Comparison of Early Education for Children with Disabilities in Peru and Kansas

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Clendening Fellowship Proposal

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INTRODUCTION: In the United States, we have federally and state funded programs that provide services to infants and toddlers 0-3 years of age with disabilities and their families. Through the provisions of Part C of the Individuals with Disabilities Education Act (IDEA), each family is entitled to receive some sort of early intervention therapy or education in the hopes of improving the child’s physical, cognitive and social abilities. In Peru, programs like these are rare because the government does not provide special services or extra funding for families to help support their children’s growth and development. With the support of the Clendening Fellowship, I plan to compare the differences between the early intervention education programs available in Kansas and those available in Peru. I will also analyze the attitudes and perceptions of parents about the importance of these programs in the development of their child and their knowledge about services that are available in their respective areas. I plan to observe several organizations in Kansas that provide services for children ages 0-3 years old including tiny-k, a Part C Early Intervention Program in Kansas, the Center for Child Health and Development at KUMC and the Down Syndrome Guild of Greater Kansas City. In Peru, I will observe and collect information from Centro Ann Sullivan del Perú (CASP) in Lima which has an early education program for children with different abilities ages 0-3 years old.

BACKGROUND: I was first introduced to CASP as a junior in college when I studied abroad in Lima. Centro Ann Sullivan del Perú is a pioneering institution that implemented one of the first curriculums for working with people with different abilities in South America. The program has developed substantially since Liliana Mayo, the founder and director of CASP, started the program out of her parent’s garage in 1979. When I studied abroad in 2011 in Lima, I spent time volunteering in the classrooms at CASP and noticed the program’s unique family-driven approach to working with children and adults with different abilities. After returning to Kansas from my short time abroad, I knew I wanted to return to Lima and CASP so I applied for and received a Fulbright Research Grant. As a result, I spent ten months last year in Peru studying the behavioral and communication development of children ages 3-6 that had certain previously-identified behaviors and characteristics.

While at CASP last year, I watched the early education program grow and expand. A group of physical and occupational therapists from Kansas came to Lima twice during my stay there to help transform the program so it could provide all-encompassing services to the children and families that attended the weekly classes. Through my involvement with CASP and these therapists, I learned about the expansive structural and ideological aspects that go into creating a program designed to support the motor, self-help, communication, social-emotional and cognitive development of the children as well as support the families as they struggle to help their child with limited resources. I was constantly amazed by the dedication of the staff at CASP and the families that went above and beyond for their children.

Upon returning to Kansas, I have remained in communication with the staff at CASP and have followed the development of the early education program and was able to return this fall to contribute as an interpreter for this Kansas group of therapists in the early education classroom. Services and supports to infants and toddlers and their families at CASP occur primarily at the center with parents accompanying their child to CASP for weekly sessions. Comparing it to programs I have learned about here, I am curious about the similarities and differences between the early intervention programs that the U.S. provides and the early childhood program that CASP provides. I have shadowed at the Center for Child Health and Development at KUMC and I was impressed by the team-driven focus that involved specialists from a variety of fields who collaborate in order to provide services to children from the surrounding area. I have also observed appointments with a physical therapist from tiny-k, a program
that provides services in the natural environment which typically means the homes and child care environments of the infants and toddlers. I have been exposed to the Down Syndrome Guild in Topeka, but I would like to learn about the resources and services the organization in Kansas City provides for parents.

Since high school, I have been working with children with developmental disabilities such as Down syndrome and Autism, and my passion for working with this population grew during my year spent at CASP. I hope to pursue a specialty in Pediatrics, so this project is interesting to me because eventually I will be working with programs like these in Kansas. I believe it is important to be aware of the strengths of each program and understand the different services that are available. Furthermore, CASP has such a unique and successful program, I think we have much to learn from their example. I hope to integrate some of their philosophies and curriculum into my future career as a pediatrician.

DESCRIPTION: My goal with this project is two-fold: firstly, I want to compare the basic structural and organizational differences between the Kansas programs and the program at CASP. In order to do this, I will collect brochures and pamphlets that are given to families as well as meet with a few staff members from each location in order to understand the referral process, general clinic or program set up, and the different services that are offered. Secondly, I will analyze parental knowledge of services available to families and evaluate the importance of these services to parents. Pending requisite approvals from each organization, I plan to observe five children’s appointments at each program and interview and survey the parents after such appointment (if the parent consents). (Survey attached in Appendix I).

In Kansas, I have specifically chosen a variety of programs in order to demonstrate the array of options available in our state. Tiny-k is a federally and state-funded program that provides services at no cost to any eligible infant or toddler with developmental delays or disabilities. This particular tiny-k program I plan to observe consists of a teacher, dietician, physical, occupational and speech therapists and psychologist who collaborate together to provide services through in-home visits. The CCHD clinic at KUMC is a specialized clinic that offers a variety of programs such as medical consults, therapy, evaluations and social skills and behavioral support. Patients are often referred by their physician to the CCHD, although some parents seek out the services on their own. This organization works with a variety of professionals, including physicians, psychiatrists, social workers and speech, occupational and physical therapists. The Down Syndrome Guild is a non-profit and family-centered program that focuses on education and support of the entire family unit. It is run primarily by volunteers.

CASP is a privately-funded organization that offers services to students on a sliding scale or free of charge, depending on each family’s economic situation. There are expectations and requirements for parents, siblings and grandparents to follow while their child is enrolled as a student at CASP. The classroom setting includes a teacher, a physical therapist and at least one parent of each child. There is also an in-home training component where the teacher visits the family in order to evaluate how the lessons from the classroom are being incorporated into their daily lives.

At the CCHD clinic, I will observe five separate appointments and then interview the parents directly afterward. I would like to observe a variety of interactions, including, to the extent possible, a one-on-one therapy session, a team meeting, an initial evaluation and a session in a preschool or classroom setting.
With tiny-k, I plan to travel with the team members to five separate appointments in family’s homes. I will observe appointments where two team members collaborate together to provide an initial evaluation of a child and also a few appointments where the professional coaches the family on strategies and techniques to use every day to enhance the development of their child. These appointments can vary in location so it will be important for me to coordinate in advance in order to allow adequate driving time and preparation for each appointment. I have my own car so transportation issues will be minimal. I also plan to observe at least one of the team meetings that are held regularly throughout each month.

With the Down Syndrome Guild of Greater Kansas City, I plan to attend fundraisers, support groups, training events or general information sessions whenever possible throughout the summer. This will be more of an informal setting, so the parent interviews will be the most informative and significant aspect within this setting.

**Timeline:**

- **Early/mid-March:** Submit parent survey to IRB for approval
- **May 26th-June 6th:** Attend parent meetings/trainings, any special events through Down Syndrome Guild of Greater Kansas City (The summer calendar is not fully updated yet)
- **June 10th:** Fly from Kansas City to Lima, Peru
- **June 11th-June 20th:** Observe and collect data from CASP
- **June 21st:** Return to Kansas
- **June 23rd-July 3rd:** Observe and collect data from Tiny-K
- **July 7th-July 25th:** Observe and collect data in CCHD Clinic
- **July:** Begin write-up of observations and comparisons of survey results

**Total length of project:** 8 weeks

*In order to maximize the number of events and appointments I am able to observe, I may end up observing at each location throughout the entire summer as opposed to a specific two-week time span, depending on the availability of patient appointments.*

**METHODS:** I have spoken with Ellen Pope, a clinical assistant professor in the Department of Occupational Therapy Education at KUMC, and she has agreed to serve as a mentor throughout my project. She has been involved in the early childhood program development at CASP, was previously the director for one of the tiny-k networks in Kansas and has served with organizations that provide services for infants birth to three both in Kansas and New Mexico. She has been helpful in reviewing my project proposal and she also plans to help me with the development of the parent survey. (See letter of support in Appendix II).

I plan to observe and collect data from each program for about two weeks. In Kansas, my goal is to observe 5 family appointments or other services at each clinic and conduct a family interview after each observation.
**CCHD Clinic**: I have spoken with Dr. Chet Johnson and shared my proposal with him and he is supportive of me observing patients at the Center for Child Health and Development (CCHD) at KUMC. (See email below in Appendix II).

**Tiny-K**: Because tiny-k goes into homes in Northeast Kansas, I plan to observe several home visits where the team members work together. I have spoken with Rachel Raydo, the co-director of Northeast Kansas Infant Toddler Services (Tiny-k) and she has offered her support for the project. (See email below in Appendix II).

**Down Syndrome Guild of Greater Kansas City**: While the complete summer calendar has not yet been posted for this organization, I have met with the director, Amy Allison, and she has agreed to help facilitate observations of support groups, trainings and conferences and interviewing a few of the families. (See email below in Appendix II).

**Centro Ann Sullivan del Perú in Lima**: The early education classes take place every Monday and Wednesday at CASP, so I plan to observe two Wednesday sessions and one Monday session. In the times outside of the actual classes, I will conduct parent interviews and collect information about the structure of the classes from the CASP personnel. I am fluent in Spanish so I will be able to converse with families directly. Liliana Mayo, the director of the Ann Sullivan Center, is supportive of my idea and eager to see a research project focused on the development of the early education program at CASP. (See email below in Appendix II).

While in Lima, I plan to stay with the same host family that I lived with while I conducted my research last year. I am very close with this family and they have given me permission to stay in their home. I would pay the same amount as last year, $20 per day, which includes two meals a day and my own personal bedroom. The other $10 listed below in the budget for room and board accounts for any other meals outside of the home.

**BUDGET:**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Round-Trip Airfare to Lima, Peru</td>
<td>$1200.00</td>
</tr>
<tr>
<td>Room and Board in Lima, Peru ($30 per day with host family)</td>
<td>$300.00</td>
</tr>
<tr>
<td>Miscellaneous Expenses in Peru (food, taxi transportation)</td>
<td>$300.00</td>
</tr>
<tr>
<td>Gas for Observation Days with Tiny-K</td>
<td>$200.00</td>
</tr>
<tr>
<td>Rent in Kansas City for June/July:</td>
<td>$500.00</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td><strong>$2500.00</strong></td>
</tr>
</tbody>
</table>

*I understand that any expenses over the $2500 will be my responsibility and I have planned accordingly.

**BIBLIOGRAPHY:**

Website References:

Center for Child Health and Development: [http://www.kumc.edu/school-of-medicine/cchd.html](http://www.kumc.edu/school-of-medicine/cchd.html)

Children’s TLC: [https://www.childrenstlc.org/index.html](https://www.childrenstlc.org/index.html)

Down Syndrome Guild of Greater Kansas City:


APPENDIX I:

Parent Survey

Demographics:
DOB of child:
Gender:
Language (circle): English Spanish
Diagnosis:
When did your child receive the diagnosis?
Location Observed: (circle one)
Tiny-k CCHD KCDSG CASP

Questions
1. How often does your child receive services?
   a. What services/therapies are included?
   b. Where are the services provided?
2. When did your child start receiving services? (Any sort of services, not necessarily with the program where the child is receiving services currently)
3. How did you seek out/come into contact with this organization?
4. What is your understanding of the philosophy of this organization?
5. What made you seek out support services so early on?
6. What did you know about your child’s diagnosis before coming to this program?
7. Did you consider other alternatives? If so, what other options did you consider or actually participate in?
8. What is the most important skill or aspect that you as the parent hope to gain from these services?
9. What is the most important skill or aspect you hope that your child will gain from these services?
10. What are you most concerned about in terms of your child’s growth and development now and in the future?
11. What is the greatest benefit of you and your child receiving these services and supports?

12. What features of the program that you are currently involved with are most important to you?  
(Please number from 1-7, 1 being most important, what has made the most difference to you)
   a. Classroom sessions with teachers/therapists
   b. Home visits
   c. Parent information (books/handouts, verbal, videos, websites, etc.)
   d. Developmental information (books/handouts, verbal, videos, websites, etc.)
   e. Interaction with other parents
   f. Journaling
   g. Coordination with other services and supports including referrals to specialists

13. What is your role as the parent in this program?

14. Will you continue to seek services for your child after this class/therapy/program ends?  
   a. How long can your child continue with the current institution/organization where he or she is currently receiving services? If the organization stops providing services at a certain age, do you know what will be the next step?
APPENDIX II:

A. Mentor Support: Ellen Pope, OTD, MS, OTR at KUMC
February 13th, 2014

To: The Clendening Fellowship Committee

My name is Dr. Liliana Mayo and I am the Founder and the Executive Director of Centro Ann Sullivan del Peru - CASP in Lima, Peru. I am writing to inform you that we wholeheartedly support Erin Atwood in her Clendening Proposal to research the early education program we have here at CASP. We worked with Erin from 2012-2013 on a separate project, so we are eager to have her back with us again working with our youngest students.

Erin has full permission to observe in our classroom and speak with the staff, teachers and physical therapist about our program. She will also be able to interview consenting parents about their perspective on their child’s development and their involvement with the program at CASP. Erin is also invite to attend any School of Families sessions, sibling or parent events or in-home training sessions that occur while she is visiting Lima.

I highly recommend Erin Atwood for your program and it would be a great contribution to us the research she is proposing and for many professionals that always want to know the similarities and differences between early education in Peru and in the US.

Sincerely,

Liliana Mayo O., Ph.D.
Founder & Executive Director
Amy Allison, Executive Director at the Down Syndrome Guild of Greater Kansas City:

Sure, that's fine. You can indicate that DSG is enthusiastic about your project as we feel it is vital for medical professionals to learn more about people with developmental disabilities and to observe them within the community and the family unit so they can understand the strengths, challenges and best ways to support a patient.

Amy Allison
Executive Director

Down Syndrome Guild of Greater Kansas City
5000 DeSoto Street
Suite 100
Mission, KS 66202
http://www.kcdsg.org
amy@kcdsg.org
913.384.4848

RE: Proposal outline

- Amy Allison [amy@kcdsg.org]

Great to meet you this morning! I love your passion for supporting families who have children with disabilities. See some links below per our conversation.

Lee Ann Brittian Center
Children's TIC
Northland Early Education Center
Maran Hope Center
Brain Studio

Let me know if you have any further questions!

Amy Allison
Executive Director

Down Syndrome Guild of Greater Kansas City
5000 DeSoto Street
Dr. Chet Johnson, Center for Child Health and Development at KUMC

Dear Erin,

I have reviewed the CSF proposal guidelines and your draft proposal. I think you have thoughtfully outlined a very worthwhile project. I am glad to provide mentoring/advisory support to you as needed, understanding that you have identified a primary mentor in your proposal. I will also help you identify children to observe at the CCHD. I look forward to working with you and to learning what you discover as a result of your research. I congratulate you for taking on this kind of worthwhile project and for your educational experience during your undergraduate medical education. The overall process and your findings will enrich our understanding of children and families and also enrich your career.

Yours very truly,

Dr. Johnson

Rachel Raydo, Tiny-k Alliance

Hi Erin,

That sounds very interesting. We don’t have a parent survey set up right now so I often wonder about how families view our support. I would be happy to help facilitate what I can from our end in order to support you.

I have also included Kris Pedersen on this email, as she has more experience with the research side of things and may have some ideas as well. Just keep in contact and let me know as things develop.

Rachel
Dr. Fred Holmes, CSF Faculty

Hello Erin,

Thanks for your note.

Any Clendening Fellowship project in a foreign country has to have a Kansas/Kansas City phase, even if only for data analysis, writing, and working with a mentor. The time and activity balance between the two places is not fixed. In that you already have established yourself at the CASP you are "kilometers ahead" of students like Jason who invaded eastern Peru with high hopes and a lot of good luck! (I do like Jason, he is a lively chap). Dr. Ellerbeck would be a good person to have in your corner. Ellen Pope would seem to be a perfect mentor for you.

I had a large research program in cancer epidemiology in my years at KUMC. One of the great lessons I learned early was always to do a pilot program before the main study, if possible. You could even do that in Kansas City before you go to Peru. If you could find a program accommodating special needs babies with Spanish speaking mothers here that would be superb!

Having said these things I have to tell you that I am long retired from KUMC and have no power there whatsoever. But you may say that I find your project, as briefly described, quite worthy.

All best regards,

Fred Holmes

Dr. Tomas Griebling, CSF Co-Director

Clendening Follow-up

Hello Erin,

Yes, I think your project sounds very interesting. The idea of comparing systems between the different countries and cultures also sounds very feasible.

Dr. Cremmer would be good since he has been a longstanding faculty leader with this program.
Dr. Ellerbeck from pediatrics would be great – especially if she has a connection to the project in Peru already.

Good luck with creating your proposal

Best, TG