

**Pain, Aching, Stiffness and Swelling  
Growing and Sustaining State Arthritis Programs  
Results of a Systematic Review of  
State Arthritis Programs funded by CDC 1999-2005**

**Background:** Following the development and publication of the *National Arthritis Action Plan: a Public Health Strategy* CDC received a Congressional appropriation (1999) most of which was used to support arthritis program capacity building, program planning, and implementation in state health departments.

Currently, states are funded under consolidated Program Announcement (PA) 03022--Chronic Disease Prevention and Health Promotion Programs. PA 03022 specifically supports cooperative agreement funding for seven program components: 1) Tobacco; 2) Nutrition, Physical Activity, Obesity; 3) WiseWoman; 4) Oral Disease; 5) BRFSS; 6) Genomics; and 7) Arthritis. Thirty six states receive cooperative agreement funding to support the Arthritis component of PA 03022.

In 2005, the Arthritis Council, National Association of Chronic Disease Directors (NACDD), initiated a systematic review to build on previous work done to assess state arthritis program capacity since CDC cooperative agreement funding was initiated in late 1999.

**Purpose:** The purpose of the project was to review the progress of State Arthritis Programs (from 1999--2005) by gathering information on the successes and challenges experienced by these programs; to extract lessons learned; and to identify facilitators and barriers to success. This information will be useful to increase efficiency and our ability to reach people affected by arthritis.

**State Program Activities:**

Twenty-eight states currently receive Capacity Building Level A funds (average \$140,000/year). Level A recipients were asked to

- Support a full time arthritis program manager;
- Establish and maintain an advisory group or coalition;
- Conduct surveillance using the BRFSS and make the data widely available;
- Develop a state plan for arthritis;
- Implement and measure the reach of one or more evidence based self management interventions.

Eight states receive Capacity Building Level B funds (average \$250,000/year). Level B recipients were asked to

- Implement all Level A activities;
- Implement and measure the reach of two or more evidence based self management interventions on a broader basis than level A funded states.

Program direction became more specific after 2000: CDC recommended implementing three evidenced-based programs (Arthritis Foundation Self Help Program, Arthritis

Foundation Exercise Program, and the Arthritis Foundation Aquatic Program). When the health communications campaign became available in 2000, this was also added to the list of evidence-based interventions.

States were viewed as successful if they accomplished the activities as outlined above. Based on the information obtained in the site visits, the program announcement, and program guidance given to states, we provide a definition of success for eight of ten components reviewed. Because awareness and policy activities were not addressed in the program announcement and no guidance has been given around these two components, a definition of success is not given for them.

**Process/Methods:** A standard protocol was developed to address overall program status and ten component-specific activities (funding, program operations and staffing, surveillance, advisory group, partnerships, state plan, interventions, program evaluation, public awareness and education, and policy development.). A team of three reviewers conducted fifteen two-day site visits between January 24 and November 10, 2005. The review team included a CDD Consultant who led all 15 visits, a CDC Arthritis Program Project Officer, and a CDC Arthritis Program Scientist. See Appendices 1 and 2 for a detailed description of the protocol and the protocol forms. See Appendix 3 for a list of states visited.

A retreat was held November 30 through December 2, 2005, to review the findings from the 15 site visits, identify major overall themes, define success in the 10 cooperative agreement subcomponents, and look for common facilitators and barriers for success or lack thereof. Proposed solutions were also identified, based on suggestions from the states and the retreat committee. See Appendix 4 for a list of people participating in the retreat.

## **Results:**

### **Overall impressions/observations:**

The positive includes the following:

1. There are currently 36 state arthritis programs working to improve the quality of life for persons with arthritis. There were only two (Missouri and Ohio) in 1998.
2. Because of state arthritis program activities, money was appropriated by state legislatures in several instances. The funds did not necessarily go to support the state arthritis program, however.
3. States have data available about arthritis and data have been disseminated to partners, policy makers, and the public.
4. Although still limited, arthritis is more visible as a public health problem than in 1999.
5. The availability of evidence-based interventions has improved.
6. The states and CDC have actively pursued and applied lessons learned and are willing to work together to modify program goals and how they are achieved.

Specifically-

- Setting goals and objectives for CDC and state arthritis programs.
- Identifying infrastructure needs for evidence-based programs and how to meet them.
- Clarifying roles between CDC and states, and states and their partners.

- Improving communication.
- Developing defensible, practical surveillance.

The challenges includes the following:

1. State arthritis programs lack visibility. Arthritis receives little attention internal or external to the health department. Most arthritis program managers do not experience much interest or receive much oversight from upper management. Overall, arthritis is not a high priority problem in the health department or within chronic disease programs. Solutions:
  - a. CDC needs to increase the visibility of arthritis at National Center for Chronic Disease Prevention and Health Promotion, Coordinating Center for Health Promotion, and with the NACDD.
  - b. CDC Arthritis Program needs to explore reestablishing a relationship with Council of State Governments (CSG).
  - c. The Arthritis Council needs to increase the visibility of arthritis as a public health problem and arthritis programs in the state health departments and with CDD leadership, and consider having special sessions at chronic disease meetings.
2. Staff turnover seriously interferes with progress. Because most arthritis program supervisors have very little experience with arthritis, new coordinators struggle without adequate direction and mentorship. Solutions-
  - a. CDC should provide technical assistance shortly after new state arthritis program managers are hired. If possible, an experienced state arthritis program manager should be included in the site visit.
  - b. New program managers should be linked with an experienced manager.
  - c. The supervisor of state arthritis program managers should attend the technical assistance site visits.
3. Measurable goals and objectives have not been available. Program direction has changed (i.e., become more specific) over the past five years. States felt that having clear expectations (goals and objectives for which they would be held responsible) would help them set priorities and decrease the number of activities underway. Solutions-
  - a. Complete the current goals/objectives/strategies/actions document.
  - b. Conduct a conference call to further discuss and finalize.
  - c. Standardize technical assistance around the goals/objectives/strategies/actions.
4. Program managers often lacked the tools to develop, maintain, and enhance partnerships. Because most of the work of state arthritis programs is to broker/facilitate embedding evidence-based programs in existing delivery systems, skills necessary to work with others are essential. Solutions-
  - a. Highlight need for these skills to supervisors of arthritis program managers.
  - b. Encourage state health departments to train managers in partnership skills.
5. Partnerships have been difficult to develop and maintain. In many places, the partnerships with the Arthritis Foundation Chapters have been especially challenging. There are significant issues around partnerships: 1) Money

- complicates the relationship. Partners may now expect to get paid for activities they did before CDC/state funding became available. Without partnership co-investment, sustainability of efforts is unlikely; 2) Specific roles for partners are often unclear, resulting in unclear or unreasonable expectations and lack of progress. Solutions-
- a. Encourage co-funding activities with partners.
  - b. Clarify roles in all partnerships.
6. Surveillance expectations from CDC have not been clear. Most states wanted more epidemiologic support at the state level, although they could not articulate how this would help them reach their overall program goals. Program announcement language could imply that states should explore other data sources. Solutions- See number 8.
7. States are interested in CDC being more directive when providing program guidance. In several areas, there was different understanding about CDC expectations among the states and between CDC and the states. Solutions- see number 8.
8. Communication has not been adequate. See numbers 6 and 7. Although CDC communicates program direction through the program announcement, technical assistance, at grantee meetings, and by e-mail, there is not a common understanding of program direction in all components. Solutions for 6, 7, and 8-
- a. CDC needs to further clarify direction and expectations.
  - b. CDC needs to communicate more clearly around direction and expectations and check for common understanding.
  - c. Technical assistance needs to be standardized.

## Component-Specific Findings

### *Funding*

#### Definition of Success

- CDC funding is used specifically for projects within the scope of the cooperative agreement.
- Funds are balanced between staff support and program implementation.
- Sub-awards have clear deliverables and accountability mechanisms, and are consistently monitored.
- Carry-over amounts are minimal (limited to 10--20% of the total award).

#### Facilitators

- Availability of federal funding.
  - Without federal funding, state arthritis programs would not exist.

#### Barriers

- Limited available funding.
- The consolidated cooperative agreement causes problems at both CDC and state levels, particularly around submission of financial status reports and requesting carryover funds.
- CDC delays in processing and approving carryover requests.
- Closely aligned federal and state fiscal years that complicate funding logistics.

#### Observations

- Higher funding levels are not associated with more evidence-based program activity.
- In-kind support and/or state dollars do not ensure visibility or active health department support of the goals and objectives of Arthritis Program.

#### Short-term solutions

- Ensure messages and technical assistance from CDC and CDC project officers are consistent.
- Ensure states and CDC project officers are monitoring state sub-awards.

#### Long-term solutions

- Consider one base level of funding for all states in future program announcements rather than having two funding levels for essentially the same scope of work.
- Seek to eliminate the need for consolidated grants announcements in the future.
- Move toward having funding levels be based on performance.

## *Program Operations*

### Definition of Success

- Arthritis Program is appropriately staffed.
- Energy and efforts of staff are focused on activities consistent with the program announcement.

### Facilitators

- Appropriate staff with appropriate skills (i.e., interpersonal, organizational, partnership building), and who are hard-working and committed to program goals and objectives.
- Strong senior management support at least two management levels above the program coordinator.
- Stable staff and organization.
- Full time Program Coordinators who operate without competing demands.
- Strong organizational support.

### Barriers

- Staff turnover.
- Delays caused by hiring processes.
- Lack of early orientation/technical assistance site visits for new program coordinators.
- Re-organizations in health departments.
- Arthritis viewed as a low priority, competing for leadership and resources.
  - Multiple chronic disease programs take attention away from arthritis programs.
  - Insufficient management support resulting in the program being ignored and given permission to “fly under the radar.”
- Consolidated cooperative agreement—the consolidated agreement requires additional layers of coordination and paperwork within the health department requiring additional arthritis program manager’s time.

### Observations

- Organizational placement does not appear to be a facilitator or barrier by itself—success is more of a result of the partnership building skills of the program coordinator.

### Solutions

- Increase visibility of arthritis at CDC, National Association of Chronic Disease Directors, and within state health departments.
- States should provide program coordinators with partnership skill building training.
- Conduct orientation-based site visits within 1--2 months for new program coordinators and invite management to attend.

## *Surveillance*

### Definition of Success

- BRFSS used as main source of arthritis surveillance data; more to the point, standard tables provided by CDC Arthritis Program used as main source of surveillance data.
- Data products (burden reports/fact sheets/burden section in state plan) are produced in a timely manner and distributed widely.
- Data are used to increase visibility of program to public, health professionals, and policy makers.
- BRFSS management module used.
- Other data sources are not pursued without specific purposes.

### Facilitators

- Use of standard tables as the initial data source. If no epidemiologist is available, state can use standard tables for burden report, facts sheets, etc.
- Access to epidemiology expertise to help interpret and use standard table data and develop products. A full time epidemiologist does not appear to be warranted.
- Geo-coding the location of the evidence-based intervention classes to identify underserved areas of the state.

### Barriers

- Lack of clarity around the depth and breath of surveillance activities. States need to know how much surveillance data is enough.
- Limited staff resources consumed finding and analyzing data of questionable value (i.e., having unclear program purposes). More precisely defining the arthritis problem does not get programs to the people that need them.
- Having a full-time epidemiologist encourages a search for data of questionable value.

### Observations:

- Surveillance data has high credibility and partners rely on departments of health for sound and timely data.
- States desire more epidemiologic support, with unclear program justification.
- Guidance is needed around how to address co-morbidities and quality of life data.
- Co-morbidity and quality of life data need to be addressed in standard tables.
- States would like more information on the percent of people with various types of arthritis. This is currently not available; state programs were unable to articulate how this would promote programs.
- States want regional and county-level arthritis data, and data about arthritis among children.

### Solutions:

- CDC needs to clarify expectations around surveillance.
- CDC should consider expanding surveillance data provided to include data on health-related quality of life, co-morbidities, and arthritis among children.

## ***Burden Reports/Information***

### Definition of Success:

- Burden information is available in a timely fashion and is widely accessible
- Burden information is used by arthritis program and other stakeholders to
  - increase program awareness.
  - increase program reach.

### Facilitators

- Flexibility in scope and form of data products.
- Access to epidemiologic support.

### Barriers

- State review processes delaying dissemination.
- Unclear expectations around form and scope of reports (e.g., large burden reports versus fact sheets).

### Observations/Issues

- States felt that the burden reports lend credibility to the arthritis program with partners and the public.
- The standard tables and the footnotes to the tables are frequently used and are valuable.
- Data has opened some doors and has the potential to open others.
- States felt that it was important to do one comprehensive, burden report. Subsequent data dissemination could take the form of fact sheets.
- Dissemination is often difficult; multiple channels may be necessary (e.g., Web or Internet and print).

### Solutions

- States should have greater flexibility in report form and it should meet the state's needs.
- Technical assistance needs to be standardized around burden information.

## *Coalition / Advisory Group*

### Definition of Success

- Coalition has a clear purpose that advances mission of program.
- Coalition is action oriented to address arthritis in the state through a variety of partnerships
- Coalition helps develop a state plan and is guided by it.
- Partners (coalition members) provide critical link to organizations and access to populations of interest.
- Coalition members have the capacity and willingness to commit their organizations to take action (i.e., to implement tasks or objectives including those of the state plan).

### Facilitators

- Roles of the coalition members are clear and include action to address arthritis.
- Coalition has developed a plan with measurable objectives, timeline, and monitoring activities.
- Coalition ideally reflects the state's population (demographic and geographic representation), includes a balance of public health and clinical expertise
- There is consistent follow-up on planned actions.
- For large groups, a steering committee is used to facilitate progress.
- Group understands and utilizes the public health model.
- Group evolves in both activities and members as the plan moves from development to implementation.

### Barriers

- The amount and intensity of staff time to build and maintain group.
- State rules and regulations about advisory committees/coalitions interfere with development and progress.

### Solutions

- CDC should provide a clear explanation of the public health model and a way to educate coalition about this.
- Identify and disseminate success stories around coalition building.
- Develop and offer training on maintaining coalitions.

### Observations on building the coalition

- A professional facilitator helps the coalition coalesce and develop an action plan.
- A supportive and committed Department of Health lends credibility to the efforts.
- The inclusion of health care providers (e.g., physicians, physical therapists, occupational therapists) provides balance and a different perspective.
- People with arthritis should be included to bring the consumer perspective.
- Recognize that most members of the coalition will have little knowledge or understanding about public health; allow enough time to educate members/partners on the public health model.

- Group members should represent organizations with interest in arthritis AND have individual interest and expertise in arthritis, or public health.

Maintaining coalition momentum after action plan is developed

- Members need to be involved in the development of agendas.
- Orient new members early: new members may not understand public health or know about the progress to date.
- Frequently monitor progress on whether objectives etc. are met; designate someone to be responsible for tracking objectives, activities, and tasks.
- Acknowledge what members do well (and keep awareness of what they can't do) and recognize their accomplishments.
- Encourage members to take responsibility for a job to help keep them engaged over time.
- Arrange for frequent, consistent communication with members and opportunities for feedback through the use of e-mail, Listservs, and newsletters.
- Hold working meetings; they are better attended than meetings with presentations only.
- Open membership for groups help to reach a broad audience in the state and keep them informed about arthritis program activities.
- Structure meetings so each participant benefits in some way.
- Work with your Arthritis Foundation partner to gain mutual understanding and facilitate meaningful participation.
- State Aging groups with links to AAAs seem to be very helpful in reaching seniors.
- If the Advisory Group gets too wrapped up in implementation they may lose ability to provide objective advice.

## *Partnerships*

### Definition of Success

- Partners are actively involved in expanding the reach and sustainability of evidence-based programs.
- Partners provide access to populations with arthritis.
- Partners create greater awareness of arthritis.

### Facilitators

- Partners and Arthritis Programs share or have overlapping visions/missions.
- Partners meet each others' needs to help achieve missions.
- Partners participate with both dollars and in-kind support.
- Partners have mutually supportive relationship.
- Partners and program share credit for successes.
- Roles for partners are clearly defined; they may overlap but should be complementary.
- Partners are members of each others advisory boards.

### Barriers

- Lack of role clarity for activities.
- Changes in arthritis program and partners leadership; staff turnover; leadership instability.
- Lack of interpersonal skills necessary to sustain relationships.
- Limited time, funding and staff to invest in finding and maintaining partner relationships.
- Partners view of the state health department as being in control of all activities.
- States and Arthritis Foundation Chapters have different expectations from the partnership.

### Observations

- Successful partnerships are not driven by money alone; there are activities that can be done without funds (i.e., in-kind support for activities).
- Successful states have larger bases of partners and more frequent communication
- Successful partnerships foster sustainability.
- States wish to limit partnerships to those that work.

### Solutions

- Clarify parameters of successful partnerships: develop fact sheets.
- Partner with those that have an interest in the arthritis evidence-based interventions.
- Clearly define partner roles.
- CDC should allow states to limit partnerships to those that are productive.
- Foster sustainability of program efforts through partnership.

## *State Plans*

### Definition of Success

- State plans are developed for the state and do not only address the health department role for a public health approach for arthritis.
- State plans are used to provide ongoing program direction that lead to implementation of activities and accountability.
- State plans are inclusive of national (CDC) and state goals, objectives, strategies, and action steps.
- State plans served as a catalyst for bringing partners to the table.

### Facilitators/qualities of a good state plan

- Goals of the plan are prioritized and include action steps.
- Plans facilitate the ability of the state arthritis program and state to measure progress.
- Plans promote stakeholder buy-in.
- Plans are targeted toward decision-makers and system wide implementers.
- The intended audience and use of the plan are clear.
- The development of the plan is used to build new partnerships.

### Barriers

- The amount of time needed to develop a state plan is large.
- The use of the plan is unclear.
- The partners involved in developing the plan do not understand the purposes of the plan.

### Observations

- State plans added credibility and value to state arthritis programs.
- The use of outside facilitators resulted in a speedier process and reduced the amount of time needed from program coordinators.
- States with plans modeled after the *National Arthritis Action Plan: A Public Health Strategy*, endorsed by the commissioner and/or other high profile level of management do not appear to be associated with more program activity.
- States having difficulty in setting program direction and expanding the reach of evidence-based interventions tended to completely overhaul their existing state plans while more successful states tended to make appropriate revisions of existing plans.

### Short-term Options

- Provide technical assistance around state plans regarding format, timelines, and revisions.
- Give states the option of combining the required burden report with the state plan or to create a separate report to ensure maximum flexibility.

### Long-term Options

- Require state plans in future program announcements, but encourage the use of complementing implementation plans (how-to guides).
- Plans should be regularly reviewed for relevance and to guide revision.

***Interventions -- Packaged Programs***  
***Arthritis Foundation Aquatic Program***  
***Arthritis Foundation Exercise Program***  
***Arthritis Foundation Self Help Program***

Definition of Success

- Reach of evidence-based interventions increased
  - Interventions were delivered.
  - State program able to track growth in reach.

Facilitators

- Leaders were facility-based
  - Agency staff who lead program as part of job, or
  - Volunteers attached to a facility.
- State program invested in staff or partners to support intervention delivery (i.e., regional coordinators, grants to community agencies).
- State program partnered with community agencies who saw program delivery as a means to meet their own mission and serve their clientele.
- State program focused on a limited number of interventions, rather than attempting to implement all of them.

Barriers

- Unclear partner roles; unclear and/or unfulfilled deliverables from grantees or contractors.
- Lack of monitoring or holding grantees/contractors accountable.
- Perception that Arthritis Foundation Self Help Program is too long, training is too long and/or requirement for two leaders is unrealistic.
- Difficulties collecting reach data, and lack of confidence in reach numbers, particularly for PACE and aquatics.
- Competing priorities within the Arthritis Foundation between fund-raising and program delivery.
- Lack of shared commitment between State and Arthritis Foundation to expand the evidence-based interventions.
- Lack of non-Arthritis Foundation licensed interventions. States reported that working with the Arthritis Foundation chapters often hampered implementation efforts.

Solutions

- Clearly define roles.
- Clearly delineate roles and deliverables in contracts and hold contractors/grantees accountable.
- Emphasize embedding programs in systems with access to relevant populations and multiple local partners or delivery points (i.e., hospitals, health clubs, health plans' Area Health Education Centers (AHECs), University Extension Services.

- Expect to collect reach data from any delivery site that state program has had any involvement with (i.e., direct funding, support for training, marketing) and include this expectation in memoranda of understanding.
- Consider eliminating aquatics from the list of potential interventions for state program focus (Reasoning: state arthritis programs have small role; and in most areas, program is running near capacity).

#### Issues to clarify

- Scope of reach numbers to collect—just those for which the health department has some involvement, or total numbers for entire state, including those implemented by the Arthritis Foundation
- Clarify state coordinator’s role whether they should be trainers and/or leaders.

### *Interventions -- Packaged Programs Health Communications*

#### Definition of Success

- Campaign implemented as designed.
- State able to estimate reach/impressions.
- State able to leverage resources (donated ads, pooled airtime).

#### Facilitators

- Using multiple elements of the campaign.
- Using local community partners as an on the ground implementation force to deliver campaign materials.
- Partnering with community leaders and getting into community with plenty of lead time.
- Supplemental funding.

#### Barriers

- The amount of time and labor needed to distribute brochures and flyers/
- Difficulty measuring impact (No baseline on awareness; difficulties measuring changes in awareness).

#### Solutions

- Be more focused: target specific areas or populations.
- Recruit strong community partner and on-the-ground implementation force.
- Collect, at a minimum, impressions and other process data.

## *Program Evaluation*

### Definition of Success

- States monitor progress toward program goals/objectives in state plan and program work plans.

### Facilitators

- Ability to obtain reach data.
- Evaluation efforts are established during program planning.
- Evaluation efforts are prioritized and are consistent with priorities of program announcement and state program.
- Progress is monitored over time.

### Barriers

- Lack of evaluation expertise, time, and other resources.
- Lack of understanding among partners.

### Observations

- Some states are measuring impact without having solid reach numbers first.
- Some states are evaluating activities that are low priority and fairly easy to evaluate (i.e., advisory group satisfaction) rather than intervention expansion efforts.
- Struggling states tend to use the required annual report as their primary evaluation tool.
- Successful state evaluation efforts are focused on monitoring reach of evidence-based interventions rather than health outcomes.

### Solutions

- Reiterate the importance of obtaining reach data through partners.
- Establish evaluation priorities.
- Provide evaluation guidance and training for program coordinators.
- Clarify importance and use of the Impact Tool to capture program reach data.

## *Awareness and Education*

Only observations are given.

### Observations:

- Awareness activities were not addressed in the program announcement; therefore success was not defined. In addition, few state programs were doing any evaluation of their awareness activities.
- Most awareness activities were very nonspecific; rarely was “awareness of what” defined.
- Rarely were awareness activities linked to achieving program goals.
- State programs who were investing more time or energy in awareness or educational activities spent less time in expanding the reach of evidence-based interventions.
- Health fairs, conferences, and exhibits consumed staff resources and time, and did not appear to add value.

### Proposed Indicators of Success:

- Awareness activities are well justified.
  - Target of activity (i.e., awareness of “what”) is clearly defined.
  - Activity is clearly linked to advancing program goals.
- Results were measurable and were measured.

### Solutions

- CDC should standardized guidance around awareness and education activities.
- Awareness activities should only be done to expand the reach of evidence-based interventions.
- States should track resource investment in awareness activities.

## *Policy*

Because success was difficult to define in the area, only observations are given.

### Observations

- Arthritis advocacy and policy issues are predominately the responsibility of partners (i.e., Arthritis Foundation).
- States have helped raise awareness and obtain Arthritis Month resolutions, but having a resolution is not associated with visibility, leveraged funding, or success.
- Increased national attention is needed.

### Short-term Options

- Work with partners to identify policy gaps and advocacy priorities.
- Discuss policy needs and options with the CDC policy group.
- Consider engaging the Council of State Governments.
- Present results of the Comprehensive Site Visit project to Chronic Disease Directors; request that CDD suggest legislative action and help establish policy priorities.

### Long-term Options

- Engage the Arthritis Foundation—National Office in discussions on how to influence chapters to be more active in state advocacy activities.
- Engage in national level activities to bring more national attention to arthritis.

### *Top List for Immediate Technical Assistance*

Nominees for the Top Ten or Golden Rules list:

- Partner with those that have an interest in the arthritis evidence-based interventions.
- States may limit partnerships to those that are productive.
- Clearly define roles of partners, define expectations.
- Emphasize embedding programs in systems with access to relevant populations and multiple local partners or delivery points.
- Focus on a limited number of interventions and do a couple well rather than attempting to implement all the interventions.
- For health communication campaigns, recruit strong community partner and on-the-ground implementation force before implementation begins.
- Limit awareness activities to those that lead to expanding reach of evidence-based interventions.
- CDC will try (as travel budget allows) to conduct technical assistance/orientation-based site visits within 1--2 months for new program coordinators and invite management to attend.
- States are allowed to limit surveillance activities to the standard tables and tracking the reach and location of evidence-based intervention programs.
- CDC will expand available surveillance data to include data on health-related quality of life, co-morbidities, and arthritis among children.
- Burden reports should meet the state's needs and can be a large burden report, fact sheets, or some other mechanism that results in timely and widespread data dissemination.
- States have the option of combining their burden report with the state plan or create a separate report to ensure maximum flexibility.

## *Appendix 1 -- Process/Methods*

A standard protocol was developed to address overall program status and 10 component-specific activities (funding, program operations and staffing, surveillance, advisory group, partnerships, state plan, interventions, program evaluation, public awareness and education, and policy development). Where possible, facilitators and barriers were identified. The protocol was developed with the input of an Arthritis Council (AC) consultant with more than 40 years of state/federal program experience, AC members and CDC staff. The protocol, consisting of a state preparation checklist, pre-visit assessment and the site visit assessment, was field tested in two states (NY and UT) and revised using feedback from the site visits, UT and NY state arthritis program staff, and CDC. Fifteen 2-day site visits were conducted between January 24 and November 10, 2005. Site visit teams were comprised of the AC, National Association of Chronic Disease Directors consultant and CDC representatives. All site visits were facilitated by the AC Consultant, who coordinated the pre-assessment, the site visit teams, ran the meetings and developed the final reports. The other members of the teams were CDC scientists and project officers. To maintain objectivity in collecting information, the science consultant and project officers assigned to a particular State Arthritis Program were not permitted to serve on the review team for that State Arthritis Program.

Reports were developed by the AC consultant based on the pre-assessment, the collection of documents provided to the review team at the on-site review, and the on-site discussions. Drafts were shared with other members of the site visit team, revised and then shared with the state arthritis program manager to check for accuracy.

A retreat was held November 30 through December 2, 2005, to review the findings from the 15 site visits, identify major overall themes, define success in the 10 cooperative agreement subcomponents, and look for common facilitators and barriers for success or failure. All participants read all of the site visit reports. Two participants were assigned to each component for more intense review. Specifically they worked together to define success for that component (if possible), identify facilitators and barriers, contrast states who appeared to have more success in that component to those who do not, identify any issues for further discussion and make recommendations for next steps. This information was presented to the group for further discussion. Two areas did not lend themselves to defining success (public awareness and policy). Observations are listed for these sections.

*Appendix 2 -- Pre-assessment and Site Visit Protocols*

State Preparation Checklist	22
State Arthritis Program Review – Pre-assessment	27
On-site Review Team Guidance	34



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*Appendix 3 Participating states and review schedule*

New York	January 24--25, 2005
Utah	February 2--3, 2005
Tennessee	March 11--12, 2005
Ohio	April 11--12, 2005
California	April 14--15, 2005
Oklahoma	May 16--17, 2005
Arkansas	May 19--20, 2005
Minnesota	June 6--7, 2005
Missouri	June 9--10, 2005
Illinois	June 13--14, 2005
Indiana	June 16--17, 2005
Florida	July 18--19, 2005
Alabama	July 21--22, 2005
Georgia	August 29--30, 2005
Connecticut	November 10, 2005

*Appendix 4 – Retreat Participants*

**Arthritis Council, NACDD**

Larry Burt, Consultant for the National Association of Chronic Disease Directors  
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Julie Bolen, Epidemiologist

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Lee Ann Ramsey, Project Officer

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