Strategic Thinking Report: LEND and DBP Programs

Association of University Centers on Disabilities

Results of conversations that sought to better understand the emerging environment in which MCH training programs are operating, as well as the opportunities and challenges that lie ahead.

February, 2015
Contributing Staff
Jamie Perry, MD, MPH, Director, MCH Technical Assistance
Benjamin Kaufman, MSW, Program Manager

Consultant
Elizabeth Vasquez
Management Consulting Associates

Funder
This report was funded by the Association of University Centers on Disabilities through cooperative agreement #UA5MC11068 with the Maternal and Child Health Bureau. The contents of this document do not necessarily reflect the views or policies of the Maternal and Child Health Bureau, Health Resources and Services Administration, US Department of Health and Human Services, or the US Government.

Publication
Association of University Centers on Disabilities
1100 Wayne Avenue, Suite 1000, Silver Spring, MD 20910
www.aucd.org aucdinfo@aucd.org
Contents
The “Strategic Thinking” Project ................................................................. 1

Input from Stakeholders ........................................................................... 1

Recommendations from LEND and DBP Directors .................................... 1
  Strategic Direction #1: Expand training pipelines for LEND and DBP programs .... 2
  Strategic Direction #2: Create models of training and clinical care that are accessible and can be sustained ................................................................. 2
  Strategic Direction #3: Create new opportunities for trainees to learn and apply principles of MCH leadership training .................................................. 3
  Strategic Direction #4: Increase collaboration with Title V and non-MCH partners .... 4
  Strategic Direction #5: Advance policies and practices important to LEND and DBP programs, individuals with disabilities and their families, and the professionals who serve them ................................................................. 4

Full Recommendations from LEND and DBP Directors ................................ 6

Appendix: Stakeholder Recommendations ................................................... 14
The “Strategic Thinking” Project

Recently having completed an organizational strategic planning process and now approaching the next five-year funding cycle for the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs, AUCD took the opportunity to pause and engage in strategic thinking about future directions for the LEND and Developmental Behavioral Pediatrics (DBP) training programs. With the help of program directors and other maternal and child health (MCH) stakeholders, AUCD was hoping to better understand the emerging environment in which MCH training programs are operating, as well as the opportunities and challenges that lie ahead. With these insights, AUCD and the Maternal and Child Health Bureau (MCHB) can begin to think collectively about what can be done to produce the greatest benefit to trainees, children with disabilities and special health care needs and their families, and the broader health community. AUCD engaged the expertise of a consultant, Elizabeth Vasquez of Management Consulting Associates, to assist us with this effort.

Input from Stakeholders

“Strategic Thinking” discussions were put on the agenda of the January 2015 LEND and DBP Directors meeting. To prepare for that session, we interviewed 20 stakeholders – family faculty members, former AUCD Virtual Trainees, MCHB project officers and directors, self-advocates, and organizational partners – to get ideas from their different vantage points that could serve as a starting point for the LEND and DBP Directors’ conversations. The stakeholders were remarkably forthcoming, sharing information and impressions about the health care environment, how it’s changing, and what MCH training programs should do if they are to continue to make an impact on the quality of care and support that children with disabilities and special health care needs receive. From the stakeholders’ wide range of observations, ten major themes, or strategic issues, emerged:

- Sustaining training program capacity (financial and other resources, leadership, etc.)
- Capacity issues in the broader MCH workforce
- Adapting to changing healthcare delivery systems (ACOs, medical home, ACA, etc.)
- Serving increasingly diverse children and families
- Emphasis on the transition to adulthood
- Promoting the use and dissemination of evidence-based practices
- Applying lessons learned from the LEND/DBP experience in real world settings
- Increasing opportunities for trainee interaction and learning across training programs
- Working in partnership with families, self-advocates, and other community members
- Coordinating the efforts of LEND/DBP programs with state Title V initiatives

Recommendations from LEND and DBP Directors

Working in ten breakout groups at their January meeting, LEND and DBP Directors considered the strategic issues and offered their thoughts on what programs should do, how AUCD and MCHB can help interdisciplinary training programs respond to the opportunities and challenges ahead, and what additional supports programs will need to be successful. About 100 recommendations for action and needed supports were generated; these are presented (by issue) following this summary.
Certain recommendations clustered around key strategic directions. A few examples are offered below to illustrate one way the recommendations can be used to think and talk about the path forward.

**Strategic Direction #1: Expand training pipelines for LEND and DBP programs**
LEND and DBP programs have an integral role to play in helping to address MCH workforce capacity issues. In order to expand the pool of professionals with the knowledge and skills to provide interdisciplinary, family-centered, culturally competent care that meets the unique needs of children with disabilities and their families, programs need to engage in recruitment approaches that start early and attract diverse candidates; programs require flexibility to consider trainees from non-traditional disciplines; and programs need training approaches that reach beyond typical long-term preservice graduate level training.

Recommendations include:

- Bring more practicing professionals into LEND and DBP training (e.g. using Saturday courses, on-line courses, or creative job relief)
- Consider non-traditional trainees such as business, social entrepreneurs, law, vocational rehabilitation, etc. that have relevance to transition, as well as disciplines related to organizational/health care leadership
- Access people from a wide variety of disciplines early in their professionals careers to get them excited about maternal and child health and inculcate the LEND philosophy of care
- Build better partnerships with organizations that target diverse and/or underserved populations in support of trainee recruitment
- Allow for greater funding flexibility relative to short- and medium-term versus long-term trainees

Funding flexibility is key - the ability to fund short- and medium-term trainees from the MCHB training grants was recommended by several groups as an important way to strengthen and enhance the training pipeline through support of a more diverse array of trainees (e.g. practicing professionals, non-traditional disciplines, racially and ethnically diverse individuals) who can help to meet workforce needs for children with disabilities and special health care needs. Directors also reported that long-term financial incentives would be helpful to attract trainees to the field, such as loan forgiveness to individuals entering certain health or education-related fields and to providers working with designated populations such as transition-age youth.

**Strategic Direction #2: Create models of training and clinical care that are accessible and can be sustained**
LEND and DBP programs are continually striving to meet competing needs related to their primary training mission and to the provision of clinical care and other services. At the same time, programs are often being asked to do more with the same or fewer resources. In order to maintain high quality training and care delivery and to ensure that all populations who need access to services provided by LEND and DBP programs can be reached, programs will have to embrace technology and develop new models.

Recommendations include:

- Increase use of technology to boost programs’ capacity for distance training/learning and continuing education, minimizing faculty time for didactics and enabling them to educate trainees on systems change activities (e.g. grants, program development, and research)
• Support creation of a standardized training program curriculum that could be used at the discretion of programs to supplement existing faculty resources
• Utilize telehealth to increase access for underserved populations such as those in rural areas
• Develop new models of screening and assessment to identify and better serve diverse populations in a culturally competent manner
• Identify existing and develop new business models for services such as interdisciplinary clinics, telehealth, and developmental screening that work in current/emerging reimbursement structures and share these

Directors reported needing supports in the area of strategically “marketing” their programs both within and outside the university, exploring alternative funding options for non-reimbursed care, and sharing of successful training practices and service models that have been developed within the network.

**Strategic Direction #3: Create new opportunities for trainees to learn and apply principles of MCH leadership training**

LEND and DBP programs have a long history of MCH leadership training that incorporates principles of interdisciplinary, family-centered, culturally competent care. If programs are to be successful, graduates must be able to apply and adapt what they have learned to fit real world settings that reflect U.S. demographics and the current health care system. Trainees would benefit from training opportunities that afford them new perspectives, including those of family members and individuals with disabilities, and different settings to enhance their preparation for future roles as leaders in the field of maternal and child health.

Recommendations include:

• Connect with other systems of care (developmental disability agencies, early intervention, schools, home visiting, etc.) to expand experiential learning related to follow-up care
• Consider trainee exchanges (single session, short-term, long-term) and support of joint trainee projects such as conference posters, webinars, and journal articles across programs
• Strive to have family members as trainees and faculty in all training programs; the inclusion of individuals with disabilities as trainees and faculty should be embraced as an emerging priority that LENDs and DBPs should position themselves to meet at the individual and national level
• Provide more direct/in vivo training on how to help families work through the diagnosis process and treatment decisions; provide opportunities for trainees to get a better understanding of real-life health care issues through shadowing of diverse families or other learning partnerships
• Provide more leadership training on how trainees (as health professionals) can engage with the broader public around disability issues; for example, learning how to speak to the media about research and evidence-based practices as it relates to their discipline

Directors reported that additional investments would be needed by their programs and partners to support many of these ideas, as well as flexibility in the use of current funding. In particular, Directors reported that programs would need new resources to develop the capacity to include individuals with disabilities as trainees and faculty, including funding and sharing of best practices from programs currently doing this. Directors noted that guidance language could be considered to support these recommendations, specifically related to cross-program collaboration and inclusion of family members and individuals with disabilities.
in training programs. Lastly, Directors identified the importance of creating standardized evaluation measures to show that LEND and DBP programs are accomplishing their objectives at the trainee and program level.

**Strategic Direction #4: Increase collaboration with Title V and non-MCH partners**
Leveraging the full potential of the LEND and DBP networks related to training, technical assistance, continuing education, and service delivery requires strategic partnerships and sharing of resources between individual training programs and a variety of MCH and non-MCH partners; these include Title V and other national, state, and local agencies and organizations. These collaborations are critical for achieving joint goals in support of children with disabilities and their families, as well as establishing LEND and DBP programs and their faculty as thought leaders and key resources within their states and nationwide.

Recommendations include:

- Improve integration of MCH funded programs/agencies at state level; require Title V grantees to organize at least yearly meetings with all MCH grantees for information sharing and identification of areas for collaboration
- Create specific funding mechanisms and organizational processes for collaborations between training programs and Title V programs that focus on special health care needs, such as two-way training, data collection/analysis for collaborative grants, and having trainees assist with projects
- Build better partnerships with non-MCH funded programs/agencies that target diverse and/or underserved populations including foster care and child welfare systems
- Increase collaboration between training programs, University Centers for Excellence in Developmental Disabilities (UCEDDs), and other partners (e.g. employers) around transition issues
- Maximize relationships with professional organizations (e.g. discipline-specific associations)

Directors would like to share successful models of LEND and DBP collaboration with MCH and non-MCH partners. They suggest that partnerships could be more strongly supported at the federal level through better information sharing about MCHB-funded grantees within a state and through specific grant language or requirements.

**Strategic Direction #5: Advance policies and practices important to LEND and DBP programs, individuals with disabilities and their families, and the professionals who serve them**

The interdisciplinary care model, which is the hallmark of LEND and DBP training programs, can only be achieved in practice when there are policies and practices in place to support it. Programs should identify policy levers where they can have an impact and use their unique expertise to educate and support changes that will ultimately improve the quality of care for children with disabilities and their families. Involving trainees in these efforts gives them a real world opportunity to develop advocacy and leadership skills.

Recommendations include:

- Work with professional societies to get LEND and MCH leadership principles into the curriculum, recognizing the importance of licensure/certifying exams
- Become involved in efforts to inform Accountable Care Organizations (ACOs) of the financial benefit of treating people with disabilities, which can be a model for other chronic care conditions
• Assist with educating the Department of Health and Human Services and lawmakers about the need to designate individuals with disabilities as a medically underserved population
• Participate in the development and evaluation of new models of practice such as expanding the “health home” concept from the Affordable Care Act (ACA) to children and youth with special health care needs (CYSHCN)
• Engage faculty and trainees in state-level advocacy around promoting the use and dissemination of evidence-based practices; leadership projects can be focused on making changes at systems levels

In support of these recommendations, Directors need continued assistance at the national level for information dissemination about policy issues and the development of strategic relationships that will help further policy goals. This could include leveraging relationships with former trainees who may now be in a position to influence policy.
Full Recommendations from LEND and DBP Directors

The following section includes a table listing all of the recommendations that resulted from the LEND and DBP Directors’ strategic thinking session on January 23, 2015. The recommendations are organized by the 10 strategic issues. For each set of recommendations, supports needed by LEND and DBP programs are also listed.

<table>
<thead>
<tr>
<th>1. Sustaining training program capacity (financial and other resources, leadership, etc.)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Recommendations for LEND and DBP programs:</strong></td>
</tr>
<tr>
<td>• Use technology to boost training programs’ capacity for distance training/learning, thereby minimizing faculty time for didactics and giving them more opportunities to educate trainees on systems change activities (continuing education, grants, program development, research, etc.)</td>
</tr>
<tr>
<td>• Standardize training program curricula; this may be beneficial for programs with more limited faculty resources</td>
</tr>
<tr>
<td>• Increase marketing of LEND and DBP training programs</td>
</tr>
<tr>
<td>• Use CME opportunities within states to help with branding and building program awareness</td>
</tr>
<tr>
<td>• Develop connections with professional organizations and employers in the health care field who can endorse the value of LEND/DBP training</td>
</tr>
<tr>
<td>• Create standardized evaluation measures to show that training programs are accomplishing their objectives at the trainee/program levels</td>
</tr>
<tr>
<td><strong>Supports needed by LEND and DBP programs:</strong></td>
</tr>
<tr>
<td>• Guidance on how to “market” programs within and outside their university communities</td>
</tr>
<tr>
<td>• Technical assistance around fundraising and finding other financial options to make up for the lack of non-reimbursed care (e.g. special arrangements with hospitals)</td>
</tr>
<tr>
<td>• Greater funding flexibility relative to short- and medium-term vs. long-term trainees; this may promote greater sustainability (i.e. more trainees and a broader local/regional impact)</td>
</tr>
<tr>
<td>• More funding opportunities and additional supports (perhaps some type of mandate) for programs to collaborate with state Title V agencies and other programs</td>
</tr>
<tr>
<td>• Adequate reimbursement for clinical services, including developmental screening and team care</td>
</tr>
</tbody>
</table>
### 2. Capacity issues in the broader MCH workforce

**Recommendations for LEND and DBP programs:**

- Look to in-service training to address workforce needs, encouraging practicing professionals to push to the top of their education and skill level by: (1) bringing more practicing professionals into LEND/DBP training (e.g. Saturday courses, online courses, or creative job relief); and (2) using other educational strategies to achieve in-service training for medical professionals such as office-based detailing vs. mini-internships at a center.

- Participate in the development and evaluation of new models of practice (e.g. expanding the “health home” concept from the ACA to CYSHCN, applying LEND clinical models in the community, and developing curricula for care coordination that is appropriate to train a range of professionals and non-professionals as chosen by families - pastors, neighbors, support group members, etc.)

- Create opportunities that excite young people about the MCH field by: (1) accessing people early in their professional careers to inculcate the LEND philosophy of care in trainees from a wide variety of disciplines; (2) building opportunities to work with the MCH population in AmeriCorps and other service organizations; (3) pushing the LEND model into new settings with an emphasis on core values such as family-centered care and cultural sensitivity; and (4) looking at WHO interprofessional training models for inspiration.

- Address the mismatch between training and what is needed in professional practice by: (1) working with professional societies to get LEND principles into the curriculum, recognizing the importance of licensure/certifying exams; (2) advocating for expanding the notion of Entrustable Activities, similar to ACGME, so people with experience can move more quickly through training; (3) teaching the principles of working with the MCH population rather than the facts; and (4) finding a balance between university students and practicing professionals, as well as the classroom and field within training.

**Supports needed by LEND and DBP programs:**

- Funding for short- and medium-term trainees
- Investment in and dissemination of new practice models
- Institutional support for changing pediatricians’ roles (e.g. using nurses, NPs, social workers, educators, and/or developmental specialists to assume delegated responsibilities with appropriate training may be one way to enable pediatricians to work at the top of their skills and increase capacity)
- Institutional supports for pre-service training that take the long-term view of building capacity, such as incentives (signing bonuses, loan forgiveness, etc.) for individuals to go into MCH fields, like Child Protective Services does for social work education
- Interprofessional information on board/licensure/certification exams
3. Adapting to current/changing healthcare delivery systems (ACOs, Medical Home, ACA, etc.)

**Recommendations for LEND and DBP programs:**

- Inform insurance companies and ACOs about the financial benefit of treating people with disabilities, which can be a model for other chronic care conditions
- Educate HHS and policymakers about the need to designate individuals with disabilities as a medically underserved population
- Emphasize preventative services (a major ACA priority) during LEND/DBP training

**Supports needed by LEND and DBP programs:**

- Identification and dissemination of exemplary service models within the network that are financially sustainable
- Adequate reimbursement for services such as interdisciplinary clinics, developmental screening, and telehealth
- Partnerships with state Title V programs for potential funding to pilot innovative interdisciplinary, multidisciplinary clinics
4. Serving increasingly diverse children and families

**Recommendations for LEND and DBP programs:**

- Build better partnerships with non-MCH funded programs/agencies that target diverse and/or underserved populations, for example: (1) foster care and child welfare systems, as the high prevalence of CYSHCN in the foster care population makes this a special group for LEND/DBP (and Title V) collaboration, and the large numbers of children in kinship or relative care have many of the same needs as children in foster care; and (2) school/public health nursing in rural areas to identify and serve school-age children.
- Develop new models of screening and assessment to identify and better serve (with improved cultural competency) diverse populations, for example: (1) develop tiered assessments with midlevel evaluations to improve access to evaluation and services for diverse populations by closing the gap between screening/identification and access to service; and (2) create an expedited process of intake and service for immigrants.
- Utilize telehealth to increase access for underserved and rural populations.
- Incorporate outreach to diverse populations, including those who are underserved, so that these populations will be fully integrated into all aspects of training from curriculum (e.g. guest lectures from various populations and agencies serving them, community placement/project opportunities and individual advisory committee representation) to faculty engagement and student recruitment and participation.
- Ensure that individuals with disabilities and families members, including those from underserved ethnic and cultural groups, are well represented in the program as students and faculty.

**Supports needed by LEND and DBP programs:**

- Mechanisms for communication between programs who have experience in these topic areas (e.g. special interest groups).
- Forum to leverage diversity experts from within the network.
- Loan forgiveness for providers working with diverse and underserved populations.
- Designation of individuals with NDD and IDD as medically underserved populations.
- Improved integration of MCH funded programs/agencies; at state level, requirement for Title V grantees to organize at least yearly meetings with all MCH grantees.
5. Emphasis on the transition to adulthood

**Recommendations for LEND and DBP programs:**

- Consider non-traditional LEND trainees (business, social entrepreneurs, law, vocational rehabilitation, other sciences, etc.) that have relevance to transition
- Explore short- and medium-term traineeship opportunities for people working in the community
- Increase collaboration with UCEDDs around transition issues
- Collaborate with other transition partners such as the Center for Health Care Transition, self-advocate support groups for those with IDD or ID/MH dual diagnosis, DD Council partners, vocational rehabilitation, and groups focused on employment and health care transition issues
- Ensure that trainees (especially pediatricians) are learning about aging populations and caregivers; build capacity by having adult and family medicine specialists provide training/consultation on transition within programs
- Create a training module on the transition to adulthood with respect to disability and sexuality

**Supports needed by LEND and DBP programs:**

- Technical assistance regarding the identification and exploration of other funding sources in support of transition training and services
- Clarification regarding the scope of what transition/life course means when LENDs/DBPs have traditionally been focused on MCH
- Incentives for professionals working in the area of transition-age youth as an underserved population
- Incentives to develop links with Med/Peds and Family Medicine training programs to establish medium- or long-term training experiences in NDD with special emphasis on the transition challenge
- Forum such as Transition Workforce Summit or other mechanism to address network-wide transition topics
### 6. Promoting the use and dissemination of evidence-based practices

**Recommendations for LEND and DBP programs:**

- Instruct trainees on evidence-based practices (specific to each discipline) and levels of evidence as they relate to screening, diagnosis, and treatment
- Involve faculty and trainees in state-level advocacy around promoting the use and dissemination of evidence-based practices; leadership projects can be focused on making changes at systems levels
- Instruct trainees on how the concept of “evidence-based” is a moving target and how they can be good consumers of research; journal clubs that require students to read/respond to scholarly articles can be a helpful strategy
- Provide more direct/in vivo training on how to help families work through the diagnosis process (e.g. debunking the immunization myth) and treatment decisions (e.g. being more deliberate about the harmful consequences of alternative treatments); have trainees shadow families to get a better understanding of real-life healthcare issues
- Provide more leadership training on how trainees (as health professionals) can engage with the broader public around DD issues; for example, learning how to speak to the media about research and evidence-based practices as it relates to their discipline
- Educate trainees on QI methodology and consider adding more disciplines related to organizational leadership

**Supports needed by LEND and DBP programs:**

- Information and training resources related to media relations and quality improvement for future health professionals, which are areas in which few programs have in-house expertise
- Collaboration with universities (especially journalism or marketing departments) to learn how to disseminate evidence-based information to consumers in the most effective manner

### 7. Applying lessons learned from the LEND/DBP experience in real world settings

**Recommendations for LEND and DBP programs:**

- Pair trainees at all levels (LEND/DBP, residents, med students) with paid host families for longitudinal home visit experiences; develop family visit curriculum guidelines and best practices, perhaps working to update past efforts of the LEND Family Discipline group
- Present a workshop about family mentorship and home visits at annual SDBP meeting
- Connect with other non-clinical systems of care (DD agencies, EI, schools, home visiting, etc.) to expand experiential learning related to follow-up care: (1) immerse/link trainees with these other community resources, and (2) collect interview guides/tools/manuals for field experience
- Use simulated interdisciplinary visits
- Develop a business model that works in current/emerging reimbursement structures

**Supports needed by LEND and DBP programs:**

- Mechanisms for sharing successful strategies such as a workshop presentation about family mentorship and home visits at annual SDBP meeting
- Technical assistance regarding policy/reimbursement for telehealth, which would include reimbursement for non-MD delivery of care
- A medium-term trainee program with stipends for practicing healthcare professionals and other disciplines
8. Increasing opportunities for trainee interaction and learning across LEND/DBP programs

**Recommendations for LEND and DBP programs:**

- Create trainee awareness of the scope of the network and understanding of the value of interacting with other trainees/programs
- Ensure that program and training directors are aware of other potential collaborators in order to establish the working relationships necessary to create joint training opportunities; in addition to other MCH training programs, these could include: (1) leadership training offered in other programs such as public health, education, business; (2) training in NDD offered to health care professionals including medical residents and students, trainees in other health care disciplines, and community service providers; and (3) Title V
- Promote cross-program interaction and learning through program coordination of schedules and advertisement of opportunities; consider trainee exchanges across programs (single session, short-term, long-term)
- Develop virtual methods to highlight and recognize trainees such as trainee profiles/spotlights, and videos of an experience to be shared
- Provide support for joint trainee projects such as conference posters, webinars, and journal articles
- Consider regional agreements to support trainee interaction and learning through activities such as conference stays and continuing education projects

**Supports needed by LEND and DBP programs:**

- Additional resources/investments as well as flexibility in use of current funds (ex. trainee travel); consider a sub-award to support a national organization like AUCD to facilitate the development of cross-program learning opportunities
- Central “clearinghouse” where training opportunities from different training programs (not just across LENDs or DBPs, but also other MCH training programs) could be announced or disseminated
- Continuation and expansion of scholarships for conferences such as AUCD, DPS, MLC with trainee focused activities such as discussion groups and trainee symposia; increase in trainee-focused learning opportunities at above conferences and efforts to include trainee-focused activities in appropriate conferences that do not already offer them
- Continued support of existing and creation of new tools such as trainee listserv, regional/collaborative websites, marketing materials, etc.
- Positive reinforcement/encouragement mechanism for programs that collaborate and offer joint learning opportunities so they can get positive feedback (from MCH project officers, public, the program’s university); this “publicity” might engage new collaborators with our networks and motivate programs to look for joint learning opportunities
- Requirement for a trainee liaison at all training programs could be considered by MCHB
- Grant review criteria/points on cross-program learning could be considered in the program guidance/funding opportunities
9. Working in partnership with families, self-advocates, and other community members

**Recommendations for LEND and DBP programs:**

- Strive to work in partnership with families to have: (1) family members as trainees, and (2) family faculty with comparability with other LEND faculty (i.e. equality in status, responsibility, and participation with other discipline directors)
- Embrace the inclusion of individuals with disabilities in training programs as trainees and faculty as an emerging priority that the LENDs/DBPs should position themselves to meet at the individual and national level

**Supports needed by LEND and DBP programs:**

- Increased support to develop programs’ capacity to include individuals with disabilities as trainees and faculty, including funding and sharing of best practices from programs currently doing this
- Stronger guidance language to support these recommendations
- Revision of the family/youth/consumer performance measure (PM 07) to ensure appropriate reflection of program activities and impact

10. Coordinating the efforts of LEND/DBP programs with state Title V initiatives

**Recommendations for LEND and DBP programs:**

- Share ideas/mechanisms and strategies used to develop effective partnerships with Title V programs
- Create specific mechanisms (funding, recommendations on the organizational processes to do it) for collaborations between training programs and Title V programs that focus on special health care needs, such as: (1) two-way training (Title V → trainees and LEND → Title V); (2) working on collaborative grants (e.g. data collection, analysis); and (3) projects trainees could assist with for Title V

**Supports needed by LEND and DBP programs:**

- Assistance from MCHB with connecting LEND/DBPs, Title V, and other MCHB agencies with one another to create opportunities to work together; this could be facilitated through creation of a master list of grantees in each state
- Incentives for partnerships in grant processes (to training programs and Title V)
Appendix: Stakeholder Recommendations

The following recommendations came from interviews with 20 stakeholders—LEND family faculty, former AUCD Virtual Trainees, MCHB project officers and directors, self-advocates, and representatives from partner organizations—conducted in December 2014 and January 2015. Gathering stakeholder input was part of the preparation for the “Strategic Thinking” discussions at the LEND and DBP Directors Meeting on January 23, 2015.

Stakeholders’ recommendations were offered in response to a series of questions, which focused on such topics as:

- The environment in which LEND/DBP programs operate
- What trainees should be learning and what supports they need
- How LEND/DBP programs can evolve to meet emerging needs
- Program strengths and opportunities for improvement
- The role that LEND/DBP programs can play in developing systems of care
- Building partnerships
- Proactively aligning with state Title V initiatives
- How MCHB and AUCD can more effectively support programs

Stakeholder recommendations from the interviews are presented below; they have been de-identified, resorted, and listed under the 10 issues that were the focus of the directors’ “Strategic Thinking” session as well as one cross-cutting issues category.

1. Sustaining training program capacity (financial and other resources, leadership, etc.)
   - Make better use of technology for teaching and learning and for bringing more trainees into programs (e.g. from rural parts of the country or Puerto Rico)
   - Continue the development of a common core curriculum
   - Focus on succession planning; actively develop former trainees, for example, with appointments to committees, and encourage them to take leadership roles that are opening up as baby-boomers retire
   - Improve advance communication with potential trainees about what participation in the program requires
   - Do better trainee follow-up; link and tap into alumni in more ways
   - Link to other Federal and non-Federal programs and initiatives

2. Capacity issues in the broader MCH workforce
   - Shift from a focus on long-term training to medium- and short-term training to get more professionals into programs
   - Increase opportunities (i.e. funding) for people to get involved in LEND/DBP programs; doing so could help avoid staggering costs in the future
   - Provide grants to do mini-training with select groups
   - Involve more disciplines in LEND/DBP training, including surgeons and psychiatrists
3. Adapting to changing healthcare delivery systems (ACOs, medical home, ACA, etc.)
   - Ensure that trainees learn about:
     - The ACA; ACOs; the medical home model of care; how to stay current with the
       system amidst constant change; how to develop a population health perspective;
       value-based purchasing; telemedicine; and practice transformation
     - Establish partnerships with community health centers under the ACA and ACOs
     - Work with the National Center for Medical Home Implementation; their resources
       would be of great use to LEND/DBP and other funded training programs
     - Strengthen the technology skills of trainees and faculty

4. Serving increasingly diverse children and families
   - Focus on cultural and linguistic competence in leadership training, as well as
     communication skills for a range of people and situations
   - Overcome cultural distance created by university programs vs. CBOs, clinics, etc.
   - Continue to work on increasing program diversity, including getting more males
     involved
   - Work to create medical homes for different cultural groups

5. Emphasis on the transition to adulthood
   - Help trainees learn to see the whole life cycle of a child with disabilities - they grow
     up
   - Add focus on employment to training and establish relationships with people in the
     business community

6. Promoting the use and dissemination of evidence-based practice
   - Emphasize critical thinking skills and the importance of evidence-based practice in
     training
   - Identify and disseminate best practices among training programs; integrate evidence-
     based practices from other programs
   - Add more content on quality improvement methodologies
   - Put in place more measures of immediate impact of programs; programs should also be
     evaluated in terms of improved outcomes for children
   - Make evaluation processes more consistent through use of common data elements
   - Consider qualitative data to enhance the evidence base beyond numbers

7. Applying lessons learned from the LEND/DBP experience in real world settings
   - Help trainees be prepared to apply their learning in the real world, which is so
     different from the LEND/DBP experience
   - Make connections that enable trainees to get out in the community and that create a
     demand for their services
8. Increasing opportunities for trainee interaction and learning across training programs
   • Keep groups of participants small to allow for maximum interconnectedness
   • Bring directors together for meetings, workgroups, etc.
   • Help trainees better understand the broader LEND/DBP network; the variability presents a challenge to understanding it (idea: video-based toolkit to help graduates understand and use the network)
   • Do more to promote cross-fertilization and bring trainees together online

9. Working in partnership with families, self-advocates, and other community members
   • Help trainees learn about:
     • Working in partnership with families regarding shared decision making and mutual decisions; seeing through the eyes of family members; resolving conflict; connecting with community advocacy leaders; appreciating the person as unique and distinct from their disability; and how to support self-advocates
     • Consider new supports for family involvement such as the introduction of pre-LEND training for families to learn skills they’ll need in the training; set up “flare” plans for family trainees, i.e. what they will do if something goes wrong (pre-think solutions); have technology training for families, ex. PowerPoint
     • Incorporate non-traditional care providers (e.g. grandparents) in training
     • Establish and strengthen partnership with family groups
     • Ensure that the family voice is heard through incorporation into grant guidance by MCHB
     • Engage more self-advocates as both trainees and faculty with a self-advocacy discipline in training programs
     • Make training more accessible for self-advocates, including opportunities to participate in training without their family members present and having self-advocates accompany other trainees to clinical learning experiences

10. Coordinating the efforts of LEND/DBP programs with state Title V initiatives
    • Work through Title V to get trainees into the field
    • Create guidance for programs on how to connect with Title V agencies
    • Have Title V family delegates or other staff become LEND trainees and have LEND trainees do internships in Title V programs (clinically and programmatically)
    • Share staff between LEND/DBP programs and Title V agencies
    • Ensure that LEND/DBP faculty sit on Title V Advisory Councils
    • Have LEND/DBP programs help Title V agencies meet new reporting requirements; align requirements between LEND/DBP and Title V and create incentives for collaboration
    • Educate legislative staff in state agencies
    • Get involved at the local level; there is so much variability among counties
11. Cross-cutting issues

- Integrate MCHB programs at the federal level, reduce silos
- Establish or strengthen training program partnerships with:
  - Schools of Public Health; UCEDDs; DD Councils; Medicaid, CHIP, and other government programs; Head Start; Early Intervention; hospital systems; private health insurance companies; durable medical equipment companies;
- Identify and share best practices among the training programs
  - Bring programs together for cross-fertilization - face to face and online
  - Disseminate grantee knowledge more effectively, including publishing LEND/DBP research more broadly