DISABILITY AND REHABILITATION
RESEARCH COALITION
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DRRC PRIORITIES REGARDING IMPLEMENTATION OF THE AFFORDABLE CARE ACT (HEALTH CARE REFORM)

10/8/10

Below are possible areas for DRRC's advocacy efforts regarding implementation of those provisions of health care reform directly related to disability and rehabilitation research. DRRC will need to establish priorities, given other pressing issues on our agenda (NIDRR, NCMR, and CDC), and identify ways to leverage the coalition's efforts by relying on the efforts of individual member organizations. The DRRC should prioritize the following opportunities:

I. NATIONAL STRATEGY FOR QUALITY IMPROVEMENT IN HEALTH CARE

The Secretary of HHS is directed to establish a national strategy to improve the delivery of health care services, patient health outcomes, and population health. In determining priorities under the national strategy, the DRRC will:

- Advocate for improving outcomes, efficiency and patient-centeredness on behalf of persons with disabilities and chronic conditions, including improving their health and function through research related to rehabilitation, behavioral health treatment, chronic disease management, and recognition of health care disparities;
- Educate policymakers and administrators in HHS that the term "chronic condition" should not be limited to the acute care medical model, thereby limiting the term to persons with illnesses such as heart disease, pulmonary disease, diabetes, and similar conditions. Instead, educate policymakers that the term includes persons with chronic functional limitations, including persons with stroke and other chronic neurological conditions, not simply acute medical conditions;
- Identify rehabilitation-related examples under the mandated priorities called for in the statute, including examples related to addressing gaps in quality, efficiency, comparative effectiveness information, health outcome measures, and data aggregation techniques;
- Propose a definition (for purposes of the Affordable Care Act) of rehabilitation research (that includes research related to restoring, improving, maintaining, and/or preventing deterioration of function); and
- Provide ongoing input as part of the Secretary's transparent collaborative process used to establish the national strategy.

II. APPOINTMENTS TO WORKING GROUPS AND ADVISORY PANELS

The DRRC will help facilitate nominations of its member organizations' experts to key working groups and advisory panels that focus (or could potentially focus) on disability and rehabilitation research, including the:

- Advisory Group on Prevention, Health Promotion, and Integrative and Public Health to the National Prevention, Health Promotion, and Public Health Council;
- Preventive Services Task Force and Community Preventive Services Task Force;
- Expert Advisory Panels to Patient-Centered Outcomes Research Institute;
- Commission on Key National Indicators;
- Consultation Cultural Competency, Prevention and Public Health and Individuals with Disabilities Training; and
- National Quality Forum Consensus Panels related to outcome measurement in medical rehabilitation.

DRRC will not independently appraise the individual nominations but will rely in its member organizations to put forward quality candidates. DRRC will serve as a facilitator to simply package names and resumes of DRRC candidates for boards and commissions that relate to rehabilitation and disability research, not all commissions or boards that may impact rehabilitation and disability generally. The DRRC will not incur any expenses for those selected for these positions as they will not be specifically representing the coalition.

III. QUALITY MEASURE DEVELOPMENT

The Secretary is required to identify gaps where no quality measures exist and existing quality measures need improvement, updating, or expansion. The Secretary shall give priority to the development of quality measures that allow the assessment of health outcomes and functional status of patients and the equity of health services and health disparities, including outcome measurement for chronic diseases, and primary and preventative care for distinct patient populations. The Secretary shall convene multi-stakeholder groups to provide input on the selection of quality and efficiency measures. In this connection, the DRRC will:

- Advocate for the inclusion of persons with disabilities and chronic conditions as a distinct patient population requiring priority attention;
- Define "quality" to include adjusting accurately for case mix to avoid denying services to subpopulations of patients e.g., persons with disabilities and chronic conditions;
- Identify and advocate for a priority focus on research related to quality measure development applicable to functional status of patients with disabilities and chronic conditions;
- Advocate for the use of computer-assisted testing (CAT) technologies to simplify the administration of quality outcome measures and patient assessment tools;
- Identify and advocate for a priority focus on research initiatives related to health disparities experienced by persons with disabilities and chronic conditions;

- Participate as a stakeholder providing input on the selection of quality and efficiency measures; and
- Advocate for the public disclosure of case-mix adjusted quality and outcome measures in a manner that will allow consumers to make informed choices when selecting a health plan, a provider, or a particular therapeutic intervention in keeping with their health care needs.

IV. DEVELOPMENT OF NEW PATIENT CARE MODELS; HEALTH CARE DELIVERY SYSTEM RESEARCH

The Secretary is required to select models where there is evidence that the models address a defined population for which there are deficits in care leading to poor clinical outcomes or potentially avoidable expenditures. Centers within HHS shall conduct health care delivery system research with priority on, among other things, health status and function of patients, including vulnerable populations. The DRRC will:

- Advocate for the inclusion of persons with disabilities and chronic conditions as vulnerable populations for purposes of prioritization of the research agenda related to health care delivery system research;
- Advocate for research (including identification, development, evaluation, and dissemination) regarding new and innovative patient care models, methodologies and strategies, as well as quality improvement practices that represent best practices applicable to the defined population of persons with disabilities and chronic conditions;
- Decide whether DRRC should take a position regarding Medicare bundling pilots, including the Continuing Care Hospital concept, and if so, agree on a position and communicate it to policymakers; and
- Communicate to DRRC members specific research opportunities identified in the Federal Register and elsewhere.

V. PATIENT-CENTERED OUTCOME RESEARCH

- Take advocacy steps to ensure that research and evidence synthesis conducted through support of the Patient-Centered Outcomes Research Institute considers variations in patient subpopulations, including persons with disabilities and chronic conditions.
- In identifying national priorities, adopt advocacy steps to ensure that the Institute takes into consideration and emphasizes the needs of subpopulations such as persons with disabilities and chronic conditions.
- Communicate to DRRC members specific research opportunities identified in the Federal Register and elsewhere.

VI. PREVENTION

- Provide input regarding the development of a national prevention, health promotion, public health and integrative health care strategy that addresses the needs of persons with disabilities and chronic conditions, including the role of rehabilitation medicine and the prevention of secondary and tertiary conditions.

- Advocate for targeting funding to address special population needs, including individuals with disabilities.

VII. DATA COLLECTION, ANALYSIS, AND QUALITY.

The new health reform law requires that any federally conducted or supported health care or public health program, activity, or survey collects and reports, to the extent practicable, disability status.

- Take advocacy steps to hold the Secretary accountable for conducting and supporting activities, surveys and reports that include disability status.

VIII. LIMITATIONS ON USES OF COMPARATIVE EFFECTIVENESS RESEARCH

The new health reform law places numerous limitations on how the Secretary may use comparative effectiveness research (CER), e.g., the Secretary may only use evidence and findings from CER to make certain coverage determinations if such use is through an iterative and transparent process which includes public comment and considers the effect on subpopulations. The legislation also includes numerous restrictions/limitations regarding the use of findings from CER that relate to individuals with disabilities. The DRRC will:

- Participate in the iterative and transparent process regarding the use of evidence and findings from comparative effectiveness research to make coverage determinations by providing comments on the effects of the research on the subpopulation of persons with disabilities and chronic conditions.
- Develop a position paper exploring the meaning and intent of the restrictions and limitations on the use of evidence and findings from the perspective of persons with disabilities and chronic conditions.