A Coaching Approach:

Education Coaching As a Support Offered to Advocacy Trainees

In an Inclusive LEND Course

McCafferty Kenmon

aka

Susan Kermon, BFA

May 5, 2016

LEND Project, 2015-2016

Acknowledgements:

Deborah Zuver, MA, LMFT, RDT, Angela Rosenberg, DrPH, Claudia Fernandez, DrPH, MS, RD, LDN, and my fellow Self Advocate Trainees who taught me so much.

Part I

INTRODUCTION

LEND - Overview and Requirements

The basic idea behind the **L**eadership **E**ducation in **N**eurodevelopmental and Related **D**isabilities (LEND) program at the **C**arolina **I**nstitute for **D**evelopmental **D**isabilities (CIDD) at the **U**niversity of **N**orth **C**arolina (UNC) is to improve the health of children with disabilities and that of their families. LEND works to accomplish this goal through a curriculum designed to foster clinical and leadership skills in an interdisciplinary cohort consisting primarily of graduate and doctoral students from health care, education and related fields, all of whom have an expressed interest to work with the **I**ntellectual **D**evelopmental/**D**isability (IDD) population, as well as professionals, family members and community advocates. The LEND program consists of several main components, including a Core Course seminar series or Problem-Based Learning Course (PBL), Clinical Experiences, a Community Project, Self-Paced Learning Modules, the Interdisciplinary Leadership Consortium, and Various Workshops. Individuals selected as trainees will complete some or all of these components, based on the type and length of their traineeship. Each trainee works closely with a faculty mentor to plan and execute their individual learning goals and projects as they simultaneously work as an integral part of the program whole.

There are currently 43 LENDS in 37 states. All are structured in such a way as to be central and standardized while allowing for each one to be unique with their own area of focus and expertise. This creates a rich and diverse structure across the country to share resources and information. One current commonality in every LEND is that they all include parents and family members of an individual with an IDD with standards in place that unify these family members as a discipline across the network. The success of this family point of view has made clear the glaring lack of input from individuals with IDD themselves. The LEND at the CIDD became one of the first LEND programs to acknowledge this lack and take steps to rectify it. In 2010 the CIDD began including trainees with IDD by recognizing the discipline of Advocacy.

LEND Requirements for a Self - Advocate

Advocacy is one of the many disciplines represented in LEND at the CIDD, with the opportunity for a **S**elf-**A**dvocate (SA) from the community to represent this focus of study. By participating in this graduate level program, the students representing the field of advocacy are expected to add their point of view to the conversation and to develop their skills and expectations as they work through this nine-month educational commitment. The LEND at the CIDD is an inclusive program, meaning that all trainees complete the core PBL course with the same expectations and standards. Because Self-Advocate trainees may have a different educational background and experience, they are provided an Education Coach. The coach is primarily provided to support the SA as they participate in the PBL course, but also to be available across the program as needed. Just like the rest of the cohort, the SA trainee will work with the faculty mentor to develop their individual program goals, projects, community involvement activities, etc.

Problem-Based Learning (PBL) - Description and Weekly Schedule

The core course of the LEND program is the Problem-Based Learning course entitled *Developmental Disabilities Across the Lifespan*. It is a hybrid class carried out through both a weekly class meeting and by an online discussion group forum. This approach to learning and problem solving is student driven and interactive, based on universal design to accommodate all learning styles and strengths. The cohort is divided into 5 or 6 small groups composed of varied disciplines which they will maintain for an entire semester. Every 2 weeks a case-based scenario is presented, designed and facilitated by a guest clinician, researcher, educator, or community partner working with persons with IDD and their families. The students are given an overview of a case scenario and its challenges, along with reading material and website connections designed to help them gain a basic understanding of the issues that the case entails. They then discuss the case in an online forum within their small group prior to meeting with the guest facilitator and the rest of the class. This discussion involves answering a series of questions included with the case. When the entire class comes together, each group reports their findings and then the guest facilitator leads them in a continued, broader discussion. This collaborative approach encourages students to share knowledge from their own field as it relates to the case, to remain receptive to the input from other fields, to ask questions, research options and to work as a group to strive for creative, cooperative solutions that include the support of community resources to benefit the individual subject of the case and the family involved.

Most of the cases are issued and resolved over a 2-week time frame. A new case is introduced at the end of a class session with the online information for that case becoming available at the conclusion of the class. With each new case, 1 student from each group assumes the role of Student Facilitator for the group. The student facilitator is responsible for starting the discussion, clarifying the questions to address, guiding the group throughout, and highlighting their online discussion to the entire class. At the end of each case, the facilitator for each group will submit a "case brief", or a 1-page summary of the group's conversation process and resolution that includes three community resources and three scholarly articles that relate to the case. The timeline for this online process remains constant every week throughout the entirety of the course.

Thursday: 4:30-6:00 PBL class meets at the CIDD

6:05 New case information becomes available on line

Saturday: by 12:00 Student facilitator has initiated week's discussion concerning new information

Tuesday: by 12:00 all students have submitted a minimum of 1 post

Thursday: by 12:00 all students have submitted a minimum of 2 posts total, 1 of which contains a reference.

4:30-6:00 PBL class meets at the CIDD…

6:05 New case information becomes available on line

Role of the Education Coach

The role of the **Education Coach** (EC) is to ensure that the SA trainees have access to all elements of the PBL class and to support them as necessary throughout their participation. The EC works individually with the SA and tailors whatever support is provided to suit their specific needs, all in the context of meeting the minimum requirement of the class. This begins with a structured meeting schedule that correlates to the class schedule and may fade as the year progresses. This meeting may include a review of the week's information, development of discussion comments, search for resources, research strategies, etc. Like a coach in any arena, the goal is to isolate a skill set and to then guide coachees through the practice of these skills so that they might execute them more effectively in a future situation. Each new situation offers the opportunity for the coach to identify what worked well and why and where additional improvements might be made.

Because this may be an unfamiliar experience for the SA trainee, it is the job of the Education Coach to support them in the new environment and to ensure that they have access to the conversation. This inclusion, perhaps for the first time ever, offers them an opportunity for their voice to be truly heard and marks their contributions as relevant. Their opinions are asked for and then they are listened to. They are peers among many in an educational setting where there are high expectations placed on all who participate. The job of the EC is not to muffle this valuable voice with their own, but to help ensure that its insight and uniqueness can be clearly heard by all. While this inclusion offers an opportunity to the SA on an individual level, it does the same thing for each member of the cohort. By interacting with the SA as a peer, individuals with IDD become peers and partners rather than subjects of study or problems in need of assistance. This is where the systems level change can occur, as new professionals enter their respective fields eager to take on leadership roles where this paradigm shift can be perpetuated, potentially affecting individuals with IDD and their families for generations to come.

Part II

A COACHING APPROACH

The following is an outline of the approach that I take when working with SA trainees as the Education Coach in the LEND program at the CIDD. As a person with an Autism Spectrum Disorder (ASD) diagnosis and former LEND trainee myself, I am able to approach the trainee as a true peer. This is the position I maintain as we begin to build rapport and I assess skills, challenges, interests, motivation, work styles, etc., all within the context of actively participating in the PBL class. The LEND program presents as a complicated and confusing process to nearly all trainees of every discipline at the beginning, but as things get started, the structure, methods, goals and reasons why become clear and students begin to be fully immersed in the curriculum.

My goal is for the SA to participate fully to the best of their ability and to show improvement over the course of the year. We work steadily to this end, driven by their level of internal

motivation, abilities, interests, and willingness. Our relationship is built around the work they do in class. The consistent schedule of the class creates a natural structure for me to use as a point of reference and a criteria to gage a trainee's strengths, weaknesses and progress. I find this approach naturally increases skill levels as the semester runs its course and potentially helps to increase self-awareness, clarify interests, develop strategies, build confidence and expand options. Ultimately, I want them to develop/increase a variety of skills, self-awareness, and confidence at a level for them that is meaningful as they successfully complete graduate level work at a major university. As with any student, the hope is that this hard work and accomplishment will in some way inform their future endeavors.

Because my individualized approach is dependent on whomever I am working with and happens in real time, I have attempted to identify 5 common themes and distill them into what I consider to be guiding principles. They are:

1. **Process**
2. **Relating questions directly to the case information**
3. **Point of view**
4. **Positive nagging**
5. **Pointing out what works, why, and building on it**

I provide examples from email correspondences that support and clarify these principles in the context of my work at the CIDD.

1. Process

Process is ever present and I pay focused attention early on. The format and expectations of the PBL class are not readily apparent at the beginning of the program, so the only way I know to approach it is just to start. There are so many moving parts; an unfamiliar building, a new computer system, medical terminology, acronyms, etc. Once I am relatively certain the SA has access to the information, knows where to find what, how to contact me, and seems to have an idea of how to begin, I like to let them have at it and respond to what they produce. A lot of these emails are me explaining the process as it works for me. From this, I attempt to establish an approach that can be applied to most basic situations and be used as a foundation to build and expand upon. I work to be precise, clear, practical, and to remain open to a different way of doing things that may work better for them.

Email examples:

In order for me to be prepared when we meet, I must go over the case information the same way that the SA does. I use this opportunity provide an example of what I am doing and why in the hope that when we are together, we are all prepared.

Email #1: *I have been reviewing the case information and hope that you are doing the same. I recommend that as you each read through the case information that you look up anything that you read (word, acronym, device, etc.) and don't know what it means (like we did at our meeting last Monday). I just looked up 6 things. Doing this helped me in several ways. First (and most basic) I was able to read through the information and understand what I was reading. Second, as I researched these things online, I began to see the details of the situation more clearly and, Third, I began to think of ways to answer the questions. I am now ready to discuss.*

Your group has assigned questions so we will talk about the one specific to you. If you have already written a draft, that will be great (if not, we'll work on it).

By going through the steps I outlined above we will be good to go. And remember, it is extremely helpful to read through the case info multiple times. It is important to understand the details of Jane's situation and the responses/efforts of her mother because that's where the clues are. These clues help you focus your research to answer the questions and add to the discussion.

Email #2: *I find that* ***by reading the case information several times carefully and looking up terminology that I don't understand****, I am then able to selectively read the articles. We can work on this tomorrow if you would like. (Selective reading, that is - you should have already looked up unfamiliar terminology). Of course you each are developing your own approach (as evidenced by your increasingly excellent posts) and we will use that too.*

If you were to include the information that you just wrote to me ALONG WITH the information you posted on Sakai, you would create a stronger, clearer, even more relevant post. Great! If your next post contains resources, consider these questions again before you submit it. Have you written down "why this one?" "Who is it intended for?" "What specific issue(s) does it address?". If you do, your writing will get even better.

Email #3: *Think about the "pattern" that the discussions all follow.*

Have you read through all of the info?

Have you looked into any of the websites?

Often the case objectives can be read as questions and give you a path to research. Try rephrasing them as questions and then answer one. Has the facilitator posted yet? If so, is there something they said that you can ask for clarification on? If you do this, make sure you've done your homework first; you know, get familiar with the case.

2. Relating questions directly to the case information

The most common similarity that I have encountered with my particular trainees is that they tend to be very concrete thinkers. Inference is a skill that I have worked on with every one of them. By the very nature of these cases, students are supplied with a minimum of information (the highlights of the case) that require inference, deduction, generalization, and an ability to think several steps ahead, all based on what is often an unfamiliar topic. Inferences must be made to fill in gaps to create a more complete picture of what is going on in the scenario and to determine what involves/impacts who, and how to ask oneself questions that will lead to research that will support answers to the questions presented in the assignment.

This aspect of my approach is closely related to process, but I think it can be separated out as a more exact way to address the questions specifically. Whatever category I isolate in an attempt to explain my process only makes it more clear to me how everything we do is interrelated.

Email examples:

In this example, the question was "answered" by simply listing a source. While technically it is a "correct" response, it isn't in keeping with the spirit of the question or the discussion process. I attempt to break it down in a way that helps the SA think about the question in a new way. Because the SA shared with me a desire to write professionally and to work in a setting that would use many of the skills required in the class, I used that goal to clarify and explain what I was asking him/her to do and why.

> ***Email #1:*** *The trick here is to keep in mind that a source reference supports the post. Simply listing a source doesn't make for a very strong post. So instead of "post" what if we call it an "article"? Now the assignment is:*
>
> *Based on your source material, write an article that identifies and describes different living options for adults with High Functioning Autism (HFA).*
>
> *You will then site your source for 2 reasons:*
>
> > *1) so your article (post) is factual and accurate and the reader knows that you didn't make it up, and*
> >
> > *2) so that the reader can visit the source themselves if they would like more information. Remember, you are answering a specific question with your article (post).*
>
> ***Email #2:*** *I checked out your Hospice source...very interesting. I was not aware of that particular division of Hospice, though I'm not surprised. I've only ever heard great things about every aspect of that organization.*

If you continue in this vein, here are some things to potentially think about.

- *How does Hospice relate to D. and her family now, after the fact of the brother's death? I get the impression that his death was unexpected due to complications. What programs does Hospice offer in these situations?*
- *Any other resources specific to adult individuals with disabilities who are dealing with the loss of a family member?*
- *How might the effects of grief mix with D's approach to self-care related to SB?*
- *How might this loss "complicate" her progress?*
- *What might the health care professionals she works with need to know about the situation and what are some things they should be on the lookout for (i.e. missed appointments, depression, weight gain, guilt...)?*

Of course, you may be inspired by the discussion posts to go in another direction completely.

3. Point of View

By point of view I mean the ability to think about a situation outside of one's own personal experience, to determine how specific details apply to the overall interdisciplinary approach, and to know how to research an issue from an unfamiliar frame of reference.

A common theme I have observed is that a SA in the early stages of the program is sometimes quick to answer questions and offer comments based directly on past personal experiences that stem directly from their area of expertise while overlooking other details. Sometimes they don't appear to take into consideration the scenario we have been presented with at all. The answers they produce may not relate to the stage of life of the patient, diagnosis, family circumstances, required care, projected outcomes, etc.

By discussing the case in our coaching sessions, I work to expand the focus in a way that I am able to draw attention to the specific circumstances presented in our case scenario. I attempt to establish the context of the questions, such as explaining the boundaries inherent to the stage of life of our subject (newborn, adolescent, adult), who is impacted beyond the primary subject of the case (family members, professionals, etc.), what is the diagnosis, what might it entail, what urgent issues does it present immediately and what might develop in the future (based on documented research of outcomes). I stress that we base our research and ideas solely in the context of our case scenario rather than our personal experience. I listen to suggestions and acknowledge their validity, but steer them back to the case specifics if these suggestions don't apply.

Real progress is made when the SA begins to understand how to dissect the given case information in a more focused manner, directed by the information contained explicitly within the scenario. Now is when the SA can begin to integrate personal knowledge and direct

experience with an understanding of the information to inform an approach to address the needs of the specific case at hand.

Email examples:

This is an example of how I might respond when a question is only talked around from a personal point of view in such a way that it doesn't actually answer the question at all.

> ***Email #1:*** *As usual, you have a lot of insight to offer and you are off to a good start.*
>
> *One thing that I like about this case is that the question you address reads to me like it is to be answered from the point of view of the pediatric dentist. This requires me to research "what a pediatric dentist would do" as well as read about issues of spina bifida and how they might relate.*
>
> *What if you were to answer the question like that? In addition to your personal vantage point you answer as if you are the dentist.*
>
> *So, you Dr. [SA], are talking to your dental assistant when your receptionist Mary walks by and makes her comment. What do you do/say RIGHT THEN?*
>
> *When I think about the question as Dr. Kenmon, I imagine that Mary is old, has worked with me for years and doesn't mean to be hurtful. In the "Guideline for Behavior Guidance for Pediatric Dental Patients" I found a section under "Dental Team Behavior". This gives me some ideas on the steps I would take to address this situation in a way that I think a dentist might.*
>
> ***Email #2:*** *I know you will have a lot to say on this particular subject because I know how involved you were with your own education. The challenge is going to be to really think about the questions as they apply to Jane and her family while not thinking about how you and your family responded. I wonder… if you take what you learned personally while also pretending that you have never even heard of an Individual Education Plan (IEP), if that might help you look at the situation in a more removed way. To think critically about Jane's situation while not thinking about your own.*
>
> *Then, when you mix the two, you can address the situation with great insight and find unique alternatives to this situation that are in some ways parallel, but at the same time very different from your own.*

4. Positive Nagging.

Positive Nagging is my term for prompting and reminding, usually aimed to promote or encourage a desired outcome or behavior in a way that motivates rather than annoys. I use this most when a SA demonstrates a tendency to be late (either to meetings or with posting), or I have reason to think the SA isn't doing secondary work, like reading journal articles.

Email examples:

> ***Email #1:*** *I've been watching the posts and you're on it, picking a question so early. How is the reading? Are not some of the statistics staggering?*
>
> ***Email #2:*** *I didn't even ask you - how is the next post coming? Have you been keeping up? This group puts out a lot of information. Checking in at least once a day keeps it from becoming an overwhelming amount to take in.*
>
> ***Email #3:*** *Well... I just read the case. Are you ready? Rhetorical, you are. I think it wise to get started today so that you can begin with a strong post, one with a reference/resource so you can focus on keeping up with, responding and questioning, the discussion - you're good at that.*
> *Did you check out the Wunderlist App on the opening page of Sakai? I went to the blog and watched the tutorials. The second one, via lynda.com, is the good one, the first is basically just an ad. I thought you might be very interested in it so I highly recommend checking it out.*
>
> *So:*
>
> - *Read the case again.*
> - *Look over the resource articles*
> - *Be thinking about how to answer your first question by accessing a resource*

5. Point out what works, why, and build on it.

This approach is directly related to work produced by the SA. It usually involves several individual ideas/skills that we have been working with that are then successfully integrated and/or implemented. The momentum of this technique naturally builds on itself with each new issue addressed and each successful incorporation of a new skill or new way of thinking. As new principles are introduced, grasped and demonstrated, I consider this an invaluable tool to perpetuate progress. I point out clearly what works and why, the various considerations it took into account and how it might be repeated and even improved. One thing to remember is that

because a skill was demonstrated once does not mean it will be again. This does not derail the process at all, I simply loop back to the success, explain why the current example isn't as strong, compare/contrast, perhaps come at it from a different angle and then we plan for the next one to be stronger. These skills require practice. As long as I remain consistent and honest in my assessments, I have experienced nothing but improvement with all of my trainees. It is not a race; we are in no hurry to bypass potentially meaningful skills. Steady improvement, whatever that means to each individual, is always my goal.

Email examples:

> ***Email #1:*** *I just read your Sept. 30th posting and it is excellent! You did exactly what we discussed last Monday. You processed the information that you read in other posts and that you gathered through your own research. You then presented it in a very precise (yet conversational), resource based (yet personal) way. Your writing was strong and your ideas thought out and complete. Excellent.*
> *Let's do the same thing this week. Read through the case and the resources before you arrive on Monday morning and we will talk through any questions you have about it.*
>
> *See you Monday!*

> ***Email #2:*** *I just read last weeks later postings. Excellent! You really stepped up your writing. You found a source, read it, then picked out important points you wanted to use and conveyed them in an interesting and relevant manner. Each person can read your post and make valid connections without having to do the research themselves. They can also access your resource if they want clarification or more detailed information. Your post informs and it moves the conversation forward.*
> *When I read through the entire discussion, I see a real shift in the strength of your writing. Your posts have more "presence". Excellent!*
>
> *Now you've got it! Writing is a craft and the more you practice, the more your skills improve (and the more engaging the articles you write become!)*

> ***Email #3****: Wow, you've been busy.*
> *This is your strongest post yet. It is thought out and well written. You have answered the question and explained your answer. I know who/what you are talking about and why you are saying it. Your ideas are presented clearly. I think this is key - the clearer you present your ideas, the more likely they are to elicit a esponse. And that equals a discussion! (An exchange of ideas).*
>
> *Another thing that you have done really well is proof read and correct before posting. That is time well spent. You have taken the time to fix typos, misspellings,*

etc., and this is important, too. These words carry your ideas to others. They are important.

Great job! Your effort really shows. Gold star for you.

Part III

ADDRESSING THE BRIEF

I see the brief as a task that utilizes and incorporates all of the different skills and practices that we have been working on and building within the group discussions, a microcosm in the macrocosm of the class. Because it constitutes a significant portion of the student's grade, I think it is important to address here. It has proven to be particularly challenging to the SAs as it introduces a new way of thinking about the case, one where the SA is in charge and in addition to dealing with their own research they must now take into account the research of the entire group, while they orchestrate and synthesize a range of ideas into a coherent whole. It includes a strict format from which there can be no deviation. There are new things to take into consideration, a larger work requirement, and additional responsibilities. The completion of the draft is allowed one week's time, while simultaneously a new case begins, demanding the usual level of participation with the standard requirements. The finished case brief is the SA's project and I only respond to what they put forth. I decide when to consider a brief ready for submission based on each individual's progress within the boundaries of the assignment and the amount of time and effort they have demonstrated. With each SA I have worked with, the difference between the first brief from semester one to the second brief in semester two has shown a marked increase in ability to synthesize ideas, make connections, general writing skills, and overall understanding of what the assignment entails. It is a difficult challenge that yields a tangible accomplishment.

<u>Examples:</u>

The following is a paragraph (shown in black) from a brief. I comment directly in *red***.**

In week 2, we discussed Jane's care at the rape crisis center.

What about it? What was done well? What needed to be done differently? How was Jane's experience an example of the treatment individuals with IDD receive as a whole?

[Another group member] mentioned some tips for dealing with people with intellectual disabilities such as: not treating adults as children and allowing extra time for them to learn certain skills.

"[Group member mentioned]" sounds so casual…what is her main point and how does it relate to future victims of sexual violence who have IDD receiving appropriate services?

We believe professionals should be trained to work with the disability community.

Exactly who would benefit from training or education? Which professionals? What about

parents, in-home care workers, teachers, nurses, etc. What kind of training should be available/required? I am getting these questions based on [another group member's] post…might help to read it again"

Here are a list of comments I made on different briefs, all in the final stages of completion:

*"Really? You guys discussed the position statement? Is that **really** what you mean?"*

"What does this [copied] paragraph say? Tell me in your own words."

"You've listed some good examples, but don't say why these details are relevant. How do they benefit the population they are aimed at?"

Part IV

CONCLUSION

I think that the LEND program is an excellent example of the whole being greater than the sum of its parts. At the individual level, the LEND program provides an educational opportunity for select students with IDD to expand their interest in advocacy and to learn how their role as a self-advocate is important and valuable through the completion of a graduate level program at a major university. This is considered a big accomplishment for all who do so, but the SA may find themselves in an unfamiliar situation, one where they are expected to contribute rather than told to be quiet, where they are treated as equal rather than expected to be less. That, I think, is the brilliance of this inclusion; students with IDD participate as peers rather than as the subject of study. They are not expected to be less. And by being experienced as peers and equal partners in the learning environment, perceptions shift, misconceptions are discarded, and true experiential learning takes place for every student involved from every discipline.

The LEND program has been proven to produce leaders and innovators in disciplines throughout the entire public health care and education system. Each student who moves from LEND into the professional arena will have the potential to impact every person they encounter on both personal and professional levels. Each will encounter endless opportunities to influence perceptions and expectations, from a parent struggling to understand their child with IDD, all the way to public policy. This is the true strength of the LEND program, that by changing individual viewpoints and understanding, it creates a ripple effect that can potentially impact society at every level and create a stronger, more equitable, more inclusive world, where no one is discounted outright due to fear, ignorance, or a lack of imagination.

Resources

Fernandez, CSP. (2012). Peer Coaching. MCH Leadership Consortium, University of North Carolina at Chapel Hill.
Online at: a.sph.unhttp://medic.edu/adobe/mhch790/peer_coaching/ viewed *April, 2016.*

UNC Carolina Institute for Developmental Disabilities. Leadership Education in Neurodevelopmental Disorders (LEND)
https://www.cidd.unc.edu/Education/default.aspx?id=28 viewed *April 13, 2016*

Azer, S.A. (2004). Becoming a student in a PBL course: Twelve tips for successful group discussion. *Medical Teacher,* 26(1), 12-15.

Gwee, M. C. E. (2009). Problem-Based Learning: A Strategic Learning System Design for the Education of Healthcare Professionals in the 21st Century. *The Kaohsiung Journal of Medical Sciences*, *25*(5), 231-239.

AUCD Association of University Centers on Disabilities
http://www.aucd.org/directory/directory.cfm?program=LEND viewed *April 13, 2016*

iCan House. http://www.icanhouse.org/about/history/ viewed *April, 2016*