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Exploring Special Needs Adoptions and the Applicability of Life Care Plans

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Abstract

At the end of 2015, there were approximately 111,820 children in the United States foster care system awaiting adoption, and 81.3% of this population were classified as having special needs. Despite the increase in the rate of special needs adoptions, the number of children awaiting placement has remained relatively stable. Research has shown that the length and number of foster placements greatly impacts a child's emotional well-being. As such it is important for these children to find permanent placement that will provide them with stability. Therefore, the purpose of this study is to explore the issues present with special needs adoptions as well as the potential of life care planning to address them. Due to limited research on the topic, qualitative methods were used to investigate this phenomenon. Specifically, qualitative interviews were conducted with parents who had adopted children with special needs. Parents were also shown an example of a life care plan and questioned regarding their perceptions on its applicability to the adoption process. When examining the qualitative interviews, a number of themes were revealed including decision making characteristics, emotions regarding the adoption process and challenges in adopting and raising a child with special needs. Furthermore, parents felt that a life care plan is a useful tool to address some of the issues identified in this study. Future research on the application of life care plans was discussed as well as the impact of the findings on clinical practice.

Introduction

According to the United States foster care system, a child with special needs is defined as any child diagnosed with emotional, mental, or physical disabilities (Child Welfare Agency Gateway, 2012). Children with special needs currently comprise 81.3% of the 111,820 children in foster care awaiting adoption (U.S. Department of Health and Human Services, 2015). In 2014, 69,350 adoptions were finalized, of which of 88.5% were classified as special needs adoptions. This represented a 42.4% increase in the number of special needs adoptions between 2007 and 2014 (Jones & Placek, 2017). Despite this increase in the number of adoptions the rate of children within the foster care system remained relatively unchanged with 111,820 children awaiting adoption at the end of 2015 (U.S. Department of Health and Human Services, 2016). This is compared to 118,867 children who were awaiting adoption at the end of 2007 (U.S. Department of Health and Human Services, 2009). Therefore, there is need to continue focusing on tools that will assist in recruiting parents for children awaiting adoption.

The basic concept of adoption has been around for more than 4,000 years, with the first records appearing in Babylonian Code of Hammurabi in 2285 B.C. (Adamec & Miller, 2007). Of course, adoption has evolved since that time and currently is sanctioned as a legal process carried out within the United States court systems (Moe, 2007). Adoption is the legal process of terminating the birth parents rights' and obligations and bestowing these rights onto the adoptive parents (Zamostny, O'Brien, Baden, & Wiley, 2003). The adoption process is managed through a variety of public and private agencies responsible for matching the child with an adoptive family and helping the family complete the adoption process (Office of Program Policy Analysis & Governmental Accountability, 2008). Both public and private adoption facilities utilize adoption case managers to recruit and assist parents through the legal process of adoption. Adoption is a complex process and the adoption case managers must understand all aspects that potential parents must complete.

Identifying specific barriers that make it more difficult to place children with special needs has become a focus of research. Specifically, Florida's Office of Program Policy Analysis & Governmental Accountability (OPPAGA) published a review of the state's child welfare system. This report revealed that Florida consistently lagged behind national standards in the total number of successful adoptions. The report discussed some of the major barriers contributing to the lack of adoptions. The number one barrier identified by adoption agencies was locating families who are willing to adopt children with special needs. The agencies reported that a number of the children in their care had either medical or behavioral issues that deterred potential parents from considering adoption. Another issue preventing adoption was that potential adoptive parents felt they were unable to obtain adequate information regarding the child's needs to feel comfortable with becoming responsible for the child's care (Office of Program Policy Analysis & Governmental Accountability, 2008).

Another issue to consider when examining adoption is the dissolution rate. Dissolution of adoption occurs when the adoptive parents decide that the adoption is not going to work and the child is returned to foster care (Moe, 2007). Adoption agencies keep records of the number of failed adoptions revealing that up to 20% of special needs adoptions result in dissolution, compared to a 3% dissolution rate for all other adoptions (Smith & Howard, 1999). As a result of high

adoption dissolution, research was focused on the factors that contribute to a parent deciding to disrupt the adoption. One of the prominent reasons documented by more than ten research studies is the number and severity of the child's needs at the time of adoptive placement (Adamec & Miller, 2007). Parents often report that the child having emotional, cognitive, or physical problems was too difficult to handle (Mallon & Hess, 2005). Another major reason for dissolution expressed by adoptive parents is the lack of information regarding the extent of the child's care prior to adoption. The parents felt that they were not prepared for what was expected of them, resulting in the decision to dissolve the adoption (Mallon & Hess, 2005). Other studies have identified the two barriers to successful adoption most often mentioned by adoptive families were lack of information about where to go for services and the cost of services (Festinger, 2002; Soderlund, Epstein, Quinn, Cumblad, & Petersen, 1995).

One potential method of addressing the barriers within the state adoption system, including limitation in training and case manager's knowledge base, is through the use of life care plans (LCPs). Life care plans are dynamic documents that organize a concise plan for the current and future needs of individuals with disabilities (Berens & Weed, 2010). Plans are created for both children as well as adults and examine the disability through life expectancy. Each life care plan is based upon published standards of practice, comprehensive assessments, data analysis, and research (IARP, 2015). Specifically, the life care planner makes recommendations about the medical, psychological, social, and environmental needs based upon the person's functional abilities as well as published standards of care (Weed, 2004). The plan explains the frequency, duration, rationale, and cost of the necessary recommendation. Organization of the plan can vary among life care planners, but they generally cover 16 basic areas: projected evaluations, projected therapeutic modalities, diagnostic test/education, wheelchair needs, wheelchair accessories, orthotics/prosthetics, home furnishings and accessories, aids for independent functioning, medication, supply needs, home care/facility care, projected routine medical care, aggressive medical care, transportation needs, architectural renovations, and leisure or recreational equipment (Deutsch & Sawyer, 2002). The life care planner uses a consistent methodology when establishing recommendations to assure valid and reliable plans that will meet the individual's needs.

Life care plans are currently used in personal injury and other types of litigation cases in order to educate their audiences (Weed, 2004). Education regarding accurate disability related needs is one of the primary goals of LCPs. For this reason LCPs can be an organized and concise method for adoption case managers to communicate the disability related needs when attempting to place a child with special needs.

Rationale

Very little research is available that examines the parents' perspective when adopting and raising a child with special needs (Adamec & Miller, 2007). The primary goal of the current study is to explore the potential of life care planning in the adoption system. The purpose of using life care plans is to provide parents with a disability-related tool to assist in understanding the child's needs. Parents have firsthand experience regarding the challenges associated with adopting children with a disability and as such will provide essential insight into the current problem and potential usefulness of life care planning.

Methods

This research question is exploratory in nature, due to the lack of research available on parents' experiences adopting and raising children with special needs. Therefore, the principal investigator chose to employ qualitative methods guided by grounded theory (Glaser, Strauss & Strauss, 1967). Grounded theory researchers seek to discover and ground the phenomena in theory that is based on reality, believing that theory emerges from the data collected (Corbin, Corbin & Strauss, 1990). This is particularly useful when researching a phenomenon that has little to no prior theoretical background to support the research questions (Given, 2008).

Inquiry Paradigm

The constructivist paradigm of inquiry assumes that individuals "construct" knowledge from their social interactions and experiences. People who ascribe to this paradigm believe that research is aimed at understanding the phenomena by constructing meaning from the subjective realities of informants (Denzin & Lincoln, 2000). The constructivist paradigm corroborates the grounded theory emerging from the data, since both are grounded in the assumption that understanding phenomena is achieved through perceptions of others. One method of constructing grounded theory is through constant comparative analysis. Constant comparative analysis involves the development of the conceptual model by comparing data in order to identify similarities or differences (Given, 2008; Glaser, Strauss & Strauss, 1967). This method will be discussed further in the data analysis sections later.

Sampling Technique

This investigator employed semi-structured qualitative interviews in order to fully understand the current problems with special needs adoptions. In accordance with the constructivist paradigm, the researcher chose to use criterion-based purposeful sampling techniques (Patton, 2002). Purposeful sampling involved the strategic selection of individuals who would provide information rich data on the phenomena of special needs (Patton, 2002). Since there is little knowledge about the potential applicability of life care

plans in the adoption process, purposeful sampling provided the best strategy to gather the necessary exploratory information (Patton, 2002). The criterion used to recruit participants was adoption of a child classified as having special needs at the time of adoption, and adoption occurring at least five years prior to the interview. The researcher developed a flyer that was distributed at mental health and social services agencies located in rural community in North Central Florida. The flyer solicited parents who had adopted a child with special needs who were interested in participating in a qualitative interview. Interested parents contacted the researcher who screened them to determine their eligibility for participation in the study.

Participants

For qualitative studies, sample size is determined by factors including: the purpose of the study, the goal of researcher, the depth of data sought, and feasibility given available time and resources (Patton, 1990). The primary goal of qualitative research is to gain an in-depth and highly contextualized understanding of the phenomena being studied. Therefore, qualitative studies, like this one, are well-suited to a small sample size (Given, 2008). Based on small sample sizes, qualitative studies commonly depend upon theoretical saturation or redundancy of data to determine the appropriate sample size (Patton, 1990). Saturation is achieved when the interviews no longer generate new information (Given, 2008). Specifically for this study, theoretical saturation was achieved at nine participants.

The researcher recruited a total of nine participants who adopted children with special needs. Based on the criterion established prior to recruitment, all participants had adopted a child classified as having special needs at least five years prior to the interview. Also considered in recruitment efforts was the type of special needs with which participants' children were diagnosed. This consideration yielded three participants in each of the following categories: physical disability, emotional disability, and a combination of both.

Nine interviews were conducted with parents who have adopted children with special needs. Specific demographic information is described in Table 1. Eight of the participants were female and one was male with ages ranging from 45 to 65. All of the participants were Caucasian and lived in small, rural communities in North Central Florida. The number of years since adoption ranged from five to twenty-eight years, and the special needs of the adopted child included: physical (3 participants), mental/emotional (3 participants), and a combination of both (3 participants). Prior to making the decision to adopt, seven of the nine parents interviewed had biological children who did not have disabilities. Seven participants had experience either in the medical or social services field, while one participant had contact with her children who worked in the medical field. Only one participant had no experience or contact with anyone who had prior knowledge of the system or disabilities themselves. All of the participants were well educated with education levels ranging from some college education to obtaining a master's degree. Finally, five of the nine participants were foster families prior to choosing to adopt the child.

Procedures

Table 1. Participant demographics

Participant	Gender	Age	Special Needs	Years Since Adoption
P1	F	60	Mental/emotional	14 years
P2	F	58	Combination	26 years
P3	F	59	Mental/emotional	14 years
P4	F	45	Physical	5 years
P5	F	58	Combination	10 years
P6	F	65	Physical	28 years
P7	M	63	Physical	26 years
P8	F	50	Combination	9 years
P9	F	55	Mental/emotional	14 years

This investigator decided that using semi-structured qualitative interviews would be the best method for fully understanding the current challenges with special needs adoptions. By utilizing qualitative methods, the researcher was able obtain data that provided a deeper understanding of the rationale, process, and contexts of special needs adoptions (Lehoux, Poland & Daudelin, 2006). Semi-structured interviews are a common method of collecting qualitative data and are consistent with grounded theory. The use of qualitative interviews allowed the researcher to obtain data about the thoughts and feelings of participants related to all aspects of adopting and caring for children with special needs. Further, qualitative interviews are a powerful tool because they assist the researcher in obtaining diverse opinions from the research participants (Given, 2008).

An interview guide was developed and used to help facilitate the face-to-face interviews with the participants. The interview guide consisted of a set of ten open-ended questions, which summarized the content which the researcher covered during the interviews (Given, 2008). The questions included in the interview guide were carefully worded to allow each respondent the opportunity to answer the same questions with essentially the same wording. Using an interview guide ensured that the same basic lines of inquiry were pursed with each person, which increased the comparability of responses (Patton, 1990). Furthermore, the development and implementation of an interview guide helped assure that the interviewer carefully determined the best method of utilizing the limited time available during an interview (Patton, 2002).

After the participants were screened and determined eligible for participation in the study, the researcher scheduled a time with them to complete the face-to face interview. All of the interviews were conducted in a quiet and private location of the participant's choosing. This included locations such as the researcher's office, the participant's home, or the office of the participant. Prior to each interview, the participants were informed of their rights as a research subject and signed an informed consent form. All of the interviews were audio recorded for later transcription and analysis. All of the interviews started with an introduction of the life care planning process and the participants were provided with a copy of an actual life care plan for reference. After a brief introduction of life care plans, the interviewer followed the interview guide in order to the gather the necessary information. All digital audio recordings were transferred onto a storage device and transcribed into Word ® documents for analysis.

Data Analysis

The researcher chose to use Microsoft Word ® software as a method of managing and organizing the large amount of information collected from the nine interviews. Utilization of Microsoft Word ® during the data analysis process provided the researcher the opportunity to identify commonalities amongst the data. These commonalities were labeled using codes and organized to establish a coding tree. The program allows for the researcher to browse themes, electronically code data, develop coding framework, and create displays of the theoretical framework. The researcher established date and time codes within the program to track the changes to the coding framework, thereby creating an "audit trail."

According to grounded theory, data collection, analysis, and theory formation is an ongoing and simultaneous process (Denzin & Lincoln, 2000; Glaser, Strauss & Strauss, 1967;Patton, 1990). Therefore, data analysis began when the interviews were transcribed. The researcher immediately began to analyze/interpret the data to form a coding framework. The immediate analysis of the interview is necessary because the interpretive information collected is then used to guide the next interview. This process ensured that the investigator would not miss any salient information throughout the interviews (Corbin, Corbin & Strauss, 1990).

In keeping with the grounded theory and the constructivist paradigm, the researcher used constant comparative methods to analyze the data. This approach combines specific coding procedures with theory development and encourages the comparison of codes across data sources (Glaser & Strauss, 1967). The comparative analysis method provided the researcher the opportunity to refine the coding framework, ensure codes were representative of the data, and minimize redundancies in codes. The comparison of codes within and across nodes allowed the researcher to compare data across study participants and modify coding as necessary, thereby assuring that the final coding framework was representative of the participants' experiences. (Glaser, Strauss & Strauss, 1967)

The process of coding began with reading the transcripts repeatedly to achieve immersion and obtain a sense of the whole (Tesch, 1990). The next step was to read each line of the transcript in order to derive codes by highlighting the words from the text that appear to capture important expressions regarding the topic of interest. As themes or concepts emerged, they were added to the coding framework and given a descriptive label. Each line of the transcript was analyzed according to the coding framework and labeled accordingly. The codes were then added to the theoretical framework as appropriate. This process continued for each interview, until the final theoretical framework was achieved.

Trustworthiness

To overcome research bias, this investigator included methods to maintain "reflexivity" during the research and analysis process. Reflexivity assures that the researcher attends systematically to the context of knowledge construction throughout the research process. This was especially important when examining the effects of the researcher and her biases during every step of the research.

Malterud (2001) states that when reflexivity is maintained, personal knowledge and biases are a valuable resource to research process.

Minimizing the effects of researcher bias was achieved through the researcher taking many steps to maintain awareness of the context of knowledge and construction at every stage of the research process. The first step used to minimize researcher bias was completion of applicable coursework in qualitative methods from professors experienced in conducting this type of research. Through this coursework, the researcher developed an understanding of basic qualitative research methods, theoretical frameworks, how to develop discussion guides, and conduct interviews. The next step used to maintain reflexivity was being trained on the utilization of software, Microsoft Word ®, for analyzing qualitative data. Furthermore, the trained qualitative researcher was available for consultation throughout the research process.

Another method of assuring coding accuracy was to have other researchers review the codes and obtain congruence among the codes. This investigator frequently met with other researchers to review the analysis. This step allowed for continual validation of the research findings. Finally, this researcher maintained awareness that her personal bias and experiential background may influence the qualitative process. A personal bias statement was included as part of this study as well as an audit trail of codes that outlined the researcher's thoughts and opinions as codes were developed.

Findings

Themes were organized into two broad areas with additional themes organized within each. The first area identified was the parents' experience with special needs adoptions, based upon the emerging relationships among the themes to develop a theoretical framework. The theoretical framework which describes parental experience is based on Bronfenbrenner's ecological model (Bronfenbrenner, 1979). Ecological model is a general systems theory that focuses on relationships between a living entity and the aspects of their environment. Therefore, constructs were categorized in the following: micro, meso, exo, and macro systems. Microsystem constructs included personal construct of decision making and emotions. Next, the mesosystem included the interactional construct of perceptions and process. The third system level, exosystem, included system constructs of foster care system, legal process, and adoption process. The final systems level is social construct which includes social views, social pressure, and peer pressure. Based on Bronfenbrenner's model, the person's behaviors affect and are affected by the environment, therefore this interaction is depicted by the bi-directional arrows between each level of the environment.

The focus of this article is on the applicability of life care plans within special needs adoptions. The findings focus primarily on the second area of themes regarding the use of life care plans. During the interviews, each participant was given an example of a life care plan and questioned on their opinion of the use during the adoption process. When reviewing the data, it is evident that the themes fell into two categories. The first category is the thoughts regarding life care plans applicability and the second category is recommendations for the life care plan. Themes regarding the *guidance*, and *knowledge* were apparent in the first category. The second category included broad themes of *availability of services*, as well as *transportation*.

When presented with a life care plan, some of the participants expressed how having this tool would have provided some much needed *guidance* regarding their child's care. Parents often talked about the frustrations they experienced when locating or knowing what types of services to arrange for their child, and felt that this resource would have altered that experience. These comments by P2 show how she felt a life care plan would provide potential parents with guidance.

> P2: Personally, I think it's a wonderful – you know, something like that would have been so helpful. Because, I mean, we were just no guidance whatsoever, no help, whatsoever. With the first child and all his emotional problems, you know, that would have, I think, curtailed a lot of it, you know, just having these steps to be followed because things got so out of control with him.

P1 talks about how she has been feeling isolated regarding her child's issues without any assistance on what to do. This participant expressed thoughts on how the life care plan could provide some clarity regarding the situation.

> P1: You know when she got diagnosed, ADHD? I'm like how do you get any hope for this child? I kept saying, something's not right. Finding out this was going on was only the first step. Then we had to find services and no one was there to help us know what we could do or what she would need. So yes, definitely. This would be awesome, it would really help guide someone to the types of services the child would need.

The second theme regarding the applicability of life care plans is in providing knowledge. One area of knowledge that the life care provides is the time frame for services as well as a holistic view of the disability needs. The participants felt that providing guidelines on when services would be necessary would be of great help. One participant discussed how having something like a life care plan would have prevented the delay in diagnosing their child. She noted that if she and her husband knew to have their child evaluated by a psychiatrist for behavioral issues, the family may not have gone so long trying to figure out where to get services. Furthermore, the parents note that this information would also allow them to monitor the services provided to the child. It was expressed that having a life care plan would provide the parents more autonomy and control over their child's

care.

Some of the participants discussed how the knowledge gained from the life care plan will help parents understand the magnitude of the child's needs. Participants felt that this knowledge would be helpful in a couple of ways. First, it would allow the potential parents gain insight into the magnitude of care regarding the child's special need. This knowledge would allow for the potential parents to make a more informed choice regarding their ability to care for that child. The second area discussed by the participants was the ability to provide potential parents with the understanding that adopting a child with special needs will require a long-term commitment, which is discussed by P3.

P3: I think this (life care plan) would help because you would see that it was lifelong, that this therapy isn't going to take two years and it's gonna be over with. It's ending at the end of that child's life. And then for parents who don't have Medicaid, the financial end of it they really need to look at also. I just feel that parents really need to know.

P5 talks about how the life care plan will aid people without any medical background gain knowledge on the disability as well as the related needs.

P5: I think it is wonderful idea, because some people don't have any idea. Not everybody that adopts a child is that aware of medical aspects. I have a daughter who is an occupational therapist and a son-in-law who is a speech therapist. From them I knew about Medicaid and I was well aware that all of those things are covered you know things like that. So I knew a lot of the stuff because I was exposed to it and a lot of people aren't and they have no clue what to expect. So for somebody who do not know, obviously this would give them some peace of mind regarding some of the things that they would worry about when adopting that child.

Similar to P5's comment, P4 also notes that the life care plan would help parents with no medical experience gain knowledge regarding the types of services necessary. Furthermore, she notes that this type of knowledge would have the potential to empower parents in controlling their child's medical care, particularly regarding the type and amount of services that are recommended.

P4: Well, I think it's good for people that are not familiar with the system because you kinda know when the evaluations are supposed to happen, so if they were happening more frequently you could say, "What's going on?" You know when it ends, 21, what to expect as far as frequency of services. I believe that this could really help parents who don't understand disability gain some of that knowledge.

Here P2 looks back on her experiences of raising a child with special needs and how the knowledge gained from a life care plan may have improved the outcome of her situation.

P2: But with the boy…. his needs were so great … the counseling and then all the expense there was, of course, way more than we had ever expected. And if we had really realized it…. we could have had him maybe on Medicaid and…under programs where the government would have helped us. But we had no idea and so we were grasping for straws, if we had a life care plan then, we might not have gone through so much with him.

The final area of knowledge participants reported the life care plan provided was that of available resources. P7 talked about how even educated people do not always know what resources are available for people with disabilities and how this plan will assist parents to identify the types of resources obtain for their child.

P7: People even people who are resourced and maybe even still don't know about these kinds of things and in some cases may know about them, but are not sure what help they can provide their child. For us it was the Medicaid Waiver program, we did not really know about this service and even when it was brought to our attention we stated that are child did not need it. Eventually it brought to our attention that we were being selfish by not helping our son get on the waiver program, because as it was explained to us these services will help after we are no longer here to care for him. So I can see where this plan will help people understand what services are out there, as well as how that can aid in the child's care.

While reviewing the life care plans, participants were questioned about what modification to the model would improve its applicability to the adoption system. One of the recommendations was to consider the area and *availability of services* for that area. Specifically, P3 talked about how living in a small town meant that she has to go out of town to find the necessary treatment for her child. She notes that traveling to receive the necessary services has been a major challenge for her and was not something that entered her mind prior to adopting the child. For this participant, she felt the service recommendations are great, however it is important to understand that they might not always be readily available to the adoptive family. Therefore, she indicated that the life care plan should include awareness that services might not always be available or will require traveling in order to locate the necessary treatment.

In addition to the availability of services in the local area, *transportation* for treatment was discussed. This participant notes that the amount of money and time that goes into traveling to receive services is not something that she considered while preparing to adopt the child. P3 also talked about traveling to receive the necessary treatments for her child and how including transportation considerations in the plan might be important.

Discussion

Currently there is limited research regarding parents'

experience of special needs adoptions and the barriers that they face. Furthermore, there is even more limited research on methods of supporting parents who do choose to adopt a child with special needs. This study's findings regarding the use of life care plans fills a gap in the field. Utilizing life care plans as a method of educating and supporting adoptive parents appears to be a viable tool in the adoption process. Based upon the findings of this study, the consensus among participants was extremely positive. Parents reported that the life care plan provided a large amount information regarding the child's potential needs. This information was reported as helpful to parents in gaining a realistic perspective of caring for the child. Furthermore, parents felt that having a life care plan would provide them with guidance on the evaluations, supplies, and services that their child may need. Parents noted that having this information would provide them with the ability to take charge of their child's care, which is something that some parents felt was missing from their parenting experience.

Parents were asked to comment on the amount of information provided by a life care plan. Overall, parents reported that there was a lot of information provided by the plan and the information was adequate to address the necessary perspective that parents will face. The parents expressed that it was important for people to gain a realistic understanding of what caring for a child with special needs will look like. Furthermore, the parents felt that having this amount of information would allow parents to prepare for upcoming needs that may not be covered by Medicaid or other insurance policies. The ability to understand and prepare for future needs will alleviate one of the barriers identified by case managers, specifically the perceived financial strain of adopting a child with special needs vs. adopting a child without special needs.

Another interesting finding when discussing the life care plan was how it would encourage parents to recognize the need for services sooner. Specifically, one mother discussed how it was difficult for her and her husband to recognize and accept the fact that their adopted son was displaying mental health symptoms. She felt that having a life care plan could have made a huge impact on timeliness of acquiring services, and subsequently the child's overall functional ability.

The life care plan was identified by parents as a tool that would impact a number of the frustrations that they experienced throughout the process. Parents talked about how having a life care plan would have alleviated some of the frustration of being provided with little information regarding the child's background as well as current and future needs. As discussed earlier, a lack of information has been identified as a major barrier during the adoption process, especially when placing children with special needs. The life care plan will address this barrier and allow the parents to acquire a realistic perspective of the child's current and future needs.

Parents knowing what types of services would be appropriate for the child's need was another area of frustration. The life care plan would provide the parents with a post adoption roadmap to help reduce the frustration around the lack of responsiveness from the adoption agency after adoption.

As stated earlier, one of the characteristics that impacted people's decision to adopt a child with special needs was medical knowledge. Parents often reported that their professional knowledge of disease or disability meant they had a better understanding of the child's needs. The goal of life care plans is to educate its intended audience and when provided to potential parents, educate them regarding the child's needs. This level of education will be essential in helping parents form an educated decision regarding adopting a child who has special needs.

Educating parents has the potential to impact adoption in both a positive and negative manner. First of all, information and education was identified as essential parts of the decision-making process. Therefore, by providing parents with this knowledge, parents may realize that they are able to care for the child and the child's needs are manageable. This could potentially increase in the number of special needs adoptions. Alternatively, the parents may view with the information contained in a life care plan as overwhelming, leading to a decrease in the number of adoptions. The potential of life care plans to negatively impact the number of special needs adoptions is not necessarily bad, as the dissolution rate of special needs adoptions is significantly higher than that of children without special needs.

Based upon their experience of raising a child with special needs, parents were asked to make recommendations that would make the life care plan more applicable to the adoption system. A couple of themes were identified as important. First, the parents recommended that the plan consider the family's geographic area of residence as some of the parents noted difficulties in locating the necessary services. This was of particular concern to parents who lived a small community and would travel for an hour or greater to receive appropriate treatment. This recommendation is extremely important thing to consider in the development of a life care plan.

In association to availability of services, is the amount of time and money necessary to travel to medical appointments. Some parents pointed out that it takes both time and money to travel the necessary distance to keep regular medical and mental health appointments. One parent's recommendation was to include travel expenses in the life care plan as way of preparing parents for the out of pocket expenses that would be required. Including travel expenses is a recommendation that could be easily included in the plan.

Research regarding the use of life care plans during the adoption process is extremely limited and to date there is only one study that has explored its feasibility (Buckles, Pomeranz, & Young, 2009). This study found that basing a life care plan on Medicaid was a viable option, therefore increasing the applicability to special needs adoptions since

the child will maintain Medicaid coverage. Further research is necessary to continue exploring the applicability of life care plans. If there continue to be positive responses to its use in adoption, clinical practice should make efforts to implement this model.

Limitations

This research study has limitations that are inherent with qualitative research methods. A primary limitation of the current study is that the sampling technique, purposeful and criterion-based sampling, created a homogenous sample. A homogenous sample limits transferability of the results to the broader population. The sample of parents was homogenous in gender, socioeconomic status, and geographical area. The homogeneity of the sample limits the transferability of the results; however, this was not the goal of the current study.

Another major limitation to the study is the sample size, which included only nine individual interviews. This creates limitations in the reliability of the studies finding, however again the primary goal of this study was to gain rich information regarding the phenomena. Additional research is warranted to gain further insight into the experiences of a more diverse group of parents and case managers.

Clinical Implications

The need for more education is evident in the findings of this study. This includes education for the potential parents as well as education for adoption case managers. One of the primary factors discussed by the adoptive parents as essential to their comfort level of dealing with special needs was the knowledge they had from their professional experiences. Therefore, it is important for the adoption system to recognize the need for more specialized training of potential parents regarding the dynamics of raising a child with special needs. Another potential method to educate potential parents is to provide them with informational pamphlets, articles, or general information that will increase their health literacy. This study also displayed the importance that a life care plan will have on the potential parents' awareness of the child's needs, thus providing them with individualized educational tool that will also increase health literacy. The increased health literacy will allow parents to gain a holistic and realistic view of the disability that will aid their decisions to adopt a child.

As stated earlier, life care plans are dynamic documents that organize a concise plan for the current and future needs of individuals with disabilities (Weed & Berens, 2010). The primary goal of the life care plan is to educate its intended audience and as such the life care plan is well designed to address some of the issues identified by this study. First, knowledge was identified as an important determining factor in choosing to adopt a child who has special needs. The life care plan will be a tool that adoption case managers can provide potential parents during the assessment process to provide them with an individualized knowledge of the child's need. This knowledge will aid the parents in making an informed decision and provide them with the assurance that the disability is manageable.

Finally, life care plans will aid the parents after the adoption has been finalized. A major finding of the study was the lack of support and direction provided to parents after the adoption is finalized. Providing parents with life care plans at the time of adoption will address this concern. Furthermore, it will empower parents in understanding, directing, and being proactive with their child's care.

Future Research

This study is the first to examine the possibility of utilizing life care plans with special needs adoptions, therefore further research regarding the applicability of life care plans is necessary. Research should not only focus on the applicability of the life care planning model, but also on modifications that may be necessary. The goal of this study was to gain rich information regarding the phenomena of special needs adoptions, therefore, future studies should include larger, more diverse, sampling to increase the reliability and transferability of results. Furthermore, future research is necessary to explore methods of implementing life care plans within the adoption system. Applying the life care planning model to the field of special needs adoptions is an exciting new arena that needs further exploration.

Conclusion

This study sheds light on the some of the issues present in the adoption system. The study's findings support the use of life care plans with special needs adoptions. Case managers described some of the barriers that they had witnessed in their experiences of placing children with special needs. These barriers were based on potential parents' opinion of adoption as well as what it means to raise a child with special needs. The identified barriers are some of the reasons for lower adoption rates of children with special needs.

A number of areas important to adoption decision-making were identified from the interviews with the parents. This information sheds light on areas where the current adoption system is failing to provide the necessary information and support to those who choose to adopt. The combination of this information along with the reports from case managers highlights the need for a comprehensive tool to educate both the parents and adoption case managers. One potential tool is a life care plan. This preliminary study showed promise for the application of life care plans within the adoption system. Further research is necessary to continue development of an adoption life care planning model and methods of implementing this model into practice.

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