



CHILD LIFE IN ALTERNATIVE SETTINGS

by

Julie Daniel

A Senior Honors Project Presented to the

Honors College

East Carolina University

In Partial Fulfillment of the

Requirements for

Graduation with Honors

by

Julie Daniel

Greenville, NC

May 2014

Approved by:

Faculty Mentor (signature required):

Sandra Lookabaugh

Julie Daniel

My role Co-teaching

During my co-teaching experience, I was given many responsibilities. I met with Dr. Triebenbacher prior to the class beginning and helped create syllabus outlining the subject matter that the class would cover. There was an existing syllabus that we used as a guideline, but I introduced a few additional topics that I felt were important for introduction to child life students to learn. These topics included child life in alternative settings and covering in detail the roles that a child life specialist plays (including facing a child's death and supporting the family through that situation). Both of those subjects were important for child life students to learn early on so that they would be aware of what their major and career goal actually entails. I have noticed in the past that students have changed majors after they learned this information later on in their academic career and I wanted to try to decrease this late change of major. I also suggested an assigned tour schedule. During my introduction to child life class, tours were offered, but not scheduled based on the students' individual schedules. I wanted to offer every student the opportunity to learn about child life in alternative settings so I was placed in charge of putting together the schedule. This involved getting each student's individual schedule, finding five sets of time that together can cater to every student, and contacting the child life specialists at TEDI BEAR CAC and the Pediatric Hematology Oncology Clinic to finalize the schedule. This required a lot of adapting and changing to fit each student in, but in the end students were given an opportunity to learn about their future career from those who were actually working in the field.

In addition to contacting the child life specialists in the area for tours, I also contacted child life specialists for the professional panel that the class had in April. During the contact, I found four child life specialists who were able to attend, finalized the date, collected themes of

the class's questions, provided the list to the panel in advance, and met the panel members prior to the discussion to provide parking passes and directions to the classroom.

Another role I played was researching child life in alternative settings and creating a class presentation for the students on the subject. I mainly utilized "Child Life Beyond the Hospital" as my guide for teaching. After I had covered this subject matter, I was also able to assist in creating the midterm exam. I submitted multiple questions that covered the class that I had taught on child life's role in alternative settings. I also helped in grading the virtual tour papers, the video reaction papers, the midterm exams, and other class assignments. During the PBS video days, I was placed in charge of the classroom. During those days I would set up the video, play the video, and answer questions related to the video after it had ended.

Every week I attended the class. Prior to the class I would meet with Dr. Triebenbacher and finish any small task she had for me to do, to help prepare for the day's class, as well as cover other questions related to my project. A few of those tasks were placing grades on blackboard, placing announcements and information on blackboard, finding information about free child life information sources, and evaluating papers for plagiarism. Within the classroom, I provided the viewpoint of a student who is farther in the program for many of the discussions Dr. Triebenbacher was guiding. I also stayed after class in case any students had specific questions for me.

Reflection of Co-teaching

I have learned a lot during my semester co-teaching. I have learned more about the various areas that child life specialists can work in alternative settings, which better prepares me for the second part of my project. I was not aware of how many places that child life can expand to and how all of those locations are places where child life is desperately needed. This information has not only helped me in my own growth in understanding child life, but also in other areas. For example, this semester I am a member of the Dean's Student Council in the College of Human Ecology. Dean Siguaw was talking to us about how she has found ways to help get money for the college through using the majors within the college to help local businesses. She had found a way that every major could play a role in helping a funeral home (merchandising, interior design, hospitality management, etc.), but she had not found a way that child life could factor in. I was able to educate her that child life is expanding beyond the hospital and that there is information about child life having a huge role in funeral homes helping children who have recently lost a family member cope more effectively. During that moment, I was able to really appreciate all of the work that I have been doing this semester because it helped me better advocate for my major as well as better understand what a child life specialist is.

I have also learned more about the role of educators in preparing child life specialists for their careers. I have a greater respect for the educator because I have realized how much work goes into just one class. I loved seeing education from a teachers' perspective because I was able to see the students' excitement over the subject, their interest through questions, and their "aha" moments. I feel like teaching child life courses could be seen as an alternative setting for child life. I say this because you are applying the education that is needed to become a child life

specialist, you are working with youth (they are not technically children, but not adults yet either), and you are providing support for the students (helping them with stress).

I have learned a lot through my literature review, but mainly I have realized that there is not a lot of research on child life in alternative settings. There was a blatant discrepancy in the amount of information that was in the “Child Life Beyond the Hospital” book and the research that I could find that fit my topic. I was surprised at the lack of current articles; in fact about two thirds of the articles I found were too old to be relevant (written in the 70s to the 90s). I think that more research on this area would definitely benefit the growth of child life in alternative settings because there would be a guide on how to approach such a goal.

Literature Review

Method:

I first did a search through ECU library one search for “child life specialist”. I had tried a more specified search for such as “child life and alternative settings”, but this search came up with no results. I then went onto Jstor, LexisNexis Direct, and SocINDEX with the “Child Life” search. I also searched google scholar using the search term “Child life”. This search came up with results, but many of those were inaccessible for me. Finally, I accessed the archives of childlife.org for articles related to the subject. This is the location where I found most of my usable information. I chose articles for the literature review based on the subject (talking about child life beyond the hospital) and the amount of information on child life specialists in the article itself. I also restricted the articles to only those written from the year 2000 or earlier. This restricted a lot of my information because there was a large amount of information related to my subject written in the 1980’s. Although the information was relevant, I felt like information found before the year 2000 was likely outdated and thus would not provide the support that I wanted out of this literature review. Finally, to fill in the gaps, I have researched child life through a book about the subject. It is very difficult to find current research on child life in alternative settings. I found one article on child life working in an eating disorder program, three on child life in alternative settings as a whole, three on death and dying, and one on child life in adult units.

Results

Why

According to one article, a child life specialist is an expert on child development. Through this knowledge, the child life specialist can provide insight that no other professional in

the setting can provide. That insight includes the knowledge of the impact that a trauma has a child at each developmental level. In addition, child life specialists recognize how a child reacts and understands what is happening in the traumatic situation based on their developmental level. Child life is also called upon to educate those in the child's family about development as well as reactions to traumatic situations expected from a child of a certain age. Furthermore, child life provides support for those facing death. They do this in many ways including facilitating support groups (Hicks, 2005). These skills of child life specialists are what make them so versatile. Children face traumatic situations outside of the hospital and this knowledge is needed in many arenas to better serve the children. The skills that child life has are needed in the community because no other professional has the same skill set. Not only are the skills needed but also theories support the use of child life in other areas of the community. According to another article the ecological systems theory supports expanding the role of child life beyond the hospital (Burgbacher, 2012).

Implementing

The first step according to the article in Child Life Focus is to find what skills of child life are transferable to the alternative setting you want to work in (Hicks, 2005). This is shown in table 1-1. It is encouraged to incorporate child life into an organization that is already well-established, but it is also possible for child life to begin services without an established organization. There are many considerations that should be made when considering working in an alternative setting. This includes “assessing existing services, utilizing contacts and alliances, knowledge of the service the child life specialist plans to provide, and business knowledge” (Hicks 2005).

Implementing Challenges

According to the article on non-traditional settings, one challenge is the change of environment from the hospital to the alternative setting. This is due to the fear that comes with change (Burgbacher, 2012). If the child life specialist plans to start a private alternative practice, there are challenges of costs and families to serve (Hicks 2005).

All of the information that I found highlighted the importance of child life understanding and applying child development. Another highly important topic that is widespread among the articles is the importance of documentation. In addition, prioritization is important in all of these areas to ensure the effectiveness of the child life specialist. Finally, working collaboratively with other professionals is important in the child life profession in all types of settings.

Child life's role in Rehabilitation programs

Children are not excluded to the struggle with mental health. They face many mental health disorders which include but are not limited to depression, anxiety, and eating disorders. In settings where children are being supported through their mental health problems, child life specialists can play many roles. Child life can help with coping skills, provide therapeutic interventions, provide family support, and implement strategies to support proper behaviors (Hicks, 2008). Child life specialists who are considering working in these settings need to receive specific training to help them understand how to approach these environments to prevent facing aggression in patients. In addition, there is a high rate of burnout in these settings due to the high intensity of the setting (Hicks 2008).

When beginning in an eating disorder rehabilitation organization, child life observed what triggers were for the population she was serving. It was important to know where intervention was needed. In the article that I found, the child life specialist focused on “lack of appropriate distractions to decrease anxiety and persistent fixation on media images of beauty”

(Breiner, 2003). Child life proposed her ideas to the staff to get their support on planned interventions focused towards her two goals. In applying the interventions, child life interviewed the patients in the center and provided developmentally appropriate choices for entertainment/intervention purposes. Child life also observed what times were most difficult for the patients and provided distraction support during those difficult times (primarily eating periods). Staff at this location have expressed that they have seen positive changes from the interventions (Breiner, 2003).

Emergency Department

(alternative because beyond normal hospital setting and can be found in adult ED when no pediatric ED available)

Child life specialists can have the same positive effects in the emergency department that they have on the pediatric floor. They make the healthcare experience more positive for all who are included. Child life is able to provide similar supports in the emergency department as they do on the pediatric floor due to the fact that the environment is still medical in nature, the environment is just more fast paced. Child life also has been described as having the role of a greeter in the emergency department, acting as a “liaison” which is rare in the environment currently. Child life has been described as providing emergency departments with an edge over those who lack the services. The article does state that the number of children who enter the department currently determine the ability of the organization to employ child life specialists (“Child life services,” 2004).

Hospice and Palliative Care

Child life specialists have experience in the traditional setting working with children and families facing loss. The roles that child life has practiced in related to loss are “loss of identity, independence, function, limb, and life” (Hicks 2008, p.1). Thus, the expansion of child life to

palliative care is an obvious expansion because child life has the skill set to fit this environment (Hicks 2008).

Child life has been described as playing a role in many different types of palliative care environments. First is that of perinatal hospice (when the baby that the mother carrying is expected to die). Child life specialists provide support during the pregnancy and help the family and children within the family prepare for facing the death of the infant. Child life also may play a role in helping the family come up with a birthing plan (creating a plan gives the family some sense of control in a situation where they have no control). Another role is to help the family prepare for sharing this information about their infant's looming death with others. They are bound to face questions from family and friends, so child life specialists can help the family and children come up with ways to respond and talk about the infant's death. Child life is very important in working with the siblings and creating interventions that are developmentally appropriate for the child. Child life may also work with teachers and other members of the school where the sibling is attending to help the child with support outside of the hospice environment (Roush et. al., 2007).

With children who are facing death who are older than the infants in the womb, child life can still play a role. At this point, child life specialists can begin implementing interventions with the dying child as well as the family. Child life can help those in the child's family come up with goals for the child and then advocate for those goals with the medical team. This allows the family to feel involved and empowered in the child's care. Child life is also important in affirming those facing the death (affirming the child's life, that the child is still living; affirming the roles of the family in the child's life). Child life can provide a safe environment for those who are in this situation to talk and express thoughts and feelings. It is important to note that

child life is not the lone support in this situation. Other staff members also have important roles and it is important for child life to include them in interventions and utilize the skills of others on the team (Munn and Robison, 2004).

Child life can play a role in providing support for children who are facing the death of an adult in their lives. This is a very important section because it shows child life in two alternative settings (adult units and strictly bereavement). Child life support for a child who is visiting a dying family member in the hospital/hospice can help the encounter to be more positive and less stressful for the child. Child life does this by preparing the child and family for visitation. They also work with the nurses to help the patient become less intimidating (such as sedating the adult if they are extremely out of it or are in terrible pain). Child life also plays a huge role in encouraging communication with children about family members about the dying adult. Positive coping with the situation is important and thus child life specialists act to help the child come up with coping skills including encouraging visitation if it has been declined (Leeuwenburgh 2007). There are a lot of misconceptions about children visiting an intensive care unit, so child life plays an important role in educating people about the truth related to misconceptions (Cider and Frances 2012). When it comes to the end of life for the adult, child life specialists are often utilized to help communicate the bad news to the child. In preparing for this child life educates the primary caregiver of the child. Child life specialists help the children to become resilient from this stressful and emotional experience in their life (Leeuwenburgh 2007). Through the interventions and preparation provided by child life specialists, the child is able to have a chance to accept the death of a loved one. It is important to utilize child life specialists in this area because working with children in this type of situation is their area of expertise (Cider and Frances 2012).

Finally, child life can play a role in funeral homes. Child life specialists in this setting also provide preparation and support. They can prepare the child for both an impending death as well as the procedures after the death (visitation, funeral, burial). During the time of working with a child, child life specialists also work on helping the child enhance their coping skills by providing therapeutic support (Hicks 2008). Beyond one on one support, child life can also facilitate the creation of support groups for children who are being served by the funeral home (Hicks 2008). Child life specialists also advocate for children in this setting due to their knowledge of how children grieve (Hicks 2008).

When child life considers a role in the bereavement arena, there are many aspects that need to be approached. Child life specialists should be prepared to refer support to other professionals when the support needed goes beyond their skill set. In addition, it is recommended that the child life specialist received some extra training to better prepare them for work in this setting (Hicks 2008). Finally, child life specialists need to consider if they can face dealing with death day in and day out (Hicks 2008).

Child life in camps

Child life specialists who are currently working in hospital settings are beginning to expand to camp by creating camps for the population that they serve. Child life specialists can also work in solely camp settings. The role of child life includes clarifying misconceptions that the campers have, utilizing “teachable moments”, assisting in volunteer training, and enacting therapeutic activities. Child life specialists have a specific knowledge set that is very important to the camp setting for children with illness. Child life specialists recognize the impact that the illnesses can have on children and can apply this knowledge to make the camp better meet the needs of the children it is serving. Child life can also play a huge role in preparing the volunteers

by providing information about the specific requirements of the child population the camp will be serving. This preparation helps the volunteers feel better equipped and help better meet the needs of the children being served. This education that child life provides can also extend beyond temporary volunteers to those who are on staff at the camp. It is important for child life specialists who are considering a role in a camp program to consider that camp programs require different working hours than the professional working in the hospital setting. Also, this position could be seasonal instead of a job that is year-round (Hicks, 2008, p.15-21).

Child life in medical model child advocacy center

Child life specialist working in this type of setting will be a part of a multidisciplinary team. The team together provides all of the services that a child needs when abuse is suspected. This includes “medical, emotional, legal, investigative, and advocacy services” (Hicks 2008 p.145). Child life plays a huge role in helping the child and the family overcome psychological impacts of the abuse. Child life helps with coping and support. They do this through applying knowledge of the needs of the child. Child life does not provide any service that is intimidating to the child, but instead provides the psychosocial support to help the child through their appointment at the setting and afterward. They apply skills that are important in the hospital setting such as observing what a child’s play is communicating, correct misconceptions, evaluate a child’s coping, and introduce the medical experience that the child will be facing. Child life’s services may also extend to providing support for a child’s placement into foster care (Hicks, 145-150).

Child life in Dental settings

Child life has a foothold in most medical settings, but dental settings are a new alternative medical setting where the need for child life specialists is slowly being realized. Skills of a child

life specialist in the hospital are readily transferable to a dental setting. Child life plays a role in helping the child cope, providing distraction, comfort positioning, and other support strategies. Child life also provides procedural preparation for children in this setting. Beyond the direct services, child life can play a role in indirect services such as creating preparation books, educating parents and staff, and helping to create a more child friendly environment. As with child life in medical settings, those who are working in dental settings will need to educate themselves on the medical terminology related to that setting. In addition, child life needs to recognize that there will be an added challenge of distance when providing support to the child due to the fact that the dentist and hygienist will be in closest proximity.

Child life in Early Childhood Settings

When it comes to early childhood settings, there are a lot of values that child life shares with the setting. For example, in these settings, play is very important, just as child life sees play as important for children. Child life specialists often utilize play to help with coping and creating normalcy. Child life specialists are well educated professionals so they are well-equipped to engage in the role of an early childhood educator. Although the opportunities to utilize child life knowledge are not as prevalent as in other alternative settings, child life can play a huge role in supporting those children with chronic diseases in the settings. For those children, child life can plan and implement interventions. Skills of developing quick rapport as well as having knowledge of family and child development theories can be very useful in this setting. Child life also has a special knowledge of the impact that illnesses have on children and how treatment is provided which can help them better support the child in an early childhood setting. Finally, child life specialists can provide support to children in early childhood settings when they are facing different types of loss (death, divorce, etc.) (Hicks 2008 p.71-76).

Child Life in Early Intervention

Child life has also begun to be introduced into the field of early intervention. In this setting, child life specialists work with parents to provide education on what they can do to help their child develop. Child life has many skills that are applicable such as good listening skills, quick rapport, and flexibility. Child life also has knowledge of how to also provide support for siblings by addressing their needs and also including them in the support and education sessions (Hicks, 2008).

Child Life in Legal Systems

The legal system is an intimidating location so it is obvious that the skills of child life can be utilized in the location. The role that child life could fulfill is referred to as CASA (court appointed special advocate). Child life specialists in this role would be working with volunteers, providing similar services as they do in the hospital (training, supervision, etc.). Beyond working with volunteers, child life plays a huge role in providing support for children who are in this setting. The child life specialists would provide emotional support to that child throughout the entire process. When working in this setting it is important to become familiar with laws related to children (abuse, adoption, etc.). Also, it is important to interact positively with those people who are suspected of abusing children which can be a very difficult task (Hicks, 2008p.129-137).

Child life in Trauma or Crisis Team

Child life specialists can play a huge role in supporting families during traumatic situations. The skill set that a child life specialist has is easily transferable to this setting. Child life specialists work with children who are facing traumatic situations by providing psychosocial supports. It is important to help the child in a crisis situation regain a sense of “safety and

control” (Hicks 2008 p.239). Often, child life in this setting work to help prevent media attention, or help the child cope with media attention if it is not preventable. It is important to remember self-care when in this setting due to the high rate of burnout and compassion fatigue (Hicks, 2008)

Child life in Women’s Centers

Child life specialists can also play a role in women’s shelters. These are locations that provide women escape when they are being abused. Child life specialists can help with the children of those women. They can provide coping support, enhance understanding, and address any fears. When the child(ren) first enter the center child life does an assessment to understand the child’s level of understanding of the situation. They also utilize this assessment to evaluate the impact of the abusive home situation on the child. Child life also works with the mother to help equip her with skills so that she can clarify the misconceptions that have been recognized. Additionally, child life works to create an environment of normalcy for the children while they are in the shelter. The goal of child life is to help the child(ren) feel “comfortable, safe, secure, and confident in his or her new surroundings” (Hicks 2008 p.262).

Table 1-1

This table only includes some of the skills, not every skill for every setting.

Area	Population Serve	Skills
Hospice/death support	Perinatal, adult units, children	Provide Resources Work with siblings (support through death) Facilitate memory making Preparation Facilitate communication Facilitate coping Educate Support Affirm roles of family Advocate Work with interdisciplinary team

		Psychosocial support
Eating Disorder Program	Ages 12-22 (usually girls but not exclusively)	Distraction Decrease anxiety Facilitate emotion expression Advocate
School Reentry	School age children	Establish communication Educate Advocate
Emergency Department	Emergency situations birth-18	Procedure support Medical play Alternative focus Greeter
Camp	6-18	Planning, coordinating, and executing activities Educate Work with volunteers Therapeutic interactions Managing issues Documentation Facilitating support groups Communication Support staff
Dental Setting	3-18 (the age group that first visits)	Preparation Work with parents Desensitization Coping strategies Distraction/support/comfort Documentation
Early childhood	Birth to 3 (focusing on those with chronic illness/medically fragile)	Communication Team work Confidentiality Multicultural knowledge Support Assessment Quick rapport Strength-based view
Early Intervention	Birth to 3 (with special needs)	Parent educator Listen Knowledge of impact of chronic conditions Understanding siblings
Legal Systems	Birth-18 , focused on those who are being removed for abuse or neglect	Work with volunteers Knowledge of laws Advocate
Medical Model Child Advocacy Center	Birth to 18- children who are victims of abuse	Support Coping techniques

		Education Creative expression
Trauma/Crisis team	Birth to 18- children who are in circumstances that require police, fireman, or ambulance support	Quick rapport Support Coping
Women's Center	Birth to 16	Coping Clarification Education Assessment Collaboration

Gaps

I have found that there are a lot of gaps in research related to child life in alternative settings. I had to get almost all of my information from the child life council website due to the fact that information that I found from other sources was often outdated and thus probably no longer relevant. Of the information that I did find, there was large amount of information about child life in bereavement settings, but other settings provided very little information at all. In most settings I could only find up to two articles to support the role of child life. The areas that stood out the most for needing more information were child life in early childhood and early intervention settings. The information that I did find was sparse and did not include the information that I desired. Neither source provided a large definition of how a child life specialist would play a role in the setting. Many of the locations that the book on child life in alternative settings mentions have little to no other research available on child life's role in the setting. Thus, roles such as child life in trauma settings and women's centers could benefit from further research. Child life as a whole could benefit from further research, but especially the expanding role of child life is currently quite lacking in supportive research and current information. Without further information on how child life plays a role in alternative settings, the role of child life in those settings may be unsure.

Works Cited

- Breiner, S. (2003). An evidence-based eating disorder program. *Journal of Pediatric Nursing*, 18(1), 75-80.
- Burgbacher, K. L. (2012). N is for non-traditional child life settings: making the move from traditional to alternative settings. *Child Life Council Bulletin*,
- Child life services can provide competitive edge. (2004, October). *ED Management*, 115-117.
- Cider, J. & Frances, M. (2012). helping children say goodbye to loved ones in adult and pediatric intensive care units: Certified child life specialist-critical care nurse partnership. *Child Life Council Bulletin*,
- Hicks, M. (2008). *Child life beyond the hospital*. Child Life Council.
- Hicks, M. (2005). The expanding practice arenas of child life specialists. *Child Life Focus*,
- Leeuwenburgh, E. (2007). Child life specialist: Advocate, educator, and supporter of children confronting the dying and death of a loved one. *Child Life Focus*,
- Munn, E. K. & Robison, K. S. (2004). Palliative care and the role of child life. *Child Life Council Bulletin*,
- Roush, A., Sullivan, P., Cooper, R., & McBride, J. (2007). Perinatal hospice.

TEDI BEAR Child Advocacy Center

Interview

Can you tell me about the population that you serve, and if there is a population or demographic that you serve more often?

Most of the kids that we see obviously are going to be 0-18, but most of the kids that we see are preschool and school age kids. We see a lot of young kids, and as the age groups get a lot older, like middle school and high school we see fewer of those kids, so mostly preschool and school age.

What is the scope of your responsibilities?

Child life specialists see kids and we have other responsibilities as well since we are nonprofit everybody has to kind of chip in and do their share. Most of our responsibilities are making sure families understand what is going to happen while they are here. We do a lot of preparing kids for the evaluations and a lot of developmental assessments and things like that. And of course assisting in the medical evaluation as well, answering the questions that kids have and that kind of thing.

What child life skills do you utilize? Which did you learn in the hospital and which did you learn on the job?

That is very specific. Lauren: I said that the child life skills that we utilize here are preparing, assessment, distraction, that kind of stuff and I started in the hospital so I learned the basic information there of how to work with the kids and then kind of adapted it to the procedures that we do here. Katie: so I think as far as what you learn in your internship at a hospital or setting like that is preparing for procedures and that kind of thing. Any experience that you have working with children you are going to learn what is normal, what is not normal, how to handle

certain situations, and then of course when you are in the job you are going to learn specific to that job and how to apply the theories that you have learned to an actual real life patient and family. I think anything that you are learning now as far as what you are learning in the books, you are going just be able to apply that in real life, because I think that it is very different learning it on paper and understanding it and then able to actually do it. As far as supervising students, I feel like that struggle with that. They know it in their head all of the things that they have been told to do, but when they are actually working with the patients having to make some professional decisions and how do I go with this, how do I make these decisions and what is the expectation for the center. We have to think a lot about these cases going to court so we have to really be mindful of the fact that you just can't say anything and everything to the kids, you can't have them disclosing to you because you want them to disclose to the appropriate person at the appropriate time, in the interview room, to the interviewer, on the video. So being able to put all that in practice and even know what the center's expectations are for what the child life specialist is and making sure that you aren't crossing those lines.

Do you work with the children when they go to court?

We really don't, there are some CAC whose child advocates do help with court. We really don't do that a lot, sometimes our therapists help prepare the children who are here for therapy for court, but we typically don't do that. That is something that Lauren and I would love to do but we would really be focusing on Pitt county since this is the county that we serve specifically with MDT and that kind of thing, but we just haven't been able to break that barrier and get into that part of Child advocacy, but I think that would be a great thing for us to do.

How can preparation programs better prepare students for working in alternative settings?

I think what Lauren and I pretty much tell all students that come in is that if you learn child life skills, even if it is just in books, if you have experience working with children and families, you are ready to work in an alternative setting, you are ready to work in a hospital. As long as you know what child life is and you know child life purpose and you understand the difference between child life and basic child development. Working with students we have realized that students really don't get what child life is. And being able to separate what child life is does versus child development and just understanding typical developing children and having some experience with atypically developing children you are ready to work. You can learn the environment you are in. As long as you learn those core skills of how to work with kids and families you can learn about the different settings that you are in. That is why we tell students that are even coming here, like for practicum if you already have those skills you know what child life is and you have worked with families, you can learn the other stuff. You can learn all the procedures and how to prepare kids for it, but once you get to this point it is hard to teach people how to work with kids with separation anxiety let's say or kids don't want to stand on the scale. You have to have those basic skills to work with kids to be able to do those things; it is kind of hard to teach at this point in the game.

How did you get this position?

When I came here, of course I had done my internship and all of my coursework and I had graduated and worked for early intervention. So when I started here I had not been doing child life specifically, but I had been working with children and families for years. So I had the child life knowledge and I had the experience of working with children and families. And then of course Lauren had worked in the hospital and had worked as a child life specialist for a while before she came here, but I think that is basically having that child life degree was really

important. We are one of the only CACs that had child life. Some of the other CACs have child advocates that do kind of the child life job and do some of the core things like that, but they don't have the hospitalized child background and I think that makes a big difference.

Did you introduce child life into this program?

Actually they had a child life specialist. One of the ECU physicians actually helped start TEDI BEAR. I think from the beginning when they were writing grants, they knew that they wanted child life specialists all along. But ECU has child life, and Jacque Sauls was one of the ones that helped start child life program with ECU. So it helped being between PCMH at the time, Vidant now, and ECU who knew what child life was and realizing that child life was going to be really important working with children who have had potentially something traumatic happen to them and families being in crisis when they came in, so they sought that out. It was nice to come into a place that already understood child life and knew that it was important. And even now they don't do appointments if we are not available they do not schedule appointments. It is a team, there is the medical provider, the social worker, and the child life specialist and if you don't have all three of those components then they will not schedule an evaluation. We have actually had our medical director do child life for us if we are not here because they know that it is that important. And we have had physicians, one in particular was a fill in and she tried to do an appointment without child life one time and she said never again, it just didn't go well and she really valued child life and realized how hard it can be without it. And it is a good learning experience for our students too because I think it is a safe place to learn. Lauren and I are always here for the students as backup and answer questions if they have any. Everyone here has worked with us so long they kind of know what we are going to do before we do it and they are used to having learners. So it is a really good place for a child life student to be at because you

have a lot of support here. You aren't fighting for your way into help. They aren't going to do it without you; they are going to look for you.

What advice do you have for students who want to enter alternative settings?

I would say that my advice to any student is to understand child life and the theories and why we do what we do and have as much experience with kids and families as possible. I think a lot of students focus on the children part of it. Especially with ECU only providing experiences with young children is to have well rounded experiences with all ages including teenagers which I know a lot of people don't feel comfortable. I think students in any setting as long as you have the child life knowledge and knowledge of working with children and families.

Do you think it is necessary first to have experience in a hospital setting?

It is hard for me to answer that question, but I came from early intervention and I think that all of the knowledge that I learned there has helped me here. Anything that you learn in another job you always learn something positive from it. I feel like I do my job effectively even though I didn't work in the hospital before coming here. I did my internship at hematology/oncology so I did have some experience with an outpatient setting. I had done my case study with a child in rehab so I had a lot of experience there and I also had kids in the hospital that I was able to work with so I had experience from a lot of place before I came here. I don't know that it would be essential. Even working with someone who has been in the hospital, I have learned something from her.

What is your favorite part of working here and what is your least favorite?

I think my favorite part of working here is the variety of the appointments. I know the appointments are scheduled and we kind of go the same way every time, but you never know what you're going to get with the families that come in here. You know the situations that come

here are different, the kids are different, the families are different, and so it is really never the same, you really never know what you are going to get. So I like that part of it. Of course I like the hours, 8-5 in an outpatient setting is nice, especially when you have family. I like the support that we have here, I know that we are all women and we don't always get along, and everyone has their own different personality, and it is a really supportive environment, and we are able to talk about cases in a nice supportive way because you can't talk about it when you get home because of the privacy issues and confidentiality. But I do like that we are a pretty close knit group as far as there being a really small atmosphere where everyone knows each other really well and being able to process cases and really talk to other people is nice. I think obviously the hardest thing is when you feel like kids aren't being protected and the parents don't believe. That is the hardest part to feel like the kids are leaving and they are not safe like they should be, but I would say for the most part kids come in here like the light at the end of the tunnel, you know these bad things have happened, they have told, and know they are safe, that's a good feeling, when kids come and they are terrified and then they don't want to leave because they are having fun... That is very rewarding because as child life specialists I feel like we have done a very good job...But those are rewarding times when we know we have done a good job and helped

How do you deal with the emotions of this job?

Well I think being able to talk to coworkers and process things, I like to talk about things, I know some people like to journal, write things down, but for me being able to talk about cases with staff and coworkers on Tuesday mornings and sharing frustrations with others. Having an MDT person that is going out in the community meeting with these different agencies so when you feel

the child hasn't been served well then we can go to our MDT coordinator and she can take information back to the professional that are working to maybe do something about that.

Lauren: another thing is in some cases it is not possible, you just keep thinking about it, but most of the time we try to leave your work at work and not take it home with you because if you keep thinking about it and it keeps bothering you then you are never going to get over it. You have to learn, and I think it is a process for students especially to learn how to do that, learn your limits. When you start working in the field, your first job sometimes you really take it home with you and think about it and cry and all this kind of stuff, but is that really healthy? Is that really healthy for you to be able to keep doing it because eventually you are going to wear yourself down and you are going to get burnt out.

Katie: and once you understand your boundaries and you realize ok this is work and when they leave here the child really isn't my responsibility anymore and I can't change what is going to happen with that case, I've done what I need to do. Once you have that boundary and understand what your limits are I think you are much better off. Like Lauren said, not take it home. I think it is really important to have some other type of life outside of doing this. For me when I leave here my life gets so busy I don't really have time to think about work anymore. And I think that is really healthy to leave here and focus on yourself, focus on your family, focus on what you've got going on. For students we have some downtime when they are here so a lot of times their journals and documentation can be done before they leave and that way when students leave they don't have to go home and think about their day to write their journals. It is done here in the building and you can physically leave it behind and I have heard students say how helpful that was to be able to have boundaries by keeping all of that here and keeping a separate outside life, especially interns that were here forty hours a week, not taking things home and having to work

on them. But I think having support here helps with that too. Students can kind of talk about it and process it and then when you leave you can leave it behind because you have been able to get it out so that is helpful

Other comments:

Being a teaching facility is helpful. Child life students have been able to go to med providers and say what could I have done to be more helpful, learning from other professionals and having a well-rounded view of how the system works because it will help you in the hospital too because you will have those teams in the hospital as well, so just having those teams with the MDT (the multidisciplinary team).

TEDI BEAR Child Advocacy Center

Shadowing

I was lucky enough to be able to shadow at TEDI BEAR for two days. I was able to learn a lot about the role of Child Life Specialists as professionals in an alternative setting. I was able to see what a “typical day” entailed and how child life specialists were viewed as a part of the team. Child life played a role in interacting with the child, the family, and the other professionals on staff. It is also important to describe how TEDI BEAR is set up to truly understand how child life plays a part.

TEDI BEAR is a children’s advocacy center for children who have been abused that serves children from 28 counties in eastern North Carolina. In the center there are doctors who conduct the physicals, forensic interviewers who conduct the interview with the child, child life specialists, as well as other staff who help with the behind the scenes work. The number of patients that they see in a day is impacted by how many doctors are available that day. Ms. Wood also stated that they will not do an appointment if a child life specialist is not present. This shows how the staff values the role of child life specialists in the center. The number of cases is at most six or seven in a day due to the fact that each child takes a few hours to be seen.

During my time at TEDI BEAR I was able to observe child life’s role with several patients. Each time a new child entered the clinic, the child life specialist would first go to the front to glance over the file to make sure that they had the child’s name and other information correct. Then, they would go to introduce themselves to the child and the child’s family. The next few minutes involved creating rapport with the child through play and conversation depending on the child’s age and developmental level.

After the parents were taken back by the interviewer to receive information on what to expect, the child life specialist would offer to take the child on a tour. This tour began with introducing the child to the interview room. The activities that they could do in the room were introduced as well as the camera and microphone that were present. Each time these tools were introduced, the child life specialist would clarify that the child's parents, siblings, or people in the waiting room would not be able to see them. The only people that could watch were the detective and a few of the other staff at TEDI BEAR. Sometimes, the child would be given the choice of which interview room they wanted to be in. Next, the child would be shown the exam room. In this room the child life specialist would explain medical equipment using appropriate vocabulary as well as letting the child interact appropriately with the tools. The child life specialist also allows the child the choice of having one parent in the room with them while they are having the exam.

After the child life specialist introduces the process of the visit to the child, they record the child's height and weight, and then return to the main lobby to play again. When it is time for the interview, the child life specialist is not able to be in the room. They meet up with the child again before the exam. The child life specialist is allowed to be in the room during the medical exam. While they are in the exam room, they provide distraction for the child through games and conversations. They also give the child warning of what is going to happen and what will not happen throughout the exam. After the exam is over, the child life specialist continues to support the child through play until the parents have been debriefed on the next steps.

Child life specialists also have a role in being part of the multidisciplinary team. I was able to attend a morning meeting where all members of the team were present to talk about the cases of the day. The staff was able to talk about their roles for the day (who was seeing which

children), their thoughts, and other aspects of the day. After the meeting the child life specialists continued to communicate with the staff and vice versa. This included child life expressing to the staff a need to wrap up an appointment when a mother is angry and ready to leave as well as sharing with interviewers information about the child to better help them with conducting the interview (including developmental delay suspicions, or other information relevant to the situation). The staff makes an effort to not start any sessions until the child life specialist has had time to do their job with the child.

Child life specialists do not ignore those who come with the child. Although the child that is there for the appointment is always the priority, child life specialists also make the effort to converse with a parent of a child to help them feel more comfortable with the situation. The only interaction with siblings that I was able to observe during shadowing involved siblings who were both there for an appointment. The children were taken on a tour of the facility together. Ms. Miller said that if there is a significant age difference between the siblings then they would be taken on separate tours. The child life specialists seemed to adapt their approaches to each family and this allowed the individual families and children to best benefit from their services.

Camp Kaleidoscope Interview

Tell me about the camp

"Camp kaleidoscope was founded 34 years ago and it kind of started out with a group of the sort of chief of pediatrics, a social worker and the head of the child life program in like the 1970s, late 1970s, and they kind of wanted to have a program for patients at Duke who would not otherwise be able to attend a summer camp and the idea was to staff it with doctors, nurses, respiratory therapists. Everyone needed on the medical team to support a patient, but allow patients and kids to have a normal camping experience. So they kind of when they had this idea of a summer camp for patients at duke, they figured out where, were kind of looking at sites where they could do it. The leadership group selected camp Grione in Hendersonville NC which is about an hour north of here and is on Carr Lake. They wanted somewhere that had good area for sports and recreation, archery, things like that. They also wanted water like activities. These are things that they often felt like patients even though they might have wanted to do they might not be able to. So a lot of time spent at camp is spent on the water mixed in with archery, kickball, team building activities and just kind of arts and crafts. All sorts of activities. Now it has evolved it is three weeks over the summer in July. It is not diagnosis specific. Week one is 7-10, week two is 11-13 and week three is 13-16. And the thirteen year olds kind of teeter based on their developmental level and experiences with camp whether they go week two or week three. Each week we take 35 patients, so we take 105 total that get the opportunity to go to camp. And so how they get the opportunity to go to the camp, divisions within the hospital, cardiology, pulmonary, hem/onc, infectious disease, rheumatology, neuronc, bone marrow transplant. All get referral forms, so when we start recruiting; it is almost at the point where we are year round recruiting. In each division we have a social worker, or nurse with that group who keep their

eyes and ears out for children who would be interested in camp. So around February we send out reminder emails to divisions. So divisions have to screen children first. We don't publicize and advertise camp a lot just because we want the screening process to happen at the provider level. We don't want signs everywhere a family to say we want our child to go to camp because they may not be appropriate for camp. You know camp is a rustic setting; it has outdoor showers it has running water, but is rustic compared to a victory junction camp. And that is what we wanted, we wanted to kind of challenge the children to get out of their comfort zone, so you have to be pretty ambulatory with the terrain and as much walking, we can't take children with wheelchairs and even crutches can be hard. If your crutches or walkers are needed primary for ambulation, so there are some drawbacks to where we have camp but still some really good deserving kids go to camp. And we want to make sure that their conduction is such that they would not be able to go to other camps. You know duke children's has much more than 105 patients. We want to make sure that we're sending children deserving of this experience. Not saying that all children don't deserve this experience, but I mean a child that has pretty mild asthma and visits the pulmonologist maybe once a year and you know can go to their 4h or their y, and those summer camps. We want the child that needs that experience and would not otherwise get it.

Do you have CIT (Counselors in Training)?

The camp is an individual camp site is kind of shaped like a horseshoe and in the middle we have like a unit house which is like our gathering place where the medical supplies are stocked. We take oxygen tanks, IV pumps, breathing treatments, tons and tons of different medical supplies so we can be ready for anything. And then around that are 7cabins and each cabin can hold 6 cots. Four walls, no electricity, nothing in the cabin there. So when campers age out, after their

16th birthday have the opportunity to apply for an assistant counselor position, some of these campers have gone to camp since they were eligible at 7 years old they go for nine years, and once they turn seventeen and can't go to camp anymore. There is an application process and interview process the week two directors are a part of, so assistant counselor only go to week two, so 17-20 year olds come back to be assistant counselors. And that is the only week that they have assistant counselors. They don't do it for week one

What is the scope of your responsibilities?

Camp kaleidoscope is a camp for children with chronic illness. But the goals of camp are to strictly have fun and experience things that you wouldn't normally experience without camp because of your condition, because of your parent's ability to let you do those things, so there some you know some as they happen conversations between the campers about their conditions. We do not do therapeutic activities, or group circles about or trying to provide more education about a diagnosis because there is such a wide variety. Within a given week there could be children with asthma, extreme food allergies, post heart transplant, liver transplant, HIV positive, leukemia, any kind of oncology issue, brain tumors, not necessary one targeted population that we would do any kind of education or kind of counseling for. As a child life specialist, my job at camp is to help the kids have fun. There is usually one child life specialist that goes each week to camp. Within the scope of the other counselors, there is 2 attending physicians that go, 1 or 2 nurse practitioners, 3 or 4 nurses, respiratory therapist, physical therapist, medical students, residents, social workers, and a child life specialist. Child life by our nature and what we do gets tasked with arts and crafts activities, but beyond that we help facilitate activities, some guided sometimes not, there have been times where we wear our child life hat at camp, for example child sickle cell crisis, we actually take a lot of sickle cell kids to camp and sickle cell and

swimming don't always work well together and the extreme temperatures can put them into crisis. And the extreme heat and dehydration. So there is a rule that when you get to camp you have to keep your water bottle with you at all times, but particularly the sickle cell patients need IV hydration a lot at camp. To get an iv placed and they don't do so well with iv starts we don't have a whole bag of child life stuff, but we grab a magazine and start to talk about them magazine, or you know engage in some supportive conversation, or distraction activities to help a child cope with it. An IV start can be painful sometimes, you know the child life specialist serves as a counselor so you are a caregiver for you know 6 kids, there are 2 counselors to a cabin and usually 6 patients. A lot of the time it is just emotional support. I usually go one week one which is the you her group and we get a lot of homesickness there and usually even spent the night away from home, much less 6 nights away from home and there are no electronics allowed , the counselors can have them but not the kids so they can't call home. We encourage them to write letters and parents can send letters that we hand deliver or they can mail them too, but they actually don't get to talk to their parents for a week and that just promotes some independence and some autonomy of I can do this. So sometimes you are just up at night trying to help a child that is worried that she is going to go home and her family is not going to be there you know or just misses them and just explain that she is in a safe place and that just talking about the positives of camp. In terms of actual textbook child life practice there is not a whole lot of that that happens at camp. It is more of just experiencing and being another person that can facilitate a fun camping experience.

How can preparation programs better prepare students for working in alternative settings?

I don't think we get a lot of education period. In general child life is a fairly new field and child life in alternative settings is even more new. And I don't think curriculum really addresses child life in alternative settings very much if not just a paragraph in a textbook here or there. So just providing you know ECU particularly, Vidant does camp WholeHeart, but beyond that I don't know anymore, I think the hem/onc clinic. But kaleidoscope is just a three week program during the summer, it is not a year around job, when I go to camp I don't take time off, then it is work time, it isn't my full time job. But just you know providing children with these opportunities maybe just a camp directory, or these are camps that are available and ones that you could be a part of potentially at duke mainly for liability and staffing purposes the staff we take are duke employees or volunteers of duke that have liability insurance with duke And things like that, but it is sometimes ok for a visitor to, we work with development a lot for funding, potential donors want to see what camp is about before they contribute to it. They try to limit those just so it doesn't look like kids are in a fishbowl and we are bringing busloads of people to look at what they do at camp, but sometimes there have been visitors at camp that kind of see that. It is hard to prepare people for camp experience if it is not easy to see what they are about, so potentially hooking students up with camps that are looking for volunteers all the time, I know victory junction is one of those. And more so professional and personality skills, helping students learn to think outside the box being flexible, because a lot of times when you are in the academic setting you are learning all of the correct words to use and how to talk to a child about diabetes and you think about the clinical setting a lot so being able to step out of that still hone in on your skill set that we are learning and that is still part of child life but just in a different setting.

However it would work to support students to just learn to be flexible and learn to think on your feet and not necessarily the textbook child life, you know preparation, procedural support, and normalization activities

How did you get this position?

The camp kaleidoscope leadership structure is Bill Taub that is the director, so he is the director over all three weeks of camp, and then in the weeks, week 1, week 2, week 3 all have two directors so under bills direction there are two people for each week who actually plan and facilitate and are on site for those individual events. Shortly after I began at duke, it had been a longtime dream of Bill's to have a sibling program. My second year at duke I went to camp as a counselor and I have been going to duke as a counselor for several years since then, but we also about four years ago began the sibling program. So a pediatrician and psychiatrist at duke and myself are codirectors for it now. Do being a codirector within camp, or the sibling director or week one or week two I'm on the camp leadership committee. So right now there are monthly meetings and closet to July they will be biweekly meetings. Where we get together and talk about the planning of camp. As a leadership member we are part of the decision making. The activity planning for each individual program and then the sibling program. We kind of decide what visitors we want and then the individual codirectors kind of plan that based on their week. So I kind of speak in as a counselor and started helping with the sibling program.

What advice do you have if I wanted to work in an alternative setting?

I think just being open to adaptability and the process of it may not be a textbook kind of job. You know being willing to relocate. That is something that is a struggle for a lot of child life students I think, it's a wonderful job, but positions are few and far between, you know turnover, but there are jobs out there, for someone to say there aren't jobs in child life, there are jobs

available, but you just have to be willing to move and that's not for everyone. There are certainly family reasons, financial reasons why that is not going to happen, but being willing to take that risk. And I think that there could be a job available for child life in alternative settings, but it might not be in this area. I think being a little bit tough and persistent, anywhere that you go and someone has never heard of child life and even within the hospital here, the cardiology population child life is still working with to get in a little bit better with. Let's say in a dentist's office, for so long the receptionist, the hygienist, the dentist himself or herself they have this routine of when children come in this is what they do, and they have their little tricks that they think works and when a new person comes in and tries to take that role away from them, sometimes that is threatening, sometimes that is hard to deal with. So being able to advocate for yourself and work well as a team and educate about your rules are and what boundaries you have and how it would be mutually beneficial to both of you. I think that is the biggest way you can develop support for child life period in any setting is to show what you can do. You there have been anesthesia staff, nurses that are not very open to child life, but when they see a great iv start, when they see a great induction, where the child is relaxed and not fighting, when they tell a patient that they need to have this procedure or surgery and they are in tears, and then after an hour of talking and learning and they are feeling better about things, that is when you can get some buy in. So being able to be confident in what you do and show that to other people is the biggest buy in.

Do you think it is first necessary to have experience in a hospital or medical setting before you work in an alternative setting?

Not necessarily, I think depending on your practical and internship experience a student makes them, so you will have had several months of experience in a learning rich environment, so you

will have had some medical experience, so if you think that you would like to go into child Life in an alternative setting. I would recommend that you try to find some clinical based practicum and internship settings while seeking out some opportunities to volunteer at a camping experience so that you can, because when I work with students and help them with resumes and cover letters and interviewing skills, you want to be balanced. That is a good selling point at entry level positions to have a variety of skills of working with children in a hospital setting. In a well-child developmental play setting and then Well and children with chronic illness in a camp setting. I would say that working in an hospital may be helpful in terms of gaining some experience and confidence before you break into a new setting where there may be some pushback and having that set of skills and confidence to say I can do this. But I don't think it is required. I think someone can go entry level position into an alternative setting if they have the desire, the drive, and the confidence to sort of push through and be an innovator. Alternative setting can be there are no rules that you have to follow as to how child life should be in that setting; you can make it what will be most beneficial for the patient and family or children and families.

What is your favorite and least favorite part of working in the camp setting?

My favorite part is absolutely seeing children thrive outside of a hospital setting, seeing them explore and do things they never thought they would be able to. The first day you know we go down to the water front, and even with the siblings. Siblings of children with chronic illness are sometimes held back in their experiences because though we can't all go to the beach because it is too far from the hospital or we can't all do that because your brother is not able to do it.

Siblings miss out on those opportunities as well. So the first day we walk down to the water front that is brown water that is gross. I am not getting in that water, and at the end of the week they a

swimming around like little fish. And sometimes they have never even been in a pool. So they get swimming lessons at camp and they get to make great strides and learn new skills. There are different arts and crafts and sports games where they can push themselves and they aren't told slow down, don't go too fast. As long as we feel you are being safe, you know do it because we have the staff to support you and the milestones that they make at camp. My least favorite part. These are superficial; the lack of sleep and it is too hot. It is the longest tiring most drained week of work you will do. You know I work 40 hours a week here in the clinic. When I'm at camp you literally work 24/7. You are if a child wakes up in the middle of the night and has to go to the bathroom, you are up with them if they are homesick and crying for two hours you are up with them. There are some children who need tube feelings in the middle of the night. So you have to set the pump at midnight and reset it at 4am. And that shows me too. That I am exhausted and sometimes these kids go to bed later than me and wake up earlier than I'm having to get up and I'm seeing their energy level and I'm like alright Judy you don't have any illness and you are tired, come on you can do this. It's just tiring and it's hot, but it is all worth it. If I had to really think of a negative aspect of camp I wish we potentially had the capacity to take more kids, but we are in a place where we have a good system that works. And we have good staffing support and trying to get more of that would be difficult in the economic climate that we have now, but I think the goal is quality not quantity and I think the quality that we have is really great.

Any other comments?

Nothing that I can think of. Kaleidoscope is a unique opportunity for me because I get I'm only at camp a week during the summer and a weekend during the fall so it's not balance. I get a clinical setting and I get the alternative of camp the child life role is different there. For sibling weekend, the goals are alike. We want the siblings to have fun and it is about them, their brothers and

sisters does not go, it is just the siblings, but we do mix in some therapeutic activities so that's where I get to practice a little bit more if my child life skills where we have group discussions where we break into small groups and just some team building and some connection type activities where if siblings want to share, no one is required to do anything but if they want to share you know what it is challenging for them. And sometimes going around the circle you can see it, how they are relating to experiences that other kids have shared and that leads to talking later. You know sibling weekend, camp kaleidoscope in general, children develop friendships that last for a really long time. That is something that we talked about this morning in our presentation. That a lot of times we have patients with chronic illness, siblings feel isolated, like no one gets what I am going through, to being in a setting where you are with people who are going through potentially the same things if not the exact same things with you. And to have that sense of connectedness is really good. And can then support, be strong resilient factors for success productive healthy success later in life.

NICU Interview

Tell me about the population that you serve.

Most of the babies we serve in the NICU are premature babies, babies born 23 weeks and up.

And then we do see some full term babies who need extra care after delivery, be that respiratory support, surgery, needing all kinds of different things, blood sugar issues, things like that. But we mostly see the premies.

What is the scope of your responsibilities?

We do a lot of family support, sibling support when we are allowed to have siblings, individual support, and bereavement support, and then there are different ways to do all of that.

What child life skills do you utilize? Which did you learn in the hospital and which did you learn on the job?

All of the NICU language and diagnoses and procedures and things like that I learned hands on in the NICU. Or what the actual needs were at each of the gestational ages and what babies can tolerate, signs of overstimulation, things like that I learned hands on in the NICU. Just general medical explanations for siblings like what an IV does, what EKG leads do, those kinds of things, I learned that through school, internship, job, that kind of thing. I think some skills of family support you learn the stressors of what might be going on in school, and you see some of it in your other jobs, but I think NICU is very specific in what those stressors may be because sometimes you are here for extended periods of time. Sometimes it is a situation that has been building up, sometimes it is someone who has wanted to have a child and has had five miscarriages and now finally has a baby but it is a twenty-six weeker. So I think some of the stressors are a little bit different in the NICU. So kind of figuring out what it is like for families in the NICU I have learned in the NICU more too from just talking to the families.

How could preparation programs better prepare students for working in alternative settings?

I think grief and bereavement is a big one that needs to be taught more. I know ECU is working on a class on that, but I think you always need more time learning about that. You get in those situations and sometimes you are not quite sure, and every family reacts differently so you have to do it a little bit different each time. I think knowing things aren't going to be textbook when you come out. Like you have the textbook way of this is how you should do this and this is what it is going to happen if you do this, and that is not always the case. So being able to take those basic skills that you have learned and implement them in whatever situation you are in and being able to tweak them to the individual needs of the family and to know it's ok if it is not textbook perfect and it is ok if a child cries during an IV even if you are doing X, Y, and Z. And just that validation that you are still making a difference, knowing that it is not going to be textbook.

How did you get this position?

I was a child life specialist in northern Virginia for a little while, and then I did early intervention in Raleigh where most of my caseload was premies. And then a position opened up here and they needed a child life specialist in the NICU and I had some experience in the NICU in Virginia and through early intervention. That is how I got here. (When she interviewed here, she was contacted by a child life specialist at Vidant about a job opening. There were two openings, and they really wanted her in the NICU due to her experience).

What advice do you have for students who want to work in alternative settings like the NICU?

My advice is to try to become a part of the team that is in the NICU, like with the other staff.

You want to be a part of the team as compared to an outsider looking in because you will get a lot farther that way.

Do you think it is necessary to first have basic hospital medical experience before you go into the NICU?

I think it is helpful in some form or fashion.

What is your favorite part and least favorite part of your job?

My favorite part is watching babies reach certain milestones, being able to watch them grow and do new things. Whether it is a milestone, rolling over, sitting up, or being able to hold a rattle or if it's them drinking a bottle or getting off of oxygen. My least favorite part is probably when you have those rough social situations like the parents who have five babies and none of them are in their custody, but still keep having babies and are doing drugs.

How do you deal with those tougher situations?

I just have to focus on what the baby needs. To do that and I feel like everything happens for a reason and you have to focus on what you can do to help the baby and not to judge even though that is hard to do.

Other comments

No I think it is always good to have that base knowledge of child life and beyond that you can implement it into any other arena as long as you are creative by the ideas you have and how to implement the different things. It is all the same principles it is just how you implement them.

Shadowing In the NICU

I believe that the NICU is an alternative setting for child life specialists even though it is still a hospital setting because very few child life programs have extended child life to that area of the hospital. Also, the role of child life in interacting with the patients is very different in this setting as compared to the other hospital settings. I was able to shadow a child life specialist for two full days to explore the role of child life beyond the normal hospital. During my shadowing experience I was able to see that child life specialists have multiple roles within the NICU as you would expect. They have a responsibility to the patient, the patient's parents, the patient's siblings, the staff, future patients, and community supporters. I am going to elaborate on the role in each of these areas individually.

It appears as though there is not much a child life specialist can do for an infant in the NICU. Most of the babies in this area of the hospital are premature. Child life has explored the needs of infants who are born at different gestational stages and thus are able to provide and advocate for those needs. Many of the more premature infants do not like lights and stroking touch. They instead feel comfort in a tight and firm touch. Thus, child life specialists are able to recognize this need for the infant and provide for the child appropriately. I saw this in action a few different ways. First, when a more premature infant was receiving an IV the child life specialist provided the child with comfort positioning by holding his legs and arms close to his body so that he was in the position he would be in the womb. This allowed the child to cope better with the needle stick. I was curious as to why toot sweets were not employed in this interaction, but this calming mechanism for infants is not appropriate for the more premature infants because their bodies cannot digest the sugar. Also, with more premature infants who are

crying, child life specialists may ensure that the baby is secure or provide a pacifier, but they are aware that holding or stroking the infant would cause more distress.

With older infants, child life specialists provide developmentally appropriate interaction to help the child develop appropriately while they are in the hospital. This is vital because as we know infants that are born premature are considered at risk for needing early intervention. Child life specialists are there to provide early intervention as soon as possible so that the child can develop appropriately. This can include providing the child with human contact for the infants who have distant or no family. It can also include talking to the infant, and providing music and other stimulation. I was taught by the child life specialist that holding the infant can also provide a type of tummy time for those who have gastric problems.

Child life specialists work beyond just providing for the infant, they also provide comfort for the family. I was able to see multiple circumstances where child life was able to support parents through the tough times of having a sick infant. Ms. Tripp took time to talk to the parents like they were people, validate their actions and emotions, and provide comfort through explanations of events. Parents are inundated with people who are focusing on their child's needs, but they are often overwhelmed with the amount of people and the amount of information. Child life specialists are able to provide a more calming presence to the hospital atmosphere and allow the parent to play the role of parent which they are longing to do. Ms. Tripp did point out that often she timed her introduction to a family to ensure that she was not just another face that added to the overwhelming atmosphere and instead as a trusted person to help with supporting them through this experience.

Child life specialists also work with the siblings of the infants. I was not able to see this in action, but I was able to talk with Ms. Tripp about it and observe her offering services. The

child life program offers video conferencing for siblings who are unable to see the newborn in person due to barriers such as flu restrictions. Also, child life educates siblings on the medical equipment that is used for their younger brother or sister. This education is done through play because children learn through play. Finally, child life provides a playroom for siblings who are not able to visit their baby brother or sister. This allows the sibling who is often brought to the hospital a chance to learn and grow and enjoy themselves while one parent is visiting the infant.

I was able to see often how child life was able to support the nurses and other staff in the NICU. Ms. Tripp began her day with asking the nurses if they needed anything to help them in caring for the infants. She also assists in procedures such as IVs whenever possible providing support for both the nurse and the patient. She also provides an extra support for the nurses for example when they have a distressed infant as well as another infant that needs medication. Child life thus can provide support for the infant freeing the nurse to tend to more tasks. Ms. Tripp expressed that it is vital for a child life specialist entering the NICU to develop a relationship with the staff because it is only through having a relationship with them that child life can truly be utilized on the floor.

Future patients are also a part of the child life specialist's case load. Ms. Tripp has a relationship with the high risk clinic and patients are referred to her for a tour of the NICU. I was able to attend one of these tours. Ms. Tripp first introduced herself and then began having a light conversation with the family making it a point to ask what the child's name will be. She then takes the mother and possibly others to an empty bed in the NICU. There she explains the environment that they will encounter including the amount of people they will meet, the sounds they will hear, and what is expected from this infant's experience. The family who visited on this tour were having a baby whose intestines would be born outside of the body. Thus, child life

provided an explanation of what to expect from the surgery (ensuring to not overstep her expertise and pointing out that they would need to talk to the surgeon about the plan). The child life specialist also included information about where they could stay during the infant's hospitalization. This included the Ronald McDonald house as well as discounted hotels. Finally, the tour was ended with asking if the family had any questions and answering those questions within her knowledge base. She ended by providing her contact information.

Child life specialists also get referrals for support for families who may not be having their infant at this hospital. I was able to sit in for a referral for a parent wanting to know how to explain the situation of the baby to siblings. Child life was able to validate what the parents had done, but also provided suggestions to help with the process. The baby was going to be born with Down Syndrome as well as heart problems. Ms. Tripp pointed out that it would be important to continue to talk to the siblings about what they would expect for them as well as for the baby. For example, when the baby is born, who are they going to stay with, where will mom and dad be, and when will they get to visit the baby. Ms. Tripp said that it was important to try to get the siblings in to visit the infant. This would help them process as well as feel involved. She also gave the family information on how to get the other siblings involved when they are far away from the infant including drawing pictures to decorate the room. After the conversation she provided the family with websites and book information to help them understand and explain each step of the way as well as her information so that they could contact her if they had more questions.

I talked to Ms. Tripp after this referral and she told me that not all families are open to telling their other children about problems with the infant. Thus, she always expresses the importance of informing the siblings, but also accepts that it is a parent's final decision as to

what they are going to do. It is important to arm families with the knowledge so that they can help all of the children through the process.

Finally, as with most settings that involve children, there are members of the community who want to donate to the cause. When I was shadowing Ms. Tripp, she had a group from her church as well as a family who had recently used the sibling playroom who wanted to donate to the floor. Ms. Tripp had the job of brainstorming needs as well as creating a wish list for the playroom. She also will have to ensure that all of the donated items are appropriate for the area that they have been donated for. It is important to establish these relationships with the community because the hospital is a part of the community.

Ms. Tripp also told me that child life played a role in bereavement of the infants who were in the NICU. This includes contacting “Now I lay me Down to Sleep” (a volunteer photography group that provides professional photographs for families whose infants will never leave the hospital), creating a memory box, and supporting the family. Child life however does not play a role in bereavement for stillborns. Ms. Tripp stated that they did at one time, but then had to back off because it was taking away from their job in the NICU.

Early Intervention Interview

Tell about population you serve:

“We are the state early intervention program so we serve children from birth to the day before their third birthday. We have two different categories of kids who are eligible for our program. The first is established condition. That could be any type of diagnosis or medical condition that would put a child at risk for developmental delays. So it could be Down Syndrome, it could be autism, it could be born prematurely. It has to be before 27 weeks and under 1000 grams to be eligible. So there is multiple eligibility that children can qualify for that. And the other category is children who have diagnosed developmental delays. That’s where we’ve gone out and done assessment and we’ve determined the child has a developmental delay and they are eligible.”

What is the scope of your responsibilities?

“I’m a service coordinator so when I initially refer to or assigned to a child I do basically just their initial paperwork done. So that includes what the parents’ concerns are, doing financial paperwork to help with potential cover services, explaining our program, and then either arrange for a child to have a developmental assessment to determine their level of abilities and then follow up on any services that the child needs, so I follow them the whole time they are in our program. And so if they need physical therapy, then I help get the physical therapist in place and just continue to monitor that child’s development and any other needs, how they are progressing, if they are meeting their goals. We develop an IFSP (Individualized Family Service Plan) and my primary role is to monitor that document and to make sure that that plan is meeting the child’s needs and if it is not, what do we need to do to adjust that?”

What child life skills do you utilize the most here?

I have often said that at this job I feel that I use my child life degree more than I did when I was actually a child life specialist, which is really an odd thing because for several years that I was here my case load was entirely medically fragile children. And so I really had to have a child life knowledge of medical issues and understanding what impact that can have on a child's development. And also working with a multidisciplinary team, we have a pediatrician who works on staff, along with multiple disciplines. So being able to work with that team, being able to listen to a family and help them work through the grief process, even though it is a little bit different than what you deal with in the hospital, but you know, we are with the families a lot longer, we are in more depth, we are in their home on a monthly basis, so just helping parents and recognizing the whole process that the family goes through to accept their child's disability. So yeah a lot of child life stuff here. In fact there have been several child life specialists, we have another one working here now, but over the years we have had several that worked here as service coordinators. And I used to have interns would come here too, but I had to stop because I am not sure my plans for the summer, I couldn't take a student this summer, but

How could preparation programs help prepare students better for working in alternative programs?

Well, you know, I think that ECU does do a pretty good job because part of my training was early intervention. I remember taking classes with that and when I started working with this job I really had to think back, you know I graduated in '96, so I really had to think back to what I had learned at ECU with early intervention. And also, when I was a student they really pushed thinking of different places that you could be because the reality when I graduated was that you were not going to find a child life job, I did, I was lucky enough to find one, but yeah, I mean

they really put you in that mindset like what else can you do. So when I think early intervention is a real natural alternative for child life specialists.

How did you get this position? And what made you decide to work here?

It was a hard decision because I feel like most people who major in child life that's all you want to do and I graduated in '96, December of '96 and I had done my internship at Children's Hospital of Tennessee and the reason I picked that was I was really interested in emergency settings and part of their rotation was in a children's emergency department. And so when Wakemed opened up their children's ER I was lucky enough to get a job doing that. It was my dream job, it really was, but I was single. I didn't have kids at the time and so when you work in the ER you work 3-11 shifts, you work every other weekend, you work every other holiday, so you have all those times that don't really work that great when you want to have a little kid and a family. So I did that for almost eight years and absolutely loved it. Wouldn't trade it for anything, but then I wanted to do different things. I wanted to be home at night, I didn't want to be working Christmas anymore because I knew I would be having a baby in the next two years or so and this job opened up. And I think what got me the job here was because I had worked at the hospital. They had a lot of medically fragile babies and they wanted someone who was comfortable working with medically fragile babies and you know, the other part of that is sometimes babies don't make it so having someone that wasn't going to run screaming when that happened. You know, I was used to, I had dealt with that before, so I had dealt with the bereavement part of child life and so I think that got me the job here. So even though I was working with premies primarily and I didn't know premies because I didn't work in the NICU, I worked in the ER. So, but I learned a lot. So that's what brought me here, a better schedule.

What advice do you have if I wanted to work in an alternative setting?

Just keep an open mind because I know what it's like, when that is all you want to do and you want to work in the hospital, but just think about other places where you could truly use your degree and feel competent that you didn't waste all that time and energy because it was a very hard thing for me to think about, you know I'm leaving child life and I wanted that and you know that I need to find something different and I came here and found out I really wasn't trading anything off. I'm not a child life specialist anymore, but that doesn't really matter to me because I feel like I am still using my degree and the skills that I learned. And I have kept my certification up so. Even though I don't plan to go back, I have been able to keep my certification because a lot of trainings I use for my infant-toddler certification I can use for my child life certification. So that has been really easy to do.

Do you believe that it is first necessary to have experience in a hospital/medical setting before you start in an alternative setting?

I think so, I think yeah. I learned so much from that and I just wouldn't. Because that is how you learn the medical stuff, so I mean you don't. If I sat down and started to read a medical chart and I hadn't had that hands on experience how to read it and here we have a pediatrician that you know you sit down and people don't have to know the medical stuff you get a medically involved child, you sit down with our pediatrician and she goes over the medical records often she does the visit with you. So it's not like you have to do that, but for me I was very comfortable with opening the chart (although I certainly didn't know everything, but for the most part you kind of know the basics). So, that was helpful. And when a lot of these parents that you work with they are really savvy with their child's medical issues and they rattle off stuff just like you are talking to a doctor and often I have sat there and I've listened to these parents talk to me

and I'm understanding most of what they are saying versus if you had never had that hospital experience, what does Q24 mean? You know that kind of stuff. And you can always tell a parent, hey I don't have a medical background translate, you know so, but that was really helpful for me. And the fact that we have a wonderful pediatrician, it is her last day today and I don't think we are getting another one any time soon. Just having that support to help with stuff, so yes I think it would be good to have a hospital experience first. So try if you can find one, which there are a lot more now than there was when I was a student.

What is your favorite part of your job and your least favorite?

Well, my favorite part is sitting in in the family's home and doing those initial visits and just getting to know them and the other part of what I do is once a child is enrolled in our program and services are in place I go out on a monthly basis or every two months and see how that child is progressing. So I'll be in the home and they will be receiving their therapy session and the parents are there and just seeing how that child is progressing. You know they usually make really good progress. So just kind of seeing how early intervention works, that's my favorite part in the home and with doing home visits there is always a downside to that because you never know what you are going to get. Like I went to a home yesterday and they had no furniture and there was a huge pit-bull sitting on the porch beside the house. Snarling and growling at me and there wasn't much keeping him in that so that's kind of terrifying, but that child needs you, that child needs services so you have to be blind to that kind of stuff. Obviously you keep yourself safe, but you know, meet the family where they are, but the other part is that we are a voluntary program so usually people want us there because we don't force. If a family doesn't want us there then we don't go, we don't make them be involved unless that is the DSS saying to be involved, but for the most part the family wants you there, they want the service, so that is the

really good part is fun. The downside is the paperwork. There is a ton of paperwork we do, and when I worked at the hospital I had one form that I would fill out and that was only if I did an intervention, like only if I did like a prep. If I just took toys or whatever, I didn't have to document any of that so I went from doing maybe three or four forms a night to you know huge amounts of paperwork, but that is a state job. That's part of it, so it's manageable.

What precautions do you take when you go on home visits to protect yourself?

Well, I just keep a, just be mindful of where I am like with that pit-bull yesterday, there wasn't much I could do about it, but I just kind of had an escape route. Like what am I going to do if that dog breaks loose and how long am I going to stand on this porch and knock on this door before I go back in my car and leave. Luckily, mom answered immediately and I went into the house and all that, but just be aware of your surroundings, just common sense. If there is only one situation where I pulled up to an apartment and didn't even stop, just kept going because there was a large group of men standing right outside the apartment entrance that I had to go through, and I just wasn't going to do that. So I ended up calling the mom, I couldn't get up with her anyway, she wasn't home, so it all worked out fine, but just rescheduling. You know 'I'm sorry, something came up' you know. You have to keep in mind that that woman can't help that there is a group of men out there and she still has a child that needs services, but just, is there another time that I could come or a different time of day that I could meet her. Usually early in the morning you don't have to deal with crowds of people standing around. Just trying to adjust like that, we all have at least one case where you are kind of scared, but most of the time it's not like that. But just common sense and knowing your surroundings and making sure the family knows you are coming so they will know to be watching for you and know to open the door so you aren't standing outside knocking or wandering around. Make sure you have the address

correct so you know where you are going, so I know where you are, and just knowing if you are ever uncomfortable you just leave. You just say 'oh, I got buzzed'. Or whatever, but I have never had to do that. Know how to get out of the apartment and where you are.

How many children do you have on your case load at a time?

I have thirty five right now. We just had a lot of people leave so that is kind of inflated, but when I went on maternity leave about six years ago I had forty-eight kids. So they have hired a lot of service coordinators to keep it down. There are forty of us who do this, of course they are never all filled. There are days when it is busy, but yeah, that is pretty average now.

Any other comments?

No

I have taken a few students over the years here, even though it is harder things worked out great. Having students, I have definitely kept them very busy, it is always important to be very flexible. What is hard is if a student says, well I can only be here Tuesdays and Thursdays. Well that's great, but you are not. Summers work best, even though I can't take a student this summer, but someone flexible who lives in the area I can say ok, on Wednesday I have three visits, why don't you come in versus Friday when I have staff meetings. You don't want to sit through that, so it works out pretty good, I think they learn a lot. And it is always a grab bag of what you get to see depending on my case load, but one student got to sit with our psychologist and work with a child that had had multiple hospitalizations and high anxiety so she got to help the psychologist develop a plan for this child when they go to medical appointments, so that I could have never predicted that, but it happens. Most of them have had similar experiences.

Common Themes

After reviewing the interviews and considering the conversations that I had during shadowing, I found multiple common themes among the child life specialists in alternative settings. I will summarize the concepts and explain what they mean to child life specialists in more detail below.

The first common theme is the role of child life on a multidisciplinary team. Each one of the child life specialists that I spoke to or shadowed mentioned that they were involved in the multidisciplinary team meeting. This highlights the fact that no matter what setting a child life specialist is in, they are always part of a team. During each meeting, child life was not only invited to attend, but also seen as an important member of the team whose thoughts and opinions are valued and considered. Also, in all of the settings that I explored, child life specialists share a common need to be familiar with the medical environment. This includes understanding medical terminology, medical equipment, and the roles of medical personnel. It is through this knowledge that they can be better parts of the multidisciplinary team and prepare children for different events.

Also, there are common themes in the specific roles of the child life specialist. No matter where the child life specialists are working, they are advocates for their patients. Child life specialists play a role in any setting that is different than all other professionals. They are the people who understand what a child is most likely feeling in the situation, so they are the obvious advocate for that child in any situation. In addition, due to the fact that child life specialists understand children, they are the best for the role in normalizing any stressful setting that the child is involved in. A child life specialist in any alternative setting needs to normalize the environment, because no matter what the situation is, a child needs to be a child. Finally, child

life specialists all act as supports for families and children. Their role has been defined as a person to help children in traumatic situations. Child life specialists have a special position that helps families through all types of situations.

There are also common themes in the recommendations for students. The first common idea is that students need to learn that things are not going to be by the book once you get into the working world. Child life specialists share that students expect child life to always be by the book and are thrown when this doesn't happen. They sometimes feel like they failed if a child cries after they have done X, Y, and Z according to the book. This leads into another common piece of advice that child life specialists had which is that students need to learn flexibility. In both alternative and conventional settings, there can be unexpected changes and the child life specialist needs to adapt and conform to the new situation. Without flexibility, the child life specialist could fall apart or become less effective. Finally, it is recommended that child life programs introduce students to the role of child life in alternative settings beyond the occasional paragraph in class. It is through learning that child life specialists can extend beyond the hospital and what types of settings they can extend to that students are encouraged to actually step into working or creating an alternative child life program.

A similarity in child life specialists in alternative settings when it comes to how they get their jobs in these areas is that they advocated for themselves. They advocated for their ability to do the job, they advocated for the importance of child life in that area. This shows that it is important to market yourself when it comes to getting a job in an alternative setting because child life is a new field and it is not as entrenched in some settings as it is in others. I think it is also important to market yourself when applying for a more conventional setting as well because you are the only one who will do so.

The last common theme among the answers of the child life specialists is that they do not believe that it is necessary to have experience in a hospital setting before working in an alternative setting. Although they all agree that it can help, they point out that the skills that you learn from any setting can help you in your future career. Thus, any experience cannot count against you, and any lack of experience cannot hold you back. Many child life specialists in alternative settings have to learn on the job.