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OEI's Atlanta Regional Office prepared this report under the direction of Jesse J. Flowers, Regional Inspector General, and Christopher H. Koehler, Deputy Regional Inspector General. Principal OEI staff included:

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EXECUTIVE SUMMARY

PURPOSE

To determine how the Maternal and Child Health Bureau provides guidance for and oversight of training grants for Interdisciplinary Leadership Education Excellence in Caring for Children with Neurodevelopmental and Related Disabilities to assure the grants meet their objectives.

BACKGROUND

The Interdisciplinary Leadership Education Excellence in Caring for Children with Neurodevelopmental and Related Disabilities (LEND) is a training grant program. Its purpose is to train professionals who will improve the health status of infants, children, and adolescents, with or at risk for, neurodevelopmental and related disabilities.

The program seeks to achieve its mission through funding graduate level, interdisciplinary training which produces professionals to work with special needs children.

The Maternal and Child Health Bureau (MCHB) is part of the Health Resources and Services Administration, in the Department of Health and Human Services. The Maternal and Child Health Bureau oversees the LEND training grant program.

The Maternal and Child Health Bureau administered 34 LEND program grants in 1998. The grant programs are funded in public and nonprofit universities. LEND grants to each institution average about $500,000 per year. In 1998, LEND grants ranged in amount from $300,000 to $1.2 million.

FINDINGS

The LEND program benefits interdisciplinary treatment for children

LEND programs produce leaders in interdisciplinary treatment of children with developmental disabilities. They also play a very important role in helping to support university clinics serving special needs children. Further, LEND program graduates reduce the shortage of adequately trained people who deliver services to special needs children.
LEND grantees have mixed success in demonstrating leadership and tracking graduates

LEND grantees have some success tracking recent graduates. However, their tracking of less recent graduates is spotty and some grantees collect information that is not relevant.

Monitoring and evaluation of grantees is minimal

MCHB does not conduct monitoring visits to grantees, and thus has little basis for critical decisions regarding refunding. MCHB oversight of LEND is hampered by the lack of systematic on-site monitoring of grantees.

New grant categories are confusing

MCHB has reclassified grantees as ‘Regional’ and ‘Regional and National’. This classification is confusing, with some grantees unsure of how to declare themselves. Many grantees are concerned that incorrect designation might disqualify them from funding.

RECOMMENDATIONS

MCHB should:

- Develop outcome measures for determining the success of the LEND program.
- Work with its grantees to develop more effective tracking of the LEND graduates.
- Use on-site visits to aid program oversight and in making funding decisions.
- Clearly distinguish between categories of funding.

COMMENTS

The HRSA concurred with our recommendations. The full text of their comments is in Appendix A.
INTRODUCTION

PURPOSE

To determine how the Maternal and Child Health Bureau provides guidance for and oversight of training grants for Interdisciplinary Leadership Education Excellence in Caring for Children with Neurodevelopmental and Related Disabilities to assure the grants meet their objectives.

BACKGROUND

The Interdisciplinary Leadership Education Excellence in Caring for Children with Neurodevelopmental and Related Disabilities (LEND) is a training grant program. Its purpose is to train professionals who will improve the health status of infants, children, and adolescents, with or at risk for, neurodevelopmental and related disabilities.

The program seeks to achieve its mission through funding graduate level, interdisciplinary training which produces professionals to work with special needs children. The program focuses on health conditions of mental retardation, neurodegenerative and acquired neurological disorders, and multiple handicaps. The program emphasizes development of leadership in its trainees.

Authorization

Congress authorized the Maternal and Child Health Services Programs in 1935, with Title V of the Social Security Act. The purpose of Title V is to improve the health of all mothers and children consistent with applicable health status goals and national health objectives established by the Secretary, Department of Health and Human Services (DHHS).

Administrative Responsibility

Title V is administered by the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) as the Maternal and Child Health Services Block Grant. The Block Grant is MCHB’s principal statutory responsibility.

The MCHB serves all mothers and children in the U.S., but places an emphasis on providing access to care for low-income and otherwise isolated populations.
Funding and Administration

The Maternal and Child Health Services Block Grant was funded at $683 million in FY 1998. Of that grant appropriation, MCHB sets aside 15 percent (about $102 million) to fund Special Projects of Regional and National Significance (SPRANS).

The LEND grant program, funded at almost $18 million in FY 1998, is the largest single category of funding under SPRANS.

Thirty-four (34) LEND training grants were operating in 1998. The grant programs are administered by public and nonprofit universities. In 1998, LEND grants ranged in amounts from $300,000 to $1.2 million. A typical LEND grant was about $500,000 per year. Each grantee provides leadership training and related administrative functions with their individual LEND grant.

Organizations that receive LEND grants usually fund training that is administered by their University Affiliated Program (UAP). The UAP commonly administers LEND grant training along with training funded by other sources for related developmental disabilities.

Beginning in 1995, the grants have been renewed on a competitive basis on a staggered five-year cycle. As is required in the case of multi-year funding cycles, LEND grantees prepare an application for continuation of funding each year. These continuations, which contain an annual progress report, are funded on a non-competitive basis. At the end of the five-year period, grantees must compete against all others interested in a LEND grant. Anecdotal evidence suggests there is very little turnover in the institutions receiving grants.

Requirements of LEND Programs

LEND grant programs must provide long-term training to produce professionals to work with special needs children. The training is usually provided at graduate and post-graduate levels, and as part of continuing education programs. The LEND grant programs also provide technical assistance and consultation to providers of health care services. Examples of program activities include:

- Graduation of long-term trainees in a minimum of 12 disciplines.¹
- Training on State Title V programs.
- Technical assistance to Head Start agencies, State Title V and related agencies, and various community-based programs.
- Service by LEND faculty on national, regional, State, and local advisory boards.

¹The 12 disciplines include pediatrics, nursing, public health social work, speech-language pathology, nutrition, audiology, occupational therapy, physical therapy, psychology, health administration, pediatric dentistry, and parents of children with neurodevelopmental disabilities. The last two were added in 1998.
LEND grantees also must have a LEND project director, and a faculty representing at least the 12 different disciplines. This allows families of children with special needs to receive interdisciplinary consultation at one location. The LEND grant director must be a board certified pediatrician. The grants have additional requirements in the areas of faculty qualifications, required training curriculum, faculty research, types of trainees, and reporting and evaluation.

The MCHB has operated the LEND program for almost 30 years. During that time, MCHB has intermittently increased the number of grantees. Despite a statutory requirement to do so, MCHB has not evaluated LEND to determine that it is operating as intended. This inspection represents the first effort to do so.

**METHODOLOGY**

We purposively sampled the LEND grant programs for our inspection. We selected 17 of the 34 LEND grantees operating in 1998. We designed our sample to include grantees that represented a geographic cross section of the U.S. In addition, our sample included programs which have been funded since the inception of the grant program, as well as programs in their first funding cycle. We conducted an on-site inspection at each selected grant program.

To understand program accomplishments, we used standardized data collection instruments for interviewing relevant officials and staff at each selected grantee. In those locations where training was in session, we interviewed currently enrolled trainees. We also interviewed recent graduates to better understand their perceptions of the usefulness of LEND training. On average, we interviewed 6 to 10 officials and staff at each site for a total of approximately 135. We also interviewed over 60 present trainees. Finally, we interviewed more than 30 graduates, some in person and some by telephone.

Further, at each site we reviewed documentation on grant program funding, plans, operations, and accomplishments. This documentation included the application under which the grantee is currently funded. We also examined interim reports used to update MCHB on prior year accomplishments. In cases where grantees were scheduled to compete for the major refunding cycle, we reviewed their applications. These applications described their five-year accomplishments in great detail. The applications also projected their plans for the upcoming grant period. This information was extremely helpful to the inspection team in understanding the particular program. Finally, some grantees prepared special information for the inspection team, which we also considered.

To ensure that LEND programs were reaching out beyond the University clinics, we interviewed a number of State Title V agency staff. We also contacted a number of Head Start Directors and their technical assistance contractors to determine their awareness of and interaction with LEND grantees.

To corroborate and obtain a broader perspective on LEND program activities, we also interviewed several other knowledgeable parties, such as former LEND program
administrators and officials, university program administrators and officials with the American Association of University Affiliated Programs. Where possible we also interviewed senior University officials not directly associated with the grant program to obtain their perspectives on the program. This also gave the inspection team a sense of the prominence of LEND in the broader university community.

To better understand the implications of open competition within LEND, we interviewed former grantee officials from programs that had unsuccessfully competed in the first open competition. These programs had been forced to shut down their LEND operations. In addition, we interviewed university officials and UAP officials who had been involved in these discontinued programs. From these interviews, we obtained insights and perspectives on closing down LEND programs.

Finally, to ascertain program requirements and expectations, we interviewed relevant MCHB officials. Because of a marked turnover in MCHB staff during the time we were conducting this inspection, we interviewed members of both the former and present staff.

We aggregated data from all sources and performed a qualitative analysis to compare LEND training grant performance to MCHB grant objectives and regulatory requirements. To assess MCHB decisions on funding, we analyzed program budgets, adjusting for inflation. In light of program mandates, we assessed MCHB decisions on program requirements and expansion. Finally, to assure that MCHB selection criteria were followed, we reviewed application requirements and grantee selections.

We conducted data collection and analysis between July 1998 and July 1999. We conducted the inspection in accordance with *Quality Standards for Inspections* issued by the President’s Council on Integrity and Efficiency.
FINDINGS

The LEND Program Benefits Interdisciplinary Treatment For Children

LEND grantees produce leaders for interdisciplinary treatment for children with developmental disabilities

Central to the LEND program is its stated goal to produce leaders for interdisciplinary treatment of special needs children. However, in its guidance, MCHB does not define leadership or establish standards or outcome measures by which to determine LEND’s success in producing leaders.

While leadership is difficult to define, failure to do so or to establish outcome measures inhibits evaluation and management of the LEND program. It is clear that MCHB expects LEND trainees to continue serving special needs children. Therefore, LEND leadership is focused on a variety of professions centered around meeting the needs of such children.

In fact, we discovered a wide range of ideas on what constituted leadership while interviewing LEND respondents. These definitions included teaching and publishing professionals. They also included researchers, service providers and program administrators. We used these concepts and examples as a framework for evaluating the LEND program.

Leaders in providing services

LEND graduates and trainees are in the forefront in providing services to special needs children. The inspection team saw a large number of LEND graduates providing state-of-the-art services to special needs children in the university clinics. We identified LEND graduates who were directing a broad spectrum of innovative treatment programs, developing custom medical equipment and providing advocacy for special needs children. These clinics are a scarce and valued resource in service provision.

LEND graduates and trainees also provide services to children in the community. One such site is the public schools where many LEND graduates serve as coordinators for services to special needs children. Typically their interdisciplinary training enables them to bring together a number of services appropriate to a particular child. These services may include audiology, speech pathology, physical therapy, nutrition and social work.

The inspection team discovered that LEND graduates and trainees provide a variety of services to children who are never seen at a university clinic. Perhaps these children do
not need the level of service provided there, or are unable to travel. These children may live in isolated areas such as remote farming communities or Indian reservations. Without the LEND program, it is unlikely that some needed services could be delivered in the community.

Many LEND programs also deliver services in States other than the one in which the program is funded. For example, a LEND program may utilize its staff or trainees to establish, coordinate or create new programs which serve special needs children in other States. These States may use the resources of the LEND grantee University Clinic. Such services are often designed and delivered by LEND trainees. With LEND staff and trainees leading the way, these services are often delivered under the auspices of the Title V agencies in those States. For example, each state has a Title V program for children with special health care needs. The state programs may coordinate services with LEND programs. Such programs expand the influence of LEND well beyond the university campus. In each case, the LEND grantee is the driving force, the leader in providing these services.

Leaders in professional circles

LEND graduates and staff also provide leadership by serving on advisory and policy boards for State Title V Agencies. They also serve on a large number of related committees, councils and boards. These bodies provide oversight and policy direction for a number of organizations at the international, national, regional and local levels.

The array of such organizations is extremely broad and comprehensive, easily numbering in the hundreds. Some examples at the national level include: the National Cancer Institute, American Academy of Pediatrics, Society of Pediatric Psychology, Sickle Cell Disease Association of America, American Academy of Audiology, and American Society of Human Genetics. These are but a few examples to illustrate the influence LEND can have on science and public policy for special needs children.

Leaders in program administration

Another clear indication that the LEND grant program produces leaders is the large number of LEND graduates that direct and staff many of the present LEND grantee organizations. As a rule, the LEND grants are made to large university clinics. These clinics are sophisticated enterprises, housing service, research and teaching activities with State, regional and national scope. The clinics are the most important centers in the country for developing state-of-the-art treatment modalities for special needs children. In fact, LEND training usually represents only a small part of what they do. It is a tribute to LEND that the directors of these clinics are frequently former LEND trainees. These directors are professionals and leaders whose lives reflect a lifelong professional commitment to making a difference for special needs children.
LEND programs support and benefit from other activities for serving special needs children

As described briefly above, one of the most striking features of the LEND program is that it is usually operated in close association with university clinics. The clinics deliver important and scarce services to special needs children. In many cases, the clinics offer services which are not otherwise available in the State or region. In some cases, children from other countries arrive at these clinics for service that is not readily available elsewhere. These children and their parents often reach the clinics devoid of hope that anything can be done to meet their needs. The inspection team heard a number of testimonials about how these clinics and their staffs, many of whom are funded by LEND, had provided the only services available anywhere to meet these special needs.

While most of the clinics would exist regardless of LEND funding, LEND does play a very important role in underwriting key staffing costs. This includes paying staff salaries. It also includes providing trainees to work in various capacities in the clinics. Therefore, the LEND training grants help maintain and improve clinic services. In turn, the clinics offer a unique training opportunity for LEND trainees. According to many LEND grantee staff, the sophisticated clinic service settings provide LEND trainees unparalleled training opportunities, exposing them to state-of-the-art treatment modalities in addition to the unusual interdisciplinary approach.

LEND funds stimulate interdisciplinary training to address shortages of professionals who treat special needs children

According to several LEND grant directors, there is a shortage of adequately trained people to deliver services to special needs children. Many of the grantees report difficulty in filling their university positions, as well as practitioner positions in surrounding communities. In addition to testimonial evidence, we found a large number of unfilled position announcements that had been open for a number of months.

Further, there is a particular shortage of professionals who have received interdisciplinary training, widely acknowledged by professionals in the field to be the best training model. Individual disciplines may offer training for serving special needs children. However, the LEND grants were the only source identified for funding interdisciplinary training.

In some grantees, the interdisciplinary training program provides a synergistic nucleus which attracts trainees who are not funded by the LEND grant. In these cases, because the LEND training program exists, students who are not funded by LEND may be able to attend and benefit from the training anyway. In this way, LEND increases training in a field where shortages of professionals are a continuing problem. While these trainees may not be tracked formally by the LEND grantees, anecdotal evidence suggests that some of them continue to work with special needs children.

LEND also serves a second function in many grantee programs. It serves as a core for other training and research monies. These monies may come from other grants, including
university departments of individual disciplines involved in LEND training and the States where LEND programs reside. These departments find advantages in merging smaller amounts of money, usually in the form of stipend supplements, with the LEND stipends. In many cases this will make the LEND stipends more attractive to the outstanding student.

LEND Grantees Have Mixed Success In Demonstrating Leadership and Tracking Graduates

Factors affecting leadership

The standard model of professional leadership is one in which appropriate education is followed by professional experience, during which leadership activities may accede progressively over time. This means that LEND programs which purport to produce leaders must either produce them more immediately than the norm or keep track of graduates until they become leaders. Otherwise LEND programs will not know if they are meeting their objective. LEND grantees claim to do both.

Several factors help determine whether or when a LEND graduate becomes a leader. Grantees noted that some LEND graduates do become leaders immediately upon graduation, while others may never do so.

One such determining factor is the discipline of the LEND graduate. Within the required LEND disciplines, professional training and credentials vary widely. These differences are a strength of the LEND program. For example, some trainees are medical doctors or PhDs doing post-doctoral work in other disciplines. Trainees with such advanced education are more likely to move directly in leadership positions than trainees seeking master’s degrees.

A second factor determining the likelihood of immediate leadership is the level of professional experience graduates have. For example, some LEND trainees are post-doctoral students who came into the training from leadership positions. They complete LEND training either to return to their existing position or go into other leadership positions. Most LEND trainees, however, enter the program with little experience with special needs children. Such trainees are likely to leave the LEND training program to go into entry level professional positions, such as a school nurse. For these trainees, leadership may come later in their careers.

A third factor in determining whether a LEND graduate becomes a leader is the geographic location of their position following their LEND training. To illustrate, a practitioner who has LEND training and is located in a rural setting, with a shortage of health resources, may become a leader almost by default. We found instances of LEND graduates with very little experience beyond their training, who are serving in a variety of leadership roles in their communities. According to some LEND officials, these graduates
would not function as leaders in urban centers where practitioners with more credentials and greater experience serve in those roles.

**Tracking graduates**

MCHB requires LEND grantees to track trainees. Tracking is important for several reasons. The first is to ascertain the extent to which trainees remain in the field of helping special needs children. Another is to ascertain the extent that LEND trainees assumed positions of leadership in their fields. Finally, tracking could provide valuable feedback on the impact of LEND training. Such information can be very useful in planning, directing, monitoring, and evaluating individual LEND training programs. In fact, this information comprises much of the basic data needed to evaluate the leadership aspect of LEND.

LEND grantees reported mixed success in tracking their graduates as required. However, none of the programs we visited demonstrated particular success in tracking. As might be expected, tracking of recent graduates is relatively effective, while over time tracking becomes more difficult. Unfortunately, grantees lose track of their graduates later in their careers when they are more likely to be assuming professional leadership roles.

In some cases, tracking systems are not capturing relevant information, despite the fact that they had maintained contact with many of their graduates. For example, some grantees collect no information on the position or duties of the graduate. Instead they had collected information on the graduate’s employer such as “school system” or “State Government.” From such information, it is impossible to ascertain whether the graduate is working as a leader with special needs children. While we accepted a variety of evidence that LEND produces leaders, improved graduate tracking could better demonstrate this.

**MCHB Monitoring and Evaluation of Grantees Is Minimal**

MCHB does not conduct monitoring visits to grantees. MCHB has not evaluated LEND programs despite a requirement to do so. LEND training programs are very complex and diverse. Without direct on-site monitoring and evaluation of program activities and results, MCHB has little basis for critical decisions regarding refunding. This lack of insight also hinders MCHB as they assess changes in program policy and operations decisions.

With the absence of on-site monitoring, MCHB places the future of individual training grant programs solely in the hands of grant writers and grant reviewers. Grantees expressed concern that they would not get full credit for their accomplishments. Instead, they felt they might lose out to other institutions with no track record, but the ability to write better applications.

MCHB staff acknowledge the difficulty of administering grants of this complexity without first-hand knowledge of grantee operations and performance.
New Grant Categories Are Confusing

Many grantees expressed confusion over MCHB’s new grant categories — specifically “Regional Significance” and “Regional and National Significance.” These category designations are intended by MCHB to distinguish between large training programs which have an expanded scope and focus on a regional and national level, and smaller programs which focus only at the regional level.

“Regional Significance” and “Regional and National Significance” designated programs are subject to different funding limitations. Programs of Regional Significance may not request more than $450,000 per year. Programs of National Significance, however, may qualify for funding significantly above $450,000.

While potentially useful for strategic planning purposes, the designations were difficult to understand and subject to individual interpretation. To illustrate, for determining their refunding status, MCHB instructed LEND grantees to self-declare their program category. Many grantees expressed concern that they might designate their program incorrectly and disqualify themselves from all funding.
**RECOMMENDATIONS**

MCHB should develop measures for determining the success of the LEND program.

In order to comply with requirements to evaluate the LEND program, MCHB should specify measures for determining the success of each LEND grantee. Such measures could include a definition or set of definitions of leadership. It could also establish a standard set of proxies for leadership to be used in evaluation.

**MCHB should work with grantees to develop better methods for tracking graduates**

To better determine the extent to which the LEND graduates become leaders meeting the needs of children with special needs, MCHB should collaborate with its grantees to develop and disseminate better ways to track graduates. The more effective the tracking, the better able LEND will be to make the case that they are producing leaders in this field.

**Use on-site monitoring to aid in making funding decisions**

Site visits would enable MCHB to better access grantee operations and results. The on-site monitoring could be similar to the regular site monitoring currently employed for University Affiliated Programs. Through such monitoring, MCHB could make more informed funding determinations.

**Clarify ‘Regional’ and ‘Regional and National’ grant funding categories**

Because grantees can lose their chance of funding if they mis-designate their program, the current confusion over the funding designations has potentially serious ramifications for LEND training programs. MCHB should consult with grantees to develop a better way for distinguishing between categories of grants.

**AGENCY COMMENTS**

HRSA concurred with our recommendations. Their comments are in Appendix A.
MAR 7 2000

TO: Deputy Inspector General for Audit Services
OIG, DHHS

FROM: Deputy Administrator


We have reviewed the subject draft report. Attached are HRSA's comments. Thank you for the opportunity to review this report.

Thomas G. Morford

Attachment

GENERAL COMMENTS

HRSA's Maternal and Child Health Bureau (MCHB) staff feels that the report will be valuable in assisting them in meeting their responsibilities to direct and provide leadership for this important training investment.

OIG RECOMMENDATION

MCHB should develop measures for determining the success of the LEND program.

HRSA COMMENT

HRSA concurs. The MCHB is currently working on developing performance measures for all Special Projects of Regional and National Significance (SPRANS) grants using the MCH Block Grant measures as a model. The MCH Training Program is in the process of developing measures that would be appropriate across all of the training categories as well as working with the LEND grantees to develop outcome measures that would capture more specifically the accomplishments of this particular investment. Draft measures have been submitted to the Associate Administrator for Maternal and Child Health, and Bureau staff are working on finalizing these measures to share with grantees and other constituencies in mid to late spring. It is anticipated that final measures will be submitted for OMB clearance in the fall of 2000.

OIG RECOMMENDATION

MCHB should work with grantees to develop better methods for tracking graduates.

HRSA COMMENT

HRSA concurs. In addition to the performance measures that are being developed by the MCHB, LEND and MCH staff have already had a face-to-face meeting. There are ongoing discussions, and we have made a commitment to work collaboratively to identify ways to better evaluate program successes, including more effective tracking of LEND graduates. MCHB has funded the American Association of University Affiliated Programs to explore various data and graduate tracking issues.

OIG RECOMMENDATION

Use on-site monitoring to aid in making funding decisions.
HRSA COMMENT

HRSA concurs, to the extent that site visits are practicable. The MCH Training Program in the recent past has increased site visits to all training grants. Staff recognize the need and value of on-site visits but have, in the past, been unable to travel due to insufficient travel allowance. Staff have developed a travel plan which includes trips to as many of the training grants as possible. It is the goal of the MCH Training Program to visit all of the LEND grantees over the next 5 years. In addition, MCHB has funded the National Center for Education in Maternal and Child Health to conduct a thorough evaluation of its training investments, including on-site assessments throughout the Nation.

OIG RECOMMENDATION

Clarify “Regional” and “Regional and National” grant funding categories.

HRSA COMMENT

HRSA concurs. The MCH program staff recognize that the distinction made in the last competition between programs of “Regional” and “Regional and National” significance created some confusion among grantees. Fortunately, there were no negative consequences to any grantee as a result of this issue. This matter has been discussed in detail with grantees and will be clarified, based upon their input, in future guidance materials.