

Your Role in Advocacy



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March 2018
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This document was produced by the Association of University Centers on Disabilities (AUCD). No federal funds were used in the production of this document.

Your Role in Policy Advocacy as a Federally-Funded Program

What is Addressed in this Document?

All AUCD Network members have some responsibility to be engaged in policy education and systems change. Policy education entails informing a person or organization about policy. “Informing” is a key word because it is different than “advocating” for a specific position or action. Providing information about policy options for systems change may be different than advocating for specific policies, so these are important distinctions to remember in understanding your federally-funded role at a LEND, UCEDD, DBP, or IDDRC. Although policy education and systems change are both required roles for all AUCD Network organizations, there are also limitations, permissions, and exceptions with respect to policy education and systems change activities that apply to federally-funded Centers and Programs.

Why is this Important?

UCEDDs are required to engage in educating policymakers. UCEDD, LEND, and DBP programs have a responsibility to teach trainees/fellows/students about the policymaking process and their role in impacting policy as leaders in the field. IDDRC research activities are intended to inform clinical and public health practices; this can imply that research activities inform policies that drive practices. Understanding the requirements and limitations of each of these federally-funded programs is critical in fulfilling your responsibilities and ensuring that policy education efforts are impactful.

Since most hospitals and universities affiliated with AUCD’s network are non-profit entities and/or have a non-profit foundation arm, having a solid understanding of the Internal Revenue Service (IRS) policies and Office of Management and Budget (OMB) Uniform Guidance is also essential to do this work successfully. The [IRS defines lobbying](#) as [direct or grassroots activities](#) that attempt to influence specific legislation. Organizations and Institutions of Higher Education can [lose tax-exempt status and be subject to additional taxes](#) if it is determined an organization has acted improperly. OMB’s [uniform guidance](#) addresses administrative requirements, cost principles, and audit requirements for federal awards; thus all federal awardees are required to comply with this guidance.

Guidance is available from individual federal agencies which discusses expectations and limitations for participating in policy education activities, and is summarized below.

Entity	Audience	Summary	Guidance Source
ACL	UCEDDs	Areas of emphasis include self-determination activities, which support people with disabilities to develop leadership skills, through training in self-advocacy, to participate in coalitions, to educate policymakers, and to play a role in the development of public policies.	DD Act , Section 102 (27)
		Core functions include advising Federal, State, and community policymakers; providing training and technical assistance to policymakers; and analyzing public policy.	DD Act , Section 153(a)
		AIDD clarifies guidance on undertaking educational and informational activities to advise and assist policymakers. Prohibitions remain on political campaigning and lobbying.	AIDD Informational Memo ADD-PI-01-1: Lobbying
		All of the above.	2018 UCEDD Funding Opportunity Announcement
HRSA	LENDs	<p>The LEND curriculum should emphasize the development, implementation and evaluation of systems of health care...a broad public health perspective includes, but is not limited to advocacy, public policy formulation and implementation, legislation/rule making.</p> <p>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> <p>Core faculty members engage in scholarship directed toward the areas of integrated systems of quality care, leadership, policy analysis.</p>	2016 LEND Funding Opportunity Announcement

Entity	Audience	Summary	Guidance Source
HRSA	DBPs	<p>Leadership in the area of policy development relates to the process of translating research to policy and training, as measured in Performance Measure Training 5.</p> <p>The curriculum should include analysis of core public health functions applied to DBP issues, such as community needs assessment, program planning and evaluation, public policy, financing, budgeting, and consultation.</p> <p>The program should provide technical assistance (TA)/consultation to the field... on a range of issues, which may include program development and evaluation; clinical services; needs assessment; policy and guideline formulation; site visits; and review/advisory functions.</p>	<p>2017 DBP Notice of Funding Opportunity</p> <p>MCHB Discretionary Grant Performance Measures (Attachment B, pgs. 76-78)</p>
HRSA	LENDs and DBPs	<p>No part of any appropriation contained in this Act or transferred pursuant to section 4002 of Public Law 111-148 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 kit, pamphlet, booklet, publication, electronic communication, radio, television, or video presentation 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.</p> <p>No part of any appropriation contained in this Act or transferred pursuant to section 4002 of Public Law 111-148 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 designed to influence the enactment of legislation, appropriations, regulation, administrative action, or Executive order proposed or pending before the Congress or any State government, State legislature or local legislature or legislative body, other than for normal and recognized executive-legislative relationships or participation by an agency or officer of a State, local or tribal government in policymaking and administrative processes within the executive branch of that government.</p>	<p>HRSA SF-424 R&R Application guide</p>

Entity	Audience	Summary	Guidance Source
NIH	IDDRCs	Grantees are permitted to prepare and disseminate certain (1) nonpartisan analysis, study, or research reports; (2) examinations and discussions of broad social, economic, and similar problems in conferences and reports; and (3) information provided upon request by a legislative body or committee for technical advice and assistance. Along these lines, analysis, study, or research should contain a balanced, objective exposition of the facts to enable the public or an individual to form an independent opinion or conclusion. Materials must be posted or circulated widely to a diverse and numerous audience[s] on a nonpartisan basis and must not contain an overt “call to action.” A number of specific examples are provided.	NIH Lobbying Guidance for Grantee Activities
		While there is no direct reference to policy or advocacy, there is reference to IDDRCs evolving toward more translational approaches to disability research. Such research can and should be a catalyst to drive policy change in the best interest of people living with disabilities and their support networks.	2016 IDDRC Funding Opportunity Announcement

Legislative and administrative guidance applicable to all federally funded programs also discusses limitations on lobbying activities, and is summarized below.

Entity	Audience	Summary	Guidance Source
IRS	UCEDDs, LENDs, DBPs, and IDDRCs in non-profit settings	Ensure that direct or grassroots lobbying activities do not constitute a substantial part of overall activities or expenditures. Do not engage in any direct or indirect political campaigning.	IRS: Tax information for charitable organizations, including political campaigning, and measuring lobbying via activities or expenditures
OMB	UCEDDs, LENDs, DBPs, and IDDRCs	The cost of certain influencing activities associated with obtaining grants, contracts, cooperative agreements, or loans is an unallowable cost.	Electronic Code of Federal Regulations §200.450

Network members must also be aware of additional considerations related to their host university or hospital setting, state and local guidelines, public perception, and preserving relationships with politicians. University or hospital priorities, guidelines, and policies can impact the policy education work of network members, especially in instances when the policy priorities of the network member don't match those of its host. The governmental affairs office of the university or hospital is an important partner, and through development of good relationships, may become a critical ally in policy efforts. State and local guidelines addressing policy education and advocacy, especially related to educating legislators and other policymakers, may differ from those of the federal funder and should be followed. Public perception should also be considered, as there may be a disparity

between network members' understanding of their allowable policy-related activities and the public's understanding and/or opinion of those activities being carried out on funds provided by their federal taxes. Media often plays a role here and should be considered critical partners and allies in shaping public opinion on disability policy topics. Finally, developing and maintaining relationships with legislative and regulatory policymakers is recommended, given the long-term impact of their activities: learn their priorities, identify where those priorities intersect with disability policy, and become a reliable resource on disability topics.

How is it Done?

A range of policy-related activities exist to effect systems change. Some activities are expected professionally of AUCD network members based on the priorities outlined by their federal funders in the table above. Other policy related activities are prohibited professionally though may be performed as an individual citizen. Yet more lie in a grey area that can cross personal and professional boundaries. Any policy activity that occurs as part of a federally-funded professional role must have 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, fact-based information.

Policy-related activities expected of AUCD network members include:

- Providing education on the impact of current or proposed policies and laws
- Conducting research and producing publications
- Developing policy analyses
- Responding to requests from policymakers

Policy-related activities that may be engaged in professionally, or may be better addressed personally as an individual citizen – those activities in the grey area – should be considered in the context of the federal guidance and other considerations noted above. These include:

- Calling, visiting, and writing legislators and policymakers
- Writing op-eds for newspapers
- Speaking publicly about disability policy issues (including on social media)
- Submitting public comments

Policy-related activities that should not take place while representing a federally-funded program, but may be engaged in as a private citizen, are numerous. It is important to avoid all ties to the federally-funded program when engaging in these activities as a private citizen; avoid wearing identifying program logos, and avoid sending political emails from a work-related email address. Participate in these activities off-hours, or take and document time off to participate. Consider adding a disclaimer to materials, such as, "No federal funds were used in the production of these materials." Examples of these activities include:

- Support for specific political candidates or political parties
- Electoral or campaign organizing
- Nonviolent civil disobedience
- Advocating for a specific policy or law to be passed or defeated

With Whom do you Partner on Policy-related Activities?

Partnerships are critical in helping inform policy. A coalition of partners delivering a single message to policymakers helps express alignment within constituencies and reduces confusion occurring from inconsistent messaging. Where barriers exist in participating in policy activities (the university government relations office, for example), partners without the same barriers can help deliver the messages and educate policymakers with data provided by AUCD network members. Partners in every state and Territory include disability advocacy organizations, [Centers for Independent Living](#), [Developmental Disabilities Councils](#), [Protection & Advocacy / Disability Rights programs](#), and [Parent Training and Information Centers](#).

Where are Relevant Resources?

Additional technical assistance materials are available.

1. Recorded [webinar discussion and presentation](#) (2017) on policy education and systems change advocacy.
2. UCEDD Directors Technical Assistance Institute (2017) [materials](#) on network leadership in policy and practice.

For More Information

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