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Supporting the threads of the family tapestry : the role of child life in adoption

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Supporting the Threads of the Family Tapestry: The Role of Child Life in Adoption

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Abstract

The current paper *Supporting the Threads of the Family Tapestry: The Role of Child Life in Adoption* by Rachel N. Werner, explores the developmental, cultural and health related impacts of adoption along with effects of early adversity. The goal of the paper is to utilize existing research on adoption to argue the necessity for a child life specialist in the life of an adopted child and their family. Adopted children come from one culture and then are transplanted into another with a new family and set of rules; this can be extremely confusing for them and add a great deal of stress to their already anxiety producing situation (Suárez-Orozco, Suárez-Orozco & Suárez-Orozco, 2009). Developmental effects of adoption have been widely researched (Cohen et al., 2008; Reinoso, Juffer & Tieman, 2013; Rettig & McCarthy-Rettig, 2006; van Londen, Juffer & van Iizendoorn, 2007). Child life specialists use a background in child development to promote positive coping and provide family centered care for each unique family system individually. Because adopted children all come from a unique background, it is necessary to prepare children and families for what they may encounter and provide the appropriate coping techniques that can help them long-term. When families are provided with the proper tools, it is likely that they will have a more positive experience and become better adjusted to their new life.

Keywords: child life, adoption, culture, child development

The Weaver's Craft
By Richard Best

Threads of many colors,
the subtle and the old.
Threads that form a pattern
of origins untold.

Threads for strength,
some spun from strife,
some rough, some smooth,
the threads of life.

Often fibers that bring strength
cut, cause pain and sorrow.
The weaver's craft to understand
That beauty waits the morrow.

Fibers torn
to be mended.
Fibers new
to be tended .

Joined with strands
that came before,
by loving hands
and hearts and lore.

One pattern formed
from beginnings rent.
Merged with another
through love, not descent.

Unique patterns
from the start,
harmonized
by the weaver's art.

The weaver's craft
to mend, then blend…
to form new patterns
that join and transcend.

(Hopkins-Best, 2012)

Literature Review

Culture

The development of a child is constructed around the culture of their family (Rogoff, 2003, p. 3). "Culture has been defined as an integrated pattern of learned beliefs and behaviors that can be shared among groups. It includes thoughts, styles of communicating, ways of interacting, views on roles and relationships, values, practices, and customs" (Donini-Lenhoff & Hendrick, 2000, as cited by Betancourt, Green & Carillo, 2002). Culture is an extremely complex concept; an umbrella term that can play a role in every aspect of a person's life. Some of the factors that fall under the umbrella are: personal identity, traditions, communication, education, rituals, thought processes, value systems, and generation.

The culture that every individual child is raised in can be based on a variety of variables. The child depends on the parents for the necessities of life, however, depending on their culture, necessities of life may vary (Rogoff, 2003, p. 102). Every culture has different views on how to raise a child and in every culture; there are children that grow to be successful adults within that cultural context. "Culture is dynamic and evolves continually by adopting new behaviors, values, and norms" (Cotton & Denhoed, 2003). It is an evolving facet of life. Every generation changes a culture slightly to accommodate changing societies, and address the needs of the current generation (Rogoff, 2003, p. 105).

To make culture even more complicated, each individual person is a member of multiple different cultures. There are cultures associated with any group, organized or unorganized, that the person is a member of. Because culture is ever adapting and is

completely individual, it is almost impossible to group anyone into one culture. Each person is a member of multiple cultures, and two members of one family may be members of several different cultures. For example, a little league can have numerous cultures integrated. There is the culture of one team, the culture of the competition, the culture of the league, the culture of the siblings, the culture of the parents, the culture of the coaches, etc.; meaning one family can have four or five cultures just surrounding little league. However small the culture may be, it plays a role in the persons' life. "The family both shapes culture and is shaped by culture. Culture serves as a mitigating force, a kind of shock absorber, between the family and the world. Yet culture is never static. Even as it gives families a sense of place, a sense of belonging, and a sense of values and meaning, it is constantly changing to meet the actual needs of the community, and to be relevant to real people's real lives" (Shelton & Stepanek, 1994, p. 38).

Culture is not something we choose; it is largely something that we are born into, but it is a source for judgments and stereotypes.

> "Each family exists in a specific environmental and social context, and each family adjusts to try and survive and thrive in its given world. We have to be very careful not to succumb to the temptation to fit each family into neat little preconceived categories based on their ethnicity, race, religion, economic or educational level, geographical habitat, or any other generality." (Shelton & Stepanek, 1994, p. 39).

Every family is much more than their superficial traits. Categorizing families is an almost impossible task, as every family is a unique unit that cannot be duplicated.

Helping professionals who work with children must be aware of the role of culture in a child's life because different circumstances and traditions can produce disparities in expectations for children. Vygotsky argued that that "children in all

communities are cultural participants, living in a particular community at a specific time in history" (Rogoff, 2003, p. 10). This suggests that culture does not only apply to ethnicity or location, but that culture is all encompassing. Culture can be anything that a person identifies with, such as: religion, traditions, communication, rituals, education, generation, age, political standpoint, disability, and major life events. It is impossible to tell a person's culture by looking at them or listening to the language that they speak. It is based on each individual and their values in life. Culture can only be determined by asking and listening to what/who a family identifies themselves with.

Culture can create barriers to healthcare (Galanti, 1997). Problems most commonly arise when healthcare professionals who are not accustomed to his/her culture are treating a patient. Throughout the book *The Spirit Catches You And You Fall Down*, a book about a young Laos girl, Lia Lee, being cared for in the American healthcare system, the medical care providers made it seem as though culture was a negative thing (Fadiman, 1997). It is important for medical care providers to remember that culture is not something that is chosen; it is largely something that humans are born into or later identify with. It was obvious that the cultural barrier between the American Healthcare system and the Hmong made it difficult for the Lees to understand the importance of the medicine. Dr. Dan Murphy said that the "thing that was different between them and me was that they seemed to accept things that to me were major catastrophes as part of the normal flow of life. For them, the crisis was the treatment, not the epilepsy" (Fadiman, 1997, p. 53). The differences in culture between the Lees and their doctors made them value different things. "Every group and every individual has worth. Patients and families who do not conform to hospital culture are still valuable members of the

healthcare team. They must be accepted for who they are" (Cotton & Denhoed, 2003). Healthcare professionals must value the insight of the family, as they are the ones who know the child best and have their best interest in mind.

Culture also plays a huge role in the way children play; therefore it will most likely be seen throughout their hospitalization. Chang, Ritter and Hays (2005) surveyed play therapists about cultural disparities in the play of different children. When the play therapists were asked if they saw trends of play therapy with their culturally diverse clients, one of the themes that arose in the answers was a difference in play objects. The play therapists reported that some of the children were conscious of cultural aspects of play and some children even verbalized this feeling. It was also reported that there was more aggressive play in sessions with children from an ethnic minority group irrespective of the reason they were in therapy. When the therapists were asked about the toys that their ethnic minority children used to play with, they reported that the ethnic minority children most often chose to play with the culturally diverse dolls. To allow for this option and provide the child with as much comfort in their experience as possible, it is necessary to provide culturally diverse play options. This is true in providing activities that support development and well being also, as this is a major aspect of therapeutic play (Koller, 2008). Giving the child a culturally sensitive outlet to express their emotions is also necessary to effectively prepare children for procedures (Koller, 2007). In everything that child does in play, there should be an alternative that is culturally sensitive, in order to cater to the needs of all of the children and families.

Culture and Adoption

" A family can be as temporary as a few weeks, or as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support" (Arango, 1990 as cited by Bell, Johnson, Desai & McLeod, 2009). Family is also an umbrella term, encompassing many different ideas that all have the same theme. For a child that is adopted, they may have two families at a very young age, and as they get older acquire even more. Introducing children to their birth family is an extremely controversial topic in the world of adoption. Similarly, there are many different arguments about introducing the child's birth culture to them along with their current family culture. Lind and Johansson (2009) interviewed adoptive parents and adoption agency representatives, and found that there was a unanimous conclusion that the main goal of adoption was for an adopted child to gain an equal position in the family to that of a biological child. Some of the informants that contributed to the study argued that this position was more likely to be earned if the child was not given information about their religious background. Adoptive parents questioned the relevance of the Indian culture to a child who was not growing up in India, but also if it was a good idea to remind the child of their differences of backgrounds with their family. In other arguments about preserving the background of the adopted child, it has been mentioned that it may only be in the best interest of the ethnic minority from which the child's heritage is, and not in the best interest of the child. However, a child coming to the United States by adoption may have a very different experience than a child who was adopted to another country because of the sheer diversity of religious practices in the United States (Barnes, Plotnikoff, Fox & Pendleton, 2000). It is possible that the child may not feel as though they are members of a minority depending on where they live and the culture of the community.

When Reinoso, Juffer and Tieman (2013) conducted a study on children ages eight to twelve who were adopted to Spain from various countries, they found that children who were adopted from a racial background different from their adoptive family's developed a stronger relationship with the culture of their birth country than those who were adopted into a family who's race was the same as theirs. Researchers also found that children who were adopted internationally more strongly identified with their birth country than their current country, but Spain was still mentioned as part of the child and their story. Along with their identification of themselves, the children also all correctly identified their race, even when they were same-race adoptees. Lee (2003) found that young adopted children often identify with their birth culture, and as they get older their sense of race and ethnicity become more ambiguous. This suggests that when they are young, children define culture as race and ethnicity, but as they grow, they accept that culture is much more than physical traits. Although their idea of culture may change as they get older, when young children have awareness of their own racial group, it promotes positive psychological development (Thomas & Tessler, 2007).

Some young adopted children may identify themselves as biracial if they are given the opportunity to experience both of their cultures, and if their adoptive parents are willing to have open dialogue with them about the adoption (Friedlander at al., 2000). In order for the child to experience their birth culture, it may require their adoptive parents to educate themselves about the culture. Brodzinsky et al. (1992) found that children are more likely to have a healthy adjustment to their adoption if they have an open, active and emotional relationship with their adoptive parents.

Children may be exposed to the acculturation process quicker than adults because schools and community programs are a major site for cultural contact (Brodzinsky et al., 1992). Children are affected by cultural changes in their environment immensely. They have to learn their place in the new communities and hierarchies. Along with many other factors that contribute to their identity through adoption, they must adapt to their surroundings.

Development and Adoption

The developmental effects of adoption have been widely researched in psychology and social work literature (Cohen et al., 2008; Reinoso, Juffer & Tieman, 2013; Rettig & McCarthy-Rettig, 2006; van Londen, Juffer & van Iizendoorn, 2007). Researchers conducted a study using 240 children that were adopted from China as participants, and found that sixty-two percent of the families stated that their children were developmentally delayed (Rettig & McCarthy-Rettig, 2006). Of these developmental delays, motor delays were most commonly reported.

Variables that contribute to development. Van Londen, Juffer and van Iizendoorn (2007) found that time with a foster family prior to adoption protected the child from mental and motor delays. It is possible that the reason for this was the human interaction and play opportunities that the children received while in the foster home compared to in an orphanage. Some studies have shown that the country from which the child was adopted plays a large role in the child's overall status at the time of adoption (Pomerleau et al., 2005). Children who were adopted from a foster home showed significantly increased psychomotor development compared to children who were adopted from orphanages or other institutions (Van Londen, Juffer and van Iizendoorn).

Variations in the way children are treated cross-culturally contribute to this factor. Children in different settings may be experiencing: a lack of developmentally appropriate stimulation, malnutrition, lack of play opportunities, and interpersonal contact and communication.

Age at adoption has been related to developmental outcomes of the children, especially if they are institutionalized prior to adoption (Cohen et al., 2008). It has been found that children adopted at younger ages have better chances of catching up to their non-adopted peers in development if they were adopted at a younger age. Children adopted from institutionalization at an older age are at higher risks for social and behavioral problems.

Common developmental concerns. Adopted children show significant signs of delay in language development (Van Ijzendoorn & Juffer, 2006). Cohen et al. (2008) studied children adopted from China up until two years after their adoption. They compared certain variables of the children's development with Canadian children who were from similar family structures as the ones in which the Chinese children were adopted into. The researchers found that at arrival, the adopted children had lower scores in mental development, receptive language, expressive language and motor development than their Canadian peers. At the six-month follow-up, the children were on average functioning within a normal range on mental, motor and receptive language development measures. While other developmental concerns may diminish within in the first two years after adoption, adopted children continued to have expressive language restrictions after that time frame. Children who were adopted prior to age two have shown significant delays in communication and gross motor development at the age of 24

months, but by 36 months the adopted children had caught up to their non-adopted peers (Dalen & Theie, 2014). This shows that environment can play a large role in development of a child.

Although children who were adopted do show delays at the beginning of their adoption process, researchers have concluded that they can catch up to their non-adopted peers (Cohen et al., 2008). When researchers studied adopted children and their biological siblings who remained with the biological family, it was found that adopted children outperformed their biological siblings on IQ and school achievement measures. This suggests that the positive change in environment for the child can make a difference in their perceived cognitive abilities.

Common health concerns. Along with common developmental concerns among adopted children, there are also common health concerns that can be seen in this population (Pomerleau et al., 2005). Some common health issues that are present at time of arrival are cranio-facial anomalies, respiratory infection, gastrointestinal infection, cutaneous infection, neurological issues, non-dermatologic organic disease and eczema. Dr. Lee of Winthrop Pediatric Specialty Clinic stated "But physically the most common things that I look for are hepatitis B, tuberculosis, parasitic infections, hepatitis B, syphilis, and HIV" (refer to Appendix E).

Common Effects of Early Adversity and Adoption

Loss and Grief

> Adoption is created through loss; without loss there would be no adoption. Loss then, is at the hub of the wheel. All birthparents, adoptive parents, and adoptees share in having experienced at least one major, life altering loss before becoming involved in adoption. In adoption, in order to gain anything, one must first lose—a family, a child, a dream. It is these losses and the way they are accepted and,

> hopefully, resolved, which set the tone for the lifelong process of adoption (Silverstein & Kaplan, 1988, p. 2).

All people involved in the adoption triad, the birth parents, adoptive parents and child, experience losses as a result of the process of adoption. For children who were adopted, these losses vary based on "a range of intrapersonal, interpersonal, experiential, and contextual factors, including age, cognitive level, temperament, pre-placement history, relationship history, and current support systems" (Brodzinsky et al., 1998). Losses can be experienced differently for every person who was adopted, and losses that are felt may change over time. Although throughout the course of one's life, they may feel different losses than their adopted peers, the first loss of every adopted person is the same. "Adoptees suffer their first loss at the initial separation from the birth family. Awareness of adoption status is inevitable. Even if the loss is beyond conscious awareness, recognition, or vocabulary, it affects the adoptee on a very profound level" (Silverstein & Kaplan, 1988, p. 2). Loss is a natural effect of adoption, and there are many losses involved. In order to successfully cope with the loss, individual's grief must be addressed. "Grief is not only the expected response to a loss, it is also a positive and beneficial response, because grieving allows us to process our loss" (Robinson, 2000, p.ii).

Silverstein and Kaplan (1988) spoke about a dream as being a loss for those involved in the adoption triad. It is a loss that is not physical but rather symbolic. *Symbolic Loss* is a loss that does not occur in the wake of a death, but instead signifies loss of relationships, social systems, and hopes and dreams (Walsh-Burke, 2006). These grief-inducing situations may be more difficult to navigate because they are not as

commonly thought about as loss. According to Rando (1984), symbolic loss is not always acknowledged as loss; as it is not material, and those who are dealing with it internally are not always aware that they must allow themselves time to grieve. "Because symbolic losses so often go unacknowledged by others, the grieving individual does not receive the same kind, or amount of support that those grieving a death may receive" (Walsh-Burke, 2006, p. 10). Hence, grief is more complicated when a loss is not recognized or addressed by individuals' support systems. There is a lack of community understanding about the grief that follows adoption related loss; and due to this absence of understanding, there is an absence of support (Robinson, 2000).

The grief that occurs when the loss is not acknowledged by others, publicly mourned, or supported by the grievers' social systems, is called *disenfranchised grief* (Doka, 1989). In situations of disenfranchised grief, the mourner is not given the opportunity to grieve because their loss is not accepted by society. Brodzinsky (2011) stated that adopted children often do not feel as though as though their losses are supported and understood. Because of this lack of support, disenfranchised grief is more intensified than common grief and can lead or contribute to complicated grief reactions.

Another loss term that researchers have related to adoption is *nonfinite loss* (Bruce & Shultz, 2001; Jones & Beck, 2007). Nonfinite losses are losses that are slowly accumulated or manifested over a period of time, or throughout one's life (Bruce & Shultz, 2001, as cited by Jones & Beck, 2007). This type of loss is fueled by opportunities for the initial loss to be recognized and added to, such as milestones, birthdays and years. The continual nature of a loss through adoption provides never-ending opportunities for experiencing losses related to the initial adoption. These losses

add up over time and weigh heavier and heavier on the griever. Because this loss grows over time, the person experiencing the losses is aware that they are coming and is caught between two worlds, one that is known and one that is dreaded. Bruce and Shultz (2001) stated three conditions for nonfinite loss. "The first is that the loss must be continuous and often follows a major event. The second involves developmental expectations that cannot be met…the last condition described by Bruce and Shultz is the loss of one's hopes and ideals" (As cited by Jones & Beck, 2007).

Grieving a loss is a social process and is best coped with, with the assistance of others in the same situation (Worden, 2008). When there is stigma surrounding the loss, there may be less social support for the griever. Social views and stigma surrounding a loss can "both cause actual challenges to emotional and role functioning as well as inaccurately denigrate adequate adaptation" (Leon, 2002). An example of stigma related to adoption is the "societal definition of parenthood" (p. 656) being that the parent and the child share genes. There is a general stigma surrounding families who are not blood related. Some people may view adoption as a choice for the child therefore they should be appreciative of having a house to live in and food on the table; therefore those people do not understand the inner turmoil that adopted children deal with every day surrounding the losses that they have experienced in their lives.

Another stigmatization surrounding adoption is that is inevitably involves abandonment and rejection. This view speciously argues that all birthparents discard their child haphazardly without attention to their well-being. Unfortunately in some cases, this stigma may come true, however, surrendering a child to adoption can also mean that the birthparents were altruistic and had the best interest of the child in mind by

choosing to make an adoption plan that ensures proper care is provided to their child (Leon, 2002; Resnick, Blum, Bose, Smith & Toogood, 1990). All of the negative stigmas regarding adopted children give the connotation that they are damaged. These losses and stigmas add up to "constitute significant trauma" in the life of adopted children (Leon, 2002, p. 657).

Trauma

> Until recently, the consequences of specific traumas—such as wars, concentration camp experiences, rape, civilian disasters and child abuse—were generally described as separate entities. However, closer examination makes it clear that the human response to overwhelming and uncontrollable life events is remarkably consistent. Although the nature of the trauma, the age of the victim, predisposing personality, and community response all have an important effect on ultimate posttraumatic adaptation, the core features of the posttraumatic syndrome are fairly constant across these variables (Van der Kolk, 2003, p. 2).

While children are commonly known as resilient beings, their brains are continuously developing at much higher rates then the adult brain and early adverse effects can have a lasting impact on their development (Cahill, Kaminer & Johnson, 1999). Children who are exposed to trauma at a young age are at a significantly greater risk for mental health problems and several other developmental milestones. Trauma has been defined as "an emotional response to a terrible event like an accident, rape or natural disaster. Immediately after the event, shock and denial are typical. Longer-term reactions include unpredictable emotions, flashbacks, strained relationships and even physical symptoms like headaches or nausea" (American Psychological Association, 2013).

Researchers have found that chronic stress prevents the normal development of a child's brain and can lead to lifelong problems with social, emotional and cognitive

development (Shonkoff & Phillips, 2000). The National Child Traumatic Stress Network examined the population of unaccompanied immigrant children, a population who may experience similar traumatic events as child who adopted or up for adoption, and found that the traumatic events that this population may experience are: "lack of consistent caregivers, homelessness and lack of other basic needs, gang and drug-related violence or threats, physical injuries, infection and diseases, forced labor, sexual assault, lack of medical care, loss of loved ones, war and torture" ((NCTSN, 2014, p.1). Children who are adopted, can be adopted at any age up to 18, and can come from any country in the world that has not suspended adoption; these facts show that there are infinite number of previous home situations that adopted children can come from. The research on trauma and traumatic events make it clear that children who were adopted can be subjected to any number of traumatic events at some point on the journey to their adopted family.

Schechter & Bertocci (1990) argued that the adoptees are traumatized through the deprivation of their opinions in any aspect of their lives. They do not have the opportunity determine their own fates, they rely entirely on strangers for their future and in most cases they are not given the opportunity to have a relationship with their birth families.

All of these traumatic events can have lasting effects on the social, emotional and cognitive development of the child. Kardiner (1941) argued five main features describing the human response to trauma. The five responses are: a persistence of startle response and irritability, proclivity to explosive outburst of aggression, fixation on the trauma, constriction of the general level of personality functioning, and, atypical dream life. According to NCTSN (2014), some of the general symptoms that can present

themselves are: "hyper-vigilance and suspiciousness, difficulty engaging with caregivers due to emotional detachment and cynicism, disruption of attachment, fear or anxiety, nightmares, sadness or grumpiness, trouble paying attention, trouble managing behavior or emotions," along with many others (p. 4).

Attachment

According to theory on attachment, the loss and trauma that an adopted child experiences may have a negative impact on the development of secure attachment relationships with adoptive parents (Bowlby, 1982). Bowlby (1982, p. 371) stated that "To say of a child that he is attached to, or has an attachment to someone means that he is strongly disposed to seek proximity to and contact with a specific figure and to do so in certain situations, notably when he is frightened, tired, or ill." Attachment is an emotional connection between a child and their caregiver (Ainsworth, 1982; Bowlby, 1982). Bowlby (1982) believed that attachment develops through four phases in the first two years of life. At the end of the child's first two years is when they reach a developmental stage in which they begin to be more comfortable exploring the world, providing that they have been given a sense of security and safety from their caregivers prior to the two year mark. The four phases that Bowlby stated were: the pre-attachment phase (birth to six weeks), the "attachment-in-the making" phase (six weeks to six to eight months), the "clear-cut attachment" phase (between six to eight months and eighteen to twenty-four months), and the reciprocal relationship phase (older than eighteen to twenty-four months) (Bowlby, 1982). This sequence creates the stability for a healthy relationship between the child and their caregiver. Although all children may go through this sequence innately, the varying individual differences in people and

environments can cause the resulting attachment to differ. Attachment theorist Mary Ainsworth categorized the different attachments based on her research on mother and infant pairs (Ainsworth, 1982). The subsequent four types of attachment are: secure attachment, avoidant attachment, resistant attachment and disorganized attachment. The goal for child-caregiver attachment is a secure attachment, which can be seen when a child is comfortable to play with other children and reacts positively to strangers when the caregiver is present. They get upset when the caregiver leaves and may be inconsolable by a stranger, but they recover quickly when the caregiver reappears. This secure attachment can only occur if the child feels a sense of security from the continuous care of a parent or caregiver. This research suggests that children can only develop a secure attachment with a caregiver who cared for them from the very beginning stage of life.

Researchers studied seventy internationally adopted infants and their mothers and found that while sixty one percent of their sample were securely attached, thirty-six were classified as having disorganized attachment (van Londen, Juffer & van Iizendoorn, 2007). This percentage was significantly higher than found in a meta-analysis on disorganized attachment; concluding that there is a connection between internationally adopted children and issues with attachment. Adopted children may present with less secure attachments because they experience separation and loss from their birth parents and other caregivers at sometimes very young ages (van den Dries, Juffer, van IJzendoorn & Bakermans-Kranenburg, 2009). Although, when researchers conducted a meta-analysis of attachment in adopted children, they found that children who were adopted before their first birthday were significantly more likely to develop secure

attachment relationships with their adoptive parents (van den Dries, Juffer, van IJzendoorn & Bakermans-Kranenburg, 2009). This may be a due to a number of the children living in institutions prior to their adoption. These children are not provided with the opportunity to form secure relationships with a single caregiver; and the longer they are institutionalized, the longer they are prevented from building secure relationships with a single caregiver.

Environments of high stress such as institutions and foster homes can influence brain development and attachment behaviors (Gunnar & Kertes, 2005; Rutter et al., 2004). In addition to stressful living situations, maltreatment, neglect/lack of stimulation and adverse experiences can also have an effect on healthy behavioral and emotional development, including attachment (Gunnar & Kertes, 2005; Kaniuk, Steele & Hodges, 2004).

Attachment related disorders are categorized into the trauma- and stressor-related disorders section of the DMS-V (APA, 2013). While Reactive Attachment Disorder was previously divided into two different subtypes, inhibited and disinhibited (APA, 2000); in the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM), RAD was divided into two disorders entirely; RAD and Disinhibited Social Engagement Disorder (DSED) (refer to Appendix A for diagnostic criteria). In DSM-V, RAD covers the diagnosis that was previously known as RAD-inhibited and DSED is what was previously known as RAD-disinhibited (see Appendix A for DSM-V diagnostic criteria for RAD and DSED). While the two disorders present themselves in opposite behavior, the triggers that can cause them are the same. RAD "is characterized by a pattern of markedly disturbed and developmentally inappropriate attachment behaviors,

in which a child rarely or minimally turns preferentially to an attachment figure for comfort, support, protection, and nurturance" (APA, 2013). The main feature of RAD is a non-existent or weak attachment between the child and their caregivers. DSED is illustrated by "culturally inappropriate, overly familiar behavior with relative strangers." As a result of the association that RAD and DSED have with social neglect, they are often associated with development delays, stereotypies and severe neglect. Symptoms of RAD and DSED have been found to appear in children who are internationally adopted (Boris et al., 2005; Chisholm, 1998; Smyke et al., 2012). Smyke et al. (2012) studied institutionalized children compared with those who had been institutionalized and then placed in a home and found that the two different attachment disorders have significantly different paths to recovery. RAD symptoms significantly reduced after institutionalized children were placed in positive home environments. In the study the minimizing of signs of the attachment disorder now known as DSED was not seen after placement of the child in a home.

Rationale

Child life specialists have become an integral part of most multidisciplinary pediatric healthcare teams since the inception of the profession in the 1920's (Thompson, 2009, p. 4). Child life specialists use various healing modalities to provide psychosocial care to patients and families such as: preparing them for procedures, engaging with them in therapeutic activities, distracting and supporting them during procedures or other stressful healthcare events, advocating for them when necessary, and continually assessing their needs throughout treatment (Child Life Council, 2002, p.1). Piaget (1962) concluded that young children have a hard time

recognizing abstract ideas because they think in concrete terms. Active involvement works best when attempted to teach young children. If someone was not aware of the characteristics of the stage of development that the child was in, they may not be conveying to the child in a way they can understand (Thompson, 2009, p. 162). Based on this research, it is imperative that specialists use developmental theories when working with children and families, especially in stressful or traumatic experiences. Using play and other therapeutic modalities such as art and music, child life specialists apply their background of child development to attend to the needs of each patient and family individually (please refer to Appendix B for the Child Life Council flyer). Along with development, child life specialists are also trained in theories of: attachment, trauma, culture, loss, play and other therapeutic art techniques, and children with special needs (Child Life Council, 2002; Cotton & Denhoed, 2003; Thompson, 2009). Using this background knowledge, a major goal of the child life profession is to take an experience that can be stress inducing or traumatic and provide opportunities to turn it into a positive coping experience that has growth-promoting outcomes (Child Life Council, 2006). The duties of the child life specialist can vary based on the setting in which the specialist is working, however the skills that they are using to provide their services are transferrable.

Child Life is a profession that provides support for children and families who are enduring extremely stressful situations. Although the field of Child Life used the hospital based healthcare system as its primary setting to grow and develop, as the profession has become more established and understood, there are child life specialists who have branched out to provide services in alternative settings (Hicks, 2008). The Child Life Council's competencies serve as a guideline and baseline for how child life

specialists should conduct themselves and their services (Child Life Council, 2002, p. 5). Although these competencies are not directly specified for the population of adopted children and their families, all of the child life competencies that directly address services can be successfully utilized with this population (Please refer to Appendix C for the Child Life Competencies). For example, the first competency is "the ability to assess and meaningfully interact with infants, children, youth and families" (Child Life Council, 2002, p. 5). The first step to meaningful interaction with a patient and family is building rapport. This cannot be achieved unless the CLS fosters a medium that is open and nonjudgmental for supportive communication with the patient and family. A major role of a child life specialist is to be a safe, approachable person for the patient and family. This cannot be done successfully unless the specialist assesses their needs and addresses them accordingly. For a family that is preparing to adopt a child or has just adopted a child, there are a lot of changes happening in their lives and having a comfortable, approachable person on their team can make all the difference with how they cope.

Proposal

Culture

Culture and development play a huge role in the healthcare of a child. It is part of the job of a child life specialist to address the needs and beliefs of each family individually, taking into account their background and culture. People from various cultures experience different fears and concerns, and practice different rituals and traditions. It is essential to honor the cultural beliefs of different families as much as possible to ensure that they are comfortable with their child's treatment.

> Although culture is typically thought in terms of a group's identity, it is important to note that each of us also develops an individual

> culture based on our background family, individual characteristics, and experiences. In this sense culture can be defined as "the necessarily unique worldview or set of understandings that each of us has no matter what outward similarities align us" (Davis, 2008 p. 22, as cited by Fox & Schirrmacher, 2011).

It is imperative to remember that every child is raised in a different environment and distinct measures must be taken for each child to feel comfortable and supported. Children who are adopted are in extremely unique and confusing situations, because the culture in which they were born into may not be the culture in which they are being raised. Children who spent the beginning portion of their lives living in one culture and then are transplanted into another have many more stressors to deal with than children who were adopted at a very young age (Suárez-Orozco, Suárez-Orozco & Suárez-Orozco, 2009). When considering the stressors involved in adoption, all variables of culture must be considered.

> "Language is not the only form of communication that immigrants must learn. Social interactions are culturally structured. A Middle Eastern immigrant will need to learn that in the United States, most people stand farther apart when speaking than in her native country. Argentines will need to learn that Americans will interpret their normal volume in discussion as near shouting. A Haitian child will sooner or later find that politely averting her eyes while her teacher is scolding her (as her parents taught her) will only anger her American teacher more. A Brazilian immigrant will need to learn the culture of 'appointments'—in her new country, a nine o'clock appointment does not mean arriving anytime between nine and eleven. All immigrants must learn the new rules of engagement (p.73)."

Fortunately for children in this situation, children learn social cues much quicker than adults do in a new environment, because they are required to be in social situations quicker than adults, such as school and extra-curricular activities (Banaji & Gelman, 2013). A child who does not speak the language of their new culture will learn social

cues as they learn the language, through immersion. New adoptive parents may not be aware that their children will learn cultural cues quickly and that they adjust easiest when being completely immersed.

During the adjustment period post-arrival it is likely that the child will experience some frustration. The child life specialist can provide therapeutic art interventions to allow the child to express their feelings. Artwork allows children to express themselves while working through any feelings they may be experiencing. Utilizing therapeutic artistic activities with children can help encourage them to appreciate diversity as they experience and appreciate the artwork of others (Johnson, 2002).

Development

It is the role of child life specialists to consider the development of a child based on their specific beliefs and cultural systems. As the Albert Einstein quote goes, " Everybody is a genius. But, if you judge a fish by its ability to climb a tree, it will spend its whole life believing that it is stupid" (Douglas, 2011). A child cannot be judged on a system that they are not accustomed to, so it is important for the child life specialists to meet children where they are. In order to do this successfully, the child life specialist must take the time to get to know the child, their previous culture, and how they have been adapting to their new family and environment. The information that the child life specialist receives about the family can then be relayed back to the multi-disciplinary health care team to help develop a plan of care that best suites the child and family.

Research has shown that although immediately after adoption, children who were adopted may lag behind their non-adopted peers developmentally, within two years after adoption, it is likely that the two groups will test in the same range on mental

development, receptive language, motor development (Cohen et al., 2008; Dalen & Theie, 2014). The child's ability to use expressive language is the one variable of development that has been shown to remain lesser than the non-adopted children. Children need a way to express themselves, and if there language is not sufficient in doing this for them it is imperative that the child life specialist work with the family to suggest other ways the child can do this. Art and music are great forms of expression for children who may not have the language that they need to successfully get their thoughts out.

Because there is no requirement for child development education prior to parenthood, it is likely that the family may not understand what to expect from their child developmentally. The child life specialist can help by educating the family on developmental cues and what they can do to ensure that their child is provided with the necessary tools to grow and develop. Child life can also work with social work and psychology to provide resources that may be helpful for the family in the development of their child.

Trauma

Early adverse experiences, including those that may be traumatic, can have lasting effects on social, emotional, and cognitive development (Cahill, Kaminer & Johnson, 1999; Shonkoff and Phillips, 2000). "Emotional self regulation is one early developmental task that is often compromised by early trauma" (Benckendorf, 2012, p. 5). Children who have dealt with trauma in their lives are likely to have problems controlling their emotions and responses to various stimuli. This reaction can be a result of trauma, however having no control over internal and external aspects of their lives,

may in turn cause even more trauma for them. "There are several categories of events that frequently act as triggers for children with histories of trauma. Understanding these triggers will make it easier to identify causes and predict behaviors and will often lead to a more constructive response" (Benckendorf, 2012, p. 8).

Adoptees often have little to no control in any aspects of their lives and this in of itself can be traumatizing (Schechter & Bertocci, 1990). These children are not given the opportunity to have an opinion in their futures or the path that their lives are going to take. A child life specialist would be able to help teach the family that their children need some sense of control and they need to be able to have choices in their lives. Educating parents on how to give their children appropriate choices and control that will not jeopardize the trust and respect that the parent has built with their child.

As can be expected, life transitions both large and small can be extremely difficult for children that have had an unstable past. "In their experience, 'minor' transitions have turned into major ones—such as being picked up at the end of a school day expecting to return home, but being moved to a new foster home. Children learn to generalize those experiences; any loss or transition could become permanent, and the child is not in control" (Benckendorf, 2012, p. 8). Even some small experiences can be triggers that are extremely threatening for children who are adopted. Because trauma triggers will be different for every child, it would be the role of the child life specialist to work with the family to better understand the triggers and how to prevent them from causing trauma reactions.

In terms of trauma, there are several interventions that can be used to address the needs of the child and family. In a clinic setting, the child life specialist can work with

the family to provide them with coping tools that can help the family while they are at home and during their daily life. Some of the coping strategies that the child life specialist can recommend for this population are: development of daily routines, having security items or people, providing clear expectations, and developing ongoing activities that can act as a constant in the life of the child.

Loss

Interpersonal relationships can also be threatened by transitions in the child's life, so adopted children often experience many losses in their lives, even beyond the scope of their biological family (Benckendorf, 2012). Knowledge of the losses involved with adoption including those that are physically, symbolic, and stigma fueled, makes the view of the losses pliable. "Our society is moving increasingly away demographically from the norm of the nuclear biological family to include non-traditional families…Due to these structural changes in the family and parenting, it may become increasingly possible to define kinship and parenthood more flexibly than by solely blood ties" (Leon, 2002). This lack of knowledge or awareness leads to even more losses for the adopted child, including symbolic losses, which can further complicate the grief process. Although society is heading in the right direction, there is no immediate fix for changing societal views. However, it is possible to educate people about what family is and how every family can be unique. If people are not aware of a child's story, they begin to imagine and create a story for them. This is something that a child life specialist can help the family with. A child life specialist can help by providing education for the child's social structures inside and outside of school. The specialist can also help the child and family with a script that they can use for those who ask about their family structure. Brodzinsky

(2011) outlined guidelines that can be helpful for speaking about adoption with children. These guidelines include:

> Discussing adoption with children is a process, not an event. Adoption revelation is a dialogue, not a process of talking to children. Early telling has advantages over late telling. Be emotionally available for the child and listen. Begin the adoption story with birth and family diversity, not adoption. Keep in mind the child's developmental level and readiness to process specific information. Validate and normalize children's curiosity, questions, and feelings about their adoptions, birthparents and heritage. Be aware of your own feelings and values related to birthparents and the children's history. Avoid negative judgments about birthparents or the child's heritage. Discussing "difficult" background information. Be prepared to help children cope with adoption-related loss and grief. Foster open, honest, and respectful parent-child communication about adoption (pp. 204-206).

These are extensive guidelines that can be used by child life specialists and families together to determine the best way to address the needs of the child and family. Giving the family advice surrounding their child's adoption education can help give them the control and confidence to allow for positive family interactions.

Attachment

As per the attachment theories arguing the development of attachment relationships (Ainsworth, 1982; Bowlby, 1982), children who were adopted often miss the opportunity to develop a secure attachment with their adoptive parents. Bowlby (1982) argued that attachment develops throughout the first two years of life. Some children who were adopted may not have even had consistent caregivers for their first two years of life. Although there is nothing that can be done to change the past and the beginning stages of the child's life, it is possible to provide suggestions that may help with the development of secure attachment relationship. The child life specialist can promote positive interactions for the parent and child through distraction techniques,

comfort positioning and planning and preparation for procedures (Turner, 2009). By allowing the parents to be the safe and comfort providing person for the child in a stressful situation in can help them build the trust that is necessary for a healthy attachment.

Family Centered Care

Beginning from pre-adoption appointments, when possible, the office will provide family-centered-care to help support positive coping strategies for the child and their families. The Institute for Patient and Family Centered Care (2010) stated:

> Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care. Patient- and family-centered practitioners recognize the vital role that families play in ensuring the health and well-being of infants, children, adolescents, and family members of all ages. They acknowledge that emotional, social, and developmental support, are integral components of health care. They promote the health and well-being of individuals and families and restore dignity and control to them. Patient- and family-centered care is an approach to health care that shapes policies, programs, facility design, and staff day-to-day interactions. It leads to better health outcomes and wiser allocation of resources, and greater patient and family satisfaction.

At the pre-adoption appointment, the child life specialist will have the opportunity to prepare the parents and children for the arrival of their new family addition. Using the same techniques as they would in preparing a child for a medical procedure, the child life specialist would use previous knowledge about the family, along with conversation goals to give the family the tools that they need to be ready for their new family member. The family may need assistance with explaining the process adoption to their existing children. Depending on the age, there are a number of books that can be provided to the

family, an example of one can be seen in Appendix F.

Part of the preparation may include advocating for the needs of the child, even prior to their arrival. Conversations such as these may include speaking with the family about the words and stories which they wish to tell their child (Brodzinsky, 2011; Largen, 2012). They should be equipped with the knowledge that their child is going to ask questions and they will need to be on the same page with each other in what they wish to answer. From the developmental perspective, the child may not need to know every detail of their past at once, however they should be told the truth in order to help their identity formation process and their trust building with their family (Brodzinsky, 2011).

At this time it is also imperative to prepare the family for what to expect when they meet the child and then return home with them. Harf et al. (2013) conducted a study on the first meetings between parents and their adopted children and found that there can be a wide variety of reactions from both the parents and children at the site of the first meeting. Children can become confused, violent, upset, comforted, or excited. All are normal reactions because all of the children have had different pasts and may not understand what is happening. It is also possible for the family to have different reactions regarding the state of the child. Depending on the information that was provided, some parents may become frustrated with the appearance of the child, or elated that they are united at last. The child life specialist can help by assuring the family that not every experience is the same, while at the same time providing the possible reactions will give them the tools that they will need to cope with the reactions that may arise.

The child life specialist can also provide activities for family integration. Because the child may not speak the same language as their adoptive family when they first arrive,

it may be beneficial to provide activities that do not require the use of words, such as string stories and picture books (Holbrook, 2002; Mattix & Crawford, 2011). However, it is important for the family to be made aware that regardless of any activities that they partake in, integration does not happen immediately; it is a process (do Amaral Costa & Rossetti-Ferreira, 2009). The family will need to adapt their lifestyle, just as they would if they had a new biological baby in the house. They should continue old traditions but also create new ones that involve their new child.

The family may also need support in the area of stigma surrounding their child. The family can address the issues as they come, however they wish to and however best suits them as a unique family unit. They should be prepared for the possibility of questions and discriminations against their child. There is no right way to answer these questions, and the family will have to work through it themselves, however, they can be supported along the way.

The family will have a long road ahead of them when they first adopt, and it is imperative that they be provided with developmentally appropriate coping tools that they can utilize as they need. Some examples may be art activities, journaling, music and physical engagements such as dance or sports. All of these suggestions must be tailored to the family, as each family is it's own system.

Goodman (1993) stated:

> It seems to me that each family forms its own chorus and sings its own song, taking the meter, rhythm, tone, lyrics and melody from cultural, religious, social and economic variables, while themes may come from family history or intrapsychic sources. Some choruses sing harmoniously, others are discordant. All aspire to make celestial music; none ever succeeds. It is the practicing/refinement that really maters most (p.11).

In order to interpret the music of each family, one must hear the distinct sound that they are creating. Honoring families by where they are and what they bring to the table is the most important aspect of working with them. The only way to attempt to understand a family is to let go of biases and judgments that may block the ears from music and support for them who they are as a unique system.

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Appendix A

DSM-V 313.89 (F94.1 and F94.2)

Disinhibited Social Engagement Disorder

Diagnostic Criteria — 313.89 (F94.2)

A. A pattern of behavior in which a child actively approaches and interacts with unfamiliar adults and exhibits at least two of the following:
   1. Reduced or absent reticence in approaching and interacting with unfamiliar adults.
   2. Overly familiar verbal or physical behavior (that is not consistent with culturally sanctioned and with age-appropriate social boundaries).
   3. Diminished or absent checking back with adult caregiver after venturing away, even in unfamiliar settings.
   4. Willingness to go off with an unfamiliar adult with minimal or no hesitation.

B. The behaviors in Criterion A are not limited to impulsivity (as in attention-deficit/hyperactivity disorder) but include socially disinhiblted behavior.

C. The child has experienced a pattern of extremes of insufficient care as evidenced by at least one of the following:
   1. Social neglect or deprivation in the form of persistent lack of having basic emotional needs for comfort, stimulation, and affection met by caregiving adults.
   2. Repeated changes of primary caregivers that limit opportunities to form stable attachments (e.g., frequent changes in foster care).
   3. Rearing in unusual settings that severely limit opportunities to form selective attachments (e.g., institutions with high child-to-caregiver ratios).

D. The care in Criterion C is presumed to be responsible for the disturbed behavior in Criterion A (e.g., the disturbances in Criterion A began following the pathogenic care in Criterion C).

E. The child has a developmental age of at least 9 months.

Specify if:

Persistent: The disorder has been present for more than 12 months.

Specify current severity:

Disinhibited social engagement disorder is specified as **severe** when the child exhibits all symptoms of the disorder, with each symptom manifesting at relatively high levels.

Reactive Attachment Disorder

Diagnostic Criteria — 313.89 (F94.1)

A. A consistent pattern of inhibited, emotionally withdrawn behavior toward adult caregivers, manifested by both of the following:

1. The child rarely or minimally seeks comfort when distressed.
2. The child rarely or minimally responds to comfort when distressed.

B. A persistent social and emotional disturbance characterized by at least two of the following:

1. Minimal social and emotional responsiveness to others.
2. Limited positive affect.
3. Episodes of unexplained irritability, sadness, or fearfulness that are evident even during nonthreatening interactions with adult caregivers.

C. The child has experienced a pattern of extremes of insufficient care as evidenced by at least one of the following:

1. Social neglect or deprivation in the form of persistent lack of having basic emotional needs for comfort, stimulation, and affection met by caregiving adults.
2. Repeated changes of primary caregivers that limit opportunities to form stable attachments (e.g., frequent changes in foster care).
3. Rearing in unusual settings that severely limit opportunities to form selective attachments (e.g., institutions with high child-to-caregiver ratios).

D. The care in Criterion C is presumed to be responsible for the disturbed behavior in Criterion A (e.g., the disturbances in Criterion A began following the lack of adequate care in Criterion C).

E. The criteria are not met for autism spectrum disorder.

F. The disturbance is evident before age 5 years.

G. The child has a developmental age of at least 9 months.

Specify if:

Persistent: The disorder has been present for more than 12 months.

Specify current severity:

Reactive attachment disorder is specified as **severe** when a child exhibits all symptoms of the disorder, with each symptom manifesting at relatively high levels.

(American Psychiatric Association, 2013)

Appendix B

Child Life:

Empowering Children and Families

Children today confront a wide variety of stressful and potentially traumatic events that can overwhelm their natural ability to cope and heal. Experiences related to health care and hospitalization can lead to feelings of fear, confusion, loss of control, and isolation that can inhibit their natural development and have negative effects on their physical and emotional health.

Child life specialists are trained professionals who help children cope with the stress and uncertainty of illness, injury, disability, and hospitalization.

WHAT IS A CHILD LIFE SPECIALIST?

Child life specialists are child development experts who work to ensure that life remains as normal as possible for children in health care settings and other challenging environments. They promote effective coping through play, self-expression activities, and age-appropriate medical preparation and education. As advocates of family-centered care, child life specialists work in partnership with doctors, nurses, social workers and others to meet the unique emotional, developmental and cultural needs of each child and family.

Child life specialists work in general pediatric inpatient units, and often in specialty areas like the emergency department, surgical and intensive care units, and outpatient areas. Increasingly, child life services are also being offered in other settings, such as community outreach programs, private medical and dental practices, and special needs camps.

SERVICES PROVIDED BY CHILD LIFE SPECIALISTS

Child life specialists focus on the psychosocial and developmental needs of children, collaborating with families and other health care providers to:

- Prepare children for medical procedures or treatment using language that children understand
- Introduce coping strategies to help reduce anxiety and enhance cooperation with the health care team
- Provide support and distraction during medical procedures
- Offer opportunities for play and expressive activities, to encourage normal development and a sense of FUN in spite of challenging circumstances
- Promote family-centered care by providing information, advocacy and support to families of pediatric patients

PHOTO CREDITS (CLOCKWISE FROM TOP LEFT): MINISTRY SAINT JOSEPH'S CHILDREN'S HOSPITAL, MARSHFIELD, WI; THE CHILDREN'S HOSPITAL AT MONTEFIORE, BRONX, NY; MINISTRY SAINT JOSEPH'S CHILDREN'S HOSPITAL, MARSHFIELD, WI

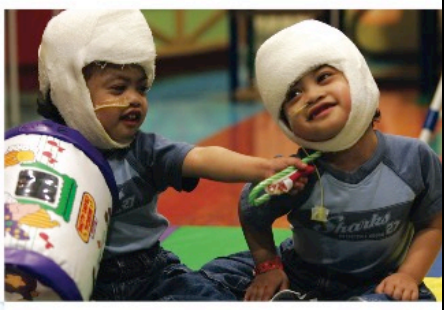
(Child Life Council, 2015, Empowering children and families)

PROFESSIONAL STANDARDS OF PRACTICE

Child life specialists have earned a bachelor's or master's degree with an educational emphasis on human growth and development or a related field of study. They adhere to a code of ethics and standards established by the Child Life Council, a professional organization which also administers the rigorous process for obtaining the Certified Child Life Specialist (CCLS) credential. All Certified Child Life Specialists must complete a supervised clinical internship, pass an examination, and adhere to standards for continuing professional development in order to maintain their certification.

RESEARCH HAS SHOWN THAT . . .

- Children who are prepared for medical procedures experience less fear and anxiety, and will have better long term adjustment to medical challenges.
- Children in the hospital who engage in therapeutic play with a trained professional exhibit less emotional distress, increased cooperation, and fewer negative physiological responses.
- Child life interventions can increase cooperation and help to reduce procedural and post-procedural pain.
- Providing support for family members enhances psychosocial outcomes for young patients. A parent or caregiver's behavior and anxiety levels are strongly correlated with how a child will respond to hospitalization.



NEED MORE INFORMATION?

If you are interested in obtaining child life services for your child and family, ask your physician or a health care administrator if child life services are available. For more information on the child life profession, please visit the Child Life Council website at www.childlife.org.

ABOUT THE CHILD LIFE COUNCIL

The Child Life Council is a non-profit organization that advances the well-being of children and families by promoting effective, quality child life services in health care environments. CLC organizes professional development opportunities for child life specialists, facilitates the exchange of knowledge and resources, and monitors the latest research and developments relevant to the child life profession. Through the administration of a professional credentialing program, CLC ensures a standard of quality and performance among those who have earned the Certified Child Life Specialist (CCLS) designation.

Child Life Council

Child Life Council, Inc.
11821 Parklawn Drive, Suite 310
Rockville, MD 20852-2539
1-800-252-4515 • www.childlife.org

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Appendix C

CHILD LIFE COMPETENCIES

Introduction

The following child life competencies are the minimal level of acceptable practice as defined by the Child Life Council, and are a guide for individuals or organizations who may wish to further define competencies specific to their situation. The order of competencies does not reflect a sequence or hierarchy of importance.

I. Care of Infants, Children, Youth and Families

A. Competency

The ability to assess and meaningfully interact with infants, children, youth and families.

Knowledge

- Articulate theories of human growth and development, play, and family systems.
- Describe formal and informal assessment techniques to determine developmental and emotional state.
- Describe the cyclical process of assessment, plan, intervention, and evaluation of child life services.
- Cite relevant classic and current research.
- Identify values related to sociocultural diversity.
- Articulate the tenets of patient- and family-centered care.
- Identify general issues in family dynamics.
- Identify diverse child rearing practices.
- Identify child and family's concept of illness.
- Identify child and family's concept of death and dying.

Skill

- Implement child life services using evidence-based practice.
- Use developmentally appropriate play as a primary tool in assessing and meeting psychosocial needs.
- Utilize therapeutic/creative modalities such as bibliotherapy to meet individual

*Unless modified, refers to infants, children and youth.

1

(Child Life Council, 2002, Child life competencies)

developmental and emotional needs.
- Match interactions and activities to developmental level, emotional state, and individual needs.
- Pace interactions in response to child's* and family's lead.
- Apply formal and informal assessment techniques to determine developmental level and emotional state.
- Apply the cyclical process of assessment, plan, intervention, and evaluation of child life care.
- Support the central role of the family, valuing strengths and needs in implementing child life services.
- Demonstrate respect for sociocultural diversity.

B. Competency

The ability to provide a safe, therapeutic and healing environment for infants, children, youth and families.

Knowledge

- Articulate the central role of play in child life services.
- Identify theories of play that best support child life practice
- Describe the essential elements of the therapeutic relationship.
- Identify effective communication skills to support a child and family.
- Identify and describe the developmental and psychosocial goals of each activity and interaction.
- Explain the impact of environmental design on human behavior.
- Identify emotional safety hazards and corresponding preventive and protective measures.
- Identify environmental safety hazards and corresponding preventive and protective measures.
- Identify knowledge of privacy and confidentiality policies.

Skill

- Design group process to meet individual needs.
- Establish and maintain therapeutic relationships.
- Create an environment where play is valued.
- Establish and maintain a therapeutic and healing environment.
- Plan and implement varied developmentally supportive activities.
- Utilize effective communication skills in the process of supporting children and families.
- Provide input about facility design to promote orientation, comfort, healing, security and normalization.

*Unless modified, refers to infants, children and youth.

- Follow infection control and safety policies and procedures.
- Demonstrate respect for and facilitate privacy and confidentiality.

C. Competency

The ability to assist infants, children, youth and families in coping with potentially stressful events.

Knowledge

- Identify factors that may impact vulnerability to stress.
- Describe coping behaviors specific to various age groups and populations.
- Describe immediate and long term coping styles and techniques, as well as their effect on adjustment and behavior.
- Articulate stress-coping theory.
- Articulate effective pain management techniques including non-pharmacological and psychological.
- Identify effective advocacy.

Skill

- Assess responses to stress; plan, implement and evaluate care accordingly.
- Facilitate opportunities for play to decrease distress and increase effective coping.
- Introduce and facilitate rehearsal of techniques to aid immediate and long term coping, with consideration for the unique needs of the individual and family, such as coping style, previous experience, developmental level, culture, spirituality, family situation and emotional state.
- Facilitate mastery of potentially stressful experiences.
- Utilize appropriate psychological pain management strategies.
- Empower and support patients and families to effectively self-advocate as well as advocate on behalf of those who cannot do so.

D. Competency

The ability to provide teaching, specific to the population served, including psychological preparation for potentially stressful experiences, with infants, children, youth and families.

Knowledge

- Identify basic terminology and processes, and expected course of care associated with the circumstances of the population served.
- Articulate learning styles and needs of individuals of different developmental levels,

*Unless modified, refers to infants, children and youth.

emotional states, and of diverse backgrounds and experiences.
- Identify literature and teaching techniques for use with individuals of diverse developmental levels and learning needs.
- Describe common fears, misconceptions and concerns of individuals in each developmental stage.
- Describe information processing theory and its implication for psychological preparation.
- Articulate fundamentals of psychological preparation found in child life literature.

Skill

- Assess knowledge level, misconceptions, previous experience, and unique sociocultural and learning needs.
- Determine realistic goals and objectives for learning in collaboration with family members and professionals, and identify an action plan to achieve these goals.
- Use accurate and developmentally appropriate teaching aids and techniques so that knowledge is increased and emotional needs are supported.
- Recognize verbal and non-verbal cues and adapt teaching accordingly.
- Use minimally threatening, developmentally supportive language.
- Describe sensory information, sequence, timing and duration of events.
- Facilitate planning, rehearsal and implementation of coping strategies.

E. Competency

The ability to continuously engage in self-reflective professional child life practice.

Knowledge

- Recognize and describe how personal challenges and learning needs in knowledge and practice skills may impact service delivery.
- Identify resources and opportunities for professional development.
- Articulate reasons for and impact of under-involvement and over-involvement of professionals with children and families
- Articulates the impact of one's own culture, values, beliefs, and behaviors on interactions with diverse populations.

Skill

- Include evidence-based practice in decisions about assessment, care and evaluation.
- Implement a plan for professional development based on the needs of the population served and the knowledge and skill level of the child life specialist.
- Seek advanced practice mentors and peer supervision.

*Unless modified, refers to infants, children and youth.

F. Competency

The ability to function as a member of the services team.

Knowledge

- Describe services and resources of other professionals and identify their roles and functions.
- Identify the unique contribution of the family and professionals in the provision of care.
- Articulate the organizational structure and function of the interdisciplinary team.
- Describe the impact of communication styles on groups and individuals.
- Identify the importance of advocacy in collaboration with the medical team.

Skill

- Communicate concisely with other professionals, integrating theory and evidence-based practice to obtain and share pertinent information.
- Demonstrate respect for the viewpoints of other professionals.
- Coordinate child life services with families and professionals.
- Integrate interdisciplinary goals into child life services.
- Create concise, objective and accurate clinical notes, documenting information pertinent to the plan of care.
- Recommend consults or referrals when circumstances are beyond the scope of child life practice.

II. Education and Supervision

A. Competency

The ability to represent and communicate child life practice and psychosocial issues of infants, children, youth and families to others.

Knowledge

- Describe and integrate the basic concepts of public speaking and teaching methods appropriate to subject matter and audience.
- Identify classic and current literature on issues related to child life services in a manner meaningful to the audience.
- Articulate the process for engaging in evidence-based practice.
- Identify and articulate a definition of advocacy.

*Unless modified, refers to infants, children and youth.

Skill

- Adapt approaches, media and content according to audience need.
- Apply child life knowledge to contribute to the education of others.
- Maintain professional presentation of self, including careful attention to verbal and written communication, as well as personal appearance.
- Demonstrate effective advocacy for child life practice and psychosocial issues.

B. Competency

The ability to supervise child life students and volunteers.

Knowledge

- Discuss supervisory styles and their impact on others.
- Identify skills and knowledge necessary for others to complete assignments and tasks.
- Articulate student and volunteer program goals and expectations in the context of providing child life services.
- Identify adult learning needs.

Skill

- Provide comprehensive orientation to the setting, and policies and procedures of the work environment.
- Communicate expectations and roles clearly and concisely.
- Structure duties and assignments, matching ability to complexity of task.
- Provide regular feedback in a constructive manner.
- Assess and respond to diverse learning needs of students and volunteers.
- Recommend dismissal, after counseling, when performance does not match expectations.
- Evaluate student and volunteer programs and modify as needed.
- Provide a safe learning environment.

III. **Administration**

A. Competency

The ability to develop and evaluate child life services.

Knowledge

- Articulate basic research methods and statistics that apply to program review.

*Unless modified, refers to infants, children and youth.

- Identify program components that require assessment.
- Identify meaningful data for effective evaluation of child life services.
- Describe resources to assist in evaluation and development of services.

Skill

- Collect and report accurate and pertinent data in a timely manner.
- Recommend program improvements based on data and existing resources.
- Develop and prioritize the range of child life services.

B. Competency

The ability to implement child life services within the structure and culture of the work environment.

Knowledge

- Identify organizational structure and relevant policies and procedures.
- Articulate the mission and goals of the work environment.
- Identify methods for obtaining and managing needed resources.
- Identify information necessary for effectively managing resources.

Skill

- Prioritize and organize workload for accurate and timely outcomes.
- Procure and maintain equipment and supplies in a cost-effective manner.
- Adhere to relevant policies and procedures.
- Advocate for positive change.

_____

*Unless modified, refers to infants, children and youth.

November 1987
Revised and Approved November 2001
Revised and Approved November 2010

*Unless modified, refers to infants, children and youth.

Appendix D

CME GROUP
COMMUNITY
FOUNDATION

CME GROUP COMMUNITY FOUNDATION GRANT PROGRAM

APPLICATION FORM

I. INTRODUCTION

The CME Group Community Foundation is pleased to provide funding opportunities for non-profit organizations through our grant program. The CME Group Community Foundation is specifically interested in organizations and projects that support children in need, education and health and human services within the global communities where we live and do business. To be considered for a grant, applicants must use this format, follow the guidelines and include all requested materials.

Please email the completed application and requested information to nancy.choi@cmegroup.com

Requests will be evaluated on the basis of programs and services offered, populations served, experience of the organization, visibility opportunities, measurable impact, quality of management and management practices, other corporate support, and financial status. Proposals will be accepted and reviewed according to the deadline schedule below. Any proposals received after these dates will be considered for funding during the following cycle. Grant decisions are made by the Foundation's Board of Directors.

1st cycle deadline: February 15; Decisions made by May 1

2nd cycle deadline: July 15; Decisions made by October 1

II. ELIGIBILITY

- All organizations requesting support must be tax-exempt under Section 501 (c)(3) of the Internal Revenue Code.
- Organizations must demonstrate that they do not restrict services or discriminate in any form on the basis of race, religion, ethnic origin or sexual orientation.
- The organization's activities must relate to one or more of the following areas: children in need, education, and health and human services.

III. EXCLUDED ORGANIZATIONS AND PURPOSES

The CME Group Community Foundation generally does not fund the following:

- Organizations without tax-exempt status
- Exclusionary organizations
- Private foundations
- Operating or capital expenses
- Individuals
- Political candidates and lobbying organizations
- Religious, fraternal, social or other membership organizations providing services to their own constituencies
- Memorials, endowments or multi-year pledges
- Fundraising efforts to benefit other organizations
- Fundraising activities related to individual sponsorships (e.g., walk-athons, marathons)
- Special events such as conferences, symposia and sports tournaments
- Athletic teams
- Video/film production

IV. GRANT APPLICATION

A. General Information

Name of Organization: Global Children's Associates

Tax I.D. #: XXXXXXX

Street Address: 21 Play Way

City: Mineola State: New York Zip: 11501

Contact Person: Rachel Werner Title: Child Life Specialist

Telephone and Direct Extension: XXXXXXXX

E-mail Address: XXXXXXX

Web Site Address: XXXXXXX

Amount of Request: $56,807

Name of Program or Project being funded: Child Life Program

Geographic Area(s) Served: Primarily Suffolk County, Nassau County, Queens County and Kings County

Target Populations and number served: The patients and their families who utilize our clinic as their medical home

B. Organization Background

Mission statement and brief history of the organization:

Global Children's Associates was founded in 2012 as a pediatric clinic that solely serves adopted children and their families. The child must be under the age of 21 and adopted to qualify for services. Our center serves as the medical home of the child. The whole child is treated and can come to the clinic for any physical, emotional, social and developmental health concerns, as well as routine medical exams. Our office provides post adoption exams, annual exams, developmental evaluations and common pediatric health concerns. We provide referrals to other specialists as needed.

We partner with community adoption agencies to encourage families to connect with our resources prior to adoption, in order to best serve the child and family when the child first arrives. At present time, we work with 200 families and our numbers are growing rapidly. As our program expands, we see the need for more integrative services at our clinic.

C. Visibility

Please include a discussion of how the organization will acknowledge the CME Group Community Foundation's support and visibility opportunities.

Global Children's Associates will proudly advertise the partnership with CME on all brochures, flyers, and pamphlets that the office distributes to the community. All literature written by Global Children's will be sent to three partner adoption agencies, reaching families all over the tri-state area. Patients and families of the clinic will receive a monthly newsletter from the psychosocial team, and CME will be greatly thanked for their support in each and every issue.

V. GRANT NARRATIVE

The following information should be included as an attachment and limited to no more than three pages:

- intended use of funding
- time schedule for implementation
- description of intended results
- highlights of program / project from this past year
- new goals of program / project for next year
- evaluation and measurement criteria

CME Group Community Foundation Grant Program Narrative and Budget

In order to provide the quality of care that we strive to attain, we require that we have staff who are trained specifically in every area of child health and development including, but not limited to: primary care, adolescent medicine, psychology, speech and language, nutrition, dentistry, and psychosocial development. The developmental impact of adoption has been widely researched in psychology and social work literature (Cohen et al., 2008). In order to provide comprehensive care, we need a certified child life specialist on staff. This grant will fund the position (an annual salary and benefits for the child life specialist that is hired) and the requirements of the position, and in turn help ensure that our clinic provides the family-centered care that our families deserve.

Prior to this year, Global Children's has offered a wide range of services including but not limited to: Social Work, Psychiatry, Dentistry, Primary Care, Infectious Disease, Genetics, and Phlebotomy. This past year we extended from the realm of medical services to also include psychosocial services. Although this is an extensive list of professionals who care for a very specific population, we feel that we are missing services that will help the children cope with this very overwhelming time in their lives. Although we have expanded our services to have a psychosocial team; the team is not complete without a certified child life specialist.

The Child Life Council's competencies serve as a guideline and baseline for how child life specialists should conduct themselves and their services (Child Life Council, 2002, p. 5). Although these competencies are not directly specified for the population of adopted children and their families, all of the child life competencies that directly address services can be successfully utilized with this population. For example,

one of the competencies is "the ability to provide teaching, specific to the population served, including psychological preparation for potentially stressful experiences, with infants, children, youth and families." This is especially important for families in the population that we serve because there are many stressful changes going on in their lives in the time period of the adoption. As members of the healthcare team, child life specialists can combine their knowledge of child development with awareness of every family's unique situation to best educate every child and family that they work with. By taking on this role, the child life specialist can become a safe, approachable person for the patient and family.

Child life specialists use various healing modalities to provide psychosocial care to patients and families such as: preparing them for procedures, engaging with them in therapeutic activities, distracting and supporting them during procedures or other stressful healthcare events, advocating for them when necessary, and continually assessing their needs throughout treatment (Child Life Council, 2002, p.1). Piaget (1962) concluded that young children have a hard time recognizing abstract ideas because they think in concrete terms. Active involvement works best when attempted to teach young children. If someone was not aware of the characteristics of the stage of development that the child was in, they may not be conveying information to the child in a way they can understand (Thompson, 2009, p. 162). Based on this research, it is imperative that specialists use developmental theories when working with children and families, especially in stressful or traumatic experiences. Using play and other therapeutic modalities such as art and music, child life specialists apply their background of child development to attend to the needs of each patient and family individually. Along with development, child life

specialists are also trained in theories of: attachment, trauma, culture, loss, play and other therapeutic art techniques, and working with children with special needs (Child Life Council, 2002; Cotton & Denhoed, 2003; Thompson, 2009).

The clinic will begin accepting applications and conducting interviews as soon as the budget for the position is approved. The office hopes to offer the position to a certified child life specialist (CCLS) within two months of the start of their search. Once someone is hired and takes all of the necessary steps towards a start date (clinic orientation, human resources paperwork, etc.), they will be given an official date to begin an orientation period. For the first two pay periods (one month in total) they will be given the opportunity to utilize the time to get to know the office, meet all of the doctors, and attend meetings with psychosocial staff to help determine the parameters of their role and place on their interdisciplinary team. The CCLS will also take this time to purchase any materials that they need with the approved budget.

The CCLS and their provided services will be evaluated in two different ways. Every month on the first of the month, the patients (if old enough) and families will be asked to fill out a reflection form of how they feel about the role of the CCLS in their child's care. The first ten families whom the CCLS works with from pre-adoption appointments, will be specifically followed throughout the year to provide a more longitudinal evaluation. The two different forms of evaluations will show the range of services that the CCLS is providing, acute services such as distraction for procedures and check-ups compared with more long term services such as family support. After the year of the grant is finished, the evaluations will be used to argue for the clinic to continue the CCLS position.

Budget Breakdown

Personnel	
Certified Child Life Specialist (Full Time)	$39,046
Benefits (20% of salary)	$9,761
Expendable Supplies	
Craft and Art Supplies	$1,000
Distraction Items	$200
Toys	$1,000
Office Related Supplies	
Computer and Software	$600
Printer/Copy Machine	$300
Miscellaneous Desk Supplies	$400
Personal Development	
Conference Fees (2 per year)	$500
Travel Expenses	$2,000
Other	$200
Total Budget	$56,807

Appendix E

Interview with Dr. Lee, Director of Adoption Clinic at Winthrop Pediatric Specialty Clinic

How did you become interested in working with this population?
There was an infectious disease doctor who started the adoption clinic here at Winthrop named Dr. Jane Aronson. In the 80's-90's there was a doctor in the clinic had adopted a child and had questions about diseases that the child could have. She started seeing patients who were adopted and began the adoption clinic at Winthrop. In that time, I worked with her here in the clinic. In 2000, Dr. Aronson left to work as an adoption specialist outside of the clinic. I continued the adoption clinic and now I am the only doctor who sees patients in this population.

How do patients get referred to you or find you?
Primarily by word of mouth. Agencies refer their clients out to me. However I work with referrals from all over. I have spoken to people from all over the country. The way that it works is (depending on the country of adoption) the family gets a medical record of the child and they have a certain amount of time to accept or reject the offer from the agency. Although the medical records can tell you a lot, I always air on the side of caution and am more pessimistic than optimistic because they don't tell you everything.

Do you work with any of the agencies in the area?
I don't have any formal arrangements with any agencies, but they do give out my information if they are asked.

What are some of the most common concerns with children in this population?
Developmental and Behavioral. But physically the most common things that I look for are hepatitis B, tuberculosis, parasitic infections, hepatitis B, syphilis, and HIV.

How long do these appointments typically last?
Phone calls for pre-adoption referrals are usually about an hour. In clinic adoption post-appointments are between and hour and a half and two hours.

What is the role of the child life specialist in these appointments?
To help with the stressful time and experience. Since the Hague agreement that the UN made to adhere to ethics and codes regarding international adoption, there are certain medical tests that are required when the child enters a country for adoption. A lot of tests are run in these appointments to adhere to the agreement made and it can be traumatizing for the child. The cls can help make the experience easier. There is a language barrier

for the children and physicians are not good at non-verbal communications. They help with distraction, are a calming energy, and help get parents at ease. Parents don't always know their role or know what to do, the cls relates to the child and feels for parent's situations. I consider adopted children a special needs population and cls specialize in that.

Do you work with domestic and international adoptions?
Yes, we work with both. Most domestic adopters don't think they need an adoption center and a medical appointment. But they get medical reports on the child and then freak out. A problem with domestic adoptions is that they know too much about the parents and there is always a concern that the biological parents will come looking for their children.

(Dr. P. Lee, personal communication, April 2, 2014)

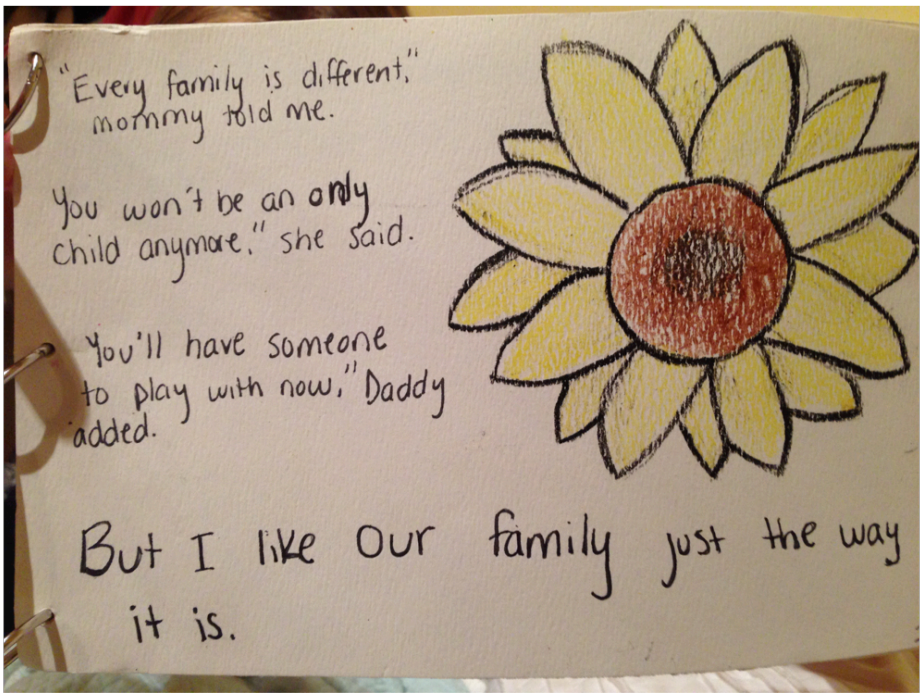
Appendix F

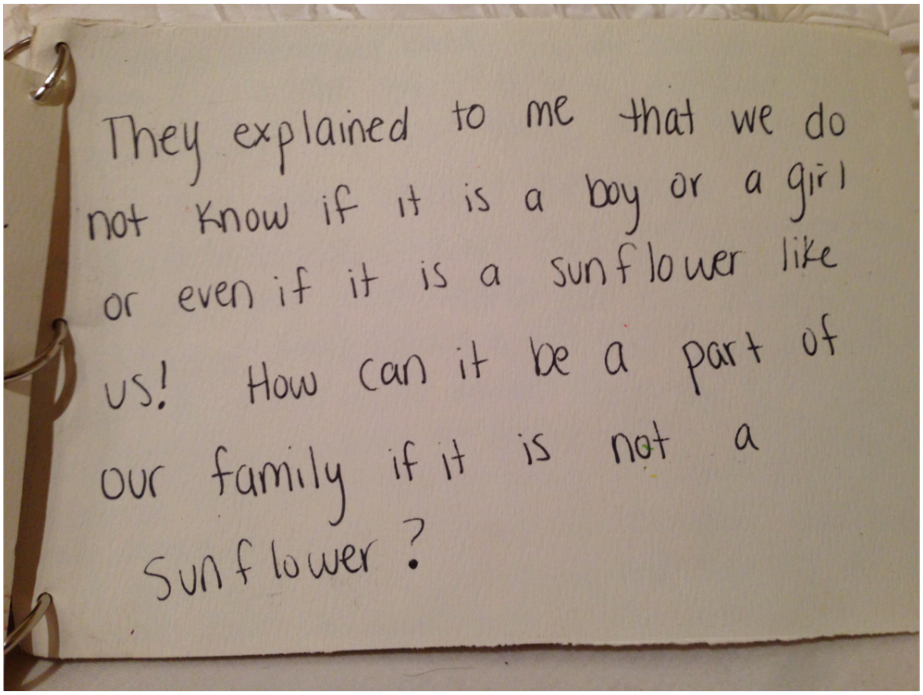
Dear Parents,

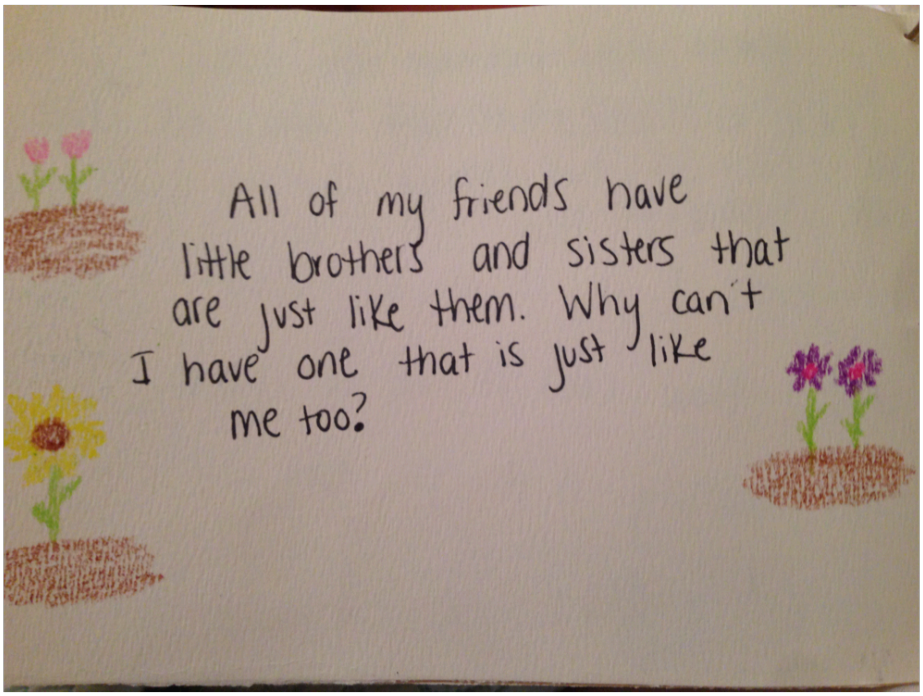
"A Multicolored Garden: A Story of Adoption," is a story about a sunflower who is gaining a new sibling that does not have the same biological parents as it. Throughout the book the sunflower asks questions that children who are gaining a sibling through adoption may ask. Through the thought process of the sunflower, the book addresses feelings that are common for children in this situation. This book is intended to address a child with the developmental age of a 4/5 year old. Some of the core developmental factors that are covered in this book are: social acceptance, need for attention, fear of change, egocentrism, awareness of similarities of differences and development of identity. I chose to write this book in the form of a metaphor to allow the children reading or being read to, the opportunity to make their own connections to the text. This would allow the child to empathize with the characters in the story while answering questions the children may have themselves. I chose the metaphor of a garden because it is not gender specific and children with many different interests can relate to it. This book is intended to help you and your child process the changes in your lives together and allow for an opportunity to open communication between the two of you. Congratulations on the upcoming addition to your family!

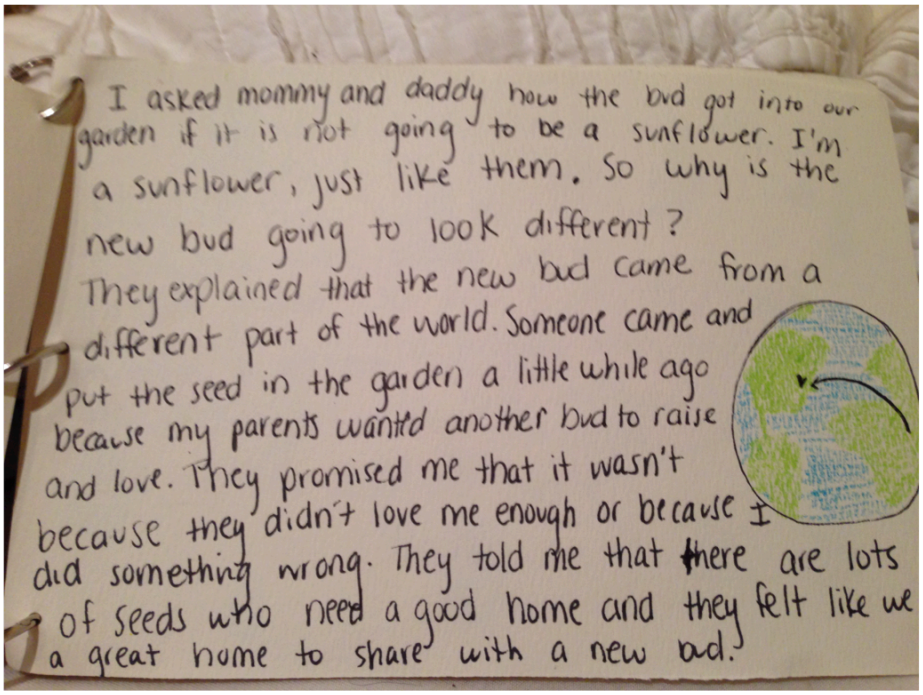
All my best,

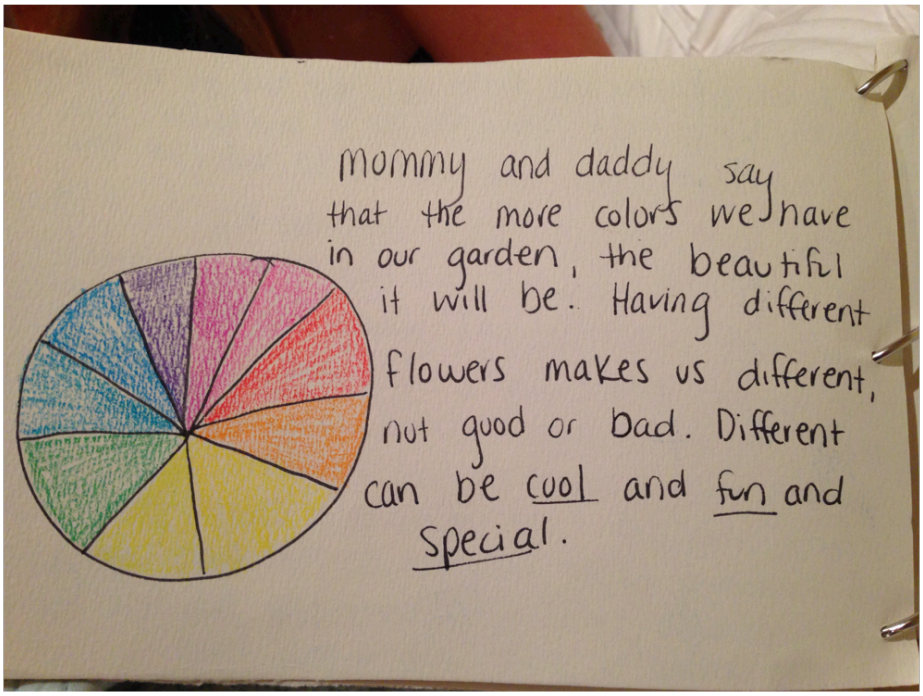
Rachel Werner

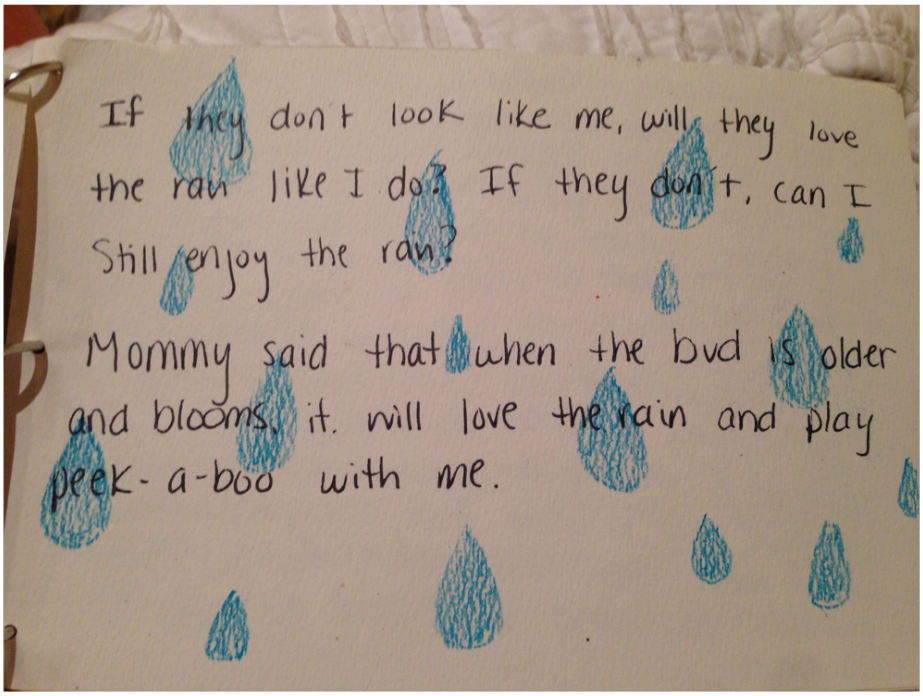


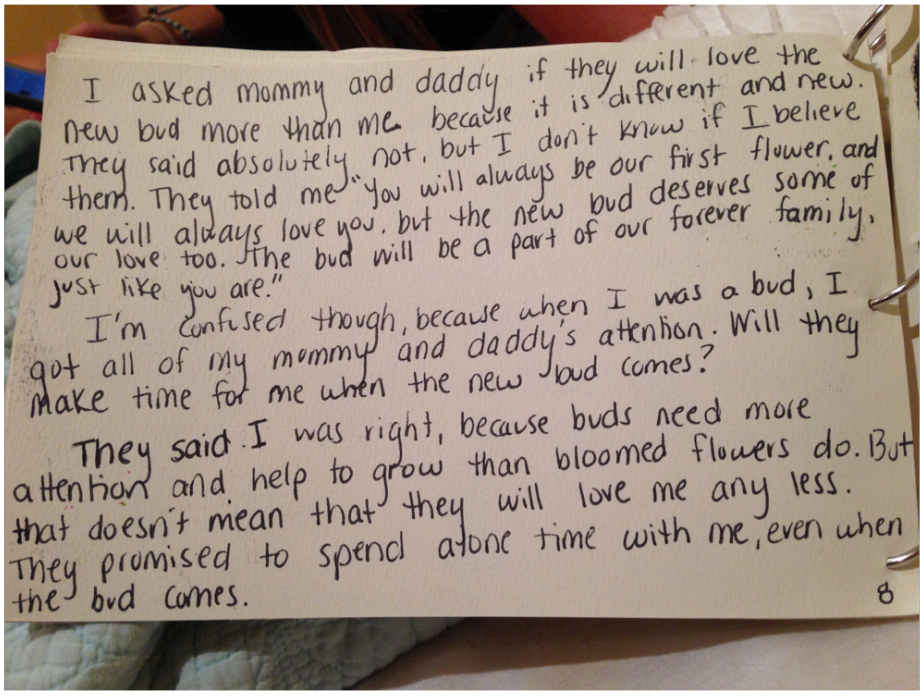










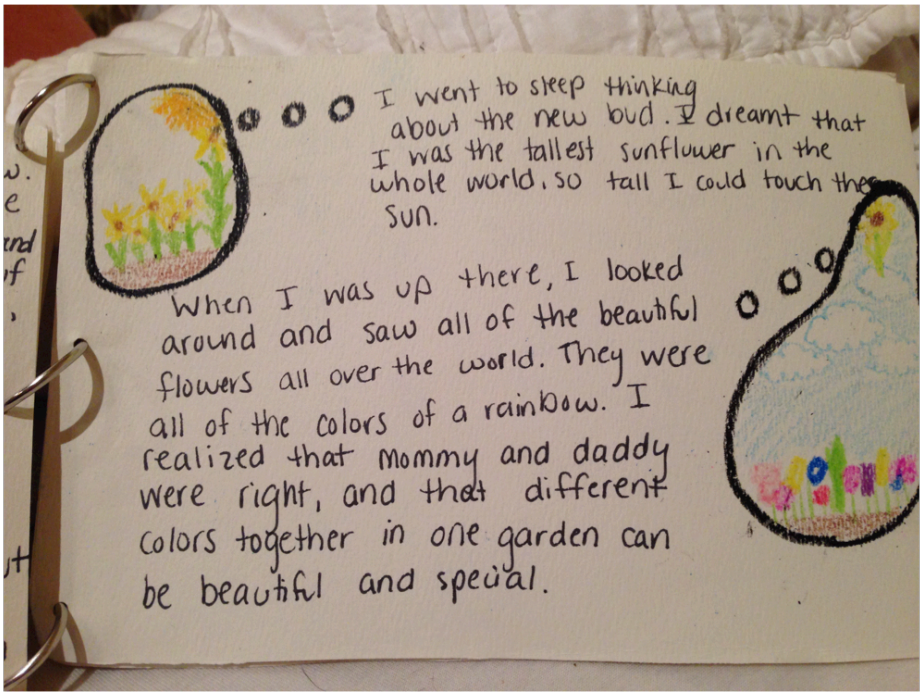


I asked mommy and daddy if they will love the new bud more than me because it is different and new. They said absolutely not, but I don't know if I believe them. They told me "you will always be our first flower, and we will always love you, but the new bud deserves some of our love too. The bud will be a part of our forever family, just like you are."

I'm confused though, because when I was a bud, I got all of my mommy and daddy's attention. Will they make time for me when the new bud comes?

They said I was right, because buds need more attention and help to grow than bloomed flowers do. But that doesn't mean that they will love me any less. They promised to spend alone time with me, even when the bud comes.

8



I went to sleep thinking about the new bud. I dreamt that I was the tallest sunflower in the whole world, so tall I could touch the sun.

When I was up there, I looked around and saw all of the beautiful flowers all over the world. They were all of the colors of a rainbow. I realized that mommy and daddy were right, and that different colors together in one garden can be beautiful and special.