

LEND Breakout Session – E Sheridan Notes

Introduction by Steve Hooper

- LEND to act as the muscle to disseminate research into practice as George mentioned this morning
- Touch on 3 goals during this session:
 - Address issues and challenges at individual programs around implementing greater autism training at LEND centers
 - Brainstorm how to move forward with specific LEND program agenda
 - Moving forward with overall goal of CAAI program (promoting collaboration with LEND network fostering collaboration with research, state, DBP partners)

CAAI LEND Survey Highlights: Challenges

- Brief overview of what we were trying to accomplish
 - Most LEND centers responded to this survey
 - Centers have clearly worked very hard and been very innovative to reach trainees in this process
 - Collaboration at all levels (Universities, state level, national level)
 - Survey results on the handout blue provided
 - Successes will be the focus of the plenary session
- **Difficulty in implementing additional training related to ASD: Almost every respondent reported difficulty with putting more ASD content into the already existing curriculum**
 - Pg 4 of handout – Table 1 summarizes this nicely
 - In NH, started using ASD as a case example and had student branch out from there (serves a multiple purpose)
 - In general, a clinical training challenge is the lack of time with residents (1 month, in which you really get 12 days to get across the information in this short time frame, ensuring that everyone gets some clinical experience)
 - Have developed online portal (building it now) that residents need to complete before beginning the rotation (Autism as a part of the curriculum, but not entire focus)
 - Will be integrated into various disciplines with the hope of building off of this knowledge base
 - Links trainees to other sites where they can find more information
 - Have developed online training that serves as a minimum competency for LEND trainees which establishes a minimum standard as what is to be expected from a trainee (e.g. a psychology student doing her dissertation on ASD does not need to spend the time learning from this portal that a social work intern who knows very little about ASD might).

- Want a way to share documents/information that other LENDs have created
 - Share-point portal – Password protected, to share exactly this kind of information in PDF or Word, post questions to the authors
 - How does competition get in the way of collaboration?
 - As training centers, we all want to move forward in a global way, yet are competing in some respects
 - Need to give credit where credit is due yet allow everyone to benefit from collaboration
 - Have integrated the didactics related to ASD and are videotaping these and making them available to everyone on the website
 - ASD journal club to expand upon basic knowledge and might also share results of these meetings on the website
 - Utilize case studies as a mechanism to tie didactics to this interdisciplinary arena
 - Have made ASD a theme occur more often in our interdisciplinary training
 - Forced to look closely at all of the offerings in the curriculum and find topics that incorporated several topics in the same setting (“double, triple dip”)
 - Created an interdisciplinary fellow team in which the fellow had to pick a topic related to ASD to focus their year long project
 - Brought in other funds that created a long-term ASD team and required fellows to observe at least 2 full diagnostic evaluations
 - **Need to stress the commonality of issues across developmental disabilities as opposed to just autism being an isolated disability**
 - Added an ASD emphasis track, with added hours, giving more exposure to assessments and interventions (e.g. ABA) beyond just that expected in the core lectures and didactic training
- **ASD goals as not appropriate for some interdisciplinary teams**
 - Developed a 2-tier system or add on curriculum to address this issue
 - Major emphasis on what limits are for people who are not trained in diagnostics (make them aware of these limits and how to make proper referrals to people trained in the process)
 - Identifying those who can diagnose and giving them more skills (e.g. spot ADOS training)
 - Elect to do additional training in ASD (e.g. screening)
 - Did not want specialization training to occur without the core training that is offered in the core curriculum
 - Most did not have time to do all of it, so came back in the second year to focus on the specialization which works well
 - Trainees really do need to have that basic core training before moving on to the specialization of ASD
 - Divided by awareness, knowledge and skill (UAB Lend)

- Level 1: trainee will know how to do screeners, take 10 session course, and follow child through the course of all evaluations
 - Level 2: trainee that will primarily only working with young children – give opportunity to learn early modules of ADOS and other concepts relevant to the early years
 - Level 3: advanced trainee in ASD assessment/intervention
 - Relevant for all disciplines to know how diagnostic processes and interventions work, even if they do not primarily want to work with individuals with ASD specifically
 - Will enable them to advocate for parents and de-bunk myths in the context of the services they do provide (even if they are not ASD specific)
 - Dedicate fellows specifically to ASD programming and use them to provide outreach education and interact during leadership activities to **provide cascades of expertise**
 - Provides a nice support system for trainees for one another
 - ASD fellow team (involving 8 different disciplines) present what they have to say from their team perspective about what they think about ASD
 - E.g. public health focused on screeners and nutrition focused on BAMBI (feeding issues)
 - Established a learning collaborative with primary care providers – included trainees to emphasize the scope of the issue that is present
 - Problem based model in core training – realizing that it is difficult to know what disciplines are speaking in the room over the course of this because they are all speaking from an information perspective (blurs boundaries across disciplines, which is a good thing since everyone is becoming so well versed in this information!)
 - Has been interested and exciting process
 - Have trainees interested in ASD really become deeply involved in the process and go off to sites in the community and beyond the LEND to make a significant impact (e.g. needs assessments)
 - Force all disciplines to be able to administer, score, and interpret the MCHAT
 - Huge need for this awareness across disciplines since there is a huge awareness (60-70% of referrals coming into the clinics with ASD ?)
- **Questions remain about capturing the CAAI data**
 - Putting ASD diagnosis on the billing record – not able to do that to get reimbursed for services (making it difficult to track these children)
 - Results in need to estimate the #'s
 - Have clinics that are not LEND run (only with LEND faculty participating) which makes tracking very difficult
 - Have created a step-by-step process to track these files (imprecise methodology, but trying to at least be consistent from year-to-year with the imprecise method)

- Only way to track this in the hospital setting is by examining what children actually come through CASD (which in turn may skew the picture of the true number coming through the clinic)
- Fund a developmental pediatrician to teach 90 residents how to use the screeners
 - Though tracking of this problematic in that many of these residents are only around for 1 year
- In Oregon, are able to do autism billing so makes tracking easier
 - Also have a family focused trainee that maintains a monthly record of children who have been diagnosed in clinic (and subsequently follows up with them by phone 2 weeks after the assessment)
- Have the department of pediatrics track the number of children being diagnosed (helps when key players are on board)
- This support is for not just autism but also related neurodevelopmental disabilities
 - **When we sort out just autism data, you may lose important other information – remembering that this is more than just autism (e.g. “other DD”)**
 - Answer on NIRS data reporting all children with a neurodevelopmental disability (This form says “ASD/DD” which does not pull out just ASD – the legislation does “cast a broad net” which does indeed include everybody, therefore impossible to say just those who were ASD referrals)
 - Too difficult to “tease out who belongs in the smaller box and who belongs in the bigger box” – challenge to get a reporting system in place
- South Dakota – Only about 50% of kids referred have ASD actually have it, making it difficult to track the numbers
- Interim measure to address trainee data – Ask trainees the questions directly (e.g. where in your classes are you getting this information, didactic related information)
- Accurately capturing this data has implications for the long term meaning of these programs and services

Training Directors Survey Results: Lessons Learned

- Wide range of experience amongst LEND directors (some fairly new while others involved for years upon years)
- “If you’ve seen 1 LEND, you’ve seen 1 LEND” – despite a common mission statement, there are many individual differences that must be taken into account across sites
- Have had to spend additional time to help faculty understand big picture of LEND – a gradual process to really make known the purpose of our centers
- The interdisciplinary training and how autism needs to be addressed in same way we are addressing all of the other disabilities

- Matches a lot of information found in the director survey, meaning directors and training directors are getting along – good thing!

Evaluation Information for LEND

- Have had conference calls to ensure that centers are meeting goals that have been set out in the course of the CAAI
- Looked at what data is already provided to the MCHB and noted that the data centers are already reporting is a good source of information (and do don't want to have redundancy)
- Developed 2 new collection methods (challenge because data needs to be collected by March 2011):
 - New NIRS module
 - Semi-structured interviews – get some qualitative information about what program has been doing to supplement quantitative data collected in July
 - Applying for ONB clearance to do these
- Make time frames for which you are asking us to report data very, very clear (e.g. past 6 months, where will need to extrapolate, versus reporting on the _____ - _____ time frame)
 - Make it **crystal clear** about what is exactly asked
- When developing the evaluation, thought that we need to chart the full range of our reach (e.g. counting everyone who has watched a DVD that was developed in one of these modules)
- Regarding qualitative data – it would be helpful to know ahead of time to enable the LEND directors to talk to other people in the program to get their insights and input into this process
 - Interview guide is included on the flash drive to give Directors a heads up as to what the interview will entail to enable them to make these contacts ahead of time
- Emphasis on how are we leveraging our resources
 - Money was given to programs that already have significant investments of personnel and resources
- **Counting issues: Are we trying to count encounters (which are difficult to get concrete numbers) or are we trying to count something else**
- Programs that are not heavy with clinical duties do not add significantly to this data, though emphasize training
 - Would like to capture more information in the interviews to provide insight as to how the LEND adds value to the community above and beyond the numbers alone
- In a more systems way, we want to know what percentage of 3 year old are identified and diagnosed in your community as opposed to what lectures have been given, ect.
 - Public health perspective important, yet difficult thing to operationalize (big priority of state system)
- No baseline data: Difficulty measuring change when you don't have the “before number” (e.g. clinical visits, # people training)

- A large percentage of what is done is accomplished on the LEND money and the ASD piece is the delta, which without knowing the before number, makes it difficult to account for the additional of the autism funding
- Intention to build upon these data – will begin to chart the progress that is made from here
- Trouble with the numbers idea – are numbers going up or down?
- How many examples of reducing barriers can be identified
 - Provide examples of ways that barriers have been removed
- Reducing lag time between screening and diagnosis
 - Initially this time will be longer since children are being identified earlier, so there needs to be qualitative data to accompany these numbers
- Marking progress towards these long term goals

Looking Forward as a LEND Network

- The bulk of LEND representatives present are not linked in to the research network
 - How do we interact with this group from a LEND perspective?
 - Rochester – LEND fellows doing their research in collaboration with other sites, it's not exclusive
 - Pediatric fellows also actively involved in this research project because the clinical piece fits (e.g. “killing multiple birds with the same stone”)
- Is there a way to integrate/make others aware of the NIH research that is occurring at LEND sites?
 - This would be incredibly helpful
- Research is occurring in conjunction with the clinical activities and this is brought into the core course
 - Specific focus groups (e.g. genetics) that trainees are invited to attend
 - Formal rotations for extended trainees to spend block time at the centers
- Have collaborative efforts with other sites (e.g. clinical nutrition)
- ATN meeting: how do we implement these guidelines – would be easy for a trainee to come to meetings like these
 - Propose that we have some representation with the ATN group to facilitate discussion
- Would be very exciting to see vertical integration (research to practice) facilitated by the LEND network
- Mailman Miami: Amy Wetherby working on a parent based intervention that the Mailman Center is going to incorporate into their LEND programming
 - Great example of research to practice
- Looking for the partnerships that work for your academic and service communities (1 LEND is not another LEND)
 - E.g. Hawaii will never have the programming that FL does
 - Encourage the natural linkages (e.g. ATN that is down the street from a LEND program)

- IDDRC – creating a dynamic that is reciprocal, using AUCD as the broker (mechanism to coordinate this discussion to help with the leadership/vision piece)
 - Some LEND centers have “stolen trainees back” by research projects that are putting students in the clinical realm
- CO LEND - Took structure of ATN database and created one that is all developmental disabilities to provide a databanking mechanism for all DD’s, including a bio-repository (6 clinical sites in system invite all participants to contribute data into the registry)
 - We need to find a good way to “invite ourselves to the party, while at the same time bring something to contribute”
- New-Born Screening Network – very important to include in this network expanding

Other relevant information →

*George Jesien Points near the end of the session:

1. What level of involvement do LEND programs want in the research network is something that needs to be determined:
 - How do the UCEDD/LEND centers get involved in IDDRC
 - Looking to where can research projects get subjects to have sufficient power? The LEND centers are a huge piece of this
 - By the time the research is published in the peer-review process there is a two year lag – how can we expedite the process of translating research into practice?
 - CTSA’s – funded around the country to do clinical research
 - Single disorder groups
 - Autism Speaks
 - AHRQ
 - NIH
2. Where are the strategic opportunities?
3. We can provide dissemination and brokerage to connect networks to networks (pair NC and FL in the ATN). How do we make networks join up with each other and use the centers to promote this network-to-network collaboration?
 - “Can serve as a convener of making this process happen – a helping role”
4. AUCD needs to serve as a motivator to get research going
 - Would be nice to have representation of these networks at the Directors meeting in the spring

*Important for down the road LEND directors meeting:

1. Issue of counting
2. Re-application

*What should be expected regarding the evaluation information for LEND from Clare Wilson:

- Within the next few weeks, Alex Secman will be contacting LEND Directors to establish point of contact for the interviews
- July 2010: Second round of NIRS data collection
- Continuation applications in April: Information will be extracted from these and will then follow up in the interviews in December
- Reporting issues were discussed and clarified
- Thankful for the 100% response rate and how seriously all centers took the questions