Strengthening the Ryan White CARE Act: Responding to an Evolving Epidemic

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR
COALITION

CAEAR Coalition

- Title I EMA grantees and providers
- Title III grantees
- CARE Act consumers
- Title II ADAP
- Active Member of Ryan White Legislative Group

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR
COALITION

Ryan White Legislative Group

- Coalition representing CARE Act providers and consumers
  - AIDS Action
  - AIDS Alliance for Children, Youth & Families
  - CAEAR Coalition
  - National Association of AIDS Education and Training Centers
  - National Association of People with AIDS
  - National Minority AIDS Council
- Draft legislation represents consensus among broad range of HIV/AIDS community

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR
COALITION

Starting Point for Reauthorization and Responding to Principles

- The CARE Act is working. OMB and GAO analyses found that the CARE Act has:
  - increased the number of PWHAs receiving primary medical care and treatment;
  - contributed to the decline of HIV/AIDS cases and deaths;
  - reached underserved groups, including the uninsured and the poor; and
  - served African Americans, Hispanics and women in higher proportions than their representation in the AIDS population.

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR
COALITION

Starting Point for Reauthorization and Responding to the Principles

- There is unmet need in all communities. Lack of access to care and disparities are the result of flat funding and rescissions, not problems with the legislation.
- Communities of color, most notably the African American community, are especially hard hit by HIV/AIDS.
- Shifting resources will not solve access problems.
- The CARE Act operates in a health care system that is unequal, inconsistent, uncoordinated and underfinanced.

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR
COALITION

Serve The Neediest First: Modernize Eligibility and Funding Criteria

- Require the HHS Secretary to certify national HIV data set by 9/30/09
- Base Title I eligibility and formula allocations on living AIDS cases and then on living HIV/AIDS cases in 2009.
- Change Title I eligibility from 2000 cases over five years to 1,500 living AIDS cases and then an equivalent number of living HIV/AIDS cases; would bring in some Title II Emerging Communities.

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR
COALITION

Serve The Neediest First: Modernize Eligibility and Funding Criteria

- Require objective, comparable, measurable, and weighted indices to determine severity of need for use in determining supplemental grant awards; any differences in data collection must be addressed.
- Index should:
  - be used only for supplemental funds;
  - not punish local/state governments that have dedicated resources to HIV/AIDS care nor reward those that have not; and
  - not be tied to private resources in a city/state.

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR
COALITION

Serve The Neediest First: Accelerate Protection Period

- Continue the Title I protection-period provision accelerating the maximum reduction rate to 21% over five years.
  - Protection period first included in 1996 to prevent destabilizing services due to year-to-year fluctuations and shifts in HIV/AIDS case counts.
  - Proposed changes for 2005 could have profound impact on funding levels and changes must be phased in over time to prevent destabilizing existing systems of care in many communities.

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR
COALITION

Serve the Neediest First: Support Hard-hit Areas

- Elimination of "80/20" Provision in Title II would harm those in need:
  - would not resolve disparities between unmeet needs and available resources.
  - Would severely harm states and localities that continue to be hardest hit by HIV; Title I EMA states have 87% of all living cases.
  - States receive partial credit for EMA cases in allocations in recognition of the significant challenges to state public health departments with such large shares of the epidemic.
  - Would cause dramatic and severe reductions in services to current clients.

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR
COALITION

Serve the Neediest First: Support Title III Clinics

- Continue to prioritize funding for existing and new Title III projects to provide high-quality, community-based primary care to low-income, underserved and underinsured populations living in rural and underserved areas.

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR
COALITION

Serve the Neediest First: Establish Capacity Building in Minority and Rural Communities

- New planning and development grants to small minority community-based organizations and to rural community-based organizations to assist in expanding their capacity to provide HIV-related health services in low-income communities and in underserved rural and minority populations.
- Grants to a funded organization could not exceed $250,000 per year and would be limited to four years.
- Funded organizations could have an annual budget up to $2 million.
- Authorized in Part F at $100 million per fiscal year.

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR
COALITION

Focus on Life-Saving and Life-Extending Services: Core Medical Services

- Require EMAs to document annually the systems they have in place to meet basic, core medical needs.
- Do not set percentage requirement for core medical services
  - Inflexible 75% set-aside contradicts stated need for jurisdictions to have "maximum flexibility to respond to the epidemic."
  - Appropriate support services enhance access to care.
  - CARE Act programs have proven their ability to increase access to medical services and provide the support services needed to access and stay in care.
  - Any core services requirement must allow for consideration of coordination with state and local funding streams available to support these services.

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR
COALITION

Focus on Life-Saving and Life-Extending Services: Set Requirements for Drug Prices

- Direct HHS Secretary to ensure that CARE Act programs receive at least the lowest price available to the federal government for pharmaceutical products.

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR
COALITION

Increase Accountability

- Require documented procedures for soliciting and responding to consumer recommendations and filing grievances.
- Require HRSA to enter into cooperative agreements with other federal programs, including CMS, to improve the coordination and efficiency of HIV-related health care services.
- Require use of HIV data for WICY waivers once data set is certified for an eligible area. Limit waivers to one year and require EMAs, to the best efforts possible, to consult with Title IV projects and other relevant parties as part of the waiver application process.

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR
COALITION

Increase Accountability:
Maintain Strong Planning Councils

- Planning council members are on the frontlines and are ideally situated to identify unmet needs and determine funding priorities to meet them.
- Community-based planning is at the heart of CARE Act's success.
- Require planning councils to submit annual reports on membership demographics and compliance with membership requirements.

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR
COALITION

Increase Accountability:
Develop Unduplicated Data

- Require HRSA HIV/AIDS Bureau to make every effort to develop a national, unduplicated, client-level data system for all programs funded under the Ryan White CARE Act.
- System must ensure appropriate level of confidentiality and have the ability to be cross-referenced within and between states.
- Grantees must be guaranteed additional resources so that developing, testing, and launching this system does not divert resources away from care.

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR
COALITION

Increase Flexibility: Create New Mechanism to Support States without Title I EMAs

- Competitive grant program in Title II.
- Support areas of severe need in states that do not receive Title I funds.
- Authorized at $80 million per year.

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR
COALITION

Strengthening the CARE Act and Improving Access to Care

- End flat funding.
- Use the data that is most reflective of the epidemic to make funding allocations.
- Don't destabilize existing systems of care.
- Build stronger, more diverse community-based providers to best serve those in need.
- Use all CARE Act titles to reach underserved communities.

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR
COALITION

Thank You

- Policy Recommendations for Reauthorization of the Ryan White CARE Act, 2005
- The Case for Ryan White CARE Act Reauthorization, 2005
- CAEAR Coalition Response to HHS Ryan White CARE Act Reauthorization Principles
- Overview of RWLG Recommended Legislative Changes

www.caear.org

COMMUNITIES ADVOCATING EMERGENCY AIDS RELIEF
CAEAR
COALITION