Demographic Services

A 10-year blueprint to serve Virginia's Area Agencies on Aging

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The University of Virginia
Weldon Cooper Center
for Public Service

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THIS REPORT

1. proposes a demographic services blueprint for Virginia.

2. presents a summary of listening sessions in which AAA professionals articulated their data needs.

3. provides a summary of an environmental scan of 49 state plans with attention to data services offered.

INTRODUCTION

Population aging is a significant demographic phenomenon in the U.S. and in Virginia, and is the result of fewer births, longer lives, and the outsized impact of the large baby boom generation. Of the more than 8.6 million residents in Virginia, nearly 1.9 million are ages 60 or older. By 2030, the population over age 60 is expected to grow to 2.2 million—close to one in every four Virginians (almost 25 percent of the population).

In addition, the large populations of older individuals in urban areas and high concentrations in selected rural areas amplify needs for area services and programs. Further, older adults living in poverty, with disabilities, or in social isolation (along with other salient socio-economic factors) create demand for services previously unseen in the Commonwealth.

In this context, the professionals who work within the Virginia network of Area Agencies on Aging are stretched to address a growing population that is living longer, requiring a wider range of services, and an environment of too few resources to meet the complex and intersecting needs of older Virginians.

Timely, accurate, and accessible data about older Virginians is essential to make the most of limited resources. Services and programs should be delivered to those with the greatest needs. Further, the capacity to identify needs which can be anticipated given projected population changes is essential to careful planning and prudent allocation of resources.

The professionals working within Virginia's 25 Area Agencies on Aging know this reality all too well. They are committed to:

- Identifying and articulating needs for services
    - to carefully target service delivery to those with greatest needs
    - to anticipate needs that may become evident or increasingly require services

- - - to thoughtfully articulate the mission and necessity of the Area Agencies on Aging to funders and the public at large
- Identifying at-risk populations with multiple intersecting needs
- Tracking services provided and resulting outcomes
- Sharing resources and expertise to maximize service to the Commonwealth.

The Area Agencies on Aging (AAAs), through the V4A organization and with the support of the Department on Aging and Rehabilitative Services (DARS), successfully promoted a 2021 budget item to study and develop a plan for providing demographic services for Virginia's AAA/PSAs. They did so to address the commitments above.

THIS REPORT HAS TWO PURPOSES:

1. The first is to summarize findings of: a) listening sessions among Virginia's V4A member organizations about their demographic service needs, and b) a thorough review of 49 state plans for aging services focusing on demographic services provided in other states.

2. The second purpose of this report is to provide a draft blueprint of a ten-year plan for demographic services to be provided in Virginia to the Commonwealth's Area Agencies on Aging and affiliated organizations. The report overall is intended to inform professionals in the field of aging as well as state government officials and legislators working with those professionals of the needs for demographic services among Virginia's network of Area Agencies on Aging.

It is our hope that the report serves as a basis for the Executive Branch of Virginia state government and the Virginia General Assembly, through the Department of Aging and Rehabilitative Services, to fund an initiative that would provide consistent, accessible, and actionable demographic information about the aging population in the Commonwealth. Better demographic data should result in maximizing the impact of limited resources and in anticipating and addressing the needs of older Virginians.

DEMOGRAPHIC SERVICES
A BLUEPRINT FOR VIRGINIA'S AAAS

THE BLUEPRINT

1. proposes reporting these data elements in data tables, visualizations, and area profiles, updated regularly, formatted for downloading, and accompanied by use guidelines and periodic training opportunities.

2. applies three criteria for data to be provided in the early stages:

   a. The data need to be available at county/city level in Virginia (to generate aggregates for all 25 AAAs and PSAs).

   b. The data need to be from credible sources, such as federal and state agencies, and university research centers.

   c. The data are regularly updated.

Like any blueprint, what we sketch here is a broad outline of the foundation upon which subsequent years of effort will be built. Our goal for this stage of blueprint development is to design a solid place to start, with a vision for what comes next—subject to change in future years and informed by consistent dialogue with AAA and DARS professionals. This foundation should be reviewed and approved before the end of June 2022.

Several factors shaped the direction and scope of the blueprint as proposed:

- Virginia's AAAs, like AAA networks in other states, are united in a common mission and, at the same time, diverse in their approaches to achieving that mission. Characteristics of the regions and of the older Virginians served by the Commonwealth's 25 AAAs highlight overarching, common needs ripe for collective action and advocacy as well as diversity requiring flexibility, entrepreneurial activities, and local coalition-building. Solid input data about demographics support the sophistication required of every AAA, when their efforts resemble those of their neighbors, and when they are distinct. A menu of demographic services designed to address the wide range of aspirations and needs of the organizations will, by necessity, begin at the level of ground common to the AAAs, and of value to the work of every organization, where available data is credible, timely, and available for all AAAs/PSAs. Over time, the blueprint's menu of services may be amended to respond to arising or pressing needs shared by clusters of (but perhaps not all) AAA organizations.

- In addition to the needs of individual AAAs, the statewide network of AAAs and their partner organizations are committed to data-driven, strategic communication and advocacy for the needs of older Virginians statewide and for state and national initiatives that improve their lives. While city/county/AAA/PSA level data is essential, aggregated data to tell stories about regions and the state (and nation) are frequently part of the work of AAA professionals. The data provided should be sufficiently flexible to support this.

- Over time, data availability may change, which could result in adjusting the data services plan. We heard very clearly that AAA professionals are seeking a broad and long list of data, including 1) administrative data compiled by other organizations and 2) data available for their regions in specific sectors, such as health care, companion care, and veterans' services. In fact, some AAAs have contractual agreements with other organizations for data sharing, and some are working to develop a statewide Community Integrated Health Network, funded by ACL. These and other entrepreneurial efforts by the AAAs adjust the data landscape in Virginia and may, therefore, change the focus of the blueprint in later years. For now, the blueprint incorporates efforts to explore, over time, high value (but currently not shared) data sets that might inform the work of AAAs, recognizing the careful calculus involved in assessing cost/benefits of data sharing agreements.

- Unfortunately, obtaining some of the desired data enumerated by AAA members may not be feasible for a variety of reasons:

    o Data for the age ranges or geographic areas required may not be available (although some extrapolation and estimates may be provided when possible).

    o Agency data may be protected by privacy or HIPAA regulations.

    o Data may not be demographic—that is, it may focus on loneliness, caregiving arrangements, transportation, or health conditions.

Nonetheless, progress begins with taking steps now, and over a period of years, to develop demographic data resources that meet the needs of the AAAs and result in better service to consumers of services and those who need services. The demands on professionals in the AAAs are many, and having easy access to useful, clear, and accurate data, could allow them to spend more of their time meeting needs of older Virginians.

The initial stages of this blueprint concentrate on these data elements (among others):

- age
- gender
- race
- Hispanic origin/ethnicity

- marital status

- living arrangements

- grandparents living with grandchildren

- poverty

- disability

The goal of the first two years of the blueprint is to **present credible and timely foundational demographic data available for all localities and the AAAs in ways that are clear and easy to use in program design and delivery, advocacy for older Virginians, and partnership development and proposals to funders.** We believe that a consistent format in data delivery, built on select and credible data, regularly updated, and easily combined with other data elements will create the strongest foundation for later years of the plan when additional data elements and data sources may be made available.

We also believe there is a solid rationale for data describing the older population in Virginia at large (and in each AAA), in comparison to the population of clients served (as is reflected in Peer Place). We believe both current and projected population dynamics will be useful to AAA professionals, and that a well-defined scope of universally available, credible, and timely data will make the services proposed in this blueprint practical, streamlined, and user-friendly.

The data delivery formats should be decided upon in consultation with the AAAs and may evolve over time as needs change. In addition to data tables, deliverables could include data briefs (2 – 3 pages) aggregated for each AAA/PSA with data highlights and visuals (bar charts/pie charts/tiny tables) updated each data cycle. The briefs would include salient bullet points and visuals appropriate to the region, such as an age pyramid, health insurance table, or heat maps reflecting the aging population for each locality. The design of the data briefs should be flexible, but once designed, should adhere to the goal of being a familiar and accessible source of solid demographic information.

Finally, the data resources should be aggregated and communicated to reflect needs across Virginia as a whole, supporting a narrative of current and emerging needs among older Virginians, and assisting in reflecting the critical mission and role of the AAAs across the Commonwealth.

PLANS FOR THE FIRST FIVE YEARS
FISCAL YEAR 2023-2027

1. In the next two years, build an accessible, consistent format for demographic data delivery for Virginia overall and for each of the 25 AAA/PSAs using the U.S. Census Bureau's data from the latest American Community Survey, recent Censuses, and age estimates, as well as Weldon Cooper Center population estimates and projections. Data reported should include but not be limited to age, gender, race (including Native Americans), Hispanic origin, marital status, living arrangement, grandparents living with grandchildren, poverty, and disability. (Data on veteran status and LGBTQ+ populations are not currently available by age at the locality level from the Census Bureau and may only be obtained if investigations of alternative data sources yield data of sufficient quality). The data that is presented should be updated annually and be displayed in a visually attractive format as well as in Excel tables, convenient for users to download. During the first year, a beta version of the formats with some selected and easily accessible data will be prepared, distributed, and offered for comments and suggestions. Year two will allow for improvement in the beta format and expansion—assuming it falls within the focus of the project on the demographic data itemized above—to include additional available data and other aspects (when possible) indicated by user feedback.

2. In the next five years, explore and assess additional data that is available at the locality level for Virginia; and if reliable, add them to the data delivery.

3. Over the next five years, maintain a data request inventory from AAAs as they encounter data challenges, particularly data frequently required for program funding and advocacy. Understanding what demographic data is required, and especially what data is not available will make it easier to better support the AAAs. Identify data need commonalities among the AAAs to select high-priority data acquisition targets.

4. To inform and empower AAAs' capacity in understanding and utilizing the demographic data, training workshops should be offered to discuss data availability, quality, and limitation, as well as how to use them properly.

5. Provide consultation services to the AAAs for their data needs.

PLANS FOR THE SECOND FIVE YEARS
FISCAL YEAR 2028-2032

In addition to updating the demographic delivery format, and continuing with items 3-5 listed above, the following effort will be made:

1. Based on newly gained knowledge from the first five years, produce additional projections specific for Virginia's older adults that will help AAAs demonstrate the priority of addressing the older population, such as how many older residents are expected to live alone by 2030, or how many adults age 75+ are expected to develop cancer or dementia by 2040. These data should be made at locality and AAA/PSA levels, and available in the profiles as well as in Excel tables.

2. Explore the potential for data sharing with other agencies after determining the actionable value of data requested relative to the barriers to data access (including possible incompatible data definitions and data dictionaries). Each agency/data source will take a significant amount of time to explore and may (or may not) result in data attainment.

3. Conduct customized studies for AAAs requesting such services. A separate contract will be made with the requesting AAA.

NOTES ABOUT CENSUS DATA

1. While the public data from the Census Bureau are timely and usually updated every year, most of the tabulations related to older adults are for the age group 65+. On the other hand, the Administration for Community Living (ACL) regularly obtains the special tabulations of the American Community Survey (ACS) data from the Census Bureau. Geographic levels of aggregation include state, county, and ACL's planning and service areas (PSAs), among others. This data is for 60+ population, but there is usually a longer time lag between when the data is collected and reported. For example, right now, the most recent ACS special tabulation data on the ACL website is 2013-2017 vintage, compared to the most recent ACS public data (2016-2020 vintage).

2. The Census Bureau has been implementing many changes to their data products (including the 2020 Census and American Community Survey data):

   a. some data tables are no longer available or are not available for small localities or geographies.

   b. some data are not comparable with previous censuses (such as race/Hispanic origin).

   c. overall data accuracy has decreased—especially for small population subgroups (such as the older population in poverty, or for smaller geographies)—due to the new data distortion measures adopted to increase privacy protection.

   Carefully monitoring data tables pertaining to the older adult population, informing DARS and the AAAs of any changes in data availability and quality, and providing information about qualitative changes anticipated in census data will be an important part of providing accurate, reliable data services to the AAAs.

BACKGROUND REPORTS
REPORT I: LISTENING SESSIONS

During the first three weeks of February 2022, researchers from the Weldon Cooper Center Demographics Research Group hosted listening sessions with leaders (and a few staff members invited by the leaders) from Virginia's Area Agencies on Aging. In addition, several individual phone conversations and comments offered by email from AAA professionals contributed to an understanding of the data usage and needs of Virginia's AAAs.

Twenty-two professionals from sixteen AAAs participated in the ninety-minute sessions, which were framed around three questions:

1. **What data about the older adult population in your area or in Virginia do you currently have access to or use regularly in your work?**

2. **What additional or different data about the older adult population in Virginia do you need, or would you like to have to accomplish your mission?**

3. **What challenges do you face that might be addressed with better data? What research on which topics about older adults in Virginia or nationally would be helpful?**

Conversations ranged across these topics, among others; and we came away with an appreciation for the commitment of the AAA professionals to incorporate data in their annual program planning, delivery, and evaluation.

The following pages report comments from the AAAs in this order: 1) data (in several categories) needed by AAAs, 2) potential demographic data services to address these needs, and 3) data currently used by AAAs. The comments offered by AAA professionals reflect data they need and currently can obtain, as well as data desired but not yet easily available. Additionally, many AAAs network with other organizations serving their areas. These organizations may provide other data for the use of the AAAs, or could also benefit from enhanced delivery of data services to the regions.

The itemized lists below reflect the ingredients of a robust demographic services program, as seen by AAA professionals who participated in these group discussions. As an ingredients list, they do not capture the complexity and desirability of the result any more than an ingredients list captures the delectability of a well-prepared dish. Further, the lists convey neither the sophistication and nuance of our discussions nor of the commitment and vision of the AAA

professionals who participated in them. As a starting point, however, the lists point to elements of a foundation upon which these professionals might build.

DATA NEEDED BY AAAS

Comments made in the sessions can be best understood when grouped into two areas: Data topics, integration, quality; and Ease of access and capacity to integrate and communicate data sets.

DATA TOPICS, INTEGRATION, AND QUALITIES

1. **Foundational demographics**

   a. Good local/regional data, including demographic variables by localities

   b. Regional comparisons on data we have now

   c. Diversity, Equity, and Inclusion demographics for each area

   d. Poverty by age group by locality

   e. Population by housing type: household composition, who is living alone, homeownership, who is rent burdened

   f. Older individuals without internet, without transportation, and who speak a language other than English at home

   g. Level of education/reading level

   h. Disability data (preferably by type and income)

   i. Employment data

   j. Marital status

   k. Insurance coverage including Medicare/Medicaid

   l. Adults 60+ at or below poverty

2. **Assessed needs or data suggestive of needs[1]**

   a. A better understanding of

      i. who is using what services; what percentage of people can access services needed (see 1b above)

      ii. the unmet needs of the population

      iii. the underserved segments of the population

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[1] These comments refer primarily to Peer Place data.

  b. Access to data

    i. that they have the capacity to clean and update in Peer Place

    ii. that suggests financial services needed

    iii. Or predictors of successfully aging in place

3. **Housing and living arrangements**

  a. A better understanding of

    i. Community tenure to be able to answer questions about how many older Virginians age in place vs in an institutional setting

    ii. Residents at risk of eviction

    iii. The chronically homeless or at risk for homelessness

    iv. Availability and use of home repair services

    v. Unsafe housing conditions

  b. Access to data that indicates

    i. Number of nursing home beds in the region

    ii. Housing availability by income ranges

4. **Health data and indicators**

  a. A better understanding of

    i. at-risk health populations—dementia, diabetes, mental health concerns

    ii. Food insecurity

  b. Access to data that includes

    i. Health Departments' CHIP data

    ii. Healthcare statistics to indicate impact and outcomes

    iii. Measures of isolation and loneliness

5. **Veterans**

  a. A better understanding of

    i. Access to transportation

    ii. Use of in-home care

  b. Data by these variables

    i. Age by veteran status

    ii. Veteran status by disability and disability type

6. **Transportation**

   a. A better understanding of

       i. Access to and use of personal vehicles

       ii. Access to safe, public transportation

   b. Data by these variables

       i. Census and ACS data by poverty, veteran status, disability, and age to suggest transportation needs

7. **Caregiver data that is reliable and regional**

   a. Identification of family caregiving burden by older Virginians

   b. Ability to access respite and day care

   c. More robust data about grandparents raising grandchildren

EASE OF ACCESS AND CAPACITY TO INTEGRATE AND COMMUNICATE DATA SETS

1. Extrapolation/estimates drawn from Census Bureau data sets to include ages 65+, but also 60+, and 80+ (some requested 60+, 65+, and 70+, 80+ and 90+)

2. A single, easy-to-use access point online for data

3. The capacity to pull and integrate multiple (more than two) Census Bureau variables at once to make the case for programs

4. Expansion of what DARS already provides of ACS data to include housing type, homeownership, transportation, and dementia status. Make this data available further in advance of the due date for area plans.

5. A select number of clear and accessible visualizations for the data most frequently needed by AAAs to make the case for their programs

6. Data and communication strategies to communicate the case for AAAs and services to older Virginians

7. A tool to overlay Census data on Peer Place data

8. Data constructed to portray status on the social determinants of health with greater integration with local health care data sets

9. Assistance in constructing annual client satisfaction surveys

POTENTIAL DEMOGRAPHIC DATA SERVICES

1. A database/dashboard of timely and the most current (updated monthly) high-quality data factored for a consistent range of ages. Include estimates (noted as such) for variables, as necessary.

2. Tools, assistance, and elements needed to make the case for the AAAs, to demonstrate need, and to suggest impact.

3. Easy online access for acquiring and interpreting data

4. Tools and instructions on how to make/modify infographics

5. Data that reflects coming need—projections and analyses of populations 50+

6. Training in how to use available data sets in combination or at the level of geography needed, and error rates associated with smaller groups of individuals/geographies

7. Training that provides an overview of large, relevant data sets and what they can get out of them

8. Quarterly data workshops/updates and opportunities for AAAs to share best practices

9. Assistance in constructing surveys and in sharing survey designs across AAAs

10. Topical papers on issues of interest to AAAs with particular attention to applying findings from national research to regions/localities in Virginia

DATA & RESOURCES CURRENTLY USED BY AAAS

1. Decennial census

2. ACS (and 5-year ACS data DARS distributes through the ACL) although these datasets are described as clunky and difficult to extract what they need

3. DARS annual spreadsheet as background for their annual plan for aging services—although this is not timely enough

4. Peer Place and No Wrong Door

5. CMS data for Medicare and Medicaid (HHS Empower map)

6. CDC Social Vulnerability Index and Map

7. UVA Weldon Cooper Center for Public Service (especially population estimates and projections)

8. George Mason University Stephen S Fuller Institute

9. America's Health Rankings

10. GIS Policy Map website

11. Data on ADLs and IADLs—not clear where to locate now

12. Regional Commissions, Planning District Commissions, and Regional Aging Networks

13. Meals on Wheels results from annual nutrition screenings

14. Uniform Assessment Instrument

15. Alzheimer's Association

16. Triennially-mandated Community Health Assessments and Community Health Improvement Plans

17. Data available from area health systems (if any)

18. Local and regional foundations

19. Health Quality Indicators and Virginia Health Indicators

20. Local partner organizations (such as organizations working on housing, food security and delivery, transportation services, respite care)

21. UVA Center on Aging Longevity Project

22. RVA Community Cares (a capital area data source)

23. Regional transportation data needed for many AAAs, especially rural ones—use databases such as Quickbase and PTMS to manage transportation services

24. County health data

25. Data from area hospitals (if available)

26. DMV data to identify senior drivers, observe retirement patterns

27. United Way's ALICE assessment (although older individuals are underrepresented)

BACKGROUND REPORTS

REPORT II: ENVIRONMENTAL SCAN OF STATE PLANS FOR AGING ACROSS THE U.S.

OBJECTIVE

As part of the foundation for developing a comprehensive 10-year blueprint for demographic data services, we conducted a detailed environmental scan of existing State Plans on Aging from other U.S. states.[2] We reviewed these plans to capture best practices that might be useful to the AAAs in Virginia.

The study revealed great diversity in the ways in which states engage with and support their respective Area Agencies on Aging. While plans from other states may suggest initiatives for Virginia, they are geared to serve the needs of their populations and would have to be adapted to suit the needs of older adults in Virginia. Further, some of the policies and methods identified in other state plans are aspirational and have not been implemented, and as such, are untested.

Demographic data services that will serve the Commonwealth best should be driven by needs of the AAAs in Virginia, which we heard and documented during our conversations and listening sessions. Nonetheless, tested methodologies and best practices identified from the other 49 states may point to options we may not have previously imagined or considered.

NOTES ABOUT STATE PLANS

This environmental scan covers the most recently available State Plans on Aging for 49 states, excluding Virginia, (as of Spring 2022). We examined State Plans on Aging as a proxy to understand how individual states handle their demographic data needs, both in the recent past and for the future years.

Comparability of the plans is limited by these characteristics:

- Since state plans are submitted to the Administration for Community Living (ACL) on a rolling basis, the plans refer to different timeframes, ranging from 2 years to 4-5 years; the plans also do not cover the same calendar cycle (for instance, Connecticut's State Plan on Aging covers 2020-2023 while the Wyoming State Plan on Aging is for 2021-2025).

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[2] The State Plans on Aging were submitted to the Administration for Community Living (ACL) or the U.S. Department of Health and Human Services.

- State Plans on Aging also vary in size and scope—Arizona's report is nearly 280 pages while Nevada's is only 24.

- Further, the content varies across states, with some (such as Ohio and Texas) having a strategic action plan on aging in addition to a broader State Plan on Aging.

- Data elements vary widely across the plans and may include the following: data required for ACL reporting, agency/program/service performance or assessment data, clients' needs/outcome/impact data, customer satisfaction surveys, input data for the Intrastate Funding Formula (IFF), fiscal strategies, or grant funding data. For this research project, our literature review/environmental scan focused primarily on **demographic data services and related matters.**

Many states collaborate with or contract out to other agencies/organizations to meet their data collection, production, or analysis needs. Most states have a database management system or data management vendor for operations or reporting (equivalent to Peer Place).

FINDINGS

IN SUMMARY

Utilizing demographic data to support and direct services to older Americans is a consistent theme across the plans. The implicit and sometimes explicit goal is to ensure that older constituents are aging well and safely, and in some cases to document constituent needs targeted by federal or state programs. Other data priorities are state specific or only mentioned in a handful of state plans.

Findings from the environmental scan are organized by the following five themes:

- Demographic Data/Census Data/Population Projections

- Direct Data Collection

- Specific Topics of Interest for Different States

- Mapping/Data Visualizations

- Miscellaneous Resources (collaborators, non-census data sources, standardized surveys, expert panels/commissions etc.)

Finally, we also provide a brief discussion on two state plans that stood out as being especially robust.

DEMOGRAPHIC DATA
(INCLUDING CENSUS DATA OR POPULATION PROJECTIONS)

USES OF THE DATA

Almost all states use some form of demographic data for targeted outreach and service delivery to their primary constituents—older Americans, persons with disabilities, and caregivers. Often these data are further illuminated by data on economic and/or social needs, or the demographic data is analyzed by geography or other variables to identify underserved populations.

SOURCES OF DEMOGRAPHIC DATA

Usually, states are best served by a combination of quantitative and qualitative data, collected directly from residents of the state or obtained from publicly available information via the Census Bureau, state and local agencies, and other databanks. The State Units on Aging often provide basic state and county demographic profiles, economic and social indicators, plus comprehensive data on socio-economic and health characteristics to guide program planning and resource allocation. The following were the most frequently used and cited sources across all state plans:

- American Community Survey data

- Decennial Census data

- Projections and Forecasts

    o General population projections of the aging population by age groups (60+ or 65+) through 2050 (or even 2075)

    o Customized modelling, such as service utilization projections showing projected future demand for long-term care services or specific forecasts of dementia prevalence.

Mining data from the United States Census Bureau is a standard practice across all states. Nearly every State Plan on Aging uses county-specific demographic information from the U.S. Decennial Census and the American Community Survey 5-year estimates, especially since the regional data allows them to capture geographic differences and significant economic and demographic trends across the state.

Alternative data sources are used also, such as: 1) the Elder Economic Security Standard Index and Insecurity in the States, 2) Sururbanstats.org (which has Current American Indian Population with Demographics and Stats by Age, Gender, etc.), and 3) Services and Assessment Evaluation Form (SAEF) for service recipients (to obtain information such as demographics, poverty level,

nutritional assessments, activities of daily living, and instrumental activities of daily living). Some states with large rural areas supplement their information with data from the *Census of Agriculture* (which is a complete count of U.S. farms and ranches and the people who operate them). Other states may utilize data prepared by the federal government to locate low-income Medicare beneficiaries.

Some states use data that has been collected for reporting purposes (or from survey participants) to better understand the demographic profile of the people they serve. AAAs in some states are the sources of such data, for example data collected in the needs assessment component of the AAA Area Plans, or through the OAA Caregiver Survey, and client satisfaction or performance measurement surveys. All of these may yield key demographic characteristics of respondents.

VARIABLES BEYOND AGE/SEX/RACE/ETHNICITY

While all states have a common goal of understanding demographics related to aging, some have data needs beyond standard demographic variables.

Standard variables include age, sex, race and ethnicity, as well as income or poverty status, language skills, living situation, etc. These basic variables may be combined to identify low-income minority older adults, older adults living in rural areas, limited English proficiency older adults, or older adults who are homeless, for instance. This is essential for monitoring the number and percent of at-risk populations, reviewing programmatic statistical data to determine if existing levels of diversity meet plan goals, targeting minority and underserved populations within a service area, and updating area plans annually.

Some states rely on additional data or methods, such as calculations for customized projections, overlaying geographic and demographic data, or mixed-method research to assess aging-related needs (for example, predictive modeling techniques to find home care consumers who are at risk of falling given their medical history and mental, social, and demographic factors.).

Some states may allocate resources to capture cultural diversity, particularly those states with sizeable Spanish, Mexican, and Native American Indian communities. Other states may look for correlations between variables, such as the use of and satisfaction with local community-based services and family caregiving; and access to primary health care, financial security, and housing. Some may require specific data on Alzheimer's disease, cognitive decline, and caregiving through the Behavioral Risk Factor Surveillance System (among other surveys).

QUALITY CONTROL FOR DATA SERVICES/PRODUCTS

Timeliness: Many state plans recognize that past Census data is inadequate for addressing current and projected needs. They may update the data each year with recalculations based on trends and new information. This annual re-evaluation may be required for budget development, programming, educating stakeholders, and informing public health policy.

Data collection practices: Many state plans mentioned improving data collection methodologies, such as standardizing service definitions, formalizing appropriate procedures for data compilation and transmittal of data, and effectively utilizing data management resources to ensure statewide consistency.

RESOURCES TO FACILITATE DATA COLLECTION AND ACCESS

IN SUMMARY

Most states have developed their own specialized approach to collecting and using data, and most state plans highlight aspirations for improving how they leverage the foundational demographic data for their individual state, including ensuring better access, currency, and utility for the baseline elements of each state's demographic data.

Several state plans include a statewide database or special reports to help them better meet the needs of their older residents, adults with disabilities, and caregivers.

Typically, State Departments/Units on Aging provide population, economic, and social data to be used by each planning and service area in the state. Some regularly provide AAAs with access to demographic updates, and offer guidance related to programs, policies, and service priorities.

Future plans are likely to include improvement to these resources, either through the creation of a searchable database or implementation of new functionalities, such as report generation or increasing the existing parameters (including, for example, gender identity, sexual orientation, tribal affiliation, sensory impairment).

Various State Plans on Aging hope to develop a more robust data services program by:

- linking demographic data between the caregiver and care recipient
- compiling and aggregating data/recommendations of regional teams to develop education, prevention, or other strategies designed to improve coordination of services

- curating consumer choice information reports completed by facilities and making this information accessible to the public

- tracking data from post-intervention follow-up by administering comprehensive health surveys.

Some plans also touch upon a more complex approach that involves building high-level and long-term connections that, via a website or database, would enable bi-directional information sharing between health system providers and AAAs (among others) with appropriate protocols and consents in place. Integrating data from various sources and systems into one administrative database that can be shared across agencies, and developing a reporting tool to analyze the integrated information would be invaluable but would require a significant investment of time, money, and interagency cooperation.

DIRECT DATA COLLECTION

Surveys are a rich source of primary data, but it is important to emphasize the distinction among three types of surveys: *1) surveys conducted to inform goals and objectives of the State Plan on Aging, 2) surveys that collect feedback from clients or AAAs for reporting requirements, and 3) surveys done to gather demographic data.*

Over 90% (45 out of 49) states have conducted some form of survey, listening session, public hearing, or stakeholder engagement to solicit input or gather feedback from their respective constituencies.

FEEDBACK IS GATHERED IN VARIOUS FORMS

Beyond the standard Needs Assessments and routine service data collection for reporting purposes, the State Units of Aging and their partners engaged with constituents in various ways, including the following: group meetings, key informant interviews, listening sessions, roundtable discussions, coffee hours, conferences, community conversations, and town hall meetings, in addition to traditional surveys.

In-depth interviews with key stakeholders provided major insights, and the interviews typically involved direct communication, such as in-person, one-on-one interviews. Virtual community forums allowed individuals to give testimony, raise questions, or share comments. The stakeholder input process also included establishing and maintaining contact with older adults, periodic meetings with program participants, informal conversations, public hearings, and small public gatherings to capture comments.

Surveys of different kinds were administered online, by mail or direct distribution, or by telephone. In many cases the survey sampling was convenience-based rather than randomized, and hence not representative of the population served.

Surveys employed by the states were varied and included the following: the Aging Network Survey, Senior Population Survey, ADRC Satisfaction Survey, customer/client satisfaction survey, Transportation Survey, Healthy Youth Survey, State Plan on Aging Survey, Community and Stakeholder Survey, Family Caregiver Survey, Adult Dental Survey, AARP Survey, Supplemental Behavioral Risk Factor Surveillance Survey, Community Assessment Survey for Older Adults, National Core Indicators for Aging and Disabilities (NCI-AD) Survey, Food Insecurity Assessment Survey, among others.

FEEDBACK WAS GATHERED FROM VARIOUS RESPONDENTS

IN SUMMARY

Area Agencies on Aging in other states frequently use a variety of methods to seek feedback and information from clients, staff, and partner organizations. Some surveys yield demographic data that could be informative for other uses.

The main recipients of most surveys were older adults, people living with a disability, and their caregivers (family caregivers or professionals). Some surveys collected responses from AAA directors and staff, service provider agencies, community partners, local government agencies, and volunteers who work with older adults, as well as other Aging Network members and professionals. Other surveys targeted specific populations, such as veterans, members of the LGBTQ+ community, grandparents raising grandchildren, or active senior center participants. Finally, valuable expert feedback was provided by the following groups: state- and nationally-recognized researchers, practitioners, policy makers, government representatives, and members of advocacy groups in the fields of health, aging, and disability.

SPECIFIC TOPICS OF INTEREST FOR DIFFERENT STATES

IN SUMMARY

Beyond data analysis and surveys, states are interested in collecting data and pursuing initiatives related to specific topics and populations. The intersections of various data sources and topics make these areas of interest complex and the solutions unique to each state.

Beyond standard demographic variables, states often seek information relevant to priority issues within their communities such as the focus areas below. The following are selected activities of some states organized by priority issues:

Language: Ability to identify older adults with English as a Second Language (ESL) or Limited English Proficiency (LEP). The focus is on inclusivity, achieved by expanding the menu of languages used or spoken, offering interpreters, and enabling communication with individuals who speak limited English to increase outreach and improve services.

LGBTQ+: Initiatives to collect data on sexual orientation and gender identity in order to meet the unique needs of LGBTQ+ community and build programs targeting disparity reduction, particularly health care disparities and issues associated with nontraditional family structures.

Social isolation: Desire to pinpoint reliable indicators of social isolation and to offer programs that reduce loneliness; allow seniors to make meaningful connections with others; provide community transportation; connect retired seniors to volunteer opportunities (like the Retired Senior Volunteer Program and the Foster Grandparent Program); and provide access to technological services, such as telehealth, telemedicine, and socialization via technology, etc.

Socioeconomic status: Initiatives to collect data on seniors in poverty and those experiencing concerns adjacent to poverty, such as affordable senior housing, nutrition and food insecurity (meal programs and services), and access to in-home services.

Health related matters: Initiatives to collect data on dementia, brain health, accident prevention; opioid and substance use and opioid-related death among adults 60+; individuals living with sensory impairment; views of COVID-19 pandemic and vaccines; affordable prescriptions; and oral health plans.

Family dynamics: Desire to identify grandparents raising grandchildren, kinship caregivers, family caregivers, caregiver health issues, etc.

Diversity and cultural humility: Initiatives to collect data and understand the influences of Spanish, Mexican, and Native American Indian cultures; collaborations with local organizations that represent Native American Tribes (AIAN) or have tribal affiliation.

Combating Ageism: Data and programs to promote the value of older adults to their families and communities through volunteerism, civic engagement, mentorship, and the workforce.

MAPPING AND DATA VISUALIZATIONS

> ## IN SUMMARY
>
> Two progressive approaches that can be incorporated into Virginia's 10-year demographic services plan are 1) identifying geographic patterns in the data and 2) presenting the data in a visually appealing and informative way tailored to the organization's goals.

Analyzing and presenting data is fast becoming a priority in practically every field. This holds true for State Units on Aging as well.

MAPPING

Alabama uses mapping and analysis of Census data for better targeting in their *"person-centered approach to service delivery designed to support older adults and persons with disabilities to help them live longer"*. Florida provides its AAAs with *"detailed instruction in using PSA and county-specific mapping tools developed by DOEA to identify neighborhoods in communities where high concentrations of seniors in disadvantaged groups are clustered so as to empower their targeting and outreach planning with population data"*. New Hampshire uses maps to *"understand healthy aging trends and disparities throughout the state"*. South Carolina and South Dakota also rely on maps to add value to their population statistics, and Oregon has an *interactive data map with detailed demographic data* for all planning and service areas in the state.

DATA VISUALIZATION

Georgia has provided statewide training to their AAAs so they can access data and reports through Tableau. Massachusetts has invested in their *"HCBS Explorer which is a business intelligence and analytics tool that uses Tableau software to present SAMS data in a dynamic, powerful, and visual way"*. Pennsylvania's plans include *"development of an electronic data dashboard designed to assist investigative staff to most efficiently manage the needs of victims"* and they plan to *"develop and launch interactive dashboards to effectively present ombudsman and Pennsylvania Empowered Expert Residents (PEER) program data"*.

MISCELLANEOUS RESOURCES

COLLABORATORS/PARTNERSHIPS

Most State Units on Aging collaborate with other state government agencies and research centers, or contract with private companies, to aid them in providing demographic data services or in conducting surveys to realize the goals, objectives, and strategies laid out in their State Plans. These partnerships may take different forms, and typically cluster under the following categories (with selected state examples):

- **University Research Centers:** Used by Arizona, Nebraska, Maine, Vermont, Kentucky, Massachusetts, New Hampshire, North Carolina, Ohio, Rhode Island, and Wyoming.

- **Support from State Data Centers and Planning Divisions:** Used by Colorado, Delaware, Florida, Iowa, Maryland, Oklahoma, Nebraska, Minnesota, Utah, South Dakota, Kentucky, Rhode Island, and Wyoming.

  - **Interagency data sharing agreements with respective State Units on Aging:** Many states have interagency data sharing agreements and examples show a wide range of potential data partners. From six state agencies in Vermont to the Commission on Latino Affairs in Pennsylvania, aging organizations across the states seek data sharing, particularly in matters of health. Below is an illustrative list:

    1. Aging and Disability Resource Center (ADRC) in Hawaii
    2. Minnesota Department of Human Services partnered with Minnesota Board of Aging (MBA)
    3. Texas HHSC Center for Analytics and Decision Support
    4. Utah Governor's Office of Planning and Budget
    5. South Dakota's Nursing Facilities Data and South Dakota Department of Social Services' Nursing Home Occupancy Report
    6. Collaboration across Vermont Department of Health, Department of Mental Health Department of Vermont Health Access, Department for Children and Families, Department of Corrections, Department of Labor, Agency of Transportation, Agency of Education, Agency of Commerce
    7. Kentucky Injury Prevention and Research Center
    8. Oregon Public Health Division
    9. Massachusetts collaborative with the Executive Office of Health and Human Services (EOHHS), Department of Housing and Community

Development (DHCD), Elder Affairs, MassHealth, and the University of Massachusetts Medical School (UMMS)

10. North Carolina Division of Public Health, Office of the Chief Medical Examiner; Ohio Department of Job and Family Services

11. PCoA, AARP Pennsylvania, the Pennsylvania Commission on LGBTQ Affairs and the Pennsylvania Commission on Latino Affairs in Pennsylvania

12. RI Department of Administration and senior centers across Rhode Island

13. Wisconsin Department of Administration, Demographic Services Center

14. South Carolina Budget & Control Board Office of Research & Statistics and the SCDHEC-Vital Records

15. Tribal Governments, State Dementia Action Collaborative, Program managers in the Home and Community Services division, DSHS Research and Data Analysis (RDA) in Washington

16. Wyoming Department of Health.

- o **Consulting Firms/Private Providers/Non-profit Foundations:** Examples include

    1. LanguageLinc™ Solutions used by Nevada

    2. MN Compass used by Minnesota, Maine Health Access Foundation

    3. Abt Associates used by South Dakota; National Research Center Inc, Milliman Forecast, Lewin Group and Paraprofessional Healthcare Institute (PHI) used by Indiana

    4. NH Center for Public Policy Studies used by New Hampshire

    5. System Wide Solutions, Inc. used by South Carolina

    6. Wyoming Survey and Analysis Center and Genworth used by Wyoming.

Some states may use a combination of these resources. For instance, Idaho's State Plan refers to collaborations with the Idaho Department of Labor, the Institute of Rural Health at Idaho State University, and contractual work with Resolution Research—a health-related market research company to administer their needs assessment survey.

NON-CENSUS DATA SOURCES, STANDARDIZED SURVEYS, EXPERT PANELS/COMMISSIONS

- **Alternative Data Sources and Reports:**

    o Births and Deaths Data supplied by Vital Records

    o Administration for Community Living, Aging Integrated Database (Louisiana, Oregon, Nebraska, Missouri)

    o Aging in Harmony data (Mississippi)

    o Kaiser Family Foundation data on Nursing Homes (South Dakota)

    o Data from Sururbanstats.org (Missouri)

    o Data from the Kaiser Commission on Medicaid and the Uninsured (Indiana)

    o Woods & Poole Economics, Inc., 2018 State Profile and Complete Demographic Database, 2018 (New York)

    o New York State Department of Health data

    o MassOptions call center data; SAMS Data; ADRC Interface Exchange Reports (Massachusetts)

    o Massachusetts Healthy Aging Collaborative Data Report

    o National Long-Term Services and Supports (LTSS) Scorecard (New Hampshire)

    o Data from the Benefits Data Trust (North Carolina)

    o Comprehensive Housing Affordability Strategy (CHAS) data (North Carolina)

    o Data from the National Adult Maltreatment Reporting System (Ohio)

    o Oregon Public Health Division's Oregon Healthy Aging (OHA) index data

    o Elder Economic Security Index for Income data (New Jersey)

    o AgingIS data (Missouri)

    o Database of transportation programs and mobility options compiled (Tennessee)

    o Data from National Aging Program Information System (Michigan, Louisiana, Mississippi)

    o Data from National Ombudsman Reporting System (Mississippi)

- **Standardized Surveys:**

    o Behavioral Risk Factor Surveillance System (BRFSS) survey (Alaska, Louisiana, New Hampshire, Washington)

- o   Supplemental Behavioral Risk Factor Surveillance Survey

- o   Community Assessment Survey for Older Adults (Indiana, Colorado)

- **Expert Panels/Commissions:**

  - o   Vermont Governor's Commission on Alzheimer's Disease and Related Disorders

  - o   New Jersey Alzheimer's Disease Study Commission

  - o   Rhode Island's Hunger Elimination Task Force

  - o   State Dementia Action Collaborative in Washington

STATES PLANS TO CONSIDER FOR FURTHER STUDY

From among the state plans reviewed, we selected two as examples of clarity and focus on the following: priority populations, provision of targeted services, impact assessment, bilateral data sharing agreements with other state agencies, collaborations and partnerships with various stakeholders, leveraging business intelligence and analytics tools, effective data collection and management, and thoughtful survey administration.

MASSACHUSETTS

The Massachusetts State Plan on Aging available for our review was prepared in 2017 for the period of 2018-2021, entitled "Aging in Massachusetts - Shaping the Future". However, a more recent plan for 2021-2025 became available in the interim. Both documents serve as excellent examples of a state-level blueprint for the programs, services, and strategic plans required to serve the needs of older adults.

Commonwealth of Massachusetts, Executive Office of Elder Affairs prepared their *2021-2025 Massachusetts State Plan on Aging*.

OHIO

The Ohio State Plan on Aging prepared in 2018 for the period of 2019-2022 as well as their Strategic Action Plan on Aging, both provide good roadmaps as to how the State Unit on Aging and their various aging network partners hope to shape a better future for all older Ohioans.

Ohio Department of Aging created *Ohio's State Plan on Aging for 2019-2022*, as well as their *2020-2022 Strategic Action Plan on Aging (SAPA)*.

CONCLUSION

Extensive use of demographic data is woven into each state plan we reviewed, and certain elements of most of the plans stand out as data priorities:

1. State- (and perhaps locality-) specific data on the current population demographics from credible sources

2. Projected future demographics

3. A capacity to combine demographic factors to understand specific elements of the older population (for example, older state residents who live in poverty and lack transportation)

4. Easily produced visualizations of demographic data about the older population for use in grant proposals, public presentations, and advocacy

5. Mapping capacity to understand areas of aggregated need

6. Thoughtful incorporation and harvesting of demographic data from surveys routinely conducted on services provided

7. Strategic identification of special populations and topics so that annual improvement in understanding of population needs or issues can be achieved as part of the plans.

These elements are foundational, but not simple. They require time to collect and maintain, as well as expertise to interpret and utilize in ways that are actionable. Beyond this broad base of data-related activities, most state plans engage the expertise of state (and area) agencies on aging to develop partnerships with organizations interested in seeking data sharing agreements and in improving outcomes for older residents in specific areas, such as health outcomes, transportation, food security, and in-home care.