



Family Centered Care Consultation for LEND Leadership Projects

Consultation with LEND trainees from other disciplines on their final Leadership projects

Continuing Education Track

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Family Centered Care Consultation for LEND Leadership Projects

- Physical Therapy
- Continuing Education
- California MCH Training Network (Website)
- Occupational Therapy

Project - Physical Therapy

Project type: Systematic review

Subject matter: Physical therapy (exercise and motor interventions for children with Acute Lymphoblastic Leukemia)

Project goal: Publish in Journal - 'Pediatric Blood and Cancer'

Articles reviewed: ~16

Target completion date: August 2019

Team - Alison Coombs, Dr. Jeremy

Project Strengths:

The topic of this research is interesting, relevant and impactful. Team was researching the impact of exercise and motor interventions for children with Acute Lymphoblastic Leukemia.

Recommendations:

PT team did not feel that their topic "review doesn't line up quite as well with" family support consult project. However, the team during their final leadership project included an excel chart showing that nearly half of the research papers which were reviewed by the team for the purpose of the systematic review relied on the exercises in the home-setting.

In looking at any study or research involving children, one understands that it would not be possible without information from the parents or care-givers. Yet, as demonstrated by the assumption by this project team, formal consideration of family-centeredness into a study considered clinical is overlooked.

One of my recommendation to the team was that if there was no mention of the family centered care which is essential for the success of any form of exercise interventions for young children but especially the exercise and motor interventions for children with such a rare disorder like Acute Lymphoblastic Leukemia, then their report should make a mention of this crucial oversight and recommend so that future studies include how the family centered care contributed to the care, outcomes and success of the interventions in the critically ill children.

Resources:

I researched information on Acute Lymphoblastic Leukemia. I had requested the project team share the excel chart which encapsulated their research articles. But since the project team did not share with me, I do not have it.

Follow-up:

I met formally two times with this team. The first meeting was with the Trainee only. The second time Dr. Jeremy and the Trainee met with me. Dr. Jeremy said that the team had finalized the research papers for their systematic review and were not able to extend their research if there were any additional research papers or articles which mentioned family centered care.

Project – Continuing Education

Project type: Brochure

Subject matter: Expulsion in pre-school age students in public, private and parochial schools

Team - Vyvy Nguyen, Brett Bufford. Faculty - Dr. Hunt

Project Strengths:

Team was researching expulsions of pre-school age students in public, private and parochial schools and its impact.

Recommendations:

Dr. Hunt included me in the initial meetings. As the team was formulating the final product the team included me in their discussions meetings and I was able to get a better understanding of their product.

Initially the team assumed their final product may be systematic review. After some review of literatures the team decided their final product would be brochure. I recommended that the team ensure that the team consider the literature that included the student and family perspective in addition to the teacher and administrator perspectives. The team included “meaningful family model” in their criteria for recommendation.

Resources:

I researched and shared with the team that a team of students at Loma Linda University had undertaken similar study. I also shared a link to the newspaper article which included several research on this very topic - https://www.nbcnews.com/news/us-news/50-000-preschoolers-are-suspended-each-year-can-mental-health-n962691?cid=sm_npd_nn_fb_ma

Follow-up:

As a follow-up, I would recommend as the team finalizes their brochure, the team share it for a review with the family support team to ensure that it contains user-friendly language and the layout of the brochure is organized for ease of use and understanding for all, parents, teachers and administrators.

Project – Continuing Education

Project type: CHLA – LEND MCH Website
Subject matter: CHLA – LEND
Project goal: Publish in Journal - ‘Pediatric Blood and Cancer’
Articles reviewed: ~16
Target completion date: August 2019

Team - Dr. Sai Kumar, Dr. Vanderbilt

Project Strengths:

This Project’s product is very much related to the CHLA’s program. The Trainee has developed the Website which showcases the program for the world to see.

Although initially the Trainee did not know if their project had any relationship with Family Centered Care concept, after our meeting the Trainee understood that the project had tremendous opportunity to share and promote Family Centered Care.

The Website is a living document so has a tremendous potential to keep updated with the latest and improve with time.

Recommendations:

I met with Sai Kumar formally two times. We also discussed the project informally during our LEND classes when we got some time.

Our discussions and suggestions were:

- Mission statement should include links to MCH main website
- Within CHLA program page, include how we include Family Support (include links to our program, and NIH/who) and family centered care
- Suggestions for other programs: should discuss with the external team about how they incorporated family centered-care/or approach in the training
- Have a list of how each program does it
- After list in is, maybe a forum about how can we improve each program's practices in family centered care training
- Have each program's page have trainee responses on how their education have impacted their future.

Changes that were done:

- Mission statement with links to MCH – DONE
- CHLA –LEND program page: Need to include links to our program still
- Gave the suggestion to the other programs, not that much interest to do it form the other liaisons
- Continue discussions in future meetings with external teams

Resources:

I made suggestions to include links to MCH website. I suggested that as the Website is being developed links to AUCD, NIH and other relevant websites can be added. I also noted that the current Website which is still in development looks a little static and mono-chromatic so including links to social media and some graphics would make the appearance of the Website more current and inviting.

Follow-up:

Since the Website is a living document, I recommend that the Trainee(s) continue to make improvements to the site. Since we, Family Support team will be at CHLA, to continue to share with them the Website after a major reconfigure or update. By making this Website inclusive of MCH and related resources, CHLA – LEND Website development team can use the CHLA website as a prototype that the other programs can follow.

[Project – Occupational Therapy](#)

Project type: Occupational Therapy chapters in a book

Subject matter: Occupational Therapy

Project goal: Publishing in a book

Team - , Dr. Surfas

Project Strengths:

This project aims to contribute chapters as an update to a book, the original version of the book was published. Thus this project has a very strong history and background to draw from. For consultation the project team needed someone to review the chapters. The chapters were not sent to me because they were in draft form and because there were major changes to the draft during the course of its development.

Recommendations:

I would recommend that the project team should meet with the Family Support consultation team early in the project and get to know the team members.

Even though the project kept changing and re-changing the shape of the chapters, it would benefit the team to meet with their Consultants in the beginning.

I will complete the review of the draft chapters and send in my impression to the team.

Follow-up:

I need to follow-up after my read of the draft documents.

Consultation Project Challenges:

We shared several challenges that most other teams shared as barriers in their own leadership projects:

1. shortage of time
2. scheduling conflicts as everyone

In addition, some other barriers in our project may have been a result of uncertainty on the part of other teams on:

1. What, why and how to include the Family Perspective in their own product
2. Hesitancy on the part of other teams on the expectations from Family Support Trainees
3. Not sure of the needs of the product
4. Emphasis or overemphasis on the differences between disciplines. Most perceiving their own discipline as 'Clinical' versus Family Support discipline perceived to be 'Non-clinical' and thus unable to contribute to any projects originating in the 'Clinical' field.

Consultation Project Lessons Learned:

- Early buy-in from Discipline Directors is essential. Interest from the Discipline Directors will greatly help the future Family Support Trainees as they start working with their teams on their Consultation leadership projects.
- Teams need a better understanding of Family Support as a Stakeholder in MCH projects. It did not seem like the Trainees especially from the Clinical discipline understood the reasons why inclusion of Self-advocates and family members in studies/research may be crucial. It is important that they understand that this patient-practitioner partnership leads to successful clinical results across the board, in clinical interventions, research and innovations. This was not clear to the young budding Trainees who tended to focus on only the clinical aspects of their project which can become a tunnel vision to realities of life.
- At least one icebreaker Consultation meeting needs to be held early-on. This is essential as often the Leadership teams may not know the team members from Family Support. An early meeting provides more opportunities throughout the LEND program for Trainees from the different teams to meet, get acquainted, know the strengths of each other and by the time, their project is shaping up for serious consultation, they know each other and thus be able to utilize each other's strengths.
- Clinical teams need more familiarity on Family Centered Care philosophy, even on the last day, some Trainees were unsure how to describe what changes if any would help make their own practice more attuned to Family Centered Care philosophy.
- Family Support means different to different teams. Since CHLA – LEND does not require specific level of technical training or educational qualifications for Family Support Trainees, other Trainees especially those from Clinical fields may assume that the Family Support fellow is not or under-qualified. Whereas in the real life, today's Physician are tomorrow's Patient. These two are not some categories born unto an unbreakable caste classifications. Family Support discipline Trainees are parents, family members, caregivers and parents, family members, caregivers may be Physicians, Physical therapist, Occupational therapists, Doctors of Philosophy, Teachers, Scientists and otherwise highly accomplished in their own field of study. Or they could be college dropouts and like Bill Gates, Steve Jobs, Mark Zuckerberg, every person who has abandoned a course of study or who has rejected

conventional society to pursue an alternative lifestyle does not mean the person is not or under-qualified in our society.

- Communication is the key. Though cliché, communication and communication skills are key to success in life, work and relationships. This holds even more true in group projects such as this Consultation Leadership project is conceptually.
- When in doubt presume competence. This is also known as “the least dangerous assumption.” The way to look at it is, thus, in the absence of any evidence one way or the other, which of two assumptions will do less harm to an individual, should it prove to be wrong: the assumption that they are competent or incompetent? When seen this way, one realizes that it is far safer to assume an individual is competent. This helps in most situations especially in the clinical field working with individuals and families of special health care needs.