

Policy Education and Systems Change Advocacy as a Federally Funded Program

Presented by

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and

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- Context of heightened civic engagement, political activity, and significant policy changes at the federal and state levels
- Tension between systems change expectations and limitations around advocacy for federally funded programs.
- Politically charged environment increases the level of risk



- Go to the guidance
 - A quick overview of relevant legislative and administrative guidance for UCEDD, LEND, IDDRRC, and DBP programs
- Consider the spectrum of systems change activities
 - Review a tool to guide the balance between personal and professional activities
- How does it play out on the ground?
 - David Deere will share his program's experiences

Developmental Disabilities Assistance and Bill of Rights Act of 2000 (PUBLIC LAW 106–402)

Section 153 PURPOSE AND SCOPE OF ACTIVITIES.

- (a) (1) In order to provide leadership in, ***advise Federal, State, and community policymakers about***, and promote opportunities for individuals with developmental disabilities to exercise self-determination, be independent, be productive, and be integrated and included in all facets of community life, the Secretary shall award grants to eligible entities designated as Centers...

[Emphasis Added]

Developmental Disabilities Assistance and Bill of Rights Act of 2000 (PUBLIC LAW 106–402)

Section 153 PURPOSE AND SCOPE OF ACTIVITIES.

- (2) CORE FUNCTIONS(B) Provision of community services—
(i) that provide training or technical assistance for ...
policymakers (C) Conduct of research, which may include basic or applied research, evaluation, and the ***analysis of public policy*** in areas that affect or could affect, either positively or negatively, individuals with developmental disabilities and their families.

[Emphasis Added]

No specific mention of policy or systems change activity in the legislation

LEND 2016 Funding Opportunity Announcement

- [The LEND Curriculum] should emphasize...appropriate didactic and experiential content relative to MCH/Title V and related legislation, such as Title X (Family Planning), XIX (Medicaid/EPSTDT), and XXI (State Children's Health Insurance Program)...A broad public health perspective includes...: community needs assessment, **advocacy, public policy formulation and implementation, legislation/rule making**, ...(p. 14)

[Emphasis Added]

No specific mention of policy or systems change activity in the legislation

LEND 2016 Funding Opportunity Announcement

- The program should provide TA/consultation to the field. TA refers to mutual problem solving and collaboration on a range of issues, which may include ... ***policy and guidelines formulation***... (p. 18)
- Core faculty members ...Engage in scholarship directed toward the areas of integrated systems of quality care, ...leadership, ***policy analysis***, medical home, and other important areas established by MCHB. (p. 24)

[Emphasis Added]

No specific mention of policy or systems change activity in legislation DBP 2012 Funding Opportunity Announcement

- At a minimum, the curriculum should include analysis of core public health functions applied to Developmental-Behavioral Pediatrics issues, ...**public policy, ...and advocacy.** (p. 22)
- Describe how the training program will ensure a workforce in clinical and public health practice, academia and **policy arenas** knowledgeable in the fundamentals of the field of maternal and child health, and possessing the skills and attitudes to meet the unique needs of MCH populations. (p. 28)

[Emphasis Added]

No specific mention of policy or systems change activity in legislation DBP 2012 Funding Opportunity Announcement

- Create, implement, and evaluate innovative approaches to practice and policy to improve the delivery of clinical and public health services and health outcomes for MCH populations; facilitate timely ***translation of research findings into training, policy, and practice*** (p. 29)

[Emphasis Added]

No specific mention of policy or systems change activity in legislation IDDRC 2015 Request For Applications

- As national resources for IDD research, the IDDRCs play leadership roles in training of new investigators for the IDD research field and educating the patient and lay communities regarding research activities.
- If the aims of the Research Project are achieved, how will scientific knowledge, technical capability, and/or clinical practice be improved?
- Is the Research Project related to one of the five focus themes responsive to the articulated goals of the program (Comprehensive –comic [sic] Approaches, Outcome Measures for Interventions or Treatments, Multi-modal Treatment Approaches, Shared Resources Across IDDRCs for Treatment or Assessment, **Public Health Approaches**)...?

[Emphasis Added]

Go to the Guidance – LEND & DBP Limitations

Source: HRSA SF-424 R&R Application Guide (2016): Anti-Lobbying, Section 503

- (a) No part of any appropriation ...shall be used, other than for normal and recognized executive legislative relationships, for publicity or propaganda purposes, for the preparation, distribution, or use of any [media] designed to ***support or defeat the enactment of legislation*** before the Congress or any State or local legislature or legislative body, except in presentation to the Congress or any State or local legislature itself, or designed to ***support or defeat any proposed or pending regulation, administrative action, or order issued by the executive branch*** of any State or local government, except in presentation to the executive branch of any State or local government itself.

[Emphasis Added]

Source: HRSA SF-424 R&R Application Guide (2016): Anti-Lobbying, Section 503

- (b) No part of any appropriation ...shall be used to ***pay the salary or expenses*** of any grant or contract recipient, or agent acting for such recipient, related to any activity [outlined above]...

[Emphasis Added]

Source: Program Instructions ADD PI-01-1 (2001)

- UCEDDs are authorized under the DD Act to influence legislation in ways that might otherwise be considered “lobbying”
- Some restrictions remain including:
 - The prohibition...on using funds to influence the outcome of a Federal, state or local election or for contributions to political parties
 - The prohibition ... on the use of grant funds to pay any person for influencing or attempting to influence the awarding of any Federal contract, grant, loan or cooperative agreement.

Source: [NIH Lobbying Guidance for Grantee Activities](#)

- Although they cannot engage in ...activities defined as lobbying, non-government grantees can undertake ...highlighting and translating public health evidence; collecting and analyzing data; publishing and disseminating results of research; implementing prevention strategies; conducting community outreach services; fostering coalition building and consensus on public health initiatives; providing leadership and training, and fostering safe and healthful environments.

Source: [NIH Lobbying Guidance for Grantee Activities](#)

- Some restrictions remain including:
 - Direct lobbying: attempting to influence deliberations or actions by Federal, state, or local legislative or executive branches. This includes communications to a legislator or executive official that refer to and reflect a view on specific measure (legislative or executive).
 - Grassroots lobbying: inducing members of the public to lobby

LENDs/DBPs

- Expected to educate trainees about policy and policymaking systems
- Prohibited from addressing specific legislation
- Translate research findings into policy analysis



UCEDDs

- Expected to inform policymakers, even when that relates to specific legislation
- Allowed to advocate on specific policies
- Translate research findings into policy analysis

IDDRCs

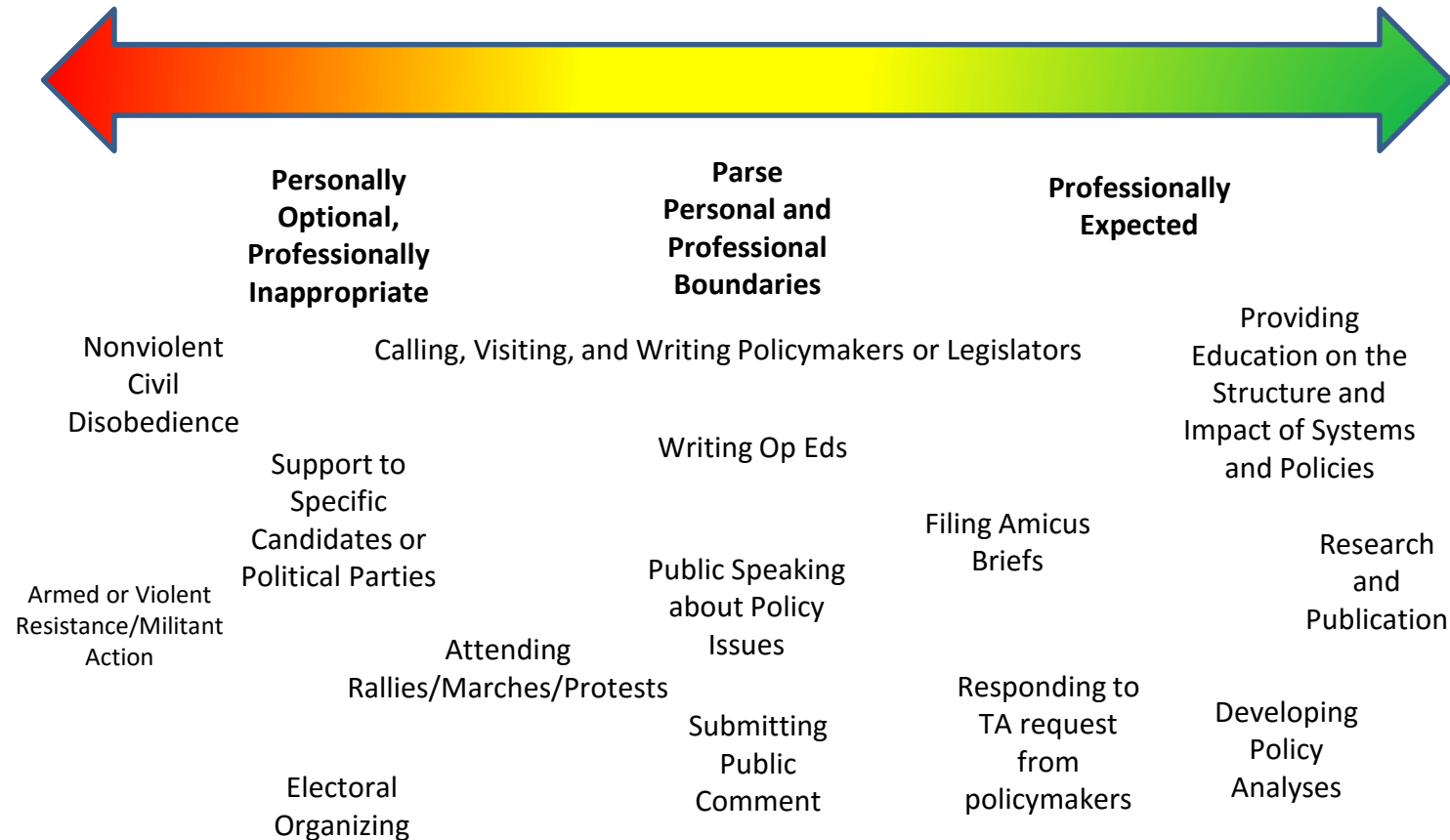
Communicate research discoveries to improve scientific knowledge, technical capability, and/or clinical practice

- University Priorities/Guidelines/Policies or Government Affairs Departments
- State and Local Guidelines
- IRS Non-Profit Limitations – [501\(c\)\(3\) substantial part test](#) and the [501\(h\) election](#) to be governed by an expenditures test
- [OMB's uniform guidance](#)
- Public Perception
- Preserving Relationships with Partisan Officials



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Spectrum of Systems Change



Use a nonpartisan approach: Refrain from presenting unsupported opinions, distorting facts, using inflammatory or disparaging terms, or sharing conclusions based on emotions rather than on objective factual information

How does it play out on the ground?

David Deere, M.S.W., M.Th.,
Director of Arkansas's Partners for
Inclusive Communities (UCEDD) and
Training Director for the Arkansas
Regional LEND



- American Health Care Act education vs. lobbying
- State Medicaid Cuts protest – Leave Requests
- Use of space and equipment
- Strategically identifying yourself
- Consider communication modality – verbal, email, social media
- Training Staff and Trainees

1. How have you seen these competing factors play out at your center or program?
2. Have you run into other limitations?
3. How do you balance the requirements to educate trainees and policymakers with the need to protect your university, center, program, or employees?
4. Are there other activities that should be added to the spectrum, and if so, where do they fall?
5. How do you communicate these issues to trainees and staff?

- Webinar Archive
- TA Resource Summarizing Guidance
- Spectrum of Systems Change Resource
- Discussion: Training Module Workgroup?

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