Acknowledgment

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Purpose

The collection, analysis, and dissemination of timely, reliable, and quality data are essential to the success of the ACL mission of maximizing the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers.

As ACL builds on its existing programming and implements new programming, new data collection processes need to be created to evaluate the performance of these programs and collect data about individuals served.

The purpose of this flowchart presentation is to illustrate the processes needed to roll out a new ACL data collection, including key activity areas, action steps, constraints and requirements, and time estimates.

Key Activities for New ACL Data Collections

Generally, the following six key activities must be completed before new ACL data collection can be implemented:

1. Identifying the data need
2. Assessing existing data and data collection processes
3. Developing new data elements
4. Obtaining required data collection approvals
5. Defining a data collection and submission process
6. Rolling out the new data collection
1. Identifying the Data Need

Data collections by ACL are driven by authorizing legislation, federal reporting requirements, program needs, and needs for information that would support ACL in achieving its mission. These sources stipulate the types of data ACL is required to collect, as well as the limitations on what data and how much data ACL can collect.

Steps for Identifying Data Needs

- **Review authorizing legislation**
  
  Authorizing statutes establish or continue federal agencies or programs, establish the terms and conditions under which they operate, authorize the enactment of appropriations, and specify how appropriated funds are to be used.

- **ACL administers programs authorized through a variety of statutes**, including the Developmental Disabilities Act and the Older Americans Act.

- **Review federal reporting requirements**
  
  Under the Government Performance and Results Act of 1993 (GPRA) and the GPRA Modernization Act of 2010, every federal agency is required to develop performance measures, which include inputs, outcomes, outputs, and impacts.

- **ACL’s outcomes measures are described, by program, in its annual Congressional Budget Justification**, including measures of program efficiency.

- **Review programmatic guidance, and information needs, and obtain input from program managers**
  
  Each ACL program has performance goals reflecting its purpose and target population(s).

  ACL program managers oversee programs that support the development and maintenance of reporting standards, provide guidance on program performance, and communicate data trends.
2. Assessing Existing Data and Data Collection Processes

Once the data needs have been determined, existing data and data collection processes must be reviewed to avoid duplication in data collection and to minimize the burden of data collection on ACL stakeholders (e.g., grantees, subgrantees, service recipients).

Steps for Assessing Existing Data and Data Collection Processes

- In compliance with GPRA and federal program reporting requirements, ACL grantees (i.e., states, the District of Columbia, and U.S. territories) submit program performance reports on the activities carried out under their programs. In the case of Councils on Developmental Disabilities, the five-year state plan drives the subsequent annual work plan and annual performance progress report. Existing performance reporting tools have been approved by the Office of Management and Budget (OMB).

- Many programs have approved and tested reporting systems to collect program performance data and data about the program’s client population. These include, but are not limited to, the Burn Model System Database, the National Adult Maltreatment Reporting System, the SHIP Tracking and Reporting Systems, the Older Americans Act Performance System, and the Traumatic Brain Injury Database.

- A logic model is a visual and systematic way to describe the relationships between available resources, program activities, and anticipated changes or results. It can be helpful to compare the outputs and outcomes listed in a logic model to the program performance data to see if there are any gaps or if there are data being collected that are not directly related to the program goals.
3. Developing New Data Elements

New data elements are developed after the data needs have been determined, existing sources have been reviewed, and ACL program staff have been consulted. When developing new data elements, it is important to have a clear understanding what the goal of the new data collection is – i.e., what are we trying to achieve with the data. This will help ensure that data needs can be prioritized and data elements are relevant for addressing the identified needs. It is also important to work with program stakeholders, such as grantees, to develop the data elements and to ensure buy-in for them.

Steps for Developing New Data Elements

- **Prioritize data needs**
  - Resources to collect, store, and analyze new data elements are likely limited. Since grantees’ focus is primarily on the implementation of program activities and services, the burden on grantees of data collection should be kept to a minimum.
  - Data elements need to be responsive to legislation or reporting requirements, new and existing authorizing legislation or reporting requirements, or new and existing program needs.

- **Select data collection method**
  - Data collection methods need to balance data collection burden, the level of specificity needed to meet data usage needs, and data quality standards. The selection of methods also depends on who the respondents are, how they can be reached, and what resources are available.
  - Data collection methods may include surveys, interviews, observations, or routine administrative data collections.

- **Draft data collection tool(s)**
  - Data collection tools refer to the devices/instruments used to collect data, such as questionnaires, phone interview questions, or computer-assisted interviewing. Tools and their content need to be designed with the end user in mind and to help ensure the quality of the data.
  - Consider existing data collection tools that have been developed for similar purposes or that measure similar concepts of interest. In many cases, there may be existing valid and appropriate tools that can be adapted for the specific purposes of your data collection activity. Leveraging existing tools can add efficiencies to the data collection tool development process and is generally a best practice for tool development/selection.
  - When developing new data elements, work with program stakeholders, including grantees, to help determine appropriate data collection strategies and questions, and to obtain their buy-in.
4. Obtaining Required Data Collection Approvals

Federal agencies, including ACL, must follow stringent procedures and obtain approval before collecting any new data or information from the public. In addition, the Paperwork Reduction Act of 1995 (PRA), 44 U.S.C. §§ 3501–3521, stipulates that federal agencies must minimize the burden resulting from the collection of information by or for the federal government on individuals; small businesses; educational and nonprofit institutions; state, local, and tribal governments; and other persons. To ensure that all of these needs are met, all new data collections must undergo several reviews and approval processes.

- All new data collection activities must be first reviewed within ACL by the appropriate Office and Center Directors and the Office of Information Resources Management (OIRM). In addition, new planned activities need to be accounted for in the Office or Center’s funding plan.
- It may also be helpful to consult with OPE as data elements and data collection methods are crafted to ensure their soundness and facilitate timely internal approvals.
- As per the PRA, every U.S. government agency must obtain approval from the OIRA within OMB before collecting any information by means of identical questions posed to – or identical reporting, recordkeeping, or disclosure requirements imposed on – 10 or more persons from the public. This is a Congressionally mandated requirement.
- The application for OMB PRA clearance includes a description of the purpose and procedures, a supporting statement, the data collection, instruments, results from pilot testing of data collection instruments, an estimate of the total burden, opportunities for public comment, and documentation of approval or review exemption from an Institutional Review Board (IRB). See the ACL intranet for guidance.

- Privacy Impact Assessments (PIAs) provide members of the public with essential information about the information collected and maintained about themselves by federal agencies. The E-Government Act, OMB M-03-22 requires federal agencies to conduct PIAs before developing or procuring information technology systems that collect, maintain, or disseminate personally identifiable information (PII) or creating electronic information collections involving 10 or more individuals. Consult with OIRM regarding PIA requirements.
- If the data collection mechanism is a system that will collect and store PII, a System of Records Notice (SORN) may be required. A system of records is a group of any records under the control of any agency from which information is retrieved by the name of the individual or by some identifying number, symbol, or other identifier assigned to the individual. The Privacy Act requires each agency to publish notice of its systems of records (a SORN) in the Federal Register. Consult with OIRM regarding PIA and SORN requirements.
5. Defining a Data Collection and Submission Process

After all required data collection approvals have been obtained, the process for collecting and submitting the data must be defined, developed, and tested. ACL’s OIRM is a key partner during this stage, to guide and review the development of any new technology services for ACL. The actual development of the system is performed by a qualified entity based on the system requirements established by ACL.

Steps for Defining a Data Collection and Submission Process

- OIRM oversees and coordinates the provision of information technology services for ACL. OIRM serves as the primary liaison to the HHS Office of Chief Information Officer (CIO), who provides management for the maintenance and operation of ACL’s information technology systems infrastructure, including the local area network, personal computers, software, hosting, and support services. The director of OIRM serves as ACL's CIO and Privacy Officer.

- As part of developing the system requirements/awarding contracts, ACL determines the needed features and the requirements for developing and implementing the data collection system. Requirements may include specifications for developing a database backend and functions that link existing data systems, export data, etc.

- Alpha testing is a form of internal acceptance testing performed to identify potential issues and bugs in the individual system components. It is performed by the system development team.

- Beta testing is conducted in a "real-world" environment with a small group of users who are not members of the system development team. It is considered a form of external user acceptance testing.
6. Rolling Out the New Data Collection

After the new data elements have been developed, data submission processes have been defined, and approvals have been obtained, the new data collection is rolled out to for testing with end-users. During this step, the data collection approach and content is tested. This may include testing the approach for selecting respondents (e.g., sample vs. census), piloting recruitment materials, and collecting responses. Final changes to the new data collection are made based on the results of the testing.

Steps for Rolling Out the New Data Collection

- Before the new data collection is rolled out, the data collection approach and tools are pilot-tested in the “real world” for usability. This may include cognitive testing (identifies potential problems in questions by evaluating the cognitive processes respondents use to answer them), testing the effectiveness of recruitment materials for recruiting respondents, assessing the usefulness of data element definitions, etc. ACL’s OPE can help with this.

- As an outcome of the testing of the data collection approach and tools, debriefings are conducted to identify and incorporate final improvements, and begin the final rollout to all end users.

- As part of the rollout, training and technical assistance (T/TA) is provided to all users. T/TA is provided to ACL staff who are responsible for overseeing, managing, and using the new data. In addition, T/TA is provided to system users who are responsible for entering and submitting data.

- T/TA for users may have two foci – the data collection system and the data elements. T/TA focused on the system is provided by the developers and supports system users on how to use and navigate the system/portal. T/TA focused on the data elements is generally provided by subject matter experts who offer guidance on the content of the data collection, including definition of data elements.
Estimated Timeline

The timeline presents a general framework to show that the process of implementing a new data collection is a complex and long process. It shows how long each activity may take to complete on average. Note: Timeframes will vary based on the needs and scope of the data collection requirements. For example, timeframes may be short for data collections that do not require the development of a new web-based data collection system.
Summary

As highlighted by the Evidence-Based Policymaking Act, “government decisions should be based on rigorous evidence and data about what works.”

As ACL makes changes to its programs and implements new programs, new data elements and data collection systems need to be developed, tested, and implemented to evaluate the performance of these programs and determine their reach. However, as this flowchart highlights, developing and implementing new data collection activities is a stringent and lengthy process that requires dedicated staff and resources. Thus, data needs have to be balanced with available resources. In addition, every effort should be made to keep the burden of data collection to grantees and other nonfederal participants to a minimum.

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