities and HHS priorities.
- **Increase the value of technical assistance:** ACL will continue to use evidence about what works, and for whom, to direct technical assistance. Conducting analyses across ACL data sets may reveal new trends across grantees and grant programs about the types of activities associated with the most positive impact. Each ACL-funded resource center may also benefit from this cross-agency approach, leveraging their specific programmatic focus, outreach, and technical assistance activities.

- **Improve funding opportunity announcements:** ACL will integrate findings into funding announcements. For example, if ACL determines that certain types of partnerships are common among the most successful community capacity-building grantees, future funding opportunity announcements might require that awardees have such partnerships in place before award. Alternatively, ACL might award developmental grants to help potential grantees build the needed partnerships to bolster their chances for success.
- **Improve ACL operations:** The learning agenda will also help inform priority questions about staffing, operations, and communication, as well as staff training, selection of new hires, and opportunities to streamline ACL operations.
- **Enhance external stakeholder engagement:** ACL will continue to solicit input from external stakeholders on agency priority questions and evidence-building activities and expand ACL’s understanding of activities occurring throughout the aging and disability networks that support the ACL mission.

## ACL’s Learning Agenda Development Process

The learning agenda was developed by the Office of Performance and Evaluation (OPE) within ACL’s Center for Policy and Evaluation (CPE). Staff employed a participatory, inclusive, and collaborative approach to develop the ACL learning agenda (Figure 1). As a result, the learning agenda reflects the overarching vision of ACL and its priority areas while incorporating the essential perspectives of each of its centers and the work they do to support older adults, people with disabilities across the lifespan, and their families and caregivers.

**Figure 1: Learning Agenda Development Process**



### *Phase 1: Engage Internal Stakeholders (November 2018 – April 2020)*

OPE held a series of meetings with directors and staff of each ACL center as well as other key ACL staff members to develop priority questions and identify existing and potential evidence.

### *Phase 2: Develop and Finalize Priority Questions (October 2019 – March 2020)*

ACL’s internal stakeholders submitted 74 draft priority questions which OPE streamlined into 11 cross-cutting priority questions and 63 sub-questions that are narrower in scope and will be used internally to focus ACL’s learning activities. The priority questions and sub-questions are reflective of ACL’s priorities – including the five pillars established by ACL leadership. The pillars are key areas of focus because they

are critically important across both aging and disability, and are areas in which ACL – and the aging and disability networks – can make a huge difference. The pillars are: 1) Connecting people to resources; 2) Protecting rights and preventing abuse; 3) Supporting families and caregivers; 4) Strengthening our networks; 5) Expanding Employment Opportunities.

ACL’s internal stakeholders ultimately selected a single question and sub-question, discussed below, for the focus of this interim learning agenda with the intention of addressing other questions as resources allow.

*Phase 3: Create ACL Evidence Inventory (October 2019 – Ongoing)*

OPE created an inventory of existing evidence produced or funded by ACL. This inventory will be maintained and updated with newly identified sources throughout the life of the learning agenda.

*Phase 4: Draft Learning Agenda (December 2019 – July 2020)*

OPE utilized an iterative development and review process to draft an interim learning agenda with the requirements set forth in the Foundations for Evidence-Based Policymaking Act of 2018, guidance from Office of Management and Budget and HHS, and internal stakeholder feedback.

*Phase 5: Report to HHS (June 2020)*

OPE submitted its agency priority question and sub-question to HHS for its agency wide evidence-building plan (learning agenda).

*Phase 6: Share Final Learning Agenda (September 2020)*

The interim learning agenda was posted on the ACL website.

*Phase 7: Engage External Stakeholders (Postponed due to coronavirus [COVID-19] pandemic)*

OPE plans to hold virtual meetings with stakeholders to provide information about the learning agenda and solicit their feedback on the framing of the selected priority question and sub-question, as well as the planned learning activities and learning products.

## ACL’s Priority Question and Sub-question

*“All people, regardless of age or disability, should be able to live independently and participate fully in their communities, and have the right to make choices and control the decisions in and about their lives.”<sup>4</sup>*

ACL’s interim learning agenda focuses on the following priority question and sub-question:

**Priority Question:** What is the efficacy and effectiveness of ACL programs and initiatives?  
**Sub-question:** Is ACL being effective in its caregiver support programs?

This question and sub-question are relevant to all of ACL’s Centers. The results will affect services for all of ACL’s target populations and a wide range of ACL stakeholders.

## The Importance of Caregiving

In 2020 there are approximately 17 million individuals living in communities in the United States who require assistance completing self-care and other activities of daily living (ADLs) due to physical, cognitive, developmental, and/or behavioral challenges.<sup>5</sup> The need for informal and formal caregivers supporting older adults and people with disabilities is increasing.<sup>6,7</sup> Between 2015 and 2020, the number of informal caregivers grew 22% to 53 million.<sup>8</sup> The number of direct care workers (formal caregivers) almost doubled between 2008 and 2018 to approximately 4.5 million and is projected to grow another 36% between 2018 and 2028.<sup>9</sup> The annual economic impact of caregiving is valued at \$525 billion for informal caregiving<sup>10, 11</sup> and \$10.8 billion for formal home health services.<sup>12</sup>

Informal and formal caregiving are becoming more complex and intense, with caregivers increasingly performing medical and nursing tasks<sup>13,14</sup> for care recipients with greater health and functional needs.<sup>15</sup> As a result, both informal and formal caregivers need a range of training and supports, including more evidence-based programs, to meet the multifaceted needs of their care recipients.<sup>16</sup> Informal caregivers also report facing difficulty coordinating recipients' care across various providers<sup>17,18</sup> and coping with the emotional, physical, and financial pressure associated with caregiving.<sup>19,20</sup> Formal caregivers have needs related to building interpersonal, linguistic, and cultural competencies to better support diverse care recipients and their families.<sup>21,22</sup>

## ACL Learning Activities

Many ACL programs and councils support and empower caregivers and family members of older adults and people with disabilities. They are listed below, and a description of each is included in Appendix A. Data from and about these programs will be compiled as part of the evidence inventory to allow easier access for ACL staff and stakeholders.

- ACL-Funded Resource Centers
- Advisory Council to Support Grandparents Raising Grandchildren
- Aging and Disability Evidence-Based Programs and Practices
- Aging and Disability Resource Centers/No Wrong Door
- Alzheimer's Disease Programs
- Assistive Technology Act Programs
- Centers for Independent Living
- Lifespan Respite Care Program
- National Family Caregiver Support Program
- Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregiver Advisory Council
- Rehabilitation Research and Training Center Programs
- Supporting Families Communities of Practice
- Title VI Programs – Native American caregiver support services
- University Centers for Excellence in Developmental Disabilities Education, Research, and Service
- Veterans Directed Care Program (formerly known as Veteran-Directed Home and Community Based Services, or VD-HCBS)

To identify gaps in the types of evidence available, the existing ACL evidence has also been organized by type (see Appendix B).

ACL will examine data from the National Survey for Older Americans Act Participants (NSOAAP), Lifespan Respite Care Program Performance Report, Alzheimer's Disease Programs Initiative Performance Report, State Program Report for grantees funded under Title III of the Older Americans Act, and the Program Performance Report for grantees funded under Title VI of the Older Americans Act.

The NSOAAP data provide information on outcomes that demonstrate the effect and quality of Older Americans Act (OAA) Title III services, including its caregiver services. Service recipient demographics, as well as health and well-being indicators, are collected. The performance data include information about the number of people served and the amount of service provided to caregivers. ACL will compare response frequencies across grantees and examine trends over time. A limited number of correlations examining topics such as the relationship between levels of funding and numbers of people served may also be calculated.

ACL will engage in process, outcome, and economic evaluations, including the following:

- National Family Caregiver Support Program (NFCSP) Evaluation (completed process and outcome evaluations)
- Evaluation of Home and Community-Based Support Services for Older American Indians, Alaska Natives, and Native Hawaiians (process and outcome evaluations scheduled for completion in summer 2021)
- Supporting Families Community of Practice (CoP) Evaluation (retrospective evaluation scheduled for completion in fall 2020)

Other sources of information are the areas of potential investment provided in the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) Long Range Plan, which includes sponsoring the development and implementation of a research agenda on informal caregivers and family members of people with disabilities. The purpose is to promote the community living outcomes of people with disabilities by understanding the economic, social, and health needs of their informal caregivers. This work includes, but is not limited to, the following projects:

- A Lifestyle Intervention Targeting Enhanced Health and Function for Persons with Chronic Spinal Cord Injury (SCI) in Caregiver/Care-Receiver Relationships: Effects of Caregiver Co-treatment, University of Miami, Miami, FL, Grant #90DP0074
- Comparing Transition Support Interventions for Family Caregivers of Acquired Brain Injury (ABI) Patients, Virginia C. Crawford Research Institute, Atlanta, GA, Grant # 90IFRE0026
- Measuring Post-traumatic Growth in Caregiving Family of Acquired Brain Injury Survivors: A New Scale, Research Fellow, Capacity Building, New York, NY, Grant #90SFGE0013
- Center for Research, Training, and Dissemination of Family Support for People with Disabilities Across the Life Course, University of Pittsburgh, Pittsburgh, PA. This NIDILRR-funded center conducts research, training, technical assistance, and dissemination under the theme of Caregiver Support Empowers the Whole Family. Its mission is to facilitate the rapid translation and dissemination of state-of-the-art research and training to inform direct services and support programs designed to improve care, health, and quality of life of people with disabilities and their families.

ACL is planning the following new data collections:

- OPE is considering adding a topical module to the National Survey of Older Americans Act Participants. This module will provide data from a representative sample of OAA clients about



caregiving needs and approaches. Survey frequencies will be calculated and, where possible, compared to other relevant data.

- A process evaluation of the National Aging Network and its return on investment, planned for fall 2020 through fall 2024, will focus on identifying members of the aging network and their work beyond that funded by ACL. ACL is interested in looking at ways to measure return on investment of the services that ACL provides through its grantees and partners. Although not the primary focus, the aging network's engagement in caregiving will be part of this evaluation. Data will be collected through records reviews, interviews, focus groups, and surveys. Analysis of the largely qualitative data will build understanding of how the aging network affects the efficacy and effectiveness of ACL programs.
- A fidelity evaluation of ACL's evidence-based programs, planned for fall 2020 through fall 2022, will focus on the adherence of programs to the implementation standards for evidence-based programming awards funded through the OAA. Several of the evidence-based programs funded under the OAA address or focus on caregivers and caregiving. Data will be collected through interviews, surveys, and focus groups. Analyses will focus on observable implementation features, such as how sites select appropriate evidence-based programs for their various contexts (e.g., resources, populations) and to what extent staff who oversee and implement the programs understand and comply with the implementation guidelines.
- A flexible evaluation and research support contract, planned from fall 2020 through fall 2025, will allow OPE to plan and implement a series of studies about the efficacy and effectiveness of ACL's suite of grants and initiatives focused on supporting caregivers across the lifespan. Of particular interest are ACL's NFCSP, Lifespan Respite Care, and Alzheimer's Disease Program Initiative, as well as the role that the RAISE Family Caregivers Act and Supporting Grandparents Raising Grandchildren Advisory Councils will have on ACL's caregiver support services. Through a combination of stakeholder engagement activities and reviews of the existing data about ACL caregiver programs, ACL will identify specific topics for research under this contract. At that point, ACL will develop data, tools, and analytic approaches in accordance with ACL's evaluation policy.

## ACL Learning Products

In addition to evaluation reports, which ACL publishes on its website, a series of issue briefs, webinars, data profiles, blog posts, and fact sheets will be published on the ACL Aging, Independence, and Disability Program Data Portal (AGID). OPE staff will present data to internal stakeholders through periodic briefings and to external stakeholders through conference presentations. OPE is also planning a panel with subject matter experts for fall 2020 or winter 2021 to discuss the interim learning agenda and to help shape ACL's learning activities and products.

## Challenges and Mitigation Strategies

ACL may encounter challenges in gathering evidence with which to answer its priority question and sub-question. Following are examples of potential challenges and mitigation strategies.

- While ACL has conducted an outcome program evaluation of the NFCSP, it has not conducted evaluations of other ACL caregiver programs, including the Lifespan Respite Program and the Alzheimer's Disease Programs Initiative, to examine their effectiveness. ACL will assess the evaluability of the programs and consider available resources and capacity to conduct outcome evaluations of them.
- While the Older Americans Act allocates funds for evidence-building activities, other ACL authorizing legislation does not. The lack of dedicated funding presents a barrier for consistent and comprehensive evidence building. ACL staff will explore funding opportunities, and OPE staff will continue to offer flexible contracting mechanisms that give ACL centers and programs an easy way to conduct high quality evidence-building activities.
- Outcome evaluations do not provide real-time information as they can require three to six years to complete. ACL will examine the feasibility of rapid-cycle evaluations to answer short-term and immediate-term outcome evaluation questions.
- The findings from ACL evaluations suggest that important and significant changes to ACL programs and congressional funding vary due to time and changes in authorizing legislation. ACL will explore how best to use evaluation results to benefit its programs and services.
- There is a danger of potential stakeholder disengagement over time. OPE will meet with internal and external stakeholders annually on behalf of ACL leadership to review and update the learning agenda.
- Agency funding levels impact the range of learning activities that ACL can conduct. The planned panel with subject matter experts and wide dissemination of this learning agenda are designed to encourage interest by external researchers. In addition, ACL will develop a stakeholder engagement plan that includes a focus on partnerships to encourage external focus on the selected priority question.

## Appendix A–ACL Caregiver Support Program Descriptions

### *ACL-Funded Resource Centers*

ACL's resource centers provide information primarily for professionals; however, many also offer consumer information to family caregivers. These include the Eldercare Locator, the National Alzheimer's Call Center, the National Center on Elder Abuse, the National Clearinghouse for Long-Term Care Information, and the Senior Medical Patrol National Resource Center. To see the full list of resource centers that provide consumer information, visit <https://acl.gov/node/2884>.

### *Advisory Council to Support Grandparents Raising Grandchildren*

Supporting Grandparents Raising Grandchildren Act (Pub. L. 115-196) established an Advisory Council to Support Grandparents Raising Grandchildren. The Advisory Council identifies, promotes, coordinates, and disseminates to the public information, resources, and the best practices available to help grandparents and other older relatives both meet the needs of the children in their care and maintain their own physical and mental health and emotional well-being.

### *Aging and Disability Evidence-Based Programs and Practices*

The purpose of the Aging and Disability Evidence-Based Programs and Practices is to help the public learn more about available evidence-based programs and practices in the areas of aging and disability and determine which of these may best meet their needs. The identified programs and practices address health and wellness, long-term services and supports (LTSS), caregiver and family support, and mental health promotion.

### *Aging and Disability Resource Centers/No Wrong Door*

The No Wrong Door System initiative is a collaborative effort of the ACL, the Centers for Medicare & Medicaid Services (CMS), and the Veterans Health Administration (VHA). The No Wrong Door System initiative builds upon the Aging and Disability Resource Center program and CMS' Balancing Incentive Program. No Wrong Door requirements support state efforts to streamline access to LTSS options for older adults and individuals with disabilities. No Wrong Door systems provide information and assistance to individuals needing either public or private resources, professionals seeking assistance on behalf of their clients, and individuals planning for their future long-term care needs. No Wrong Door systems also serve as the entry point to publicly administered long-term supports, including programs funded under Medicaid, the OAA, VHA, and state revenue.

### *Alzheimer's Disease Programs*

In 1992, Congress created the Alzheimer's Disease Supportive Services Program (ADSSP) to support state efforts to expand the availability of community-level supportive services for persons with Alzheimer's disease and related dementias (ADRD). In 1998, Congress transferred the administration of the program to ACL. Between 2008 and 2017, ACL funded 108 ADSSP projects across the nation. In 2020, ACL publicized the Alzheimer's Disease Programs Initiative, to provide funding to support and promote the development and expansion of dementia-capable home- and community-based services (HCBS) systems. The dementia-capable systems resulting from program activities are expected to provide quality, person-centered services and supports that help people living with dementia and their caregivers remain independent and safe in their communities.

### *Assistive Technology Act Programs*

This Act supports programs providing grants to states for addressing assistive technology needs of individuals with disabilities. The goal is to increase awareness of and access to assistive technology

devices and services that may help with education, employment, daily activities, and inclusion of people with disabilities in their communities.

### *Centers for Independent Living*

The Centers for Independent Living (CILs) program provides 354 discretionary grants to CILs, which are consumer-controlled, community-based, cross-disability, nonresidential, private nonprofit agencies that provide independent living services. At a minimum, centers funded by the program are required to provide information and referral, independent living skills training, peer counseling, individual and systems advocacy, and services that facilitate transition from nursing homes and other institutions to the community; provide assistance to those at risk of entering institutions; and facilitate transition of youth to postsecondary life. Individual CIL projects may also provide services to support caregivers.

### *Lifespan Respite Care Program*

The Lifespan Respite Care Program was authorized by Congress in 2006 under Title XXIX of the Public Health Service Act (42 U.S.C 201). Lifespan Respite Care programs are coordinated systems of accessible, community-based respite care services for family caregivers of children and adults of all ages with special needs. As of 2017, competitive grants of up to \$200,000 each were awarded to eligible agencies in 37 states and the District of Columbia. Participating states have developed or built upon respite infrastructures to enhance or improve access to and receipt of respite services, and they are focusing on providing gap-filling respite services to family caregivers and working with ACL to develop program performance and outcome measures.

### *National Family Caregiver Support Program*

Congress established the National Family Caregiver Support Program (NFCSP) in 2000 as part of the reauthorization of the OAA. The NFCSP provides grants to states and territories to make available five core services for caregivers: assistance for gaining access to services; training/education, individual counseling, support groups; information about available services; respite care; and supplemental services such as transportation, home modifications, medical equipment, assistive technologies, and emergency response systems.

### *RAISE Family Caregiver Advisory Council*

The Recognize, Assist, Include, Support, and Encourage (RAISE) Family Caregivers Act, which became law on January 22, 2018, directs the Secretary of Health and Human Services (HHS) to develop a national family caregiving strategy. The strategy will identify actions that communities, providers, government, and others are taking and may take to recognize and support family caregivers. To support the development and execution of the strategy, the RAISE Act also directs the establishment of the Family Caregiving Advisory Council. The council is charged with providing recommendations to the Secretary of HHS on effective models of both family caregiving and support to family caregivers, as well as improving coordination across federal government programs.

### *Rehabilitation Research and Training Center Programs*

The Rehabilitation Research and Training Center programs are funded through ACL's National Institute on Disability, Independent Living, and Rehabilitation Research. The programs conduct coordinated, integrated, and advanced programs of research, training, and information dissemination to improve rehabilitation methodology and service delivery systems; improve health and functioning; and promote employment, independent living, family support, and economic and social self-sufficiency for individuals with disabilities.

### *Supporting Families Communities of Practice*

In 2012, ACL funded a National Community of Practice for Supporting Families (CoP) to build capacity across and within states to create policies, practices, and systems to better assist and support families that include a member with intellectual or developmental disabilities across the lifespan. ACL awarded a five-year grant to the National Association of State Directors of Developmental Disabilities Services (NASDDDS) in collaboration with the University of Missouri–Kansas City Institute on Human Development and the Human Services Research Institute. The project initially included five states and a mentor state. In 2016, the CoP expanded to 10 additional states as an NASDDDS membership option.

### *Title VI of the Older Americans Act*

Under Title VI of the Older Americans Act, ACL funds programs that support American Indians, Alaska Natives, and Native Hawaiians in the areas of nutrition, supportive services for older adults, and caregiver services. Caregiver services are intended to support American Indian, Alaska Native, and Native Hawaiian families caring for older relatives with chronic illness or disability and grandparents caring for grandchildren. The program offers a variety of services including information and outreach, access assistance, individual counseling, support groups and training, respite care, and other supplemental services.

### *University Centers for Excellence in Developmental Disabilities Education, Research & Service*

University Centers for Excellence in Developmental Disabilities Education, Research & Service (UCEDDs) are a nationwide network of independent but interlinked centers, representing an expansive national resource for addressing issues, finding solutions, and advancing research related to the needs of individuals with developmental disabilities and their families. UCEDDs support activities that address a range of issues, from prevention and early intervention to supported employment. UCEDD activities also focus on supporting families and caregivers of individuals with developmental disabilities. Specific services and resources available through UCEDDs may vary, but many offer a variety of resources for families and caregivers, including education, training, skill building, planning, service coordination and referral, home modifications, assistive technology, and research.

### *Veterans-Directed Care Program (Formerly Known as VD-HCBS Program)*

In 2008, ACL, on behalf of HHS, began a partnership with Veterans Health Administration (VHA) to serve veterans of all ages at risk of nursing home placement through the Veteran Directed Care Program (formerly known as Veteran-Directed Home and Community Based Services [HCBS]). The purpose of the program is to have an LTSS system that is person centered and consumer directed, and that helps people at risk of institutionalization to continue to live at home and engage in community life. Through the program, the VHA increases access to HCBS to serve the growing demand of veterans who prefer independence at home over living in a nursing facility.

## Appendix B – Existing Evidence Presented by Evidence Type

### Foundational Fact Finding

*National Institute on Disability, Independent Living, and Rehabilitation Research*

1. **A Lifestyle Intervention Targeting Enhanced Health and Function for Persons with Chronic SCI in Caregiver/Care-Receiver Relationships: Effects of Caregiver Co-Treatment**, University of Miami, Miami, FL, Grant # 90DP0074

This project evaluates and tests a population-specific lifestyle intervention in persons with spinal cord injury (SCI) that significantly improves fitness, lessens the risk of cardiometabolic disease, and reduces body mass, thus improving the execution of daily activities.

2. **Comparing Transition Support Interventions for Family Caregivers of Acquired Brain Injury (ABI) Patients**, Virginia C. Crawford Research Institute, Atlanta, GA, Grant # 90IFRE0026

The goal of this research project is to compare the effectiveness of two interventions that offer support to caregivers of patients with ABI during the transition home from inpatient rehabilitation.

3. **Center for Research, Training, and Dissemination of Family Support for People with Disabilities Across the Life Course**, University of Pittsburgh, Pittsburgh, PA

The Center for Research, Training, and Dissemination of Family Support for People with Disabilities Across the Life Course focuses on research, training, technical assistance, and dissemination efforts under the theme of Caregiver Support Empowers the Whole Family. The mission of this center is to facilitate the rapid translation and dissemination of state-of-the-art research and training to inform direct services and support programs designed to improve care, health, and quality of life for people with disabilities and their families.

4. **Measuring Post-traumatic Growth in Caregiving Family of Acquired Brain Injury Survivors: A New Scale**, Research Fellow, Capacity Building, New York, NY, Grant #90SFGE0013

This project develops and evaluates a potential new rehabilitation data measure, the Post-traumatic Growth Scale in Caregiving Families of Persons with ABI. This self-administered clinical and research tool fills a gap in the assessment of family caregivers of adults with ABI by measuring the psychosocial and behavioral functioning of the caregivers. The development of this instrument is based on previous work that resulted in the creation of an instrument that measures personal growth in caregiving partners of persons with multiple sclerosis.

5. **Environmental Barriers and Facilitators to Assisted Toilet Transfers by People Aging With Disability and Their Spousal Caregivers**, Georgia Tech Research Corporation, Center for Assistive Technology and Environmental Access, Atlanta, GA, Grant #90IFRE0005

This project identifies environmental factors that create barriers and facilitators to caregiver-assisted transfers for individuals aging with disability to inform the development of design criteria for dyadic-centered assistive technology toilet transfer interventions.

6. **Rehabilitation Research and Training Center on Family Support**, The Board of Trustees of the University of Illinois, College of Applied Health Sciences, Department of Disability and Human Development, Chicago, IL, Grant #90RT5032

The Rehabilitation Research and Training Center on Family Support bridges aging and disability research, practice, and policies to generate new knowledge in family support, which contributes to improvements in community living, participation, health and function, and other potential data for individuals with disabilities from different racial and ethnic backgrounds supported by family members. The center conducts six research projects that develop a strategic plan for family support, identify promising practices in family support services, and understand family member roles and well-being in self-directed waiver programs. The center also studies the experiences, trends, and needs in self-directed support programs; the impact of transitioning from fee-for-service to managed care on families and individuals who receive services; and the efficacy of an intervention that engages parents of children with autism spectrum disorder in providing education and training to other parents.

**7. Advanced Training in Translational and Transformational Research to Improve Potential Data for People With Disabilities**, Research and Training Center on Community Living for People with Intellectual Disabilities, University of Minnesota, The Institute on Community Integration, Minneapolis, MN, Grant #90RT5019

The University of Minnesota's Research and Training Center on Community Living (RTC/CL) conducts research, training/technical assistance, and dissemination activities focused on community living and participation of individuals with intellectual and developmental disabilities. The RTC/CL provides a comprehensive training program that has developed and will continue to develop new generations of competent and skilled disability researchers and professionals. Outreach programs provide training and technical assistance to agencies and individuals across the country.

*Administration on Disabilities*

**8. University Centers for Excellence in Developmental Disabilities Education, Research & Service (UCEDDs)**

University Centers for Excellence in Developmental Disabilities Education, Research & Service (UCEDDs) are a nationwide network of independent but interlinked centers, representing an expansive national resource for addressing issues, finding solutions, and advancing research related to the needs of individuals with developmental disabilities and their families. They offer a variety of resources for families and caregivers including guides, videos, webinars, and training.

**9. University of Montana, The Rural Institute for Inclusive Communities**, Personal assistance services: Differences in rural versus less rural U.S. states, Montana, Grant #90DD0002

This paper explores differences in personal assistance services availability in rural and urban areas as one source of rural–urban disparities in health and participation. The University of Montana Rural Institute: A Center for Excellence in Developmental Disabilities provides education, research, and services to improve the quality of life of people living with intellectual/developmental and other disabilities, paying particular attention to the needs of those who live in rural communities.

**10. University of Minnesota, College of Education and Human Development, Institute on Community Integration**, Minnesota, Grant #90DDUC070

The project offers a nationwide, online, competency-based training curriculum to enhance the skills and knowledge of direct support professionals, frontline supervisors, and managers supporting individuals with disabilities in community settings. It is part of DirectCourse, a suite of competency-based online curricula for professionals providing services to people with intellectual, developmental, physical, and psychiatric disabilities, and to older adults.

**11. University of Oklahoma Health Sciences Center, College of Medicine, Center for Interdisciplinary Learning and Leadership,** African-American caregivers' perceptions of care needs affecting access to services for their children with autism, Oklahoma

This qualitative study identifies caregiver beliefs, knowledge, and expectations that influence their help seeking and the specific help-seeking steps they use to obtain care.

**12. University of Cincinnati Center for Excellence in Developmental Disabilities, Cincinnati Children's Hospital Medical Center, Division of Developmental and Behavioral Pediatrics,** Ohio, Grant #90DDUC0013

In the current study, a family navigation program will be created within the Division of Developmental and Behavioral Pediatrics (DDBP) in Cincinnati Children's Hospital Medical Center (CCHMC). Family navigators, or caregivers of children with developmental disabilities and/or chronic illnesses, will work with families of newly diagnosed children in DDBP to navigate the often confusing and overwhelming systems both inside CCHMC and in the family community. Data related to family quality of life, parent activation, and parental stress will be obtained and analyzed.

**13. University of Delaware, Center for Disabilities Studies, College of Education and Human Development,** Delaware, Grant #90DDUC0026

The program provides home modifications and AT to eliminate such barriers for individuals who are unable to live safely and comfortably in their homes due to an issue related to a paralysis-causing condition and who have exhausted their search for funding from other sources.

**14. Tennessee Developmental Disabilities Council,** Tennessee, Grant #1801TNBSDD

Through participation in the National Community of Practice (CoP) for Supporting Families, the Tennessee Developmental Disabilities Council partnered closely with the state Medicaid and disability services agencies in the development of a new waiver program for Tennesseans with intellectual and developmental disabilities and their families and the Employment and Community First (ECF) CHOICES program. They ensured that information shared was family friendly and that families had the opportunity to give feedback through two listening sessions/focus groups to managed care organizations about their needs before the program launched. They emphasized the need for services to support family caregivers and people living with disabilities. ECF also conducts family caregiver assessments to evaluate the needs of families who enroll.

*Administration on Disabilities  
Centers for Independent Living (CILs)*

**15. Active Re-Entry Center for Independent Living (ARECIL),** Utah, Grant #1703UTILCL

ARECIL is a community-based program which assists individuals with disabilities to achieve or maintain self-sufficient and productive lives in their own communities and homes. It offers varied programs and resources, including information and referral, independent living skills training, individual and systems advocacy, peer counseling and support, and nursing home diversity and transition. ARECIL continues to be the only rural in-home provider of the music and memory program. This program has transformed lives through music with individuals with initial stages of dementia. While it is being expanded into nursing homes, ARECIL staff felt that there were many individuals still living in their own homes who would benefit from this program. As a result, the program coordinator became a certified music and memory specialist. Funded through a special grant from the Southeast Utah Area Agency on Aging in its preventative health program, the program has 47 enrollees.



**16. Silicon Valley Independent Living Center (SVILC), California, Grant #1732CAILCL**

SVILC provides residents with support tools and resources needed to live interdependently and advocates for policies that ensure equal access and opportunity for all. SVILC is a peer-driven agency run by and for people with disabilities. It is committed to the principles of self-advocacy, personal empowerment, and independent living. SVILC launched an online portal service that specializes in matching an individual with a caregiver or a personal assistant who helps an individual with activities of daily living in their home, community, school and workplace.

**17. Loudoun ENDEpendence (LEND), Virginia, Grant #1702VAILCL**

Loudoun ENDEpendence (LEND) is a program that provides core services to people with disabilities to facilitate their full participation in community life. These services include advocacy, information and referral, independent skills training, and peer mentoring. LEND conducted workshops and other informational sessions of interest to the target population, free of charge, at widely accessible locations within the community. The workshops were open to the public, people with disabilities, their caregivers and families, and members of the medical community.

**18. Lifetime Independence for Everyone (LIFE), Inc., Texas, Grant #1715TXILCL**

In 2015, LIFE designed an "At Risk" Survey that is used to better assist consumers in maintaining their choice to live in a community-based setting. In creating LIFE's "At Risk" Survey, the center looked at several research studies and surveys that addressed nursing home placement of older adults.

## Program Evaluation

**19. National Family Caregiver Support Program (NFCSP) Evaluation**

ACL conducted a two-part evaluation of the NFCSP program. The first part was a process evaluation conducted from January to December 2015 with the overall purpose of understanding and documenting the strategies used to meet NFCSP goals. The second part was an outcome evaluation that was conducted from winter 2016/2017 to winter 2017/2018. It described NFCSP participants' demographic and caregiving characteristics and examined the impact of the program on key caregiving outcomes such as burden and confidence.

The project collected survey responses from representative groups: NFCSP caregivers, non-NFCSP caregivers, and care recipients in both groups. Evaluators used a two-stage stratified probability sample of Area Agency on Aging clients who were listed as recipients of NFCSP services. They conducted a series of difference-in-differences analyses (i.e., longitudinal difference-in-differences) to compare changes in outcomes across time for program caregivers versus comparison caregivers. Propensity score matching created pairings between program and comparison caregivers and permitted analysis of differences between program and comparison groups.

In 2018, a third part was added to this evaluation when ACL funded a small retrospective study to gather information on the service components and needs of a subset of bereaved caregivers from the NFCSP evaluation. Reports on all parts of this evaluation are available on the ACL website on the Program Evaluations and Reports page, <https://acl.gov/programs/program-evaluations-and-reports>, under The Caregiver Outcome Evaluation Study of the National Family Caregiver Support Program.

**20. Evaluation of Home and Community-Based Support Services for Older American Indians, Alaska Natives, and Native Hawaiians**

In 2016, ACL Administration on Aging funded this evaluation Title VI of the OAA which promotes the delivery of nutrition, supportive and caregiver services to American Indians, Alaska Natives, and Native

Hawaiians. The evaluation builds on earlier evaluability assessment of OAA Title VI programs. The evaluation design utilized a participatory action research model to involve stakeholders in all phases of the project. The evaluation team also provided grantees participating in the evaluation with training and technical assistance to meet their own data needs. The evaluation consisted of a two-part design: first, the implementation study (to identify program context, input and resources, activities/strategies, and outputs) and second, the outcome study (short-term and long-term program outcomes, elder and participant satisfaction).

### **21. Supporting Families Community of Practice (CoP) Evaluation**

To assess progress toward national project outcomes and identify successful emerging practices that improve support for families of individuals with intellectual and developmental disabilities, ACL funded an evaluation of the Supporting Families CoP incorporating the Charting the LifeCourse (CtLC) framework. The evaluation includes 16 states that participated in the National CoP for at least 2 years between 2012 and 2018. The evaluation team classified states in three groups, based on the time when they joined the national CoP and their prior experience with the CtLC framework. The evaluation team used four different strategies to collect data from states: reporting tools, telephone interviews, site visits, and materials review (initially, on an ad hoc basis; since discontinued). Using the value cycle framework, the evaluation team analyzed data and linked specific activities with outcomes of interest.

## **Performance Management**

### **22. National Survey of Older Americans Act Participants (NSOAAP)**

ACL conducts an annual national survey of recipients of select OAA Title III services (Homemaker, Case Management, Transportation, Home Delivered Meals, Congregate Meals, and Family Caregiver/NFCSP). The survey focuses on consumer assessment of service quality and consumer-reported outcomes. The survey also measures special needs characteristics, such as physical and social functioning of the people who receive services.

### **23. Older Americans Act State Performance Report, Program Performance Report, and Ombudsman Reporting Tool Data Collection**

ACL collects annual performance data from grantees on the programs and services provided and funded by the Older Americans Act Titles III, VI, and VII, which include performance data on caregiving support services.

### **24. Lifespan Respite Care Program Performance Data**

ACL collects program and performance outcome data from its state grantees focusing on their work to improve the delivery and quality of respite services to family caregivers.

### **25. Alzheimer's Disease Programs Initiative Performance Data**

ACL collects program and performance outcome data from its state grantees focusing on basic demographic information, numbers and types of professionals trained, hours of direct services specific to the project, and other data elements.

## References

- 
- <sup>1</sup> Administration for Community Living. (n.d.). *Advancing independence, integration, and inclusion throughout life*. <https://acl.gov/>
- <sup>2</sup> Office of Management and Budget. (2019, July 10). *Phase 1 implementation of the Foundations for Evidence-Based Policymaking Act of 2018: Learning agendas, personnel, and planning guidance*. (Memorandum M-19-23). <https://www.whitehouse.gov/wp-content/uploads/2019/07/M-19-23.pdf>
- <sup>3</sup> Office of Management and Budget. (2019, July 10). *Phase 1 implementation of the Foundations for Evidence-Based Policymaking Act of 2018: Learning agendas, personnel, and planning guidance*. (Memorandum M-19-23). <https://www.whitehouse.gov/wp-content/uploads/2019/07/M-19-23.pdf>
- <sup>4</sup> Administration for Community Living. (n.d.). *Advancing independence, integration, and inclusion throughout life*. <https://acl.gov/>
- <sup>5</sup> Scales, K. (2020). *It's time to care: A detailed profile of America's direct care workforce*. PHI. <https://phinational.org/wp-content/uploads/2020/01/Its-Time-to-Care-2020-PHI.pdf>
- <sup>6</sup> Centers for Disease Control and Prevention. (n.d.). *Alzheimer's disease and healthy aging: Caregiving for friends and family – a public health issue*. <https://www.cdc.gov/aging/caregiving/caregiver-brief.html>
- <sup>7</sup> AARP & National Alliance for Caregiving. (2020, May). *Caregiving in the U.S.* <https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf>
- <sup>8</sup> AARP & National Alliance for Caregiving. (2020, May). *Executive summary: Caregiving in the U.S.* <https://www.caregiving.org/wp-content/uploads/2020/05/Executive-Summary-Caregiving-in-the-United-States-2020.pdf>
- <sup>9</sup> Scales, K. (2020). *It's time to care: A detailed profile of America's direct care workforce*. PHI. <https://phinational.org/wp-content/uploads/2020/01/Its-Time-to-Care-2020-PHI.pdf>
- <sup>10</sup> National Academies of Sciences, Engineering, and Medicine. (2016). *Families caring for an aging America*. National Academies Press.
- <sup>11</sup> Lewin Group. (2016, March). *Process evaluation of the Older Americans Act Title III-E National Family Caregiver Support Program: Final report*. [https://acl.gov/sites/default/files/programs/2017-02/NFCSF\\_Final\\_Report-update.pdf](https://acl.gov/sites/default/files/programs/2017-02/NFCSF_Final_Report-update.pdf)
- <sup>12</sup> Holly, R. (2019, February 20). *Home health spending rate projected to surpass all other care categories*. Home Health Care News. <https://homehealthcarenews.com/2019/02/home-health-spending-rate-projected-to-surpass-all-other-care-categories/>
- <sup>13</sup> Reinhard, S. C., Feinberg, L. F., Houser, A., Choula, R., & Evans, M. (2019, November). *Valuing the invaluable: 2019 update*. AARP Public Policy Institute. <https://www.aarp.org/content/dam/aarp/ppi/2019/11/valuing-the-invaluable-2019-update-charting-a-path-forward.doi.10.26419-2Fppi.00082.001.pdf>
- <sup>14</sup> Scales, K. (2020). *It's time to care: A detailed profile of America's direct care workforce*. PHI. <https://phinational.org/wp-content/uploads/2020/01/Its-Time-to-Care-2020-PHI.pdf>
- <sup>15</sup> AARP & National Alliance for Caregiving. (2020, May). *Executive summary: Caregiving in the U.S.* <https://www.caregiving.org/wp-content/uploads/2020/05/Executive-Summary-Caregiving-in-the-United-States-2020.pdf>

- <sup>16</sup> Administration for Community Living. (n.d.). *Rehabilitation Research and Training Center (RRTC) on Family Support*. <https://acl.gov/grants/rehabilitation-research-and-training-center-rrtc-family-support>
- <sup>17</sup> AARP & National Alliance for Caregiving. (2020, May). *Executive summary: Caregiving in the U.S.* <https://www.caregiving.org/wp-content/uploads/2020/05/Executive-Summary-Caregiving-in-the-United-States-2020.pdf>
- <sup>18</sup> Administration for Community Living. (n.d.). *National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR): 2018–2023 long-range plan*. <https://acl.gov/sites/default/files/about-acl/2019-01/NIDILRR%20LRP-2018-2023-Final.pdf>
- <sup>19</sup> AARP & National Alliance for Caregiving. (2020, May). *Caregiving in the U.S.* <https://www.aarp.org/content/dam/aarp/ppi/2020/05/full-report-caregiving-in-the-united-states.doi.10.26419-2Fppi.00103.001.pdf>
- <sup>20</sup> Lewin Group. (2016, March). *Process evaluation of the Older Americans Act Title III-E National Family Caregiver Support Program: Final report*. [https://acl.gov/sites/default/files/programs/2017-02/NFCSP\\_Final\\_Report-update.pdf](https://acl.gov/sites/default/files/programs/2017-02/NFCSP_Final_Report-update.pdf)
- <sup>21</sup> Scales, K. (2020). *It's time to care: A detailed profile of America's direct care workforce*. PHI. <https://phinational.org/wp-content/uploads/2020/01/Its-Time-to-Care-2020-PHI.pdf>
- <sup>22</sup> National Academies of Sciences, Engineering, and Medicine. (2016). Family caregiving roles and impact. (Chapter 3 of *Families caring for an aging America*). NCBI Resources. <https://www.ncbi.nlm.nih.gov/books/NBK396398/>