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Child in Need of Assistance and a Lack of Rural Mental Health Care

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**CHILD IN NEED OF ASSISTANCE AND A LACK OF RURAL
MENTAL HEALTH CARE**

**An Abstract of a Thesis
Submitted
in Partial Fulfillment
of the Requirements for the Degree
Specialist in Education**

Katie L. Fisher

University of Northern Iowa

May 2007

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ABSTRACT

With the rising number of children in need of mental health services and the increasing cost of these services, methods to address these needs must be developed. The purpose of this research is to gain a better understanding of the experience of parents who have been involved in the Child in Need of Assistance process in order to meet their child's mental health needs. Participants in this study were parents of a child who participated in the Child in Need of Assistance program due to the need for mental health services. Qualitative methods were used to examine the experiences of one family going through this process. The analysis of the data culminated in five major themes. These themes as well as implication for school psychologists are discussed.

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This Study by: Katie L. Fisher

Entitled: Child in Need of Assistance and a Lack of Rural Mental Health Care

has been approved as meeting the thesis requirement for the

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CHAPTER 1

INTRODUCTION

There is a significant lack of mental health care available in the rural parts of the United States. The difficulties in obtaining needed mental health care in these areas are compounded by the lack of parity in insurance coverage of mental health treatment. Because of the lack of resources to pay for mental health care, the Child in Need of Assistance program is sometimes accessed by parents to obtain needed services.

Child in Need of Assistance (CINA) is a program funded by the Iowa state government that provides for the safety of children and allows children to get needed services if parents are unwilling or unable to meet the needs of the child (Iowa Judicial Branch, 2002). This process involves a parent signing a petition that gives the state custody of the child. The state then makes decisions for the child regarding placement and care. According to the Annual Statistics report of the Iowa Judicial Branch (2002), there were 12,329 juvenile filings during 2002; 5,234 of these filings were CINA cases.

Because the CINA program provides services to a child whose parents are unwilling or unable to meet his or her basic needs, many children may benefit greatly from this program that strives to create stability for children from neglectful or abusive homes. The CINA program can be very effective in keeping children safe and providing them with the services that they need to be healthy, happy children. Sometimes all a family needs to get back on their feet is a little assistance. By providing frequent visits or accessibility to parents, and teaching parents skills to create in their children secure attachment bonds, the legal system can assist children's development and provide them

the ability to value themselves and develop enduring and intimate relationships throughout their lives (Kuehnle & Ellis, 2002).

In some cases the CINA process may not be in the best interest of the child and his or her family. It is up to the court to decide the appropriateness of CINA for individual cases, but the experiences of families involved with CINA must be understood in order for appropriate decisions to be made. Furthermore, the changes in power structures in cases where the parents voluntarily relinquish their parental rights must be understood.

The Problem Statement

With the rising number of children in need of mental health services and the increasing cost of mental health care, methods to address the needs of children with mental health issues must be developed. The current processes by which families access these services, and the related outcomes, must be understood. The appropriateness of the use of CINA to access needed services should be examined.

Purpose of the Study

Parents are often the main support and guidance to their children. Yet, many parents report they feel unprepared to adequately meet these needs. The purpose of this research is to gain a better understanding of the experience of parents who have been involved in the Child in Need of Assistance process in order to meet their child's mental health needs. It seeks to determine what type of assistance needs to be provided to families to promote family preservation.

Specific research questions that were addressed:

1. How were you informed about the Child In Need of Assistance program?
2. How do you feel this program worked?
3. What services are available in your area that you can access for you child?
4. Are these services beneficial to your child?
5. How were you supported during this process?
6. How could you have been better supported during this process?

Significance of Study

There is very little research that delves into the Child in Need of Assistance program from the perspective of the family of a child with mental health needs. This study will contribute to the understanding of the effectiveness of the CINA process. The results may give insight into the family's experiences as they go through this process, the mental health options available for children, and the future of mental health programs for children.

Definition of Important Terms

In order to gain an understanding of the process of a child being adjudicated as Child In Need of Assistance it is important to understand the terms that will be used often.

Adjudicatory hearing: Means a hearing to determine if the allegations of a petition are true (Iowa Code sec. 232.2)

Custodian: means a stepparent or a relative who has accepted a release of custody, or a person appointed by a court or juvenile court. [Iowa Code sec. 600(A)(2)].

Guardian: means a person who is not the parent of a minor child, but who has been appointed by a court or juvenile court, to make decisions, which have permanent effect on the life and development of that child, and to promote the general welfare of that child [Iowa Code sec. 600(A)(2)]

Guardian ad Litem: a person appointed by the court to represent the interest of a child in any judicial proceeding to which the child is a party, and includes a court appointed advocate.

Parent: Iowa code states that a parent is a father or mother of a child, whether by birth or adoption [Iowa Code sec. 600 (A) (2)].

CHAPTER 2

LITERATURE REVIEW

It is estimated that more than 13 million children are in need of mental health or substance abuse services and 1 out of every 10 children and adolescents in the U.S. endure mental illness. In any given year, only 20% of children with mental disorders are identified and the receive mental health services they need (Facts, 2006). According to Kataoka, Zhang, and Wells (2002) most children who need a mental health evaluation or mental health services do not receive them. Ethnic minority youth and uninsured children have especially high rates of unmet needs compared to other children.

Needed mental health care may not be accessed for a number of reasons. A lack of insurance or a lack of insurance coverage for mental illness is one reason for not accessing the needed treatment (Insurance coverage, 2000). According to McLaughlin (2004),

Mental health care services are not covered by health insurance packages and health plans to the same degree as physical health care services. Not only are there usually more services excluded as covered benefits, but those services that are covered are often subject to higher co-pays and are capped at a maximum number of covered treatments (p.221).

According to Hauenstein (2003),

Individuals in rural communities have limited access to mental health providers. Mental health problems are just as common in rural areas as they are in cities, but rural residents are less likely to have access to or seek out mental health services. Fewer qualified professionals exist in rural areas and insurance reimbursement rates are often lower for mental health professionals in these areas (p. 1).

Although 20% of the U.S. population lives in non-metropolitan areas, only 9% of physicians practice in these areas. Most of the 9% are general practitioners who may

have limited knowledge of mental health (Petterson, 2003). If there are no mental health services available for a child in his or her area, services may need to be sought elsewhere. This may require travel of an hour or more to receive the necessary services (Hauenstein, 2003). The needed travel is not only expensive, but may require a parent to take significant time off work, resulting in lost wages.

A third reason for not accessing mental health services is stigma. For some people there can be a stigma attached to mental health providers and facilities (Petterson, 2003). In rural areas there may be a lack of anonymity that may cause some to be too embarrassed to get his or her child the services he or she needs.

Regardless of the reason for a child not receiving mental health services, national studies have indicated increasing rates of depression and a shift to a younger age of onset (Wu et al., 2001). One reason for the mismatch between mental health problems and services accessed may be a lack of mental health insurance coverage (Glied, Hoven, Moore, Garrett & Regier, 1997)

Child in Need of Assistance

Child in Need of Assistance (CINA) is a program funded by the state government that is being used to get children the mental health care they need when the parent does not have the resources. CINA allows children to get the safety and services they need if parents are unwilling or unable to meet the needs of the child (Iowa Judicial Branch, 2001). According to the Annual Statistics report of the Iowa Judicial Branch (2002), there were 5,234 CINA petitions filed in 2002. In Iowa approximately 150 to 200 children are placed in the CINA program every year so they can gain access to mental

health services (L.K. Heddens, personal communication, June 28, 2004). The CINA program is one means for providing mental health care to children in need. This review will discuss the CINA program in Iowa and the availability of rural mental healthcare.

Judicial Authority

If a parent is unable to provide what is in the best interest of a child, or a child's basic needs are not being met, the state may intervene. According to the Iowa Judicial Branch (2001), if a child is in danger of any kind, the State can seek to remove the children from the custody of his or her parents. In order for a parent to re-gain the right to have the child live in their home, he or she must provide for the needs identified by the court and show that he or she is able to care for the child again. If a parent does not demonstrate that he or she is able or willing to meet the needs of the child, a juvenile judge may enter an order terminating parental rights (Iowa Judicial Branch, 2001). Termination of parental rights means a complete severance and extinguishment of a parent child relationship between one or both living parents and the child [Iowa Code sec. 600(A)(2)].

A parent has the responsibility to meet the basic needs of his or her child. When this does not happen it is up to the judicial system to intervene and provide assistance to the children and their family. One way this can be accomplished is through a program called Child in Need of Assistance (CINA).

Judicial Requirements

In the State of Iowa, when a child's needs are not being met because the parent or parents are unable or unwilling to meet them, a child can be adjudicated to be a Child in

Need of Assistance. There are sixteen statutory grounds in which a child under the age of eighteen, can be adjudicated to be a child in need of assistance (Iowa Judicial Branch, 2001). As stated in the Code of Iowa, CINA means an unmarried child:

1. Whose parent, guardian, or other custodian has abandoned or deserted the child
2. Whose parent, guardian, other custodian or other member of the household in which the child resides has physically abused or neglected the child, or is imminently likely to abuse or neglect the child
3. Who has suffered or is imminently likely to suffer harmful effects as a result of either of the following:
 - a. Mental injury caused by the child's parent, guardian or custodian
 - b. The failure of the child's parent, guardian, custodian, or other member of the household in which the child resides to exercise a reasonable degree of care in supervising the child
4. Who has been, or is imminently likely to be sexually abused by the child's parent, guardian, custodian, or other member of the household in which the child resides
5. Who is in need of medical treatment to cure, alleviate, or prevent serious physical injury or illness and whose parent, guardian or custodian is unwilling or unable to provide such treatment
6. Who is in need of treatment to cure or alleviate serious mental illness or disorder or emotional damage as evidenced by severe anxiety, depression, withdrawal or untoward aggressive behavior toward self or others and whose parent, guardian, or custodian is unwilling or unable to provide such treatment

7. Whose parents, guardian, or custodian fails to exercise a minimal degree of care in supplying the child with adequate food, clothing or shelter and refuses other means made available to provide such essentials
8. Who has committed a delinquent act as a result of pressure, guidance or approval from parent, guardian, custodian, or other member of the household in which the child resides
9. Who has been the subject of or a party to sexual activities for hire or who poses for live display or for photographic or other means of pictorial reproduction or display which is designed to appeal to the prurient interest and is patently offensive and taken as a whole lacks serious literary, scientific, political or artistic value
10. Who is without parent, guardian, or other custodian
11. Whose parent, guardian or other custodian for good cause desires to be relieved of the child's care and custody
12. Who for good cause desires to have the child's parents relieved of the child's care and custody
13. Who is in need of treatment to cure or alleviate chemical dependency and whose parent, guardian, or other custodian is unwilling or unable to provide such treatment
14. Whose parent's or guardian's mental capacity or condition, imprisonment, or drug or alcohol abuse results in the child not receiving adequate care

15. In whose body there is an illegal drug present as a direct and foreseeable consequence of the acts or omissions of the parents, guardian, or custodian. The presence of the drug shall be determined in accordance with medically determined tests.
16. Whose parent, guardian, or custodian does any of the following:
- a. Unlawfully manufactures a dangerous substance in the presences of the child
 - b. Knowingly allows such manufacture by another person in the presence of the child
 - c. Possesses a product in the presence of the child containing, ephedrine, its salts, optical isomers, salts of optical isomers, or pseudo ephedrine, its salts, optical isomers, salts of optical isomers, with the intent to use the product as a precursor or an intermediary to a dangerous substance [Sec. 232.2(6)].

Judicial Process

If a child seems to meet any of these requirements the process of adjudication may begin. The first step in this process is to hold an adjudication hearing. At the adjudication hearing, the state is required to prove that the child is in fact a Child in Need of Assistance within the meaning of one or more of the 16 CINA grounds (Iowa Judicial Branch, 2001). During this process the child is provided a guardian ad litem to represent the child's best interests in all CINA proceedings (Iowa Judicial Branch, 2001). After the placement of the child is decided, a disposition hearing is held. During this hearing, the

judge decides what services are needed for the parents of the child. The judge will take into consideration the factors that led to the adjudication and what the parents are doing or neglecting to do, for the child. If the child was removed from the home, the judge will impose conditions the parent or parents must meet to regain custody. All CINA cases where the child is removed from the parent or parent's custody are reviewed every 6 months to evaluate the progress of the parents and the placement of the child. The most commonly prescribed services for parents are a psychiatric evaluation, therapy, parenting classes, in-home support services, drug and alcohol treatment, and sexual offender programs (Iowa Judicial Branch, 2001).

The next step in the CINA process is a permanency hearing. During the permanency hearing, the court will make one of two decisions: enter an order to return the child to the parent or parents' custody or enter an order to continue out of home placement of the child for another 6 months. If it is ordered that the child will remain in out of home placement, another permanency hearing is held following the 6-month period [Iowa Code sec. 232.104(2)]. If the court agrees that it is in the best interest of the child to terminate parental rights there are two possible outcomes: the guardianship and custody can be transferred to the Department of Human Services or other fitting private agency, or to a parent or relative who does not have physical care of the child [Iowa Code sec. 232.117(3)]. If the court rules to terminate parental right and awards guardianship and custody to another party, the guardian needs to submit a case permanency plan for that child [Iowa Code sec. 232.117(3)]. As stated in the Iowa Code, a case permanency plan is designed for the child to gain placement in the least restrictive, most family-like

environment possible in close proximity to the parent's home, if being near his or her family is in the best interest of the child [Sec. 232.2(4)]. This will ensure that the child is placed in an environment that is stable and appropriate.

In the 150-200 CINA cases that were granted due to a parent's inability to pay for needed mental health treatment for their child, the same procedure is required. The Courts may develop a set of conditions that must be met for the parents to regain custody. During this process the parent or parents sign away their parental rights and the court appoints a guardian ad litem for the child.

The CINA legislation can be very beneficial to children, but at times it is used for purposes that are not consistent with the spirit in which it was written. Cases exist in which parents have been advised to use CINA as a method to obtain the mental health treatment recommended for their child. In these cases the child is removed from the parent's custody so mental health treatment can be made available. Mental health services are not always covered by insurance, and the cost of these services is substantial. In a time when the mental health needs of children and adolescents are on the rise and access to behavioral health, mental health, and substance abuse services are decreasing, it is important to understand how difficult it may be for some families to get the help they need for their children (Insurance coverage, 2000). According to Glied et al. (1997):

As expected private insurance coverage increases with income, whereas Medicaid coverage is concentrated about the poor. More than one quarter of children in poor families and nearly one quarter of those in low-income families had not health insurance coverage for mental health services. (p.169).

Children in low-income families have lower rates of insurance for mental health services, when they are the very ones with the highest rates of psychiatric disorder and

mental health impairment (Glied et al., 1997). Low income families are greatly affected by a lack of options in rural mental health care, but middle class families are as well. Middle class families who do not have mental health insurance may seek help and pay for services out of pocket. This can put middle class families in much the same position, by narrowing choices for financing mental health care services.

CHAPTER 3

METHODOLOGY

Qualitative research methods were chosen for this study because this method has an interpretive character, aimed at uncovering the meaning events have for those individuals who experience them and the interpretations of those meanings by the researcher (Hoepfl, 1997). Qualitative research is not done for purposes of generalization but rather to produce evidence based on the exploration of specific contexts and particular individuals (Brantlinger, Jimenez, Klingner, Pugach & Richardson, 2005). The purpose of this study was to examine the experiences of a family who had a child in need of mental health services and the availability of care. Due to a lack of literature on this subject a case study was used to gain a deeper understanding of the CINA process as well as one family's experiences during that process. Information derived from qualitative studies can lead to an understanding of individuals in need of services, their families, and those who work with them (Brantlinger et al., 2005).

Participants

Participants in this study needed to be a parent or parents of a child who has participated in the Child in Need of Assistance program in Iowa due to the need for mental health services or a parent or parents that have used the mental health waiver. Participants were identified by the Family Support Coordinator of Access for Special Kids at the ASK Family Resource Center who, as a child and family advocate, works with families involved with the CINA system and the mental health waiver. One family was identified, because of their involvement with CINA system.

Confidentiality statements and forms were reviewed and signed. Interviews took place during late morning, in Steve and Susan's dining room. The atmosphere was relaxed and questions were addressed thoroughly by both parents.

The participants in this study were parents between the ages of 30 and 55. Both parents have at minimum a college degree and both were employed full time at the time of the study. The participants have two children. Their oldest child has significant mental health issues that required residential treatment.

Procedures

Interviews

The author conducted individual, semi-structured interviews with the parents of "Tim." The interviews took place at a time convenient for the families, in their home. The interviews were audio-taped and transcribed verbatim. To ensure confidentiality only pseudonyms were used in the transcript and any identifying information was removed. At the conclusion of the study all notes and transcripts were destroyed.

Data collection

Data were collected through two face-to-face semi-structured interviews. The semi-structured format allowed the interviews to be more flexible to allow immediate examination of ideas and opinions expressed by the participant (Brantlinger et al., 2005). Two interview protocols were used. The protocol in Appendix A was used in the first interview to provide a starting point for each area. The participants were very willing to elaborate independently and seemed to work well in the parameters of the semi-structured interview.

Trustworthiness and credibility of the obtained data were assessed by employing a member check strategy during the second interview (Brantlinger et al., 2005). During the member check the participants were asked to verify the accuracy of the data and themes produced from the first interview. This was done for each theme throughout the progression of the interview. Four additional questions were constructed to clarify different themes of power in the interview.

The combination of using a member check system to validate themes and clarify responses along with conducting two face to face interviews with the same participants contributed to the credibility of this data.

Data analysis

According to Brantlinger et al. (2005) data in qualitative research needs to be reviewed, sorted and coded in a systematic and meaningful way. Content analysis involves close inspection of the interview transcripts to understand and identify themes or perspectives of the research participant (Brantlinger et al., 2005). The first step was to take the data from the first interview, analyze and code it with several different themes. These themes emerged from the data and were not predetermined. Confirmation statements were developed that represented major themes and conclusions. These statements were used in the second interview to validate themes and conclusions. Following the second interview data were analyzed and five major themes were identified: limited mental healthcare options, trading custody for care, the learning curve, navigating agencies, and learning to cope. The data were analyzed and it was determined which theme they best fit under. Questions to be asked during the second interview were

determined at this stage. After the second interview the data were analyzed and no new themes emerged.

CHAPTER 4

RESULTS

The results from the analysis of the data culminated in five major themes: limited mental healthcare options, trading custody for care, the learning curve, navigating agencies, and learning to cope.

Limited Mental Health Care Options: “She said, well this is all we have...”

Data analysis revealed limited options for appropriate mental health services for this child and his family. Further, funding for services became a significant problem with very limited solutions. Steve and Susan, Tim’s parents, were told that there were limited options for their child because he did not carry a diagnosis of Mental Retardation or Autism along with his other significant mental health needs. Susan stated that she felt “The only options for those who weren’t mentally retarded or autistic was CINA.” “At every step there was the chance that if we didn’t have an exceptional person, the system itself would put Tim in a juvenile facility or in a group home.” Tim’s parents were informed by a DHS caseworker that the only way that Tim could be treated for his mental health needs would be for them to sign a CINA petition and terminate their parental rights. Sue reported being told by a caseworker, “we know you are really okay, but you have to do this, look at this part, see, it says if parents cannot provide for the child... You just can’t pay for it yourself.” Susan remembers how this information was presented to her and states “in order to get services we had to go under this specific piece of paper that hands down said abuse or neglect... but my son just has a mental illness.”

In summary, Steve and Susan were looking for options to treat the significant mental health needs of their son, Tim, and found they were given only one option. That option was a CINA petition.

Trading Custody for Care: “We were asking for a couple of adolescent years and people were reacting like we were giving him away and not wanting him.”

Steve stated that living with Tim was, “literally...living with Dr. Jekyll and Mr. Hyde, which one is going to be here a minute from now?” Over time Tim was increasingly unable to control his behavior, “the violence escalated, he grew, violence was more targeted, and it would go on for days. He threatened suicide, he threatened homicide, and he had a list of people he would kill...” It was clear that something needed to happen in order to ensure the safety and well being of Tim as well as that of Steve, Susan and their daughter, Amy.

During the CINA process a parent is asked to temporarily sign away parental rights. In this case the parents so desperately needed to find help for their child that they agreed to these terms. Tim’s parents stated, “He got worse and we entered the CINA process. We can tell you exactly how we got into the CINA, but clearly it was out of desperation.”

Tim was adjudicated as a child in need of assistance and the parents found “it’s not just a legal piece of paper, it’s the whole system that is CINA oriented.” Steve and Susan agreed to sign the CINA petition, thinking that it would help them get their son the mental health services that he so desperately needed. Susan stated, “that at every point it [CINA] disrupted his [Tim] progress, his stability, and the way the family was framed.”

Data analysis revealed that because of the way the system is structured, CINA was not adequately set up to address Tim's needs. Professionals involved in this case were not equipped with knowledge of mental health or mental health services. Susan remembers that "people had to break rules to treat it as a mental health issue." Tim's parents felt that there was a huge need to "turn it into a mental health intervention against this huge CINA wave that colored it juvenile justice and/or a parental substitution piece."

Steve and Susan reported that as soon as they signed the paper they were "treated as adversaries. Physically, legally and in practice we were not allowed to do certain things and other people [DHS, lawyers] were. Communication lines were structured according to the way they dealt with parents who were neglectful or abusive." When a CINA petition is filed there are many people who then become involved. Susan stated that there were "...essentially five people, only one of them trained in mental health, but all of them used to the CINA procedures and options" involved in Tim's case. These "five people, who had just met Tim would decide..." what was appropriate for him in terms of mental health services. Analysis revealed having so many people involved in one case proved to be very difficult when trying to develop a plan of action. Susan stated that "CINA put us at least on a six month delay when making good choices about Tim and we just had to deal with it." Because they did not have parental rights they were not able to make decisions for Tim. He was appointed a guardian ad litem and Steve and Susan were informed that they could not speak directly to the guardian but needed to communicate through their lawyer. They felt this was because "he was Tim's lawyer,

and because that is the way that CINA is set up. The parents are bad and the kid needs an advocate, the parents have failed.”

Tim’s parents indicated they had been assured that they were the exception, they were not neglectful or abusive parents, but parents who were trying to do the right thing for their child. They found out that this may not have been the case:

They didn’t tell us things, because we are not responsible parents, because we are parents under the CINA. So, immediately all that stuff about, you’re not *really* under the CINA... if you’re under CINA, you’re under CINA, it was all happening. It was dangerous for mental health.

Data analysis suggested and Tim’s parents confirmed that they were in such desperate need for mental health services that they would do anything, including as a last resort, temporarily give up parental rights, in order to help their son.

The Learning Curve: “We were neck deep in CINA rules and regulations.”

Steve and Susan found that there is so much to learn and very little time to learn it, when it comes to the rules of the CINA process. “We knew nothing about CINA, we had no clue what this was, we were both well educated, but ignorant.”

The legal system

Tim’s parents were trying to learn as much as they could, while still trying to advocate for their son. Susan and Steve had to quickly learn about the complexities of the legal system and the specific laws that would directly affect their child. Susan stated that:

There is a series of laws that come into play; one is that you can’t keep a child in [a psychiatric facility] more than 24 hours without a judge’s consent, so there are mental health commitment issues. So, we first had to get a judge to say, yes, he can stay more than 24 hours, but then that is reviewed on an on-going basis, because they don’t just let you put someone in a psychiatric facility and stay there

because there have been abuses. As soon as we passed the 23 hour mark, we were in the legal system with no preparation for being in...that system.

The role of parents

According to Steve and Susan, “parents are ultimately responsible for everything.” For example, when Tim needed residential care, they looked into residential settings that were available for him. If they were told there was no other place they felt that it was their responsibility to find a place that would work for him. “They say there isn’t a place, what would you do as a parent? I’m going to go find a place, and that is what we did.” Tim’s parents were responsible for not only finding their son an appropriate placement, but they were also still trying to teach him appropriate ways of acting and doing things. Steve and Susan spent many hours trying to learn how the CINA system worked and how it could help their son. They were still very much his parents, even though CINA said otherwise. Steve and Susan felt they needed to be participating members of the CINA team, and spent many hours researching appropriate placements for Tim. They carried much of the responsibility of finding Tim a placement and making sure there was a place for him, but ultimately the decision was not theirs to make; they legally did not have the right to make any choices for him.

Time and money

When the CINA petition was signed, both Steve and Susan had full time employment, so, “on top of full time jobs, trying to research Tim’s disability, and meeting with the lawyers... we were also each spending 15 to 20 hours per week working and learning about CINA and Tim’s case.” They put a lot of time and energy into learning the legal system and rules and regulations of the CINA process. They were

doing so much work from home that they invested in a copy machine and fax machine. In their home they also have a room devoted specifically to all of the file boxes full of paperwork that goes along with having a child “in the system.” The knowledge gained through researching and learning about this process was passed along to others. Steve stated, “We have educated a lot of people along the way.”

Lawyers

Some of the people that Steve and Susan have had to educate have been the lawyers involved in the CINA process. Having lawyers that were not trained to deal with mental health issues was difficult not only for the family, but for the lawyers as well. Tim’s guardian ad litem advocated for Tim going home. He would ask Tim where he would like to go and if Tim said home, he would fight for that. Susan remembers:

There was only communication with Tim at 13 or 14, as if he was going to manage that piece...he would get letters from this lawyer and we would have to say “Tim, did you get anything from the lawyer, is it okay if we see it?””

During one of the hearings that took place during the CINA process, Tim’s guardian ad litem was going to have him brought from the residential setting where he was placed to the courtroom, which was 30 miles away. At the time that he was to be transported, “he was raging.” Tim’s parents suggested that their lawyer, along with Tim’s lawyer, “go see him in this place.” Steve and Susan felt that they both needed to see “in a gut wrenching sort of way” the behaviors that Tim was exhibiting. Susan recalls:

They got there and he was raging, you could see kids mad..., which is upsetting, and annoying and worrisome, but to see a kid raging, when you see madness come on a person... They are not like that all the time, you see psychosis, it’s a shock and these two lawyers didn’t have any training in this.

Tim's lawyer and Steve and Sue's developed a better understanding of the intensity of his behavior and need. They also were able to see "Tim in solitary, and say "okay, we really get it, he wants to go home, but he can't..."

The learning curve is steep for all who are involved in the CINA process and mental healthcare cases.

Disadvantage

Not everyone who goes through the CINA process has the means or education that Steve and Susan possess. And while they have struggled with many aspects of this process they feel that their status allows them the opportunity to challenge the system and stand up for what they believe in. Tim's parents feel that:

Poor people, people of color, or people who don't speak English as their first language, people who are not dual parent families...have much fewer advantages than we have. They have much less power, we had enough money to step up to the system and not everybody does.

Steve and Susan were able to be present at all hearings and court proceedings, as well as visit their son almost every night, even though it was miles away. Because of their determination and persistence, they were able to advocate for their son, even though others were saying they could not or should not. They feel that "those people [disadvantaged] are not going to court, because they don't even make it there, they don't even make it." Steve feels that it is most likely that "their child is institutionalized in a state facility for life, or they end up in [the] juvenile" justice system.

Navigating Agencies: “We can’t coordinate that...”

When a child is in need of mental health services, and is involved with the CINA process, there are many people and agencies that become a part of that child’s life. Tim’s parents felt that there were very different rules for each agency:

So you have the school rules, you have the DHS rules and sometimes they overlap, but they also have their own individual rules, then you have the CINA, which overlaps with some DHS stuff and overlaps with some school stuff, but it also has it’s own stuff. Then at the end throw in parents, because we also have some of our own ideas.

Steve and Susan provided a drawing (See Figure 1) of what it would look like in their opinion, if agencies would try to work better together.

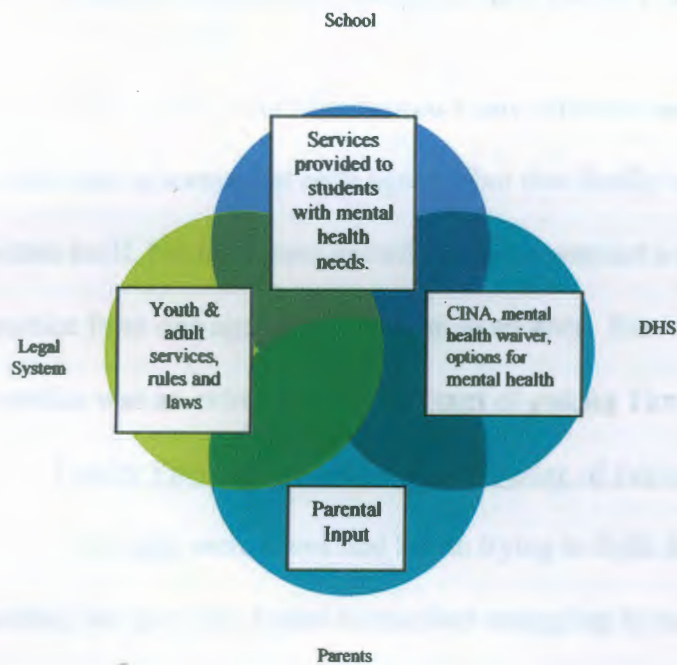


Figure 1. Service Diagram

Tim's parents feel that if agencies would collaborate on service delivery as well as rules and regulations, it would not be as difficult to navigate. They feel that the system as it is currently runs on a "...theory of dysfunction." Susan felt that every time that the process was slowed down because of a miscommunication between agencies, or delays due to scheduling, it was time lost that could benefit Tim. She indicated that Tim was not the main focus, as he should have been.

Steve indicated that while Tim was adjudicated it was very difficult to keep up on all of the different sets of laws that are necessary when a child is in need of assistance.

We did not appreciate before we worked closely with a legal counselor that laws are pretty specific, and to get good at special education law is something. And then go on and learn human services law and then juvenile justice law and CINA and Medicaid.

Steve and Susan experienced many different agencies and the way they worked. In this case it seems that each agency that this family worked with was set up to function within itself, but not across agencies. There was not a common language or common practice from one agency or program to another. Steve and Susan found that navigating agencies was an extremely difficult part of getting Tim the help he needed.

Family Finances: "Teetering on the edge of falling into some serious poverty"

Not only were Steve and Susan trying to fight for their son to get the services he needed, but they also found themselves struggling to make ends meet, they found themselves "teetering on the edge of falling into some serious poverty". Steve stated:

I had \$40,000 in savings before we started the process, to pay for both children's education, that had been raised by both our families, grandparents and savings bonds. That was gone, quite frankly, that was gone in about three or four months. We were about \$100,000 in debt as we sit. We went to court again, and filed for bankruptcy. We are bankrupt.

Steve and Susan feel that they are lucky though, because they “have a beautiful house in a beautiful neighborhood” and they are, “going to be able to keep it.” Steve and Susan are extremely concerned about the future with regard to their children’s education. Steve stated, “We don’t know how our kids are going to go to college.” Steve and Susan have spent a significant amount of time and money trying to coordinate services for their child. They had hoped that the CINA process would help them by providing the financial support they needed to get Tim the services he needed. In the end that did not happen.

Future services

The process of getting help for their son has been a very long and difficult one for this family. The process does not seem to be any different now that Tim is older. Now the question becomes, “How does Tim receive adult services?” Steve stated, “We are now working the phones and learning the adult services that are around.” They have had to navigate many different agencies and learn many different sets of rules, regulations, and laws in order to help their son. As he becomes an adult, there are new rules, regulations and laws to be learned. When talking to this family it becomes clear that services are not collaborative, in fact in many cases it is the opposite.

Learning to Cope: “You are grieving.”

Steve, Susan, Amy and Tim went through serious life changing events during this time in their lives. Susan stated, “Basically my daughter was terrorized; we were terrorized, black and blue.” Tim struggled greatly with controlling his behavior while living at home, but that did not change right away when he was placed in a residential treatment facility. Susan recalled one of the most difficult times while Tim was placed in

a residential setting, "...our kid was the worst. That's not a good feeling. You go to a mental health facility and your kid is the worst." She felt that "everybody was at wits end." While working with a psychologist, Steve remembers, "Susan and I were teary and sitting in there and he said to us that we were grieving. I had never had it put to me that way. You are grieving." The entire family is in "therapy for post-traumatic stress." During the interview Susan received a phone call reminder of her therapy appointment, and then stated, "we have legitimate post-traumatic stress, not just from Tim's behavior, but from what it took going through hearings and court trying to get...services."

While trying to access services for their son to address his mental health needs, Steve, Susan, and Amy's mental health was greatly impacted. Steve stated:

I haven't even started to deal with issues too much of having a son with a disability. I'm still dealing with issues of people who are allegedly supposed to help your family be caretakers [of Tim] but just doing absolutely the opposite.

When getting involved in the CINA process Tim's parents thought they would be able to help their son with his mental health needs. They had no idea how much they would have to deal with the mental health repercussions even after the process had ended. It seems as though the very services that are available to address mental health issue are also those that can hinder progress.

CHAPTER 5

DISCUSSION

The results of this study contribute to current literature by exploring the experience of one family's journey through the mental health care system with relation to coercive power, expert power, legitimate power, as well as funding, insurance, and treatment.

Power

According to French and Raven (1960) coercive power is the power to force someone to do something against their will. The parents in this study experienced coercive power when they were presented with the information that other than paying for treatment "out of pocket," CINA was the only available option for receiving mental health treatment for their son. They were informed that the way the rules and regulations were written did not apply to them, but they needed to sign the papers in order to receive the help Tim so desperately needed. They were informed that unless they were able to pay for a private treatment facility, the only option would be to sign the papers. As residential treatment costs thousands of dollars per month, paying for private treatment was not feasible, leaving CINA as the only option.

Once Tim's parents signed the papers agreeing to the CINA process, they stated they were almost immediately treated as if they did not want or understand what was best for their son. Expert power is when a person or agency has knowledge or skills that someone else requires (French & Raven, 1960). Each agency possessed expert power,

while it seemed as though the parent's expert power (knowledge of their child and ability to make decisions in his best interest) was taken away.

The parents stated that each agency had its own set of rules and regulations. Tim's parents sought to gain the knowledge that each agency possessed so they could work in conjunction with the systems to meet the needs of their son. Despite the knowledge gained, the parents felt they continued to lack the expert power that the agencies possessed.

Before the CINA petition, Steve and Susan had legitimate power over the situation. Legitimate power is the perception that someone has the right to prescribe behavior due to election or appointment to a position of responsibility (Raven & French, 1960). They were able to make decisions they felt were in Tim's best interest. One would believe that parents always have legitimate power but once the CINA petition is signed that is not longer true. Once signed the power went immediately to strangers. For example, the judges and lawyers that handled Tim's case possessed legitimate power. It seems as though Steve and Susan had the power to say to the Court, "we can't meet his needs" and suddenly their power as parents was gone.

Even Tim, who at 13 was in need of significant mental health services, was awarded more power than Steve and Susan. Tim was appointed a guardian ad litem, who would advocate for Tim to go home if that is what he said he wanted.

Funding, Insurance, and Treatment

The five themes that resulted from data analysis seemed to be tied together by money. According to Zimmerman (2005) income has been shown in several studies to

have an effect on seeking treatment. Families who do not qualify for Medicaid, and do not earn enough to pay for private treatment seem to be affected greatly by the rising cost of mental healthcare services. The limits on insurance for mental health issues, and the high cost of treatment, put parents in a position where they have no choice but to hand over power to someone else.

Between the time this research study was proposed and the participants were recruited, a legislation change occurred. In April of 2005 the Iowa legislature passed an act that enables a parent or parents who have a child, in need of mental health services, the opportunity to qualify for a mental health waiver, instead of relinquishing rights in the CINA process.

This act states:

If a child has an emotional, behavioral, or mental health disorder, the psychiatric institution does not require court proceedings to be initiated or that a child's parent, guardian, or custodian must terminate parental rights over or transfer legal custody of the child for the purpose of obtaining treatment from the psychiatric institution for the child. Relinquishment of a child's custody shall not be a condition of the child receiving services (Iowa Code sec.135H.6(1)).

This bill is designed to allow parents to retain their parental rights while their children receive needed mental health services that are funded by the State of Iowa. The process begins with the Department of Human Service submitting a waiver to the United States Department of Health and Human Services for a child who qualifies. The requirements of qualification are:

1. The child needs behavioral health care services and qualifies for the care level provided by a Psychiatric Medical Institution for Children (PMIC).

2. The child is in need of treatment to cure or alleviate serious mental illness of disorder, or emotional damage as evidenced by severe anxiety, depression, withdrawal, or untoward aggressive behavior toward self or others and whose parent, guardian, or custodian is unable to provide such treatment (Iowa Code sec. 234.7 (2a 1-2)).

There are a limited number of “slots” available under this program, resulting in a waiting list.

Limitations

The data analyzed in this study are based on the opinions and experiences of one family who went through the CINA process. This case may not be representative of all families who have gone through the CINA process. Recruitment was more difficult than expected due to the highly personal nature of the research topic.

Implications for School Psychologists

With the number of children in need of mental healthcare services in Iowa and the country, school psychologists will likely encounter the CINA process or other similar processes that will allow access to mental health treatment. It is important for school psychologists to be aware of these processes and the difficulty parents may face in getting needed support and treatment. School psychologists should stay informed about the policies and procedures for accessing mental health care. For example, the new waiver program in Iowa that does not involve parents giving up parental rights, but provides children with the services that he or she needs. According to the National Association for School Psychologist’s Professional Conduct Manual (2000):

School psychologists consider children and other clients to be their primary responsibility, acting as advocates for their rights and welfare. If conflicts of interest between clients are present, the school psychologist supports conclusions that are in the best interest of the child. (p. 25).

It is extremely important for school psychologists to know and understand current mental health policies and practices in order to be advocates for children with mental health needs. Knowing policies and programs available to students of any socioeconomic background can be very beneficial in seeking treatment for a student and providing parents with needed support. It is also important for school psychologists to keep a close eye on public policy and not only advocate for the child but for policies that will benefit all children.

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APPENDIX A
Interview Protocol
Child In Need of Assistance

1. **How were you informed about the Child In Need of Assistance program?**
2. **How do you feel this program worked?**
3. **What services are available in your area that you can access for you child?**
4. **Are these services beneficial to your child?**
5. **How were you supported during this process?**
6. **How could you have been better supported during this process?**

APPENDIX B

Interview Protocol for Second Interview

When you were seeking services mental health issues didn't fit like MR or Autism, so you were told that CINA was the only option.	
When you were looking at the CINA requirements, you didn't feel that you fit the criteria, but a professional told you that you did because you could not provide for Tim financially.	
You were told by a professional that the CINA rules would not apply to you, but they did.	
After the CINA you felt you were viewed as an unfit parent and "the enemy."	
Once the CINA was in place, professionals wanted to keep it even when Tim was living in your home. They felt that it was good to have in place in case it was needed again.	
CINA affected Tim's progress and stability because of the delays in getting treatment (or making decisions?) and some of the requirements. For example, you talked about all that was involved in getting Tim to meetings.	
Do you feel you were treated as unwilling or unable to help Tim?	
What would it have looked like if the systems worked well together?	
You indicate bureaucracy tries to intimidate. Do you believe that is the way the system is set up or individuals and their roles or is there some other cause? (coercive power)	
You talked about the importance of having a psychiatrist that understands the system. How do you feel you eventually got access to a good psychiatrist?	
You feel like people without your advantages cannot advocate like you have for your child and family.	
The issues with Tim's health and the difficulty getting his needs met, affected your job as well as your emotional state.	
At one point, work policies did not accommodate family issues (reward power)	
While you were working to have Tim's needs met, you were still trying to parent him (teach him, provide for him) and your other child, as well as take care of your own emotional needs. How did you decide what came first?	