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.