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## Hospital to School Transitions for Children: A Multiple Case Study of Family Experiences

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HOSPITAL TO SCHOOL TRANSITIONS FOR CHILDREN: A MULTIPLE CASE  
STUDY OF FAMILY EXPERIENCES

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**THE GRADUATE COLLEGE**

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## ABSTRACT

### **Hospital to School Transitions for Children: A Multiple Case Study of Family Experiences**

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Children with emotional and behavioral disorders (EBD) often present with significant impairments in social, emotional, and academic functioning. For those with the most severe impairments, hospitalization is an essential intervention. Prior to releasing children from the hospital, a discharge plan is typically created in order to facilitate successful transition from the hospital setting. Ideally, these plans set the stage for post-hospitalization supports by outlining a course of action for caregivers and coordinating services, with the ultimate goal of helping children maintain gains and reducing recidivism. Research suggests that current practices do not incorporate educational needs and supports into discharge plans. Although there is literature on what constitutes good discharge planning practices, there is very little research focusing specifically on discharge planning practices for youth. As such, it is unclear to what extent children's discharge plans are not only consistent with effective discharge planning practices, but also whether educational needs and supports are included.

The current study provides an exploration of this problem from the perspectives of caregivers. Moreover, it was suspected that caregivers were primarily responsible for facilitating hospital to school transitions. This is problematic because caregivers likely experience barriers during this process, including receiving inadequate hospital discharge plans, which are thought to have a negative impact on their ability to effectively facilitate transition and advocate for their child's needs.

The purpose of this study was to explore caregiver experiences with hospital to school transitions, including ways in which hospitals assist in identifying the child's critical needs and encouraging maintenance of skills. This study also explored caregiver needs at the time of discharge, caregiver knowledge of the educational system, and transition barriers and facilitating factors.

Results of this multiple case study suggest that although caregivers embodied diverse circumstances, there were several common themes unifying their experiences. In general, caregivers were unsatisfied with their hospital experiences because they were provided with very little helpful information. As a result, caregiver and child needs were often left unmet. Caregivers did not have adequate knowledge of the educational system and compounding this problem, they experienced several other barriers to effective transition. Results were used to devise recommendations for policy and practice in the hospital and school settings.

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## TABLE OF CONTENTS

ABSTRACT .....	iii
ACKNOWLEDGEMENTS .....	v
LIST OF TABLES .....	x
LIST OF FIGURES .....	xi
CHAPTER 1: INTRODUCTION .....	1
Introduction.....	1
Background of the Study .....	3
Purpose of the Study .....	6
Statement of the Problem.....	7
Significance of the Problem.....	7
Nature of the Study .....	8
Theoretical Propositions and Research Questions .....	9
Definition of Key Terms .....	11
Assumptions.....	11
Limitations and Delimitations.....	12
Implications for School Psychology .....	12
Summary .....	15
CHAPTER 2: REVIEW OF RELATED LITERATURE.....	16
Hospitalized Youth .....	16
Overview of Mental Health Problems .....	16
School-Based Support.....	16
Schools and Student Health .....	18
Children in Need .....	18
Systems Theory.....	20
Barriers to Learning .....	22
Schools as Community Centers .....	24
The Continuum of Care .....	25
Students with Significant Mental Health Needs .....	29
Emotional and Behavioral Disorders .....	29
Hospitalization .....	29
Length of Stay.....	30
Aftercare .....	31
Nature of Hospital Discharge Planning .....	35
Post-Hospitalization.....	46
Caregiver Experiences with Hospital to School Transitions .....	52
Summary .....	56

CHAPTER 3: METHODOLOGY .....	58
Statement of Purpose .....	58
Effective Discharge Planning .....	58
Barriers to Effective Hospital to School Transitions .....	60
Needs .....	61
Theoretical Propositions .....	61
Research Questions .....	62
Research Design.....	63
Case Selection.....	64
Recruitment Site.....	64
Participant Selection .....	65
Instrumentation .....	67
Data Collection .....	69
Participant Interviews .....	69
Document Collection .....	70
Reliability and Validity.....	71
Data Analysis.....	73
Summary.....	76
CHAPTER 4: FINDINGS .....	77
Overview.....	77
Case Overview .....	80
Case A.....	81
Background Information.....	81
Research Question #1 .....	86
Research Question #2 .....	88
Research Question #3 .....	89
Research Question #4 .....	91
Case B.....	94
Background Information.....	94
Research Question #1 .....	98
Research Question #2 .....	100
Research Question #3 .....	104
Research Question #4 .....	106
Case C.....	109
Background Information.....	109
Research Question #1 .....	112
Research Question #2 .....	116
Research Question #3 .....	118
Research Question #4 .....	120
Cross-Case Analysis .....	123
Background Information.....	123
Research Question #1 .....	126
Research Question #2 .....	127
Research Question #3 .....	129
Research Question #4 .....	130

Summary .....	133
CHAPTER 5: DISCUSSION.....	137
Overview.....	137
Study Purpose and Procedures.....	137
Interpretation of Findings and Assertions.....	137
Background Information.....	137
Caregiver Experiences with Discharge Planning and Transitions.....	138
Caregiver Needs.....	140
Caregiver Knowledge of the Educational System and the Hospital’s Role.....	142
Transition Barriers and Facilitating Factors .....	143
Implications and Recommendations for Policy and Practice .....	146
Current Practices and Needs .....	146
Facilitating Transitions and Coordination of Care.....	146
Significance.....	154
Recommendations for Future Research .....	155
Limitations .....	156
Conclusion .....	157
APPENDICES .....	158
Appendix A.....	158
Appendix B.....	163
Appendix C.....	165
REFERENCES .....	166
VITA .....	179

## LIST OF TABLES

Table 1. Summary of Main Findings .....	134
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## LIST OF FIGURES

Figure 1. Multiple Case Study Organizational Structure.....	79
Figure 2. Case History Similarities and Differences .....	125

## CHAPTER 1

### INTRODUCTION

It is estimated that upwards of 20% of all children in the United States will experience some sort of mental disorder with at least mild functional impairment. Further, it is estimated that approximately 10% of children have a serious mental illness, or an emotional and behavioral disorder (EBD), terms encompassing several diagnosable mental health problems that severely disrupt children's ability to function socially, academically, and emotionally (National Institute of Mental Health [NIMH], 2007; U.S. Department of Health and Human Services [DHHS], 1999). Hospitalization is often a necessary course of action for mentally ill children. Upon completion of this phase of treatment, hospitalized children are expected to return to their typical routines, which include going back to school. Effectively transitioning these children from the hospital to school setting poses significant challenges for the families and professionals working with these children.

Children with mental illness present with a variety of symptoms that interfere with their ability to adapt to change and cope with stressful situations (U.S. DHHS, 1999). They are also at significant risk for a variety of academic problems, including frequent school absences (Madan-Swain, Katz, & LaGory, 2004), and grade retention (Bessell, 2001). Furthermore, these children are at significant risk for substance abuse (SAMHSA, 2005, December). Not only do they present with significant social-emotional and/or behavioral problems, but also notable academic deficits (Trout, Hagaman, Chmelka, Gehringer, Epstein, & Reid, 2008b). In general, children with mental illness

experience a variety of challenges that can interfere with healthy functioning. Consequently, hospitalization is an essential part of treatment.

For hospitalized children, it is standard practice to develop a discharge plan. This is done to facilitate the transition from the hospital back to the home placement with coordinated outpatient services. It has been established that follow-up services post-hospitalization help children maintain gains achieved during admission and reduce the likelihood of significant problems in the future (Blanz & Schmidt, 2000; Goldston et al., 2003; Guterman, et al., 1987; Leichtman & Leichtman, 2002; Leichtman & Leichtman, 2004; Trout et al., 2010). Currently the literature is devoid of information pertaining to the nature of discharge planning for children leaving inpatient psychiatric care. Furthermore, there is little information available about how educational supports are incorporated into discharge plans. It has been suggested that the burden often lies on caregivers to effectively transition hospitalized children back to the school setting (Simon & Savina, 2010). However, there is little research exploring this issue from the perspectives of caregivers.

Children spend a significant portion of time at schools, which places schools in a unique position to provide structure and support for children transitioning from inpatient care. The general health and well-being of children is considered a prerequisite for learning (Adleman & Taylor, 2006), and as such, schools should have a vested interest in creating an environment that promotes optimal health and development. Schools generally create such environments, which can mitigate existing risk-factors for problems (Anderson, Kerr-Roubicek, & Rowling, 2006). For example, teachers play a critical role in supporting the social-emotional development for youth (Aviles et al., 2006).

Additionally, schools play a very important role in easing transitions (Adelman and Taylor, 2000b), such as school re-entry post-hospitalization, for students. However, it is apparent that schools are not typically involved in post-hospitalization consultation (Blanz & Schmidt, 2000; Goldston et al., 2003; Petersen, Scherwath, Kruthoff, & Koch et al., 2006). The current study explored the nature of this problem by highlighting family experiences with the hospital discharge planning process, particularly ways in which educational needs and supports were included in hospital discharge plans. Because it was suspected that families would have the responsibility of facilitating such transitions, this study focused on the perspectives of caregivers. Furthermore, results from the study were used to develop recommendations for caregiver advocacy, as well as future policy and practice related to effective hospital to school transitions.

### **Background of the Study**

The nature of the issue relates to hospital to school transitions for hospitalized youth. Compared to other disability groups, children with EBDs are at significant risk to fail one or more classes, drop out of school, be suspended or expelled, and have interpersonal difficulties and problems integrating socially (U.S. Department of Education's Office of Special Education Programs [OSEP], 2001). Eventually, these children are discharged from the hospital back to home and expected to reintegrate into the community. One main transition for youth post-hospitalization is reintegration to the school setting.

Schools are able to support all students' well-being in a variety of ways. Many schools offer support through provision of school-wide positive behavioral supports

(PBS). This level of support reaches out to all students, encouraging positive relationships and shaping appropriate social and behavioral skills (McKevitt & Braaksma, 2010). Supports can also be offered through a multi-tiered service delivery model (National Association of School Psychologist [NASP], 2009). Through this framework, universal supports are provided for all students. Additionally, targeted supports are available for those continuing to struggle with academic, social-emotional, and/or behavioral functioning. At the most intensive level, targeted, individualized supports and ongoing progress monitoring is provided when lower levels of support are unsuccessful. Ongoing support is provided and adapted based on the changing needs of the child (Glover & DiPerna, 2007). For children whose difficulties persist, a referral for evaluation for special education programming (U.S. Department of Education Office of Special Education Programs [OSEP], 2010) or accommodations via Section 504 of the Rehabilitation Act of 1973 (U.S. Department of Education Office of Civil Rights [DOEOCR], 2007) may be warranted. More generally, it has been shown that students feel supported when school staff create a positive and safe environment and encourage making connections with their students (Anderson, Kerr-Roubicek, & Rowling, 2006). Schools can provide a safe and supportive environment, which is considered not only a prerequisite to learning (Bruns et al., 2004), but also a way to buffer against the risk for potential poor outcomes for students with mental health needs.

Clearly, schools have the capacity to provide a continuum of support for youth post-hospitalization. However, it appears that educational supports and school consultations are not typically incorporated into hospital discharge plans (Blanz & Schmidt, 2000; Goldston et al., 2003; Petersen, Scherwath, Kruihoff, & Koch et al.,

2006). As a result, families must facilitate transitions and serve as educational advocates (Simon & Savina, 2010). This is problematic for several reasons. First, caregivers may lack adequate resources (e.g., financial, transportation) to execute this function (Dryfoos & Barkin, 2006; Owens et al., 2008). Second, caregivers often lack sufficient knowledge of the complex health care and educational systems to effectively advocate for their children's needs, and at times are unaware of their right to request services (Madan-Swain et al., 2004). Third, immigrant and non-English speaking families frequently face language barriers inhibiting effective communication with service providers (Madan-Swain et al., 2004). Finally, families often receive inadequate hospital discharge information (Keatinge et al., 2009), meaning parents might not have adequate information to share with schools and advocate effectively for services.

The current study explored the nature of this problem. It has been suggested that aftercare services can facilitate maintenance of gains achieved during hospitalization and assist in preventing future hospitalizations (Goldston et al., 2003). Logically, it would seem appropriate to include schools as a source of support in discharge plans; however, this does not usually happen. Results from this study have helped clarify caregiver experiences with this process in an attempt to offer suggestions for future advocacy efforts as well as changes in policy and practice, with the ultimate goal of improving outcomes for children.

## **Purpose of Study**

The purpose of the proposed study was to explore the nature of hospital to school transitions from the perspective of caregivers. Although many have argued the importance of aftercare for hospitalized youth, little is known about what goes into coordinating the discharge planning process (Goldston et al., 2003). In addition, even less is known about how educational supports are incorporated into such plans and what family experiences and perceptions of the process are. Children spend a significant amount of time at school, a critical place for support and social intervention (Fagan & Wise, 2000). It is clear in the literature that aftercare services benefit children in a variety of ways; however, schools are rarely mentioned as a source of support post-discharge (Blanz & Schmidt, 2000; Goldston et al., 2003; Petersen et al., 2006). Thus, caregivers are suspected to be responsible for facilitating hospital to school transitions, but this result is fraught with problems. This study explored caregiver experiences with hospital to school transitions. The study also explored whether caregiver experiences with hospital discharge planning procedures were consistent with the literature on effective discharge planning. Furthermore, the study explored the extent to which educational supports are addressed in hospital discharge plans, the role of the family in hospital to school transitions, the caregiver's perceived needs of the child upon hospital discharge, caregiver knowledge of school-based resources and support, and barriers experienced by caregivers in the transition process. Through exploration of these issues, it was hoped that caregiver experiences and needs during the discharge process would be uncovered. Results of this study were used to guide the development of recommendations for advocacy and effective discharge planning/transitioning practices.

## **Statement of Problem**

After discharge, hospitalized youth are expected to reintegrate into their previous environments and routines (Kaffenberger, 2006). For this reason, hospitals develop discharge plans to facilitate the transition from hospital back to community settings. Discharge plans have the primary goal of stabilizing the patient post-discharge (Guterman, Hodges, Blythe, & Bronson, 1989). School consultations and educational supports are not typically included in hospital discharge plans for children (see Blanz & Schmidt, 2000; Goldston et al., 2003; Petersen et al., 2006), placing the burden on caregivers to facilitate this process. Currently there is little research investigating the nature of hospital to school transitions from caregivers' perspectives.

## **Significance of Problem**

The significance of this problem is evidenced by the suspicion that caregivers are ultimately responsible for facilitating hospital to school transitions. Research has shown that caregivers face a variety of barriers preventing them from effectively carrying out this responsibility (Dryfoos & Barkin, 2006; Keatinge et al., 2009; Madan-Swain et al., 2004; Owens et al., 2008). As a result, previously hospitalized children are at risk for receiving inadequate support at school, which puts them at greater risk for social-emotional, behavioral, and academic problems. This is important because academic success or failure has a profound effect on self-esteem, identity, and opportunities for the future (Leichtman & Leichtman, 2002).

Effective discharge and transition plans will help increase the likelihood that children will maintain and generalize gains achieved during hospitalization (Guterman,

Hodges, Blythe, & Bronson, 1989). Discharge plans should target the specific, individualized needs of the patient, and for youth, that means including educational needs. Through incorporating the range of appropriate supports, discharge plans have the goal of improving youths' long-term outcomes. It has been established that students and communities benefit from the support and services offered by schools (Adelman & Taylor, 2000a; Bruns, Walrath, Glass-Siegel, & Weist, 2004; Dryfoos, 1994; Dryfoos, 1995; Owens, Murphy, Richerson, Girio, and Himawan 2008) and as such, school consultations and educational needs should be incorporated into hospital discharge plans. By exploring this issue from the perspectives of caregivers, it was hoped that additional barriers and supports to the hospital to school transition process would be uncovered to guide recommendations for improving this process in the future.

### **Nature of the Study**

The current study was qualitative in nature, employing a multiple-case study design (Yin, 2009). A qualitative methodology was selected because the focus of the study was on understanding the problem from individual participant perspectives. This is considered a hallmark of qualitative research (Marshall & Rossman, 2006). Consistent with case-study research, multiple forms of data were collected. First, participant survey interviews were conducted to collect demographic information as well as health, developmental, and educational history of the child. Survey data has the potential to yield quantitative data that can be analyzed in relation to other sources of evidence (Yin, 2009). Second, semi-structured participant interviews were conducted to further explore the nature of the problem from each participant's perspective. These interviews provided

detailed descriptions of participants' experiences. A final component of data collection involved reviewing of archival documents. Archival documents were limited to educational records, such as grades, attendance history, and discipline reports.

Data analysis for case study research does not follow a standard protocol or "cookbook" approach (Yin, 2009). Rather data analysis depends upon the researcher's style of thinking as well as careful consideration of alternate interpretations of the data. The theoretical propositions for this study guided the development of research questions, research design, as well as analytic strategy. Interviews were coded using a priori themes, pulled from the literature, but there was flexibility for inclusion of emerging themes. The general analytic strategy was to rely on the theoretical propositions guiding the study (Yin, 2009). Each case was analyzed individually, with repeated reductions in data, prior to aggregating overall findings across cases. Multiple sources of data were used to triangulate the data and ensure reliability. Similarly, peer review was used as a check on researcher biases and interpretations. Member-checks were conducted as a way of validating the researcher's interpretations of participants' experiences. Qualitative computer-assisted data analysis software (i.e., Atlas.ti) was used to facilitate the data analysis process.

### **Theoretical Propositions and Research Questions**

To date, the literature is scarce with information pertaining to the ways in which educational supports are included in hospital discharge and transition plans. As such, the primary goal of this study was to explore the nature of hospital to school transitions, particularly the way in which educational needs and supports are included, with a focus

on caregiver experiences. The following theoretical propositions guided the development of this study:

1. Hospital discharge planning procedures are inadequate due to a failure to incorporate educational needs and a failure to support families in the transition from hospital to school.
2. Because of inadequate discharge planning procedures, caregivers are burdened with the task of facilitating the transition process. Compounding this problem is the assumption that caregivers face significant barriers adversely impacting the transition process.

The following research questions were used in this study:

1. What was the caregiver's experience with the discharge planning process? Specifically, how did staff involve families in the process; who was involved in the process; how did staff help families identify the child's critical social-emotional, behavioral, and educational needs; and how did the hospital encourage the maintenance of skills gained during admission?
2. What were the caregiver's perceptions of their child's and the family's needs at discharge?
3. What knowledge did caregivers have about the educational system, and what role, if any, did hospital staff play in providing parents with information about potential educational supports?
4. What barriers and supports did caregivers face during the discharge/transition process?

## **Definition of Key Terms**

In an effort to provide a uniform structure through which concepts in this study can be discussed, the following definitions will be clarified:

**Emotional and Behavioral Disorder (EBD):** According to NIMH (2007), a serious emotional disturbance is a general term encompassing several diagnosable mental health problems that severely disrupt a youth's ability to function socially, academically, and emotionally. The term "emotional and behavioral disorder" will be used, however, to reflect the fact that behavioral difficulties are often comorbid. Of note, educational and clinical definitions of disability are not parallel. Thus, use of the more general term EBD, rather than specific diagnoses or disabilities, will be used in the discussion.

**Youth:** The term "youth" will be used to generally refer to both children and adolescents. Although children and adolescents represent different stages of development and are often separated in studies, for the purposes of the proposed study such delineation is unnecessary.

## **Assumptions**

The following assumptions are inherent to this study. First, it is assumed that the participants have accurately reported their child's academic and hospitalization history. Although this assumption is difficult to verify completely, it is assumed that participants were not motivated to falsify this information as there is little suspected benefit from doing so. A second assumption is that there will be researcher bias. In an attempt to eliminate the effects of researcher bias on data analysis and interpretation, the researcher identified biases prior to data collection. The researcher engaged in peer consultation

with research partners who were able to question her analyses. Furthermore, data were checked and rechecked with the intent of exploring possible alternative explanations. Finally, member-checks were conducted to allow participants to validate researcher interpretations.

### **Limitations and Delimitations**

This study contains several limitations and delimitations. One limitation possibly affecting the outcome of this study is using participant interviews. Participants may not have answered truthfully or their recollection of events may have been inaccurate. Another limitation is the recruitment method, where participants were called randomly. This approach may have limited the scope to a particular demographic. A final limitation was the Institutional Review Board's decision that participant medical records could not be solicited as archival records. Delimitations imposed by the researcher include limiting the scope of study to behavior schools in Southern Nevada; including only those participants who spoke English; recruiting adult caregivers of hospitalized children, rather than children themselves; and only including participants whose children were hospitalized for at least 72 hours.

### **Implications for School Psychology**

According to the National Association of School Psychologists (NASP; 2010): "School psychologists help children and youth succeed academically, socially, behaviorally, and emotionally. They collaborate with educators, parents, and other professionals to create safe, healthy, and supportive learning environments that

strengthen connections between home, school, and the community for all students” (para 1). School psychologists working in an educational setting can play a critical role in facilitating hospital to school transitions. In fact, NASP describes this as one of the key functions of school psychologists when working with community providers. In addition, school psychologists work with students to provide counseling, instruction, and mentoring for those with social, emotional, and behavioral problems; address barriers to student learning by identifying the best instructional strategies; promote wellness and resilience through reinforcing healthy social-emotional and behavioral responses; and understand and accept students of diverse backgrounds.

This study also has implications for ways in which school psychologists can work with teachers and administrators. Often, the mental health support that schools can provide is limited (Adelman & Taylor, 2000a). However, teachers and other school professionals can be educated about the needs of hospitalized youth, as well as how to best recognize those needs (Aviles et al., 2006). School psychologists can work with teachers and administrators to reduce barriers to learning through the development of student progress monitoring systems, academic and behavioral intervention systems, supporting of individualized instruction, promoting school policies to ensure the health and safety of all students, responding to crises, and comprehensive school mental health program (NASP, 2010). In a survey of teachers working with students who had been previously hospitalized due to mental illness, Simon and Savina (2010) found that 83% of teachers would like more information about the child’s disorder and over half would like a consultation with the school psychologist. Additionally, more than half the teachers reported having to deal with significant problem behaviors, including disruptive behavior,

anxiety, and aggression, and indicated a desire to have additional training in learning how to effectively manage those behaviors. Clearly, school psychologists are in a prime position to provide such training to school staff.

Importantly, the current study also has implications for working with families. Simon and Savina (2010) found that, after a hospital discharge, the burden is on the families to understand and share information about their child's hospitalization with the school. Although well-intentioned, parents typically are neither educational nor mental health specialists. School psychologists fit this role, and NASP (2010) identifies school psychologists as being in prime position to teach parents skills and enhance home-school collaborations. Although school psychologists may not be the first point of contact at the school when a student is reentering, their involvement in reintegrating youth back to the school setting is critical. Because school psychologists might not be the first point of contact within the schools, school psychologists also need to promote awareness of their role and function within the schools. Parents and teachers might be unaware that school psychologists exist, let alone understand their role and function. Therefore promoting the role of the school psychologist may be necessary in order to get referrals from parents/teachers when a student is transferring from a hospital setting.

Finally, results of this study have implications for future policy and practice related to hospital discharge planning, hospital to school transitions, and provision of school mental health services. In order to best reduce student barriers to learning, it has been suggested by some that the health care and education systems collaborate and undergo complete transformation (Adelman & Taylor, 2000a; Blanz & Schmidt, 2000; Weist et al., 2001). The primary goal of this collaboration is to create a prevention –

early-intervention – intervention continuum and to develop a full range of integrative services and care. These types of true collaborations integrate educational reform with the reorganization of community resources in order for children to receive the maximum benefits of education (Dryfoos, 1994). Because complete system restructuring may be difficult due to limitations in resources, smaller level changes may be more feasible. Results of this study were used to develop recommendations for practice at the hospital level, which include strategies for improving discharge plans, empowering caregivers, and collaborating with schools. Additionally, recommendations for schools were developed, including practices at the school and district levels.

### **Summary**

This chapter provided an overview of the study, which explored the nature of discharge planning, focusing on the inclusion of educational supports and caregiver experiences. The background of the problem was presented along with the nature of the study and its professional significance. Theoretical propositions and research questions were presented along with the related assumptions. Chapter 2 will offer a more comprehensive review of the related literature and Chapter 3 will describe the methodology with more detail. Chapter 4 will present the study's findings and Chapter 5 will provide a discussion of the findings, including recommendations for policy and practice.

## CHAPTER 2

### REVIEW OF RELATED LITERATURE

#### **Hospitalized Youth**

##### **Overview of Mental Health Problems**

With approximately 20% of children experiencing at least some functional impairment due to a mental disorder (NIMH, 2007; U.S. DHHS, 1999), this is clearly a significant problem. “Emotional and behavioral disorder” (EBD) is an umbrella term that can be used to describe an array of mental disorders, including but not limited to externalizing disorders (e.g., conduct disorders, attention deficit hyperactivity disorder), internalizing disorders (e.g., anxiety, depression), and psychotic disorders (e.g., schizophrenia). A report from the Surgeon General (U.S. DHHS, 1999) defines mental health as “the successful performance of mental function, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and to cope with adversity.” Children with mental disorders are much more likely to use alcohol, drugs, and tobacco than their mentally healthy counterparts (SAMHSA, 2005, December). Additionally, children with EBDs tend to have significant difficulty negotiating all aspects of their school environment (Aviles et al., 2006). Thus, mental health is clearly linked with successful school functioning and achievement (U.S. DHHS, 1999).

##### **School-Based Support**

Although the primary mission of schools is to educate children, schools play an major role in shaping the health and well-being of their students. Indeed, many of the

factors influencing academic outcomes also impact health outcomes. As a result, successful students are more likely to become healthy, productive adult members of society than are their peers who experience academic failure. Therefore, schools' abilities to improve the health and well-being of their students translate into increased educational potential (AAP, 2004).

The need for children's mental health programming has received national attention. Initiatives such as the New Freedom Commission on Mental Health (NFCMH; 2003) recommend expanding mental health services in the schools as a way to efficiently reach out to more children in need. Similarly, the National Association of School Psychologists (NASP; 2006, May) advocates for preventive social-emotional support in the schools, recognizing that increased attention to students' mental health will effectively improve both student and school outcomes. Preventive measures aim to reach out to all students, not just those receiving special education services or those targeted as at-risk for mental illness. However, schools are also capable of providing individualized services, such as counseling, for children identified as having a greater need.

Schools also provide extensive academic support, and are increasingly doing so within a response-to-intervention (RTI) framework. Response to intervention is a way to evaluate the effectiveness of academic instruction in meeting the needs of all students. Within the RTI framework, students making limited progress are provided with specific, evidence-based interventions meant to improve behavior or rate of learning. Support is ongoing and modified based on individual assessment and need (Glover & DiPerna, 2007). Although it is typically considered a general education strategy, RTI also

provides a way of identifying children with greater learning, social-emotional, and behavioral needs.

## **Schools and Student Health**

### **Children in Need**

Children are the keys to society's future, and because schools are where children spend a significant amount of time, schools have come to represent a major opportunity for social intervention. In fact, Reinke, Stormont, Herman, Puri, and Goel (2011) reported that upwards of 90% of teachers reported working with students with acting out behavior, defiance, attention problems, and family stressors. Further, the same percentage of teachers felt it to be the school's responsibility to support children's mental health needs, with the teacher playing a critical role. It is through proper instruction and support that schools can intervene against societal problems (e.g., delinquency, unemployment, poverty; Fagan & Wise, 2000).

Research has demonstrated that children with EBDs are more likely to be living in poverty and experiencing other significant family stressors. Dryfoos and Barkin (2006) estimate that at least 15% of teenagers' families live in poverty, meaning these students are likely to have poor health insurance coverage, if any. These families have few places to turn when they have a child in need of health care, including mental health care. Results from a study by Slade (2002) indicate greater use of school-based mental health services among those covered by Medicaid and those who are uninsured, compared to adolescents who are privately insured and adolescents who are covered under some other public insurance program, suggesting that schools are helping students with great need

for assistance. Additionally, about one half of children with EBDs live with only one parent, compared to about one fourth of the general population (Wagner, Kutash, Duchnowski, Epstein, & Sumi, 2005), which can exacerbate the financial difficulties experienced by families.

Racial and ethnic minorities constitute another group of children in need. This population often has unmet mental health needs, either being underserved or served inappropriately (NFCMH, 2003). Ethnic minority students present with distinct issues pertaining to mental health services, many of those being similar to children facing poverty. For some ethnic minority groups, particularly African Americans, stigma is a significant factor in determining whether or not mental health services are sought (NFCMH, 2003). In addition, this group has a disproportionately high rate of disability from mental disorders, not because of actual higher instances of disability but because of poor access to care. The NFCMH further points out that although all individuals with mental illness face dealing with fragmented services, unavailable services, high costs, and societal stigma, ethnic minorities face additional barriers. Some of these barriers include fear/mistrust of treatment, different cultural ideas about mental health, differences in communication patterns and help-seeking behaviors, racism, varying rates of being insured, and discrimination (individual and institutional).

A review conducted by Slade (2002) demonstrated an ethnic minority preference for school-based mental health services based on low cost, easier access to care, familiar setting in which services are provided, and better communication with school personnel than community-based providers. Thus, children with EBDs who are also ethnic minorities face additional burdens regarding access to care. These burdens can be

mitigated not only by providing school-based services, but also by coordinating care among community agencies, including schools.

Finally, families living in rural areas have traditionally been at a disadvantage with regard to health care access for a number of reasons. Owens, Murphy, Richerson, Girio, and Himawan (2008), in a study investigating the effectiveness of school mental health programming in Appalachia, suggest that barriers to mental health services in rural areas typically fall into categories of not available (e.g., lack of providers), not accessible (due to geographic isolation, transportation difficulties, or financial difficulties), and not acceptable (e.g., high stigma, lack of privacy in rural communities). Further, they point out that intergenerational poverty is often an issue in impoverished communities. As a result, many families face daily challenges that may interfere with participation in treatment, including substandard living conditions, transportation limitations, inadequate or no health insurance, and illiteracy. These issues are common of many rural areas, making it very difficult for families with a child with health care needs to access adequate care. As such, school-based services are an important, and may be the only, source of support for some children in need.

### **Systems Theory**

Systems theory provides a framework for understanding children's difficulties as being situated within a set of complex, interdependent systems. Bronfenbrenner and Morris (1998) describe their bioecological systems theory, explaining that a basic premise is that development is viewed as a function of forces coming from multiple settings, as well as from the interrelations among those settings. In other words, the person and environment form a dynamic, ever-changing system (Sigelman & Rider,

2003). From this standpoint, pathology, including mental disorders, is considered a developmental process that is affected not only by a host of biological and psychological changes, but also the contexts within which these changes occur (Aviles et al., 2006). Difficulties experienced by children and families are not seen as inherent deficits. Rather, difficulties are viewed as a mismatch between the child or family and various environmental contexts (Sheridan, Napolitano, & Swearer, 2005). Personal characteristics can include biologically inherited qualities (e.g., temperament), as well as acquired knowledge and skills that can be developed through interaction with one's environment. Further, systems theory accounts for personal characteristics as they are situated within the context of multiple systems. Therefore, youth development must be considered within the context of the whole society (e.g., the family, the school, the community, and the environment; Dryfoos & Barkin, 2006) and how these various systems interact with one another.

Thus, targeted intervention must involve schools and communities (Dwyer & Bernstein, 1998). When school staff and other professionals are taught to change the systems around the child, this changes the child. When the school can improve classroom management skills, use consistent problem-solving, individualize instruction, support team problem solving to back up the skills of staff and parents, children are happier, more attentive, and measurably more socially and academically successful (Dwyer, 2002). Systems theory not only highlights the importance of the role of schools in supporting students' needs, but also the importance of considering the interactivity of various systems and their impact on the child's functioning at school.

## **Barriers to Learning**

Providing students with environments that promote their skills and abilities will foster success in their ability to negotiate developmental tasks, while at the same time resulting in academic achievement. Students at risk for learning, behavioral, and emotional difficulties may be faced with a variety of barriers that could interfere with learning. Barriers include more than just health concerns, and encompass all factors that impede teachers from teaching and students from learning effectively at school (Dryfoos, 1995). Such barriers include poor instruction, lack of parental involvement, health problems, and other external factors outside of students' control (e.g., socio-economic status [SES]). Students cannot be expected to fully benefit from their educational experience when faced with these various adversities, which ultimately could lead to disengagement from school (NASP, 2008b). Children with EBDs often face many of these barriers.

Systems theory provides insight into the multiple determinants of student behavior, and how the role of teachers, and more generally schools, can be critical in influencing outcomes for children. In fact, a positive school climate, (i.e., students' learning environment) is considered a prerequisite to a host of positive educational outcomes (Bruns, Walrath, Glass-Siegel, & Weist, 2004). Given the co-occurrence of learning and mental disorders, the presence of barriers to learning, and the significant socializing influence exerted by educational institutions, it makes sense that schools offer various types of support for children (Domitrovich et al., 2010). Thus, in order to adequately effect change in the individual and reduce barriers to learning, it is necessary to consider risk factors at multiple ecological levels (e.g., in community and school

settings) via developmentally appropriate programming (Bronfenbrenner & Morris, 1998). In other words, schools should be considered an integral component in the systems model of children's functioning, particularly as an agent for reducing barriers to learning.

In a review of the literature, Humphrey and Wigelsworth (2012) found that several school-level factors, such as school size, urbanicity, socioeconomic status, parent education level, and school climate, can have an influence on student mental health outcomes. In their own study, though, the researchers found that schools that promote social competencies, such as motivation, self-awareness, self-regulation, and social skills, showed significant associations with reduced student mental health difficulties. Often this can be done via systematic school-wide efforts (e.g., positive behavioral supports). The authors further point out that because of individual student differences, it is not just the school climate that determines overall student well being. Rather, promoting specific skill sets, which may require a higher level of support than can be offered via low-level school-wide efforts, may be necessary. Thus, although some factors related to student mental health are beyond the school's control, schools can provide a continuum of student support services to mitigate risk factors.

When students are viewed as existing within an environment of complex, interacting systems, it is clear that schools play an important role in social-emotional development and mitigating barriers that may interfere with students' learning. The essence of teaching, then, involves creating an environment that mobilizes students and maintains that mobilization while effectively facilitating learning (Adelman & Taylor,

2006). Consequently, schools must be considered a viable source of support for meeting students' social-emotional and mental health needs.

### **Schools as Community Centers**

Primary care physicians typically serve as the first line of professionals identifying and treating mental health symptoms in adults; however, because of mandated school attendance, it is often schools that serve this function for children and adolescents (Reddy & Newman, 2009). In fact, Reinke, Stormont, Herman, Puri and Goel (2011) found that 75% of all teachers reported either working with or referring students for mental health issues. Furthermore, the U.S. Surgeon General (U.S. DHHS, 1999) reported that the largest provider of mental health services to children and adolescents is the public school system, with nearly 11% of all youth receive mental health services exclusively within the school setting.

In the context of systems theory, schools are viewed as part of a dynamic system. Because schools are part of communities, concerns that present in one area (i.e., student health needs and barriers to learning) can be considered as overlapping with other parts of the system. Ultimately, some (e.g., Adelman & Taylor, 2006) have argued that community should be the focus the system, and families should be understood and nurtured as the heart of the community. Furthermore, schools should be seen as completely embedded within that context and not seen as a separate agent. Thus, schools should be viewed as an invaluable point of access for students and families in need of mental health services because they can provide unique opportunities for not only intensive, multifaceted interventions, but also key preventive measures (Adelman & Taylor, 1998).

## **The Continuum of Care**

Given that in many schools, students' problems initially stem from a variety of external factors, the first step in preventing learning, behavioral, and emotional problems is to improve environments and systems that affect students' abilities to flourish (Adelman & Taylor, 2000a). According to Domitrovich et al. (2010), risk and protective factors can be organized into three general domains: individual factors (e.g., social-cognitive skills, temperament), quality of interactions with the environment (e.g., positive connections to others, parent-child relationship), and broader environmental factors (e.g., home-school relationship, neighborhood characteristics). Although increased exposure to risk factors elevates the vulnerability to psychopathology, there are instances of resiliency in which a "high-risk" individual remains healthy (Rutter, 1993). The co-occurrence of protective factors is considered a buffer against the influence of risk factors and reduces the likelihood of an adverse outcome in the face of risky conditions (Fergus & Zimmerman, 2005). Thus, the positive influence a school has upon students can serve to reduce the impact of exposure to significant risk factors.

Dwyer (2002) advocates for schools to partner with parents and community resources in order to reinforce appropriate social, emotional, and mental health through aggressive programs of primary prevention that aim to focus on children's and adolescents' strength and resiliency. Generally speaking, school-community collaborations use both school and community resources to strengthen schools, communities, and student learning and development. Collaborative efforts engender diverse vantage points, coming together to achieve shared goals by forming trusting relationships and by problem-solving (Sheridan et al., 2005). This collaboration is often

referred to as a system of care, which can be defined as “a comprehensive infrastructure of mental health or other necessary support services – essentially building and coordinating a flexible community network of services to meet the multiple and changing needs of children and adolescents” (SAMHSA, 2001, p. 4, para. 4). This system requires collaboration among resources and service providers in order to provide a comprehensive array of services. SAMHSA suggests systems of care embody core values that are (1) child and family centered, (2) community-based, with decision-making responsibility resting in the community, and (3) culturally competent. Additionally, a main goal of this approach is to allow children to move through different service settings without significant gaps in service provision (Foster, 1998).

It has been suggested that the primary goal of collaboration between the mental health and education systems should be to create a prevention – early-intervention – intervention continuum and to develop a full range of integrative services and care (Adelman & Taylor, 2000a; Blanz & Schmidt, 2000; Weist et al., 2001). Such a continuum targets all students in broad-based preventive programs, providing care for those with problems as early after onset as possible, and providing care for individuals with chronic and severe problems. For hospitalized children, “a key premise of the continuum of care is that it maintains improvement realized while the child was institutionalized and postpones, or even prevents, readmission” (Foster, 1999, p. 716). Children receiving services within systems of care are more likely to receive services in less restrictive environments and stay for shorter periods of time, are less likely to receive out-of-home placements, are more likely to have better overall general functioning, have improved school attendance and performance, have fewer contacts with law enforcement,

and more likely to have parents who are satisfied with services. Additionally, systems of care appear to cost less than other methods of service delivery (Stroul, 1993) and result in greater satisfaction with services provided (SAMHSA, 2001).

Adelman and Taylor (2000b) suggest an array of programmatic activities necessary for this continuum to function adequately. In the educational arena, these activities do so by effectively (a) enhancing regular classroom strategies to improve instruction for those with mild to moderate learning difficulties, (b) assisting students and families as they negotiate school-related transitions, (c) increasing home and community involvement with schools, (d) responding to and preventing crises, (e) facilitating student and family access to specialized services when necessary, and (f) outreaching to develop greater community involvement and support – including recruitment of volunteers. Further, broad-based interventions provide a solid foundation for support programs, and can also serve as a useful screening tool for identifying specific individuals that may need additional interventions. One benefit of this model is its cost-effectiveness (Blanz & Schmidt, 2000), as many of the elements of change do not require significant additional resources or major systems overhaul. Analyses of school-community collaborations suggest that better outcomes are associated with empowering families, as well as being able to address diverse populations and contexts. Families using school-based services tend to become more interested in contributing to the school and community by creating social support networks for other families, teaching each other coping skills, participating in school governance, and creating a psychological sense of community (Adelman & Taylor, 2000a).

In order for school-community collaborations to function most effectively, Adelman and Taylor (2006) recommend a complete restructuring of existing school programs. Similarly, Dryfoos (1994) suggests true collaborations integrate educational reform with the reorganization of community resources in order for children to receive the maximum benefits of education. Complete community and school system restructuring is desirable, yet for schools and school districts to move forward in this direction, significant overhaul of the involved systems would be required. It is an important fact that education models vary widely from mental health models (i.e., schools focus on competence and education while mental health providers focus on psychopathology and treatment; Adelman & Taylor, 1998; 2000b). Additionally, significant time and money would be needed for effective system changes to occur. Thus, system integration may be a long-term goal for mental health service provisions in the schools. More feasible short-term options may include other components of Adelman and Taylor's (2000b) recommendations (e.g., enhancing classroom strategies, facilitating school transitions, increasing home and community involvement with schools) and it is likely that many schools are capable of meeting these minimum expectations.

Schools clearly have the capacity to meet many of the mental health needs of youth. Although not all schools can provide an extensive array of services, it is evident that schools can minimally provide a safe and supportive environment (Bruns et al., 2004), teachers can foster the social-emotional development of students (Aviles et al., 2006), and schools and communities benefit from these services (Adelman & Taylor, 2000a; Bruns et al.; Dryfoos, 1994; Dryfoos, 1995; Owens, Murphy, Richerson, Girio, & Himawan 2008).

## **Students with Significant Mental Health Needs**

### **Emotional and Behavioral Disorders**

Compared to other disability groups, children with EBDs are at significant risk to fail one or more classes, drop out of school, be suspended or expelled, and have interpersonal difficulties and problems integrating socially (U.S. Department of Education's Office of Special Education Programs [OSEP], 2001). In extreme cases, one possible outcome for children with EBDs is psychiatric hospitalization. Children needing hospitalization present with significant functional impairment that cannot be managed on an outpatient basis (e.g., the child is a danger to self or others or is actively psychotic) and often have significant school problems. Upon discharge from a hospitalization, it can be expected that the student will re-enter the school.

### **Hospitalization**

Residential placement/hospitalization has been commonly viewed as a "last resort placement" (Trout et al., 2008b); however, it has increasingly been seen as an essential component of therapeutic intervention and even a treatment modality on its own for children with significant mental health needs (Blanz & Schmidt, 2000). It is worth mentioning that as more effective outpatient treatments have become available, there has been a shift toward referring more severe and complicated cases for inpatient admission (Blanz & Schmidt, 2000), suggesting that the children who do end up entering inpatient facilities present with serious psychopathology. According to USDHHS (n.d.) statistics for the year 2000, approximately 7% of all pediatric hospitalizations are for mental disorders, with affective disorders (primarily depression) being the most common reason.

For the age 13-17 group, affective disorders are the most common reason for hospitalization.

Children with severe psychopathology often present with significant academic impairments as well. Trout et al. (2008b) note that the behavioral, mental health, and family-related characteristics of children in residential care have been researched rather comprehensively. However, the academic functioning of these children has received considerably less attention. This is important, given the significant impact of poor academic functioning on child outcomes. To explore this area further, Trout et al. conducted a study investigating the demographic, behavioral, mental health, and educational characteristics of children at intake in an inpatient residential treatment program. Results indicated that children presented with significant behavioral, academic, and mental health risks. Specifically, externalizing behaviors were more pronounced than internalizing behaviors. In addition, the majority of children entering treatment presented with significant academic delays in at least one subject area. The authors note the combination of risk factors experienced by their sample is common of children in residential care, and can potentially have an adverse impact on both short- and long-term school successes. Interestingly, despite the evident academic delays, only 28% of the sample was receiving special education services at intake.

### **Length of Stay**

Length of stay is an important issue for hospitalized children. On average, children's hospital stays are 29% shorter than those of adults (USDHHS, n.d.), with the average length of psychiatric hospitalization for children amounting to just four days (Blanz & Schmidt, 2000). In a review of the literature, Blanz and Schmidt discuss the

child mental health trend in which huge financial burdens have resulted in significant pressures to reduce hospital stays and provide the bare “minimum necessary” intervention for children in need. According to an analysis by Case, Olfson, Marcus, and Siegel (2007) of the nation’s largest community hospital discharge survey, the period between 1990 and 2000 saw a dramatic reduction in duration of hospital stays for the mentally ill compared to other illness as well as a decline in total days of treatment. Results indicated the length of hospital stays for mentally ill children decreased by almost 75%, with the length of stay averaging to just four days. In addition, the population served changed in terms of severity of mental illness, with higher rates of severely mentally ill children being served. Subsequent to receiving intensive and short-term inpatient services, Blanz and Schmidt (2007) suggest that children be referred to less restrictive and less expensive settings, such as outpatient services. Bickman, Foster, and Lambert (1996) demonstrated that the availability of alternatives to inpatient psychiatric services for children and adolescents significantly reduced the rate of inpatient hospital admissions.

Availability of outpatient services thus serves a critical function for children in need, especially considering the trend of hospitalizing more severely impaired youth along with the push for minimum necessary stay. Additionally, shorter hospitalization periods mean children will be required to return to school while potentially still experiencing symptoms of mental illness.

### **Aftercare**

Guterman, Hodges, Blythe, and Bronson (1989) suggest that aftercare services for youth have the primary goal of stabilization post-discharge. Furthermore, they argue that

effective aftercare should assist youth in maintaining gains made while in treatment. Aftercare services ensure the transfer of and generalization of skills obtained during hospitalization to the patient's environment (Stroul, 1993).

The literature is scarce with information pertaining to the nature of aftercare services for children discharged from inpatient psychiatric care. Prior research (e.g., Trout et al. 2008a, 2008b) has shown that hospitalized children present with significant academic deficits, which are unlikely to be remediated over the course of a hospital stay. In addition, the aim of hospitalization is not complete remediation of symptoms. Rather, it is expected that youth will be stabilized, discharged, and returned to previous home and community settings. These children are in significant need of continued treatment – emotionally, behaviorally, and academically. It is well known that the need for follow-up services and continued treatment will help children maintain gains achieved during admission, and to reduce the likelihood of significant problems in the future (Blanz & Schmidt, 2000; Goldston et al., 2003). A review conducted by Pfeiffer and Strzelecki (1990) indicated that the outcome for children and adolescents in residential psychiatric care between 1975 and 1990 was significantly more favorable if they received aftercare services. However, what is lacking in the literature is information pertaining to the role in which schools can provide post-hospitalization support.

In a review by Blanz and Schmidt (2000), aftercare services were found to be positively correlated with and one of the best predictors of a favorable prognosis. The authors highlight the importance of outpatient services in helping patients to generalize and maintain gains made during inpatient treatment, and reduce the risk for future hospitalizations. Blanz and Schmidt argue that child inpatient services are only part of a

treatment continuum, and should be functionally linked with other programs and services such as partial hospitalization, home- or community-based care, and outpatient services. Of note, despite mentioning a variety of outpatient services utilized by patients, schools were not mentioned as a potential source of support.

As previously mentioned, it has been suggested that youths receiving psychiatric hospitalization undergo shorter durations of stay. However, this is predicated on the assumption that patients will be able to obtain and benefit from outpatient services (Goldston et al., 2003). These aftercare services should presumably (a) allow for continuity of care, which helps ease the transition from inpatient to community services, (b) help children and families maintain and extend the gains achieved during inpatient admission, and (c) serve a protective function against future hospitalizations. Goldston et al. point out that little is known about the time between hospital discharge and entry into aftercare service usage. Moreover, there is uncertainty about which factors relate to initial aftercare service usage and early discontinuation of service use. To address these ambiguities, Goldston et al. conducted a longitudinal study examining adolescent patient use of aftercare services up to six years post-hospitalization. Results indicated that 73% of patients utilized aftercare services within the first month, and 57% of adolescents continued to receive their initial treatment six months after services began. Although findings indicated a relatively high proportion of service use, it was evident that a significant subset of youth did not receive timely aftercare services or discontinued service utilization after a relatively short period of time. This is noteworthy, considering the assumption of need for services by families given the recent hospitalization. Goldston et al. point out that adolescents diagnosed with depressive disorders was a

strong predictor of early discontinuation of services, speculating that families may not have perceived the need for continued services when the child's behavior was compared to initial levels of distress. Findings also suggested there were no racial or ethnic differences in initial aftercare service usage; however, minority groups tended to discontinue service usage significantly earlier than other youths. The discontinuation of services by ethnic minorities, along with the research indicating decreased stigma associated with use of school-based mental health services (e.g., Owens et al., 2008; NFCMH, 2003; Slade, 2002), lends support to the idea that schools might be an appropriate avenue to provide support to this population. Interestingly, there was no mention of schools as a provider of aftercare services or as a source of post-discharge support. This lack of school involvement suggests there is little, if any communication between community health care providers and schools.

James et al. (2010) conducted a study examining the risk and determinants of rehospitalization of children and adolescents following their first inpatient psychiatric hospitalization. Results indicated that 43% of children discharged from the hospital experienced rehospitalizations over a 30 month timeframe, with more than 75% of those rehospitalizations occurring within a year from the initial discharge. The authors concluded that rehospitalizations indicate continued crisis for the youth. This finding underscores the vulnerability of this population immediately following discharge and supports the need for explicit linkages between inpatient facilities and community-based systems of support.

Given the resounding agreement that children need outpatient services post-discharge, it is astonishing to see a lack of research investigating the role of schools in

providing such services. In a review of the literature, Reddy et al. (2009) found that interventions designed for children with emotional disturbances tend to be most effective when tailored across settings, such as home and school. This finding is consistent with systems theory, which highlights the interactivity of various systems acting upon the child. However, it is apparent that schools typically are not involved in post-hospitalization consultation (e.g., Blanz & Schmidt, 2000; Goldston et al., 2003; Petersen et al., 2006).

### **Nature of Hospital Discharge Planning**

Much of the research that has been conducted on discharge planning has been done in the field of nursing, and the literature pertaining to children's discharge planning from psychiatric hospitals is limited. Moreover, what research does exist fails to take into account the discharge planning process as it relates to the needs of youths. Arguably, children have a set of needs different than adults, such as incorporating elements of parent education and school transitions.

**Goals of discharge planning.** Steffen, Kusters, Becker, and Puschner (2009) describe the goals of discharge planning, arguing that "the main objective of discharge planning is to smoothen the transition from inpatient to outpatient care by coordinating fragmented services, and thus to improve patient outcome and medication adherence, prevent re-hospitalization, and save costs" (p. 2). Similarly, Tennier (1997) highlights the role of discharge planning in terms of overall recovery from illness, its impact on hospital readmission, and reducing lengths of hospital stay. Watts et al. (2006) also point out in a literature review that inadequate continuity of aftercare services was a significant factor contributing to hospital readmission. Discharge planning helps ensure this

continuity of care by coordinating systems of care. Importantly, criterion for discharge from an inpatient setting is not complete remission of symptoms. Rather, the hope is that problems have been stabilized to the point that they do not significantly interfere with daily functioning and can be managed on an outpatient basis (Leichtman & Leichtman, 2004).

Generally, the goals of care coordination are to (1) develop a proactive plan for the family via a multidisciplinary team, (2) help the family access appropriate services, (3) facilitate communication across professionals, (4) provide efficient services and reduce costs, (5) optimize physical and emotional well-being of the child, and (6) generally improve the child and family's quality of life (AAP, 2005). The greatest effectiveness of the continuum of care is evident when care in a more restrictive setting is transferred seamlessly to a less restrictive setting. Additionally, there are not large gaps in time in which care is either not provided or is provided inadequately (Simons, Petch, & Caplan (2002). Benefits of successful care coordination include reduced hospital admissions and length of stay, reduced inpatient charges, reduced emergency department visits, and increased patient satisfaction (AAP, 2005).

**Discharge planning approaches.** Although the literature presents a number of discharge planning models in critical health care organizations, there is no agreement upon which approach is most effective or efficient (Watts, Pierson, & Gardner, 2006). Furthermore, Hedges, Grimmer, Moss, and Falco (as cited in Watts et al.) note there has been hardly any discussion on the strengths and weakness of specific models. Despite this drawback, Watts et al. present different discharge planning models used in the field of nursing. The first model is one in which a single specialist, such as a discharge

planner or case manager, is in charge of coordinating the discharge planning process. The role of the discharge planner is to begin thinking about discharge upon patient admission. An alternate model the authors discuss is the multidisciplinary approach. In this model, a variety of health care providers are involved in discharge planning, each member offering their own expertise in order to identify patient needs. However, the authors point to the need for the roles of each member to be clearly defined regarding authority, coordination, and responsibility. A final approach reported by the authors is the unit-based approach in which the head nurse on the unit is responsible for coordinating discharge planning.

In addition, Watts et al. (2006) conducted a study using an exploratory descriptive approach by surveying nurses in critical care organizations. Results indicated that the single-specialist approach was not supported by most nurses, despite this approach being presented frequently in the literature. Rather, most nurses employed a multidisciplinary team approach (Watts et al., 2006). Interestingly, few of the nurses surveyed felt it was the responsibility of a designated discharge nurse to coordinate the process, despite their literature review suggesting otherwise. The authors explain that not only is it generally favorable to have a coordinator, but also clearly defined roles for each member of the multidisciplinary team.

In a similar study investigating the components of effective discharge planning, Bull and Roberts (2001) conducted a survey of key persons involved in discharge planning in a geriatric hospital. Findings indicated that most healthcare professionals found the multi-disciplinary team approach to be most effective for a “proper” discharge. In short, each specialist was able to bring a different type of expertise to the table in terms

of recommendations for discharge. Additionally, the authors found effective teamwork to be critical to making the multidisciplinary approach successful. They identified three aspects of effective teamwork. First was a sense of trust among team members. Second was a blurring of disciplinary boundaries, with the focus being on a more holistic approach to patient needs. Finally, effective teamwork depended on someone taking responsibility for coordinating the efforts. Interestingly, it was not mentioned who specifically should be responsible for taking on this key role. Findings also suggested that effective teamwork was dependent on effective communication within the hospital, between the hospital and family, and between the hospital and external service providers.

In addition, four stages of discharge planning emerged from Bull and Roberts' (2001) research. The first stage involved all members of the MDT getting to know the patient. During this phase, a discharge planning checklist was introduced and reviewed with the patient. In the next stage, initial discharge plans were discussed and all members of the MDT were actively involved in planning. The third stage was characterized by getting ready to go home. During this phase there was increased communication with the community team of providers. The final stage involved making the transition out of the hospital. During this phase patients established or resumed routines at home and built relationships with community team members. The authors found that gaps in communication were an impediment to effective discharge planning.

In another example from the field of nursing, Rose and Haugen (2010) identified four main components to effective discharge planning. These components were not extrapolated from the literature, but rather the authors' experience with the discharge planning process in nursing. Despite the limitations of such an approach, the identified

components are likely have some ecological validity and are nonetheless useful in helping to conceptualize a framework for discharge planning. The four components identified by the authors include assessment of the patient's post-hospital needs; collaboration with the health care team to determine an appropriate discharge date and disposition; identification and coordination of necessary resources for ongoing care; and assurance that necessary paperwork, prescriptions, and patient education were completed. Consistent with other findings (e.g., Bull & Roberts, 2001; Watts et al., 2006) the authors recommend use of a multidisciplinary team approach and consider effective communication within that team as being vital to successful discharge planning.

Based on their years of experience working in residential care facilities with adolescents, Leichtman and Leichtman (2004) propose three sets of issues to consider in the discharge planning process. The first issue is living arrangements. Families often struggle with issues of divorce and, in conflict situations, questions may arise over where the child will stay. There may also be other circumstances making it inadvisable for the child to return home, and thus, alternative living arrangements must be made. A second issue involves decisions about formal treatments after discharge. Usually discharge plans incorporate medication management, therapy, family work, and other identified needs. Once a plan has been outlined, the treatment team, including members from across disciplines, can begin coordinating services and acclimating the patient and family to new members of the team (e.g., outpatient therapists). The authors argue that facilitating the process well before actual discharge allows families to feel more secure about the upcoming discharge. The final set of issues presented involves finding ways to extend the "residential" aspect of residential treatment. Leichtman and Leichtman argue that

residential care is not only about providing therapy to adolescents, but also helping them negotiate basic developmental tasks. Thus, clinicians need to help patients reflect upon what enabled them to be successful in treatment and think about how they can apply those skills to be successful at home and in the community. The authors also highlight the important role of schools in this process and place heavy emphasis on having adolescents and their parents working closely with schools in order to address academic and psychosocial needs prior to discharge. Interestingly, the authors do not talk specifically about how parents and adolescents are prepared to negotiate the school system, advocate for student rights, and who should be responsible for properly educating parents on these issues.

In terms of individual therapy, Leichtman and Leichtman (2004) recommend several termination exercises to do with the patient. First they discuss the creation of a relapse prevention plan. These plans allow patients to (a) identify critical problems, (b) describe ways in which such issues were manifested prior to treatment and are currently displayed on the unit, (c) identify signs problems are returning, (d) identify triggers for relapse, (e) identify ways in which such problems can be dealt with effectively, and (f) specify ways in which others can help them.

Second they assist the adolescent in identifying “rules, expectations, and consequences” for the home. The idea is to prepare the adolescent for generalizing the structure of residential care into the home and accepting this structure in the home. This task consists of three steps. First, in family therapy, a comprehensive list of problems and conflicts at home are identified. Patients are then encouraged to think about ways in which they can make recommendations to their parents about expectations regarding

these issues and consequences should rule violations occur. Finally, adolescents discuss their recommendations in family therapy where the parents get to make the final decisions. Often the agreed upon strategy is tested on family visits prior to discharge, and at discharge, a social worker sends home a final written document outlining the agreement.

A third termination exercise is the creation of a crisis plan. These plans outline the steps that can be taken to address targeted problems and prevent further deterioration in functioning. In general, the adolescent identifies thoughts, feelings, and behaviors ranging from “doing well” to “having things get as bad as they can get” and then identifies an appropriate plan of action for each.

Leichtman and Leichtman (2004) argue that as patients prepare to discharge from residential care, parents assume many of the functions carried out by childcare staff members. Parents are involved in developing rules and consequences, relapse prevention plans, and crisis management plans, all to help maintain gains after discharge. The authors note that, unlike treatment plans that are processed with therapists and direct workers, discharge plans are processed with social workers, parents, peers, and outpatient treatment providers. In other words, the authors describe a multidisciplinary approach to discharge planning. It is interesting to note the emphasis placed on schools in transitioning patients out of the hospital, yet there is no inclusion of school personnel, or who is responsible for coordinating the school component, in their article.

In general, Guterman, Hodges, Blythe, and Bronson (1989) highlight a shift in residential treatment toward a more ecologically-based model of practice. This model stresses the importance of engaging (rather than separating) the child from the elements

of the child's natural ecological context. Elements from the multiple systems affecting the child are considered, including the child's peers, neighborhood, school, and importantly, family. Furthermore, the model indicates a need for continuity of care across these environments (in this instance, from family to residential care and back). Thus, aftercare treatment can be viewed as one stage of the ecologically-based model of residential services, aimed at preventing further out-of-home placements (Guterman et al., 1989).

Although the current literature base is limited (Guterman et al., 1989), experts have begun setting forth a theoretical base from which aftercare programs can be developed (Trout et al., 2010). From an ecological approach to community/home reintegration, several factors have emerged as being critical to successful outcomes for youth transitioning out of residential care (Trout et al., 2010). These factors generally include services designed to (a) maintain skills learned in residential care, (b) work with the families during the child's stay and as they transition home, and (c) identify critical social, emotional, and educational supports to facilitate the transition process. What is relevant to the proposed study is the educational component. However, although educational supports have been identified as critical to a successful discharge, there has been little, if any, discussion regarding the way in which educational supports are or should be incorporated into discharge plans. As previously mentioned, schools or educational supports are often not incorporated into hospital discharge plans. Logically, then, the burden falls on caregivers to facilitate this transition by coordinating systems of care and advocating for their children's needs.

**Discharge planning needs.** There is little understanding about what makes for a successful and seamless transition across settings (Simons, Petch, & Caplan, 2002) and moreover, there is a very limited amount of literature focusing specifically on hospital-to-school transitions for children (Simon & Savina, 2010). There is a need for more knowledge about specifically which hospital-based (e.g., social worker, case worker, therapist, transition coordinator) and school-based (e.g., counselor, administrator, school psychologist) professionals are involved in the hospital-to-school transition process and what information is needed by involved parties. Having more knowledge of this issue (e.g., who is involved, how are schools incorporated into the process) would facilitate the development of more effective and efficient discharge plans, thus making for a smoother transition and hopefully better long-term outcomes.

Similarly, little is known about children's needs at the time of transition (Trout et al., 2010). Guterman, Hodges, Blythe, and Bronson (1989) point out that despite the seeming benefits of aftercare services, most residential facilities remain undeveloped and unspecified in terms of targeting specific needs that ensure the gains made in residential treatment. Although Guterman and colleagues highlighted this gap in knowledge over 20 years ago, it remains that little is known about the specific risks and needs of children transitioning out of residential care. Understanding these risks and needs is a critical measure in developing targeted aftercare plans for youth (Trout et al., 2010).

Another area of need involves the effectiveness of discharge planning. Noting that no systematic review of the effectiveness of mental health discharge planning has been conducted, Steffen, Kusters, Becker, and Puschner (2009) conducted a meta-analytic study to determine and estimate the efficacy of discharge planning interventions

on patients being discharged from inpatient mental health care to outpatient care.

Generally, findings support the implementation of discharge interventions. They tend to reduce the length of hospital stays, improve adherence to aftercare services, and aid in symptomatic improvement. In addition, Steffen et al. argue that good clinical practice would entail at least one scheduled meeting with all parties concerned prior to patient discharge, with family involvement being one of the core elements. However, these standards were surprisingly not reflected in the published studies in their review.

Although findings seem to be contradictory (e.g., discharge planning is effective without significant family involvement), the authors note two limitations of their study that may help account for this discrepancy.

First, the authors excluded a large number of studies based upon a strict definition of “discharge planning” in order to avoid including studies in which there was no clear line between where discharge planning ended and aftercare services began. Second, Steffen et al. note that the definition of “sufficient” adherence to follow-up care contained much variability across studies, ranging from attending one outpatient appointment to keeping several appointments during a given time. Therefore, the effect of family involvement in discharge planning effectiveness appears to remain somewhat uncertain. Of note, the mean age of participants in the authors’ study was 37.8. Thus, it appears that the results cannot be generalized to a youth population, who arguably have different discharge planning needs (e.g., educational supports) than adults. Additionally, failure to include family as part of the discharge planning process may have detrimental outcomes for youth. Clearly more research is needed regarding the role of families in the discharge planning process for youth.

Another area of discharge planning need concerns the structure of the procedures. Tennier (1997) conducted a descriptive study of the discharge planning process in a Montreal hospital. She surveyed a variety of health care providers (e.g., nurses, social workers, physicians, rehabilitation specialists, etc.) and found that approximately half of those surveyed felt there was no clearly defined discharge planning procedure. Furthermore, 40% of employees felt that the roles of those involved in the discharge planning process were not clearly defined. Tennier also found that an impediment to effective discharge planning was a lack of communication across disciplines. If hospitals lack clearly defined discharge planning procedures, it cannot be expected that effective discharge planning will take place.

Simon and Savina (2005) examined the typical transition practices of inpatient therapists involved in the transition process for children with mental health diagnoses. The authors surveyed inpatient therapists about their role in transition practices. Results indicated that respondents used a variety of methods, typically prior to a child's discharge, to facilitate transition from hospital to school. Most frequently, therapists met face-to-face with caregivers, followed by phone consultation with school personnel, phone consultation with caregiver, phone call to school personnel, and face-to-face meetings with school personnel. Activities occurring post-discharge were much less frequent and often involved phone conversations over face-to-face meetings. Additionally, results suggested that therapists gave priority to consulting with caregivers over school personnel, thus placing the burden on caregivers to transmit relevant information (e.g., the child's diagnosis, effective intervention strategies, medication side-effects) to the school. Of note, although most therapists reported engaging in some form

of discharge planning consultation with caregivers, several did not, thus limiting the transmission of information from hospital to caregivers who will ultimately assume responsibility for the child. In terms of the content of consultations, the authors found that the majority of participants reported including behavior related to the child's diagnosis and interpersonal relationships with peers. However, it is unclear who initiated these discussions. In addition, therapists also reported frequently discussing common fears and concerns expressed by children prior to discharge. Finally, participants reported that caregivers and school personnel appeared receptive to the transition methods used by therapists. What is not known from the study is actual effectiveness of these transition methods. Additionally, because the research was conducted with therapists, caregiver perceptions about the process remain unknown.

Although prior research has provided a rationale for collaboration between hospital and school settings in transitioning children, it is unclear whether this rationale is being followed. In addition, the literature is remiss due to its failure to explore factors specific to the nature of transition of children from hospital to school settings (Simon & Savina, 2005).

### **Post-Hospitalization**

**Role of caregivers.** After discharge, there is a greater expectation for individuals (and their families) to have self-determination. In other words, there is an expectation upon discharge that individuals will understand their illness, carry out treatment at home, integrate treatment regimens into daily routines, and carry out daily activities (Falvo, 2005). Caregivers are expected to carry out treatment and crisis plans (Leichtman & Leichtman, 2004) and serve as educational advocates. It is concerning that parents are

expected to serve in this role despite being provided with little to no information regarding educational needs or supports in the discharge plan. Furthermore, the expectation that caregivers will be able to carry out treatment plans and reintegrate children into their daily routines assumes parents will be able to successfully navigate two potentially unfamiliar systems (e.g., the health care and educational systems; Kaffenberger, 2006).

Some families face additional barriers post-hospitalization. These barriers may interfere with caregivers' ability to successfully transition and advocate for students, which suggests children may not be in an optimal position for recovery and reintegration into typical routines post-hospitalization. Because caregivers may not have access to the resources they need, and these burdens are in part due to constraints imposed by social systems, understanding and attempting to overcome barriers becomes an issue of social justice.

As mentioned previously, children living in poverty often have poor insurance, if any at all (Dryfoos & Barkin, 2006), which translates into an additional burden of filing for Medicaid. Additionally, families in poverty may struggle transporting their children to aftercare services due to poor access or lack of transportation. Families living in rural areas often face poverty as well. Rural families also have the problem of service being not acceptable, not available, and/or not accessible (Owens et al., 2008). Illiteracy is another burden for families living in poverty or rural areas. All of these factors exacerbate the burden already placed on families to serve as caregiver and advocate to their child.

Another group facing additional burdens is immigrants. Immigrant families generally have a more difficult time than established families in meeting their child's educational needs by providing a consistent and supportive environment for learning (Madan-Swain, Katz, & LaGory, 2004). Most of these families struggle with the additional burden of having to adapt to the dominant culture and speaking a different language. In homes where English is not the primary language, families may have difficulty communicating with the school. Additionally, parents may feel a lack of understanding for the school culture, and might not realize that it is acceptable to request services for their child even when such services were first not offered by the school. Immigrant families with chronically ill children also have the burden of not only negotiating the educational system, but also the complex system of medical care.

Madan-Swain et al. (2004) mention two factors making it difficult for caregivers in immigrant families to navigate both of these complex systems. First, families' social and financial resources are often limited. Second, language barriers put them at a disadvantage for identifying available community resources. As such, some families may find it easier to homeschool their children, thus making it critical that the importance of school to a child's overall development be explained to caregivers. Hospital personnel can serve as a liaison for connecting families to community resources, including the schools. However, it is unclear that this collaboration actually occurs.

**School Re-entry.** "Successful school reentry is focused on meeting the unique needs of the individual child or adolescent, ensuring continuing academic and social skill development by appropriately modifying the school environment, and assisting parents to be effective advocates for their children" (Madan-Swain et al., 2004, p. 645). Although

there is much literature describing the school reentry process for children, there is limited empirical evidence for the process. Successful programs generally have an established formal liaison to function between various systems. Additionally, Madan-Swain et al. have identified three major phases to the school reentry process. Phase 1 begins shortly after diagnosis and involves hospitalization, initiation of community links, and development of a plan to reenter school. During this phase, the child's school behavior and parental involvement with the school prior to the illness are assessed. Additionally, interim educational programs, like homebound instruction, are arranged, and plans for educating peers are developed. Phase 2 involves contact and education of school personnel by the liaison or medical team, with a focus on providing information related to the child's illness and treatment, planning for absences, anticipating psychosocial adjustment problems, and planning for educational accommodations, including potential special education services. The focus of this phase is preparing the teacher and peers for the student's imminent reentry. Phase 3 is the final phase, in which follow-up contact with school personnel and parents occurs. Again, it is not clear whether this process is actually being carried out and if so, carried out efficiently.

Schools have the potential to play an important role in supporting children post-hospitalization, particularly for those who have no insurance or poor coverage (Slade, 2002), are of ethnic minority status (Slade, 2002), and live in rural areas (Owens et al., 2008). One way students can be supported in the schools post-hospitalization is via the Individuals with Disabilities Education Act (IDEA; OSEP, 2010) and Section 504 of the Rehabilitation Act of 1973 (U.S. DOEOCR, 2007). IDEA supports students in the schools by providing an Individualized Education Program (IEP) as a result of a

disability that significantly interferes with the ability to achieve. Targeted interventions are implemented to meet students' academic, social-emotional, and behavioral needs. Behavioral intervention plans can also be developed to help manage significant problem behaviors interfering with a student's ability or others' abilities to learn. Section 504 is more broad-reaching in that it prohibits discrimination against any student with a demonstrated disability. Through Section 504, children may receive a plan, often referred to as a 504 plan, outlining accommodations to promote academic success. An example of an accommodation is provision of extra time on tests for students who have difficulty concentrating. Additionally, students with low frustration tolerances could be offered an accommodation to go to a "safe place" to calm down.

Aside from IEPs and 504 plans, schools can provide a continuum of social-emotional, behavioral, and/or academic supports for students. Many schools have adopted a multi-tiered service delivery model, which is aimed at preventing problems, preventing the worsening of problems, and identifying and intervening on those students with the most risk for difficulties (Burns, 2011). Within this model, schools can provide an array of indirect and direct mental health services for students, including consultation, development of behavioral intervention programs, ongoing progress monitoring, direct services for individuals and small groups, assessment, evaluation of intervention programs, crisis intervention, and even referral for more intense levels of support (NASP, 2008b; NASP 2009). At the broadest level, schools can implement a positive behavioral support (PBS) system with relative ease. Through a PBS system, an environment is created by which students know what is behaviorally expected of them at all times. Schools can use PBS to promote positive relationships and offer students the social and

behavioral skills needed to be successful learners and citizens (McKevitt & Braaksma, 2010).

Schools also generally create an environment in which students feel supported. A safe and supportive environment, including supporting social-emotional well-being, is considered a prerequisite to learning (Bruns et al., 2004). When schools are able to create conditions that allow students to make positive connections with teachers and staff, they help support the wellbeing of all students and mitigate the risk for potential poor outcomes for students with more significant mental health needs (Anderson, Kerr-Roubicek, & Rowling, 2006). Demonstrating this, Anderson et al. conducted a qualitative study exploring the perspectives of school staff about how students with mental health needs are able to connect to their school, and how staff can enable that connection. Results indicated that most staff believed trust was a key factor along with relating to the students on a “human” level. Staff also highlighted their support for one another and having opportunities to connect with students as contributing to the positive environment at school. Thus, it seems that creating a “culture that cares” was an important element in students feeling supported at school. Creating this kind of environment is in line with the programmatic activities recommended by Adelman and Taylor (2000b). Furthermore, it seems that anything a school can do that is in line with these recommendations, aside from complete system overhaul, will ease the re-entry of previously hospitalized children back to school. Particularly, working with families to ease the transition would help parents to better understand and negotiate the school system in which their child participates.

One barrier to school reentry for children is a lack of information. Oftentimes families and medical teams are unaware of the specific information related to services schools can provide to children (Kaffenberger, 2006). Although model programs have been described, there are few programs in existence that facilitate school reentry and multidisciplinary collaboration between school and medical teams for children with chronic illness. Failure for multidisciplinary collaboration to occur would mean more responsibility on caregiver coordination.

Another barrier to reentry has to do with reception of the child at school. Clay, Cortina, Harper, Cocco, and Drotar (2004) conducted a survey of school personnel to gain understanding of attitudes and experiences toward children with chronic illnesses. Results revealed that nearly all participants reported knowing a child at their school with a chronic health condition; however, approximately one third reported having no academic training on the issue, with a similar proportion reporting not receiving any training in the workplace. Of note, over half of the respondents reported that they did not feel responsible for dealing with issues related to a student's chronic health condition. This is seriously concerning because it implies that school personnel may not take initiative to take appropriate measures to meet children's needs. It is even more concerning in situations where parents, for whatever reason, have failed to contact the school regarding their child's needs.

### **Caregiver Experiences with Hospital to School Transitions**

A number of barriers make cross-disciplinary collaboration between school and health care providers difficult, such as differing definitions of disability; misunderstandings about the roles of parents, educators, and health care providers; and

differing approaches to supporting children with acute and chronic health conditions. These barriers can often prevent communication between school and health care providers, resulting in a burden being placed on the family to navigate a confusing, stressful process of trying to coordinate cross-disciplinary supports (Shaw, Clayton, Dodd, & Rigby, 2004). In fact, in a policy statement by the American Academy of Pediatrics (2005), families are identified as being the primary agent in facilitating care coordination across systems. This coordination is often complicated because there is no single point of entry to the multiple systems of care, and complex eligibility criteria determine the availability of funding and services for each type of provider. As a result, families may struggle to gain access to the services that would benefit their children. However, little is known about caregiver experiences with this process, particularly with regard to the transition back to school.

Keatinge, Stevenson, and Fitzgerald (2009) conducted two linked qualitative studies aimed at identifying parents' perceptions of discharge information relating to a recent hospitalization of a child for a medical condition. Parents were interviewed via phone subsequent to discharge. In the first study, only one of seven participants expressed complete satisfaction with her child's discharge information. All parents reported receiving verbal information. However, written information, when obtained, most frequently comprised the discharge summary, which parents generally did not find helpful due to the nature of the language. One parent commented that she was told "nothing about what might happen to him (the child)" prior to his discharge. Although medication was discussed with this mother, it was done "in a fashion...but not that I

totally understood.” Several parents commented that they were uncertain about providing continued care for their child.

In the second study, parents also reported receiving inadequate information from hospital staff regarding patient discharge. In terms of discharge needs, parents identified several key components, including using simple and concise language so that discharge information could be easily understood, and providing an outline of the child’s illness. Several parents noted receiving information from hospital staff that was difficult to understand, misinterpreted, and in some cases, contradictory. Additionally, most parents described a preference for receiving some form of written discharge information along with verbal information, rather than verbal information alone. The researchers also found that some parents were under stress due to lack of sleep during their child’s hospitalization. For example, one parent reported that at discharge, “it was my fault too, but with three days of being so tired. I didn’t think of all the questions I needed at the time.” This finding highlights the fact that a child’s hospitalization results in significant stress for the caregivers. As a result, caregivers can end up in a sort of reduced capacity to advocate for their children and are thus more dependent upon hospital personnel to provide the needed information.

The authors’ findings suggest that verbal as well as written communication is helpful, plain language is important, messages from different members of the health-care team were sometimes inconsistent, and parents need information specific to their child’s circumstances. Both studies revealed that verbal information is provided more frequently (and exclusively) than written discharge information. Compounding this issue, parental stress and fatigue makes the likelihood of verbal information being remembered very

difficult. Additionally, written information that was provided was not helpful due to the language used. Many parents felt poor team cohesiveness led to lack of organization and communication, resulting in the sometimes conflicting information received (Keatinge et al., 2009).

There has been an increased awareness among health providers that comprehensive patient information needs to be provided to caregivers in a format that can be understood. There are a variety of possible formats, including verbal and written information, audio/videotapes, Email communications with doctors/care providers, and websites to access additional information. These formats stand in contrast to verbal communications only, which have the potential to disempower patients and caregivers because information might not be remembered (Johnson & Sandford, 2005). To explore this issue further, Johnson and Sandford conducted a literature review investigating the effectiveness of different formats for presenting information at time of discharge from an acute hospital setting to home. Participants in the review were caregivers of children being discharged from hospital to home. Although only two trials met inclusion criteria for the review, results were noteworthy because they highlighted the need for caregivers to receive information at discharge to enable effective subsequent care. Results further indicated that providing written and verbal information, compared to verbal information alone, significantly increased caregivers' knowledge about the child's condition. This study is important because it highlights the dearth of research that has been conducted specifically exploring caregiver perceptions of issues related to discharge and transition planning from a hospital setting.

## Summary

Current discharge planning practices do not appear to incorporate children's educational needs, nor do they consider schools as viable options of social-emotional and behavioral support. This is concerning given the significant positive impact schools can have on children's well-being. It is suspected that the responsibility lies on the parents to facilitate hospital-to-school transitions for their children. This is potentially problematic for several reasons. First, parents may also fail to consider schools as a source of support after a hospitalization. Parents might not be aware of the resources available through the school or might be uncertain about navigating the system. As such, parents might not take initiative to contact schools, which could result in schools being uninformed about a child's situation. Second, it is suspected that families experience a range of barriers preventing them from accessing the support that schools can offer. For example, families may lack the resources to contact or travel to the school, may face the burden of working extra jobs, be under emotional stress, lack the requisite knowledge of potential school supports, or fear contacting the school due to feeling intimidated or embarrassed. A final concern is that when the responsibility lies on the parents to facilitate transition, the communication between service providers (e.g., the hospital and the school), becomes muddled, if it occurs at all. Communication between providers is critical to adequately meeting children's needs.

The purpose of this study was to explore families' experiences in transitioning their children from a hospital setting back to school. The study explored issues related to family perceptions of and involvement in the discharge planning process, the extent to which educational needs are addressed in hospital discharge plans, the extent to which

hospitals involve families in the discharge planning process, the family role in transitioning children back to school, perceived needs of the child upon hospital discharge, family knowledge of school-based resources and support, and barriers and supports experienced by families in the transition process. Through exploration of these issues, impediments and supports to effective hospital to school transitions were uncovered. Furthermore, this information was used to develop recommendations for parent advocacy as well as future policy and practice.

The first chapter provided an introduction to the proposed study, along with the purpose and problem of the proposed study. This chapter provided a literature review related to the proposed area of research. The following chapter will discuss the study's research methods along with a rationale for the selected methodology.

## CHAPTER 3

### METHODOLOGY

The methodology section is organized according to the following topics: (a) statement of purpose, (b) research questions (c) research design, (d) case selection, (e) instrumentation, (f) data collection, (g) data analysis, and (h) limitations of the study.

#### **Statement of Purpose**

The purpose of this study was to explore families' experiences in transitioning their children from a hospital setting back to school. The study explored issues related to family perceptions of and involvement in the discharge planning process, the extent to which educational needs are addressed in hospital discharge plans, the extent to which hospitals involve families in the discharge planning process, the family role in transitioning children back to school, perceived needs of the child and family at the time of discharge, caregiver knowledge of school-based resources and support, and transition barriers experienced by families in the transition process. Through exploration of these issues, impediments and supports to effective hospital to school transitions were uncovered. This information was sought out in order to shed light on an issue of social justice as well as to develop recommendations that could facilitate changes in hospital to school transition policies and practices.

#### **Effective Discharge Planning**

A review of the literature to find out what makes for effective discharge planning resulted in three major categories. Those categories are: multidisciplinary team (MDT) approach (Bull & Roberts, 2001; Hedges et al., 1999; Leichtman & Leichtman, 2004;

Rose & Haugen, 2010; Watts et al., 2006), clearly defined discharge planning procedure (Bull & Roberts, 2001; Guterman, et al., 1989; Leichtman & Leichtman, 2004; Rose & Haugen, 2010; Tennier, 1997), and ecological approach (Bull & Roberts, 2001; Guterman et al., 1989; Steffen et al., 2009; Leichtman & Leichtman, 2002; Leichtman & Leichtman, 2004; Rose & Haugen, 2010; Simon & Savina, 2010; Trout et al., 2010).

**Multidisciplinary team approach.** There are three factors in this category. Those factors are (a) clearly defined roles (Hedges et al., 1999), (b) effective communication among hospital staff (Bull & Roberts, 2001; Tennier, 1997), between providers and patients, and between healthcare providers and family caregivers of patients (Bull & Roberts, 2001), (c) effective teamwork, including trust among team members, blurring of professional boundaries, and a coordinator of services (Bull & Roberts, 2001; Watts et al., 2006).

**Clearly defined discharge planning procedure.** There are nine factors in this category. Those factors are (a) all members of team getting to know the patient (Bull & Roberts, 2001), (b) discussion of initial discharge plans with patient (Bull & Roberts, 2001), (c) getting ready to go home/discussion of coordinated services (Bull & Roberts, 2001; Leichtman & Leichtman, 2004), (d) transitioning home (Bull & Roberts, 2001), (e) family involvement (Steffen et al., 2009) (f) patient living arrangements (Leichtman & Leichtman, 2004), (g) extending the residential aspect of inpatient care (Leichtman & Leichtman, 2004), (h) development of a relapse prevention plan (Leichtman & Leichtman, 2004), (i) creation of a crisis plan (Guterman et al., 1989; Leichtman & Leichtman, 2004).

**Ecological approach.** There are four factors in this category. Those factors are (a) maintaining skills learned in residential care (Goldston et al., 2003; Guterman et al., 1989; Trout et al., 2010), (b) working with families during the child's stay and as they transition home (Trout et al., 2010), (c) identification and coordination of the critical social, emotional, and educational supports needed to facilitate the transition process (Guterman et al., 1989; Steffen et al., 2009; Simon & Savina, 2010; Trout et al., 2010), (d) prevent future hospitalizations/stabilize the child (Goldston et al., 2003; Guterman et al., 1989; Steffen et al., 2009).

### **Barriers to Effective Hospital to School Transitions**

In addition to what makes for effective discharge planning, another important theme emerged from the literature review – barriers to effective hospital to school transitions. From the literature review, the identified barriers include (a) a general lack of research focusing on caregiver perceptions and experiences of the process, (b) an expectation that caregivers will understand and carry out their child's treatment plan (Falvo, 2005), (c) lack of caregiver resources, including living in poverty (Dryfoos & Barkin, 2006; Owens et al., 2008), (d) caregivers lacking adequate knowledge of the complex health care and educational systems, including knowledge that they have a right to request services (Madan-Swain et al., 2004), (e) communication barriers in non-English speaking families (Madan-Swain et al., 2004), (f) lack of training by school professionals to work with kids who have been hospitalized and/or failure by school to initiate assistance to families (Clay et al., 2004), and (g) caregivers receiving inadequate discharge information from the hospital (Keatinge et al., 2009).

## **Needs**

It has been established that aftercare services post-hospitalization are beneficial (e.g., Blanz & Schmidt, 2000; Goldston et al., 2003; Guterman et al., 1989;) and communities can benefit from the support and services offered by schools (e.g., (Adelman & Taylor, 2000a; Adelman & Taylor, 2000b; Bruns et al., 2004; Dryfoos, 1994; Dryfoos, 1995; Owens et al., 2008). In fact, public schools have been argued to be the largest provider of mental health services to children and adolescents (U.S. DHHS, 1999). However, few studies have been conducted exploring the ways in which inpatient discharge/aftercare plans are coordinated with schools. In addition, the literature that does exist on discharge planning is relatively limited to adolescents in long-term residential care and the field of nursing, and has been conducted with a focus on staff experiences. This study was designed with the intent of expanding the current literature base by exploring the three components of effective hospital discharge planning. Specifically, there was an emphasis placed on whether caregiver perceptions of hospital discharge plans and procedures were consistent with the current literature on effective discharge planning. There was also the goal of uncovering barriers interfering with the transition process. The intent of this study was to shed light on caregiver experiences with the discharge/transition process in order to guide recommendations for future policy and practice.

## **Theoretical Propositions**

Yin (2009) suggests an important element to case study design involves identifying a set of theoretical propositions. These propositions reflect important

theoretical issues and serve to guide the study by narrowing the search for relevant evidence. These propositions help determine the appropriate research design, inform research questions, and guide the analytic strategy. The theoretical propositions for this study include:

1. Hospital discharge planning procedures are inadequate due to a failure to incorporate educational needs and a failure to support families in the transition from hospital to school.
2. Because of inadequate discharge planning procedures, caregivers are burdened with the task of facilitating the transition process. Compounding this problem is the assumption that caregivers face significant barriers adversely impacting the transition process.

### **Research Questions**

1. What were caregivers' experiences with the discharge planning process? Specifically, how did the hospital involve families in the process; who was involved in the process; how did the hospital help families identify the children's critical social-emotional, behavioral, and educational needs; and how did the hospital encourage the maintenance of skills gained during admission?
2. What were the caregiver's perceptions of the child's and the family's needs at discharge?
3. What knowledge did caregivers have about the educational system, and what role, if any, did hospital staff play in providing parents with information about potential educational needs and supports?
4. What barriers and supports did caregivers face during the discharge/transition process?

## Research Design

This qualitative study employed a multiple-case design (Stake, 2006; Yin, 2009).

The case study method was selected because it is appropriate when researchers are attempting to gain further insight regarding the nature of a phenomenon, rather than engage in hypothesis testing (Yin, 2009). Stake refers to the target phenomenon being studied as the "quintain," and for this study, this refers to the nature of caregiver experiences with psychiatric hospital to school transitions for their children. Cases represent individual manifestations of this phenomenon, and the similarities and differences observed across cases serve to provide a better understanding of the quintain. As such, case study research is not so much about studying the quintain as it is the study of cases in order to better understand the quintain. The basic analytic strategy, then, involves individual analysis of multiple single-unit cases, with findings subsequently aggregated across cases (Stake, 2006; Yin, 2009). Stake cautions that although the emphasis should be on the cross-case findings, the researcher should take care not to minimize the individuality of each case. Because case studies are studies of particularization, rather than generalization, focus should be on the local situation instead of how it represents other cases in general. As such, this study was designed with the expectation that although individual case experiences would vary, similar overarching cross-case themes would be present.

Yin (2009) offers further rationale for selecting a multiple-case approach.

Multiple-case studies are often considered more robust than single-case approaches because the evidence from multiple cases is often more compelling. Additionally, multiple-case design allows for what Yin calls replication. Each case is carefully selected

so that it either a) predicts similar results to other cases (literal replication) or b) predicts contrasting, although anticipated, results (theoretical replication). Each individual case study is considered a “whole” study in which convergent evidence is sought. If results turn out as predicted, the aggregate data offers convincing support for the initial set of theoretical propositions driving the study. Because it was hypothesized that each case in the current study would have different experiences but similar results, literal replications of the findings were anticipated.

### **Case Selection**

For this study, cases were defined as individual families with a child who was previously hospitalized for a mental health condition for at least 72 hours, or three days. Because children and adolescents are routinely evaluated, treated, and discharged in about four days (Blanz & Schmidt, 2000; Case et al., 2007), three days was chosen as the minimum cutoff to account for cases where the length of stay was less than the average.

### **Recruitment Site**

Cases were selected through the Clark County School District (CCSD) in Las Vegas, NV, the 5<sup>th</sup> largest school district in the nation (“Clark County,” 2013). The CCSD houses several behavioral schools, which serve as short term intervention programs for secondary students who have committed disciplinary infractions at comprehensive schools, and several continuation schools, which provide educational programs for students who have been expelled from attendance at comprehensive secondary schools (CCSD, n.d.). The CCSD provided an opportunity for a convenience sample and was selected for several reasons. First, the district has a large enough

population to allow the researcher to conduct a sufficient number of interviews to collect adequate data. Second, the CCSD's behavioral and continuation schools were suspected to have a higher population of participants meeting study criteria.

All study procedures were reviewed and approved before beginning participant recruitment. Approvals were obtained from the University of Nevada, Las Vegas IRB and CCSD Research Committee. Specific school sites were recruited by sending an informational E-mail to the principal at each behavior school and one continuation school. Follow-up phone calls and in person meetings were conducted with principals that expressed an interest in allowing their school to serve as a participant recruitment site. A total of three principals agreed to the terms of the study, specifically two from behavior schools and one from a continuation school. Due to logistical issues at two of the schools, they were unable to serve as recruitment sites, leaving one behavioral school as the recruitment site for the study.

### **Participant Selection**

Participants were limited to the caregivers of children who have been hospitalized. Children did not participate any portion of the data collection process. Participants were solicited in multiple ways. First, a recruitment letter was given to teachers and sent home with all students. The letter, in English, provided a brief overview of the study and specified that participants were being sought if they had a child who was previously hospitalized for at least 72 hours. Caregivers were able to indicate their interest in participation by contacting the researcher via email or telephone. Second, with principal permission, the researcher obtained access to the school directory, which included phone contact information for all students. Random phone calls were made to

caregivers of students. During phone calls, the researcher provided a brief overview of the study and specified that participants were being sought if they had a child who was previously hospitalized for at least 72 hours. All participants who met study criteria and volunteered to participate were included in the study, for a total of three participants – one for each case. Although Stake (2006) generally recommends having between four and 10 cases in a multiple-case study, he notes that it is acceptable to have fewer than four.

For the present study, there was no participant response from the recruitment letters, so a significant amount of time was spent making random phone calls. Specifically, 259 phone calls yielded seven participants who met study criteria. Two participants requested calling back at another time to review the study details, but multiple attempts at contacting them were unsuccessful. For two other participants, study details were reviewed and the consent and release forms and a stamped return envelope were sent home. However, multiple attempts at contacting these participants to review the forms were unsuccessful. These repeated attempts amounted to 54 subsequent calls, for a total of 313 recruitment calls, which resulted in three remaining participants for the study. Although one to two more cases were initially desired, the researcher believed that the three cases sufficiently demonstrated interactivity between their situations.

Random phone calls involved the examiner introducing herself, including affiliations, and providing a brief overview of purpose of the study. For those who agreed to participate, the examiner provided additional information about study procedures (e.g., length of time to participate, interview format, location for data

collection), an overview of confidentiality, a review of permissions granted from UNLV and CCSO, and solicited any questions from participants.

### **Instrumentation**

According to Merriam (2002), the main instrument for gathering and analyzing data in qualitative research is the researcher. There are inherent shortcomings and biases that come with using a human instrument. However, Merriam suggests rather than trying to eliminate these biases, the researcher should identify and monitor them with regard to the way they shape data collection and interpretation. In other words, the goal is to identify the researcher's perspective as it pertains to the understanding of the current topic and how it may influence data collection and interpretation. The researcher is a Caucasian, female, school psychologist with varied experiences in educational and clinical settings, including inpatient psychiatric hospital settings. It was the researcher's personal experience with inpatient hospital discharge planning procedures that led to an interest in the current topic of study. The researcher engaged in ongoing consultation with peers and professionals, and also conducted participant member checks (discussed in more detail below), in order to gain additional insight into the data collection and interpretation processes, as a way to mitigate the effects of any researcher biases on these processes.

Prior to data collection, Yin (2009) recommends outlining a case study protocol to guide the researcher and serve as a standardized agenda for the proposed line of inquiry. The protocol serves to increase the reliability of case study research and is meant to guide the researcher in carrying out the data collection from a single case. Yin suggests the

protocol minimally include the following: (a) an overview of the case study project, (b) field procedures, (c) case study questions, and (d) a guide for the case study report. For the present study, a case study protocol was developed based on these recommendations. This protocol was used to organize the researcher and also served as a means for sharing study information with school principals.

Consistent with the case study approach, multiple forms and multiple samples of data were collected (Yin, 2009). To address the research questions, data was collected using two methods: participant interviews and collection and review of archival records. For one participant, data collection involved scheduling an appointment to meet on the behavior school campus. For the first portion of the meeting, the researcher, reviewed confidentiality and consenting procedures. Following this procedure was a brief structured interview to collect demographic information and general information about the child's health, developmental, and educational history. Finally, a semi-structured interview was conducted. This portion of the interview focused on the caregiver's experience in the hospital discharge planning and hospital to school transitioning processes. For the other two participants, interviews were conducted over the phone. For all participants, interview meeting times, including consenting procedures, lasted about 50 minutes. Prior to the interviews, packets including forms for consent and release of records, along with a stamped return envelope, were sent home. After participants received the packets, the researcher contacted them to review confidentiality and consenting procedures. When the researcher received the returned packets with signed forms, participants were called to schedule interviews. All three participants agreed to have interviews audio-recorded and transcribed verbatim.

Archival educational documents were reviewed and collected for Cases B and C, but not A. The participant in Case A provided consent to release educational records, but because her son is now an adult, permission would have been needed directly from him. The participant indicated she would try to obtain these records, but multiple attempts at following up with her to obtain these records were unsuccessful.

Finally, after case analyses were conducted, all participants were contacted to address follow-up questions and conduct “member checks.” One participant received a brief five-minute follow-up call after the initial interview. All participants received a follow-up/member-check call, lasting about 15 minutes, subsequent to case analyses. Member checking is a strategy for establishing credibility, whereby data, analyses, and interpretations are shared with participants so they can judge the accuracy of the researcher’s account (Creswell, 2007). During this process, participants were able to comment on the researcher’s interpretations and offer alternative explanations if they had any.

## **Data Collection**

### **Participant Interviews**

Two types of interviews were conducted with each participant. Yin (2009) describes surveys as a type of interview in which structured questions are employed. Yin explains that surveys are appropriate to answering “who, what, where, how much, and how many” questions. For the present study, a structured survey was designed to solicit demographic information as well as the health, developmental, and educational history of

the child. This information was solicited first and was used to help situate, or provide context for, each case.

Second, semi-structured interviews were conducted. Prior to meeting with the participants, a conversational guide, or interview protocol, was developed based on the approach and recommendations outlined by Rubin and Rubin (2005). This approach is referred to as responsive interviewing, which is almost like an extension of regular conversation. In this approach, one generally seeks to obtain interviewee responses with depth and detail that evoke vivid descriptions, and display nuance and richness. Responsive interviewing (see Merriam's Interview structure Continuum, 1998) typically involves predetermining a set of questions and even an order in which to ask them. For this type of interview, questions tend to be exploratory in nature, but there is generally a focus or direction in which the researcher is trying to go. In other words, interview questions are fluid yet remain focused on pursuing the line of inquiry set forth by the research questions (Yin, 2009). In this study, predetermined questions served as a skeleton for the interview, but consistent with the responsive interview approach, allowed the interview to explore participants' unique experiences while staying focused on the general line of inquiry.

### **Document Collection**

Documents for review included educational records for the participants' identified child. These records included attendance history; grades; disciplinary incidents, including teacher, student, and administrative reports; and special education/504 eligibility.

## **Reliability and Validity**

Yin (2009) argues that the quality of case study design should be held to the same standard as other empirical social research. The following validation strategies were used in this study. The first involves data triangulation, where multiple and varied sources of information are used to corroborate the evidence (Creswell, 2007; Marshall & Rossman, 2006; Yin, 2009), both within and across cases (Stake, 2006). Participant interviews and archival records served as the sources of data. To validate inferences, the researcher considered as many rival explanations to findings as possible (Yin, 2009). To address possible biases that may have impacted the interpretation and approach to the study, the researcher identified prior experiences, orientations, and biases. Engaging in peer review, an external check on the research process (Creswell, 2007), facilitated validity checks on the potential effects of researcher bias on drawn inferences. Additionally, Stake (2006) recommends conducting “member checks” in which the researcher reviews the case findings with participants to ensure validity of how interview content has been interpreted. For the present study, member checks were conducted in a brief interview where participants’ opinions of the accuracy of interpretations was solicited. Finally, rich, thick descriptions of case histories and experiences were provided to allow the reader to make decisions regarding transferability, or the degree to which shared characteristics can be transferred to other settings (Creswell, 2007). Similar to the quantitative concept of generalization, Yin makes an important distinction, noting that while quantitative studies rely upon statistical generalization, qualitative studies rely upon analytical generalization. In the latter scenario, the researcher attempts to generalize, or transfer, findings to a broader theory. In addition to the rich descriptions, the literal replication logic used in

this study was a means of achieving this. Furthermore, transferability to broader theory is possible because, at the onset of the study, the researcher outlined a set of theoretical propositions which served to guide the research process (i.e., development of research questions, study design, and analytic strategies; Marshall & Rossman, 2006; Yin, 2009).

Yin (2007) notes that reliability serves to minimize errors and biases within a study. To address issues related to reliability, the researcher used two different strategies. First was the use of a case study protocol (Yin, 2007). Steps of the research process were outlined and operationalized in an attempt to ensure the same procedures were followed with each case. A second strategy, reliability checks, can be of particular benefit during the data coding process. Creswell (2007) notes the importance of inter-coder agreement when the coding process is deemed highly interpretive. For this study, the coding process was relatively straightforward because codes were developed based on theoretical assumptions. As such, the researcher has flexibility in the process to create an approach that is consistent with the time needed for coding. This can involve checks on codes, themes, or both. For this study, the researcher met with her advisor to review the codebook and samples of transcripts (two samples per transcript) for each case. Because the researcher had already coded the transcripts, the researcher and advisor went through the transcripts for four of the samples together to familiarize the advisor with the codes and themes. The advisor and researcher were in 100% agreement for all coded segments. For the other two samples, the advisor independently coded the segments, which were compared to the researcher's codes and resulted in 75% reliability. Although Creswell generally recommends 80% inter-coder agreement, the 75% accounts for the fact that some portions of text were doubly coded by the researcher (e.g., Case History and

Facilitating Factor). For instances in which the second coder failed to include an additional code, this was discussed and 100% agreement was obtained.

### **Data Analysis**

Yin (2009) describes the analytic process as starting with selecting a general analytic strategy, which will guide in crafting the “story” of the data. Yin (2009) suggests beginning the data analysis process by considering the theoretical propositions guiding the study. These propositions led to the design of the multiple-case study, starting with the literature review, then development of the research questions, and subsequent data collection plan. Theoretical propositions help focus on certain data while ignoring others. Furthermore, the propositions helped organize the entire case study and define alternative explanations to explore. Yin points out that analysis of case study data does not follow a cookbook approach. Rather data analysis depends upon the researcher’s own style of rigorous thinking as well as careful consideration of alternate interpretations. Despite this flexibility, the multiple-case study approach generally involves initial individual case analyses and subsequent aggregating of the findings (Stake, 2006; Yin, 2007).

Data analysis began by transcribing participant interviews. Transcripts were initially read through using paper and pencil to write notes in the margin and highlight segments of relevant text. An initial list of a priori codes was created based on the study's literature review findings (see Bernard & Ryan, 2010, p. 81-83) on what makes for effective discharge planning, as well as the barriers faced by families during this process. Although the researcher employed a set of predetermined codes, she was open

to codes that emerged during the analysis process. The coding scheme was developed based on the theoretical propositions and research questions. However, in line with Creswell's (2007) recommendations, the coding process remained open and flexible, as additional codes emerged during the analytic process. Additionally, because an important part of cross-case analysis is considering the situated experience of case findings in relation to the research questions (Stake, 2006) and theoretical propositions (Yin, 2009), codes were developed that pertained to case background information. These codes were also used to perform a content analysis of archival documents. Marshall and Rossman (2006) refer to coding as the formal representation of analytic thinking used to identify categories and themes in the data. Five broad coding categories were used, each with their own subcodes. The following are the coding categories, with examples of subcodes: BARRIERS (lack of caregiver resources, lack of information from the hospital), CASE HISTORY (demographic, educational problems), DISCHARGE PROCEDURES (written plan/recommendations, approach), FACILITATING FACTORS (parent seeks hospital recommendations, parent research), and PARENT SATISFACTION (no communication with school, lack of information to parent).

After each transcription was coded, the researcher began linking coded sections of text to each research question and case history, as suggested by Friese (2012). Specifically, the research questions were broken down into subquestions, with memos created for each subquestion, as well as for each case's history. This way, the researcher was able to methodically search the coded participant quotes that related back to the research questions. Starting one case at a time, the quotes for each question and case history were studied and then short analyses were written, which served as the initial

method of data reduction. A general strategy for this portion of the analysis was to ask "how" and "why" questions (Bernard & Ryan, 2010), which were considered within the specific context of each case's history as well as in relation to the study's theoretical propositions.

Next, an outline for the individual case reports, the next level of data reduction, was drafted. The descriptive case histories and research question analyses were used to formulate the reports. Stake (2006) refers to the case reports as a summary of what has been done to try and get answers, what assertions can be made with some confidence, and what more needs to be studied. Consistent with an option presented by Yin (2009), case reports were composed in a question and answer format, where each research question was addressed and analyzed individually. From here, Stake recommends continuing with data reduction by writing a synopsis for each case to more clearly highlight findings and uniqueness in each case. Specifically, findings were considered within the context of each research question. In this manner, the researcher was able to finally compare findings across cases, including similarities and differences, to make stronger overall assertions. Additionally, the unique aspects of each case were not lost through this type of analysis. No cases presented with such unique circumstances that they could not be included in the cross-case analysis. Rather, because findings across cases were similar, the uniqueness of each case only strengthened the researcher's conclusions about understanding the quintain. In fact, Stake argues that the quintain is multiply contextual and functioning coincidentally, rather than being causally determined. In other words, although the diversity of each case was not necessarily the focus of the research, it was carefully studied in order to better understand the quintain.

## **Summary**

This multiple case study was based upon theoretical propositions that assume current hospital discharge planning procedures to be inadequate, and as a result, caregivers are burdened with facilitating hospital to school transitions at discharge. Three cases were selected and individually analyzed before aggregating findings across cases. Aggregated findings were then used to make warranted assertions about the quintain, which is the phenomenon of caregiver experiences with hospital to school transitions.

Chapter 3 provided a discussion of the research methodology used in the current study, which was a qualitative multiple case study. Also included in this chapter was a discussion of the data collection process and analytical strategy. The following chapter presents an examination and discussion of the findings of this study.

## CHAPTER 4

### FINDINGS

#### **Overview**

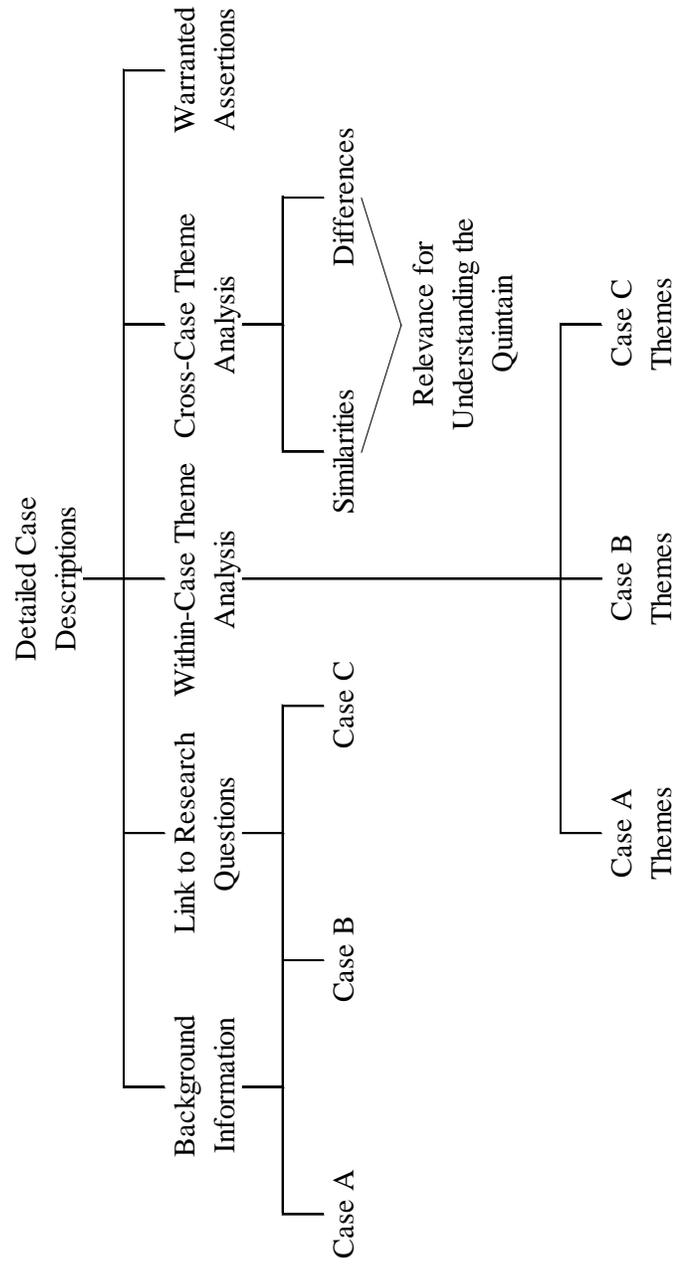
Yin (2009) suggests one option for presenting individual case information is in a question and answer format, where each research question is addressed and analyzed individually. This format can also be used to present the cross-case findings and was the approach used in the current study. Because this study's analytic strategy was to link findings to the research question, presentation of findings in the question and answer format was considered most appropriate. Specifically, the current study was designed with the intent of addressing the following research questions:

1. What was the caregiver's experience with the discharge planning process?  
Specifically, how did staff involve families in the process; who was involved in the process; how did staff help families identify the child's critical social-emotional, behavioral, and educational needs; and how did the hospital encourage the maintenance of skills gained during admission?
2. What were the caregiver's perceptions of their child's and the family's needs at discharge?
3. What knowledge did caregivers have about the educational system, and what role, if any, did hospital staff play in providing parents with information about potential educational supports?
4. What barriers and supports did caregivers face during the discharge/transition process?

The present study's design embodied a qualitative approach. Specifically, a multiple case study was employed in an attempt to explain the phenomenon of hospital to school transitions (see Figure 1). Multiple forms of data were collected, including participant interviews and collection of archival documents. Of note, educational records were the only form of archival documents collected, as permission was not granted by the IRB to solicit psychiatric records from participants. Each case's data were individually analyzed by linking coded participant quotes to each research question. To clarify the situationality of each case, this same process was used whereby coded quotes helped describe each case's history. The general strategy of asking "how" and "why" questions (Bernard & Ryan, 2010) was used to reduce data and analyze it in relation to the study's theoretical propositions and case history. Based on this information, individual case reports were drafted, as were subsequent case report synopses, each serving to further reduce the data and more clearly highlight case findings related to themes (i.e., research questions). Specifically, each case was generally evaluated in terms of its importance for understanding each theme.

The final analytic strategy was the cross-case analysis, through which convergent evidence for each theme was sought. During this process, the researcher further evaluated the relevance of each case's findings for each theme and those findings' utility for explaining the target phenomenon under question, or the quintain (Stake, 2006). These findings were compared across cases in order to make more global assertions about the quintain. Although convergent cross-case findings were the ultimate goal of this analysis, the researcher also considered the unique situations of each case. Of note,

Figure 1  
*Multiple Case Study Organizational Structure*



none of the cases were so unique in their circumstances that their findings could not be included in the cross-case analysis. Case uniqueness, juxtaposed against the convergent cross-case findings, appears to strengthen the researcher's explanations of the quintain.

Although the focus of a multiple case study is on the cross-case findings, an understanding of the situationality of each case is critical for developing an explanation of the quintain (Stake, 2006). In other words, the phenomenon being studied will be uniquely manifested in different contexts. It is the goal of the researcher, then, to highlight global themes while also considering individual case differences. These themes indicate primary information about the quintain that the research seeks and are directly related to the research questions. For the present study, these themes include caregiver experiences with the discharge planning process, caregiver perceptions of the child's and family's needs at the time of discharge, caregiver knowledge of the educational system and role of hospital staff in providing information about potential educational supports, and barriers and supports experienced during the transition process.

A brief case overview is presented next. Then, each case will be presented individually, including the background information, situating each case within its context, along with findings related to the research questions. Finally, the cross-case analysis will be discussed. All names have been changed to protect the confidentiality of the participants.

### **Case Overview**

Cases were recruited through the Clark County School District in Las Vegas, NV. Specifically, cases were selected from one behavioral school, serving a population of

secondary students who have made significant disciplinary infractions resulting in their removal from a regular comprehensive campus. The behavioral school was selected because it was assumed that there would be a higher chance of finding participants who met study criteria. Participants were limited to caregivers of children who had experienced a psychiatric hospitalization for at least 72 hours. With administrative approval, participants were recruited via a letter sent home and random phone calls made via the school directory. All participants who agreed to participate in the study were included, for a total of three. Several participants who met criteria were unable to participate, and due to the significant time involved in recruitment, the researcher limited the study to three cases. Although the researcher initially desired one or two more cases for inclusion in the study, the interactivity between case situationality was deemed sufficient.

## **Case A**

### **Background Information**

Chad Ives is a 21 year old male was hospitalized once at age 15 or 16, for approximately 10 days. He had a prior diagnosis of attention deficit hyperactivity disorder (ADHD) and was discharged from the hospital with diagnoses of ADHD, depression, anger issues, and substance abuse. Although Chad was born and raised in Las Vegas, he had been living with his grandparents in Hawaii for several months prior to his hospitalization. Chad's parents had sent him there in an attempt to manage his increasingly problematic behavior. Chad became suicidal, which was the reason for his hospitalization. After he was discharged, Chad remained in Hawaii for a few months

with his grandparents before finally returning to Las Vegas. Of note, Chad did not attend the behavioral school from which his mother (Ms. Ives, the identified participant) was recruited. Ms. Ives received a random phone call because another child who attended the school during recruitment. During the interview, it became clear that it was a different child, Chad, who had been hospitalized and was thus the focus of the case.

**Demographic information.** At the time of his hospitalization, Chad was between 15 and 16 years old and was repeating the 9<sup>th</sup> grade. His ethnic status is Native Hawaiian/Pacific Islander. He lived at home in Las Vegas, Nevada with his younger sister, mother, and stepfather who raised him from age four. However, at the time of the hospitalization, Chad had been living with his grandparents in Hawaii for several months. Chad only rarely saw his biological father, and Ms. Ives referred to the stepfather as Chad's "father." At the time of hospitalization, his mother was 33-34 years old. His mother's highest level of education was a Bachelors Degree in Business Administration and Management and she was employed in the real estate business. His father's highest level of education was high school and he was employed in construction as a heavy equipment operator. The family income at the time was approximately \$100,000 per year and Chad had health insurance. A few years after his hospitalization, Chad's parents divorced.

**Family history and stressors.** Ms. Ives reported conflict within the nuclear family surrounding the time of Chad's hospitalization. Specifically, Ms. Ives explained that Chad and his father never got along well. Ms. Ives also reported that there was stress due to the father being gone, noting

He always would work. The majority of time he was out of the state working. So, he would come home, like, on the weekends....He would be gone for a couple months, sometimes come home for a weekend and that was it. So, he was always busy working and traveling for work.

Ms. Ives reported this was difficult and contributed to marital stress. Adding to this stress was the fact that she also had a chronically ill daughter who required repeated hospitalizations during the year leading up to Chad's hospitalization. The daughter had chronic asthma and her lung collapsed several times. During the daughter's repeated hospitalizations, Ms. Ives usually stayed with her because of Mr. Ives' business travel. At this time, Chad's behaviors became increasingly more challenging, with Ms. Ives explaining that he became "really defiant" while she cared for her daughter. Ms. Ives also reported some strain on her job at that time. She was working in real estate, and although she had some flexibility, her absence during the daughter's and Chad's hospitalizations was difficult on clients. In general, Ms. Ives explained that Chad's hospitalization was very stressful on the family, stating, "It just tore the family apart. It was a huge thing." The hospitalization put further strain on the marital relationship, which deteriorated to a culminating divorce several years later. Additional stress during Chad's hospitalization included his sister having to remain in Las Vegas with paternal grandparents while Ms. Ives traveled to Hawaii to be with Chad.

Despite living in Las Vegas, Ms. Ives reported having a close relationship with her parents, who live in Hawaii. As a child, Chad stayed with these grandparents for about one month every summer.

**Educational history.** Chad was diagnosed with ADHD at age five or six. When he was younger, Chad was enrolled in a program to help specifically with symptoms of ADHD and learning. In elementary school, Ms. Ives reported grades of C and D, but by high school Chad's grades were consistently Ds and Fs. He struggled mostly with math and English. Chad went to summer school every year, starting in elementary school. Chad went to public school in Las Vegas, but in Hawaii after his hospitalization, he was enrolled in a private school. Ms. Ives indicated he performed better in this setting because he could focus in the smaller classrooms. During this time in Hawaii, Chad was found eligible special education services due to his ADHD having an adverse educational impact. Chad was only in school there for six months before returning to Las Vegas. Upon returning to Las Vegas, however, he was not found eligible for these services. Ms. Ives reported, "[The school team's] opinion of him was that he was smart, but he just didn't care anymore." At that time, he had a very high number of absences. Ultimately, Chad never graduated from high school. He reportedly spent four years in the 9th grade and eventually dropped out altogether. Prior to dropping out, Chad "just checked out," with Ms. Ives reporting that school was "just for socializing."

**Social-emotional, behavioral, and hospitalization history.** As a young child, Chad's parents tried to control his behavioral difficulties with diet and behavioral interventions. However, during his 9<sup>th</sup> grade year, his behavior became more problematic. Ms. Ives described Chad's behavior at this time as "defiant" and "very rebellious." Chad played football, with Ms. Ives noting that "everything was football, football." During his freshman year, Chad sustained an injury during a game and "could not play the rest of the season. And that's when everything changed." Chad began

associating with a different group of kids; had tried pot, cocaine, and crystal meth; was cutting classes; and was completely skipping school on a regular basis. It was this year that his parents first brought him to a psychiatrist and started him on medication to manage his ADHD. Not long after, however, Ms. Ives found out that Chad was selling his medication because he did not like taking it. Ms. Ives reported that the medication helped at first, but then Chad seemed to be "in a stupor, and he didn't like that feeling." Ms. Ives reported that she and her husband had tried "just about everything" to manage Chad's behavior, including being more strict, grounding him, and removing privileges. Subsequently, Chad's parents decided to have Chad try counseling through the church. They also sent him to briefly live with an aunt. After these strategies all failed, Mr. and Ms. Ives sent Chad to live with the maternal grandparents in Hawaii in an attempt to help his behavior because he was "out of control." However, over the next several months, Chad's behavior worsened there and he made a suicide attempt which resulted in his hospitalization.

Because the only psychiatric facility was on another island, Chad had to take an air ambulance to the facility, where he stayed for about 10 days. Ms. Ives flew from Las Vegas to stay with him at the hospital. She was at the hospital all day, every day. The father was not available for family therapy, even though he was the person with whom Chad had the most interpersonal difficulty. Post-hospitalization, Ms. Ives and her parents cared for and monitored Chad in Hawaii. During this time, Ms. Ives noted that Chad was difficult to deal with because he was in denial that he had any mental health or behavior problems. Ms. Ives described him as "very stubborn." She only stayed in Hawaii for

about a week post-hospitalization before moving back to Las Vegas, while Chad remained there.

### **Research Question #1**

Ms. Ives stayed at the hospital for Chad's entire length of stay, except for nights. Chad was hospitalized about 10 days, but the hospital initiated discharge discussion only about two days prior to his actual discharge. Ms. Ives asked the doctor about discharge procedures and was told Chad would be released when he is ready, with no specifics. She reported, "There were a lot of times I didn't know or have any clue as to when we were getting out or what was happening." The discharge plan was reviewed very briefly with Ms. Ives in 1:1 scenarios, initially with the doctor and towards the end with the discharge nurse. Further, she did not feel what was reported about Chad's activities during his admission was accurate. Although she described the Hawaiian culture as "very laid-back, nonchalant," she also said, "I definitely felt brushed off." Ms. Ives would have liked more education about what her son's problems were and what the treatment team was doing with him. She felt like his needs were not being addressed and she had unanswered questions about why he was there. She also felt frustrated about the conflicting information she received from different people.

In general, Ms. Ives felt left in the dark about everything during Chad's hospitalization. She described herself as "stubborn," having many of questions, which often went unanswered. Ms. Ives stated that she felt like she was a burden to staff and as if she was being looked down upon for having a child with significant mental health needs. She reported, "I felt like I was being scolded sometimes. It was a terrible feeling. I couldn't wait to get him out of there."

The basic components of the discharge plan, as reported by Ms. Ives, were to follow up with family counseling, a doctor for medication management, school counseling, and an individualized education program (IEP) through the school. The hospital provided phone numbers for different resources for Chad's parents to call. Despite these resources, the Ms. Ives reported, "[The hospital] was vague about a lot of things." For example, although the discharge plan included a list of Chad's diagnoses, there was no discussion about the implications of those diagnoses, including how to watch for warning signs for suicidal behavior, the reason Chad was admitted to the hospital in the first place. Ms. Ives wished she had "some kind of guideline as to what I'm dealing with. I just didn't know where to start with him or where his head was or how to get through to him." Additionally, Ms. Ives said she felt as if there was not any clear direction as to what she should do after discharge. She noted, "There was no flow. No flow. It's kind of like 'Well, now you're gone from here. Good luck. When you get back to the Big Island, call these resources and see.'" Ms. Ives had no contact with the hospital after discharge except to obtain records, which took several weeks and meant she was not able to get them to the school soon after Chad's discharge.

Overall, Ms. Ives reported an unsatisfactory experience with the hospital discharge planning process. The hospital failed to adequately involve her in the discharge process. Ms. Ives' interactions with staff were limited to 1:1 situations, resulting in conflicting and generally unhelpful information. Additionally, although she made significant efforts to immerse herself in the hospital experience, she felt dismissed and disrespected. In general, the hospital seemed to play a minimal role in identifying Chad's critical needs prior to and at the time of discharge. Ms. Ives was provided with a

resource list and several recommendations, but she nonetheless felt lost and unsupported by the hospital. Even though these efforts by the hospital appear targeted at addressing Chad's critical needs, they were insufficient. Ms. Ives lacked an understanding of Chad's diagnoses and presenting concerns, as well as of ways she could support him post-discharge. She left the hospital with many unanswered questions and a general lack of guidance on how to proceed post-discharge. The hospital seemed to push this responsibility onto her and community resources. Ms. Ives was essentially left with the burden of making the hospital-too-school transition with inadequate information to advocate effectively. An alternative explanation to the lack of hospital information is the possibility that the hospital did provide Ms. Ives with more explicit and specific information, but given a lack of familiarity with mental health/medical language, she was not able to understand the information and/or did not remember this information. Given her educational and professional history, it is suspected that Ms. Ives had the language and communication skills necessary to retain most of the information she was given.

### **Research Question #2**

In general, Ms. Ives reported wanting more information/resources because she said that dealing with Chad's behavior and hospitalization "just tore the family apart. It was a huge thing." She and Chad participated in family therapy during his admission, but Chad's father was the one with whom the most conflict existed, and he was not there. The hospital recommended continued family therapy, but Ms. Ives said she still felt lost. Ms. Ives expressed concern for Chad's social-emotional well-being, stating she wanted:

some kind of guideline as to what I was dealing with, where his head was at with his, I don't know if it's called disease, or just what his problems were and how to

really address them. And how to work with a child that has you know, ADHD and all these other issues going on. I just didn't know where to start with him or where his head was or how to get through to him.

Additionally, given Chad's significant academic difficulties prior to hospitalization, Ms. Ives reported wanting to know "how to make school something that was really important" for him. She noted that during the discharge process she would have liked some "clear guidance as to what steps to follow, because it got overwhelming." Further, she stated, "I kind of felt like a man on an island, you know, by herself. Or woman, just by herself, lost, trying to figure out how I am going to get off."

Ms. Ives' most notable needs seemed to be for parent psychoeducation and family support. Ms. Ives felt very unclear about Chad's needs and what she should do after he was discharged. She felt lost, alone, and overwhelmed. Ms. Ives left the hospital without basic information explaining Chad's diagnoses, how she could support him post-discharge, and clear steps to follow after leaving the hospital. On top of this, Ms. Ives was dealing with the stressors of being separated from her family on the mainland, her daughter's chronic illness, interpersonal conflict between Chad and her husband, and her husband's frequent traveling. There was clear validation for her concerns about her family's overall well-being and functioning. Ms. Ives' strongly voiced concern about Chad's educational needs at the time of discharge suggests she had some insight about the connection between his social-emotional/behavioral and academic functioning.

### **Research Question #3**

Besides an individualized education program (IEP; i.e., special education services), Ms. Ives was not aware of how the schools could support her child in other

ways. She was also unaware of the existence of a school psychologist or parent advocacy groups offering support in navigating the educational system. In addition, Ms. Ives had some confusion as to why her son was eligible for an IEP in Hawaii and not Las Vegas. Ms. Ives did not have clarification on this issue, noting, "We went through the process [in Las Vegas] and he was denied. I just sat there going, I don't understand." In terms of hospital support in this area, the only thing that was mentioned by the psychiatrist was to pursue an IEP and school counseling. Ms. Ives reported wishing the hospital and schools "would have worked in conjunction with one another." Aside from having a list of Chad's diagnoses, Ms. Ives was not given specific information about the nature of Chad's diagnoses, how his academic functioning may be impacted, or recommendations for intervention strategies the school may wish to consider.

In general, Ms. Ives had limited knowledge of the educational system. Her knowledge of the special education system was minimal and she was unaware of other accommodations or interventions that could be provided, like a transition plan. Her lack of understanding about the special education process was evident especially after Chad moved to Las Vegas, as she was unclear about why his eligibility changed. Ms. Ives was not aware of her rights in terms of challenging the school's response and/or filing for due process. She was also not aware of advocacy resources that could have assisted her in this area. Although the schools may be partially accountable for her lack of understanding, it is apparent that the hospital did little to educate Ms. Ives on Chad's needs and potential educational impacts. The hospital recommended Ms. Ives advocate for an IEP, but failed to help her identify Chad's specific educational needs,

accommodations/interventions that she and the school may find helpful, and recommendations for crisis prevention/intervention.

#### **Research Question #4**

The biggest evident transition barrier for Ms. Ives was the lack of satisfactory information from the hospital throughout Chad's hospitalization, including the discharge planning process. In general, she was provided with very little information, was given information that was unhelpful, and felt unclear about the discharge plan. She described the discharge process as lacking structure, noting, "There wasn't really any clear direction as to what I should do from there." The hospital made poor attempts at involving Ms. Ives in the discharge process and demonstrated poor communication with her in general. She said, "Even when he was there, I didn't really understand what he was doing half the time." She received little information about Chad's diagnoses, including risk for future suicidality; strategies for supporting Chad post-discharge; and educational advocacy information. Although she asked many questions, they were frequently unanswered. When her questions were answered, she sometimes got conflicting information, which was frustrating for her. The discharge plan was a piece of paper with recommendations for counseling, a psychiatrist, and an IEP, with a few numbers to call when she got back to the Big Island. Additionally, there was no follow-up from the hospital. Ms. Ives had to initiate getting hospital records sent Chad's school, which took several weeks. Overall, she said, "My biggest complaint was that there was no direction. It didn't feel like they helped at all."

In contrast to this barrier, a transition facilitating factor, specifically caregiver involvement with the hospital, was evident. Ms. Ives tried to take an active role in her

son's treatment, visiting the hospital daily to participate in any way she could. However, she often felt uncertain about what her son was doing and what the plan for releasing him would entail. Ms. Ives persisted even though she was treated disrespectfully and felt as if she were a nuisance. This suggests poor hospital-caregiver communication, which means critical information may not have been transferred effectively, if at all, to the parent, clearly outweighing her efforts at obtaining information.

Another significant barrier seemed to be feeling disrespected by hospital staff. Ms. Ives reported being spoken to in a condescending manner. She also felt that she was not given proper attention by hospital staff. This, along with the lack of information, left her feeling disrespected and belittled.

A third identified barrier appeared to be a lack of caregiver resources, particularly time, emotional, and physical resources (e.g., father not being present). Ms. Ives noted her husband was not present a "majority of the time" when her son's behavior was worsening and he was hospitalized. When the father was present, he did not get along well with Chad. Due to his travelling, the father was unable to participate in family therapy sessions during the hospitalization, despite Ms. Ives' report that her son's biggest interpersonal difficulties were with his father. Further, the father was not involved in the transition process, leaving Ms. Ives with this burden and causing added strain on the marriage. Ms. Ives said the hospitalization took a significant toll on the family. Mr. and Ms. Ives divorced several years after the hospitalization, indicating continued marital strain post-hospitalization. As such, not only was Ms. Ives faced with the burden of being the sole physical provider, but also the source of emotional support for her family.

Ms. Ives was in many respects functioning within this family as a single parent. Although financial burdens did not appear significant, as this was a dual-income household, Ms. Ives was faced with the burden of caring for her children a majority of the time. During the time surrounding Chad's hospitalization, the younger sibling also required several hospitalizations for a chronic health condition. The mother was the sole caregiver in the hospital, and during this time, Chad's behavior worsened. These situational factors put an increased strain on the mother's work. Although she did not report losing her job, she reported that this did in fact impact her work. Adding to this stress, Chad's behavioral and educational difficulties date back to early childhood, with the mother reporting various unsuccessful attempts at managing his behavior. The chronicity of Chad's behavioral difficulties, the presence of chronic health problems with the daughter, and the unavailability of the husband, was a significant source of stress for the Ms. Ives. These multiple stressors contributed to her sense of feeling "overwhelmed," which in turn could have made it more difficult for her to fully support Chad's emotional needs post-hospitalization. Furthermore, the physical location of the hospital on another island, and subsequently being even further away after she moved back to Las Vegas, posed a physical barrier to any in-person communicative efforts post-hospitalization.

Finally, Ms. Ives' lack of educational system knowledge and her perceived lack of school effort/unavailability of school services were evident transition barriers. Although she felt Chad's educational needs were supported in Hawaii, after she re-enrolled him in school in Las Vegas, she faced more of a struggle in navigating the educational system and advocating for Chad's needs. Ms. Ives had minimal knowledge of supports outside

of special education and was not aware of community educational advocacy agencies. Because she lacked educational system knowledge, the hospital's failure to assist her in identifying Chad's educational needs and possible supports exacerbated this barrier. When the school failed to initiate supports, Ms. Ives lacked the critical knowledge needed to educate school staff about Chad's condition and advocate more strongly on his behalf. Although she lacked educational system knowledge, her initiative in seeking out school supports serves as a transition facilitating factor.

## **Case B**

### **Background Information**

Sedona Franklin is a 16 year old female who was hospitalized once just before she turned 15. She was admitted for about two months due to increasing oppositional and defiant behavior as well as significant substance abuse. Because of her behavior, Sedona spent a month in jail prior to entering treatment. Although she had a history of receiving prior counseling, there were no reported psychiatric diagnoses prior to hospitalization. During her hospitalization, Sedona was diagnosed with bulimia, substance abuse, depression, and anger management problems, although the bulimia diagnosis was eliminated at discharge. Sedona has lived with her mother most of her life, including prior to her hospitalization. She was born in Las Vegas and moved with her mother to Missouri later during in her childhood, but her exact age at that time was not clear. Sedona's father has always lived in Las Vegas and had some contact with her. After she was discharged from the hospital, Sedona went to live with him due to a court order.

Sedona was enrolled in the behavioral school at the time her father was recruited to participate in the study.

**Demographic information.** At the time of her hospitalization, Sedona was 14 and at the end of her 9<sup>th</sup> grade year. She turned 15 while she was admitted. Her ethnic status is a Caucasian. Prior to her hospitalization she was living with her mother in Missouri, and the mother's demographic information is unknown. After being discharged, Sedona stayed with her mother for three days before permanently moving in with her 36 year old father, stepmother, and three younger step-siblings in Las Vegas. The father's family income at the time of hospitalization is unknown and all children in the home have Medicaid for insurance. Sedona's father dropped out of high school in the 10<sup>th</sup> grade and did not receive a diploma, but went to a technical school for computers. He is currently not employed but works as a stay-at-home dad. The stepmother has a Bachelor's degree in Early Childhood Development, is currently going to school, and is employed doing occasional cleaning jobs.

**Family history and stressors.** Sedona's biological parents were only together for two years before divorcing. Sedona lived with her mother up until her hospitalization discharge, when she moved in with her father, per court order. Sedona's mother was reportedly a bad influence on her. Sedona had been reported to "party" with her mother and have an otherwise volatile relationship. Post-hospitalization, there was some disagreement between Sedona's mother in Missouri and her father about how her treatment should proceed (e.g., medications, when counseling should occur); however, as primary provider, Mr. Franklin generally had control over such decisions post-hospitalization. Surrounding the time of Sedona's discharge, Mr. Franklin noted a period

of preparation, explaining that he had to set up doctor and counselor appointments. During this one-month period, his wife and children were on vacation, and he stated that Sedona's arrival "was a lot to prepare for." Although the financial history is unknown, it is suspected that the family may have been under financial constraints due to the parents' employment and children's Medicaid statuses.

**Educational history.** Mr. Franklin reported that Sedona used to like school, but now she does not. About two years ago, Sedona was eligible to enroll in honors programming. However, around the same time she began displaying significant behavior problems at home and school. She now gets poor grades and does not do her homework, preferring to "hang out with her friends." A review of archival educational records confirms Mr. Franklin's report of poor grades prior to hospitalization. In fact, Sedona's GPA declined from a 2.1 the first term of the 2011/2012 school year to a 1.2 the second term of that year, which is when she entered treatment. Her GPA her first semester post-hospitalization was a .67. Additionally, a chronology of behavior problems was available for the 2012/2013 school year, with the Fall 2012 semester serving as Sedona's first semester back to school post-hospitalization. Records for that semester indicate five discipline referrals, including two Dean's detentions; two suspensions; and two required parent conferences, where Sedona was not allowed to return to campus until after a parent meeting with administration had occurred. Behaviors included harassment, verbal altercations, classroom disruptions, profanity, and tardiness. Sedona's chronic behavior problems post-hospitalization resulted in her removal from a regular school and enrollment in the specialized behavior school.

Mr. Franklin reported that Sedona has never been retained or needed special tutoring; although, some current difficulty concentrating was reported. She was supposed to go to summer school after her hospitalization, but did not. Upon re-entering school in Las Vegas, Sedona was asked to sign a behavior contract, with which Mr. Franklin was unhappy because he felt Sedona needed help, rather than a label as a “bad kid.” Mr. Franklin reported that he felt the school, particularly the counselor, did not do an effective job at helping Sedona reintegrate into the educational setting.

**Social-emotional, behavioral, and hospitalization history.** Mr. Franklin reported that Sedona has seen a counselor on and off throughout her life since she was three. She was also taking psychotropic medications during most of that time, which was while she was living with her mother. Most recently, Sedona has seen a psychologist from September through December 2012 (post-hospitalization). Since moving in with her father, Sedona was described as argumentative and having behavioral problems, indicating continued problems post-hospitalization. However, Mr. Franklin reported a longer history of problems, becoming increasingly more significant during the year leading up to Sedona’s hospitalization. Specifically, Mr. Franklin reported Sedona was using drugs (e.g., marijuana, mushrooms, speed), having sex, sneaking out, displaying a poor attitude, and partying with her mother. She also had problems at school, which is why she did not enroll in honors programming.

The behavioral episode leading up to the hospitalization involved Sedona stealing her mother's credit card. She was arrested, went to jail, and because she had been doing drugs, was referred to an inpatient hospitalization program to focus on drug rehabilitation. Mr. Franklin was unable to participate in family therapy due to the

facility's location out-of-state. Sedona's biological mother participated in only a few sessions, citing other engagements as reasons for which she could not attend, which reportedly hurt Sedona. She was enrolled in the program for about two months in the late Spring-Summer 2012 and this was her only hospitalization. At discharge, Sedona was diagnosed with substance abuse, depression, and anger management problems. Mr. Franklin said Sedona does not like to talk about her problems and becomes very hostile when pressured to do so. Post-hospitalization, Sedona argued with her father on a daily basis for several months. Mr. Franklin reported that only recently did things start to get better because he "lets a lot of things go" in an effort to avoid her argumentativeness and confrontation.

### **Research Question #1**

In general, Mr. Franklin said the hospital did "nothing" to support him or help him prepare for Sedona's discharge and he felt there was nothing good or effective about the process. Mr. Franklin reported that Sedona was hospitalized for about two months, but discussion about the discharge process was not initiated by the therapist until the day she was released. This occurred despite Mr. Franklin having phone contact with Sedona's therapist at the hospital almost every other day. Mr. Franklin said the only person with whom he had any communication at the hospital was the therapist. Of note, Mr. Franklin said this contact was mutually initiated. Additionally, although Mr. Franklin had regular phone contact with the therapist, these conversations were limited to brief updates on her progress. Sedona's mother only attended two out of the six family sessions. Regarding the specifics of the discharge plan, Mr. Franklin stated:

They really didn't do anything. Um, they only told me her problems, and this is what she's doing. They said she needed to see a psychologist, so I scheduled a psychologist....[They told me] that she had anger management problems and she needed to work on it, and she had drug problems and she needed to work on it, and stay off of drugs – that was pretty much the gist of it.... They said she's going to be, you know, done with the program. I mean, discharge information, I didn't get anything.

Mr. Franklin was not given specific descriptions of what her diagnoses mean and how she may be impacted educationally. Further, he reported that Sedona was on a significant amount of medications, but again he was not given information on the side effects and potential educational impacts. While at school, Sedona was sick from side effects for several days, so much so that she vomited. At that point, Mr. Franklin brought her to the doctor to take her off the medication. Mr. Franklin also reported that the treatment facility did not follow up with him or the school, but he wished he was provided with some kind of "outline of what the family needs to do, the school needs to do, what the doctors need to do - just anything to outline what she needs to get better" post-discharge. He also thought it would have been helpful for the hospital to follow up with Sedona's school. Mr. Franklin was not given strategies for managing her behavior at home or a crisis plan. However, the therapist made a recommendation to the courts that Sedona be released to Mr. Franklin, not the mother, because he did not feel that would be in her best interest.

Overall, Mr. Franklin's experience with the discharge planning process was not positive. Although he was in regular contact with Sedona's hospital therapist, there was

no discussion of discharge until the day she was released. Furthermore, the information provided to Mr. Franklin at discharge was only minimally helpful. Although Mr. Franklin was given a list of diagnoses/problem behavior and general recommendations, there was no discussion about Sedona's specific needs. He was not provided with an explanation of how Sedona's diagnoses/behaviors could impact her across domains of functioning. There was no information about the medications, their side effects, and potential adverse impacts, particularly at school. There was no follow-up by the hospital with Mr. Franklin and no hospital communication with Sedona's school, placing the burden on Mr. Franklin to make the hospital-to-school transition. As such, Mr. Franklin was left to facilitate this transition without a clear understanding of what Sedona was going through and how to support her. Furthermore, he was burdened with having to transition Sedona back to school with inadequate information to advocate effectively.

### **Research Question #2**

Post-hospitalization needs addressed by Mr. Franklin include Sedona's social-emotional and behavioral functioning, specifically her anger management and drug addiction issues. Even though Sedona was diagnosed with depression, Mr. Franklin seemed to minimize its importance, which suggests he may not have viewed this condition as a relevant concern at discharge. Alternatively, Mr. Franklin may have minimized Sedona's diagnosis of depression because it was not prioritized by hospital staff, or it is possible that this diagnosis may have been a subthreshold case. In general, he reported that after discharge he wanted to make Sedona "feel comfortable and like she had a good support system around her." Mr. Franklin said there was a lot he had to do to prepare for this transition, like setting up counseling appointments and "reading a lot

about what she was going through." He explained he had to figure out how to get Sedona to adapt after having spent a month in jail, two months in the hospital, and finally transferring to his house in Las Vegas. Mr. Franklin stated, "It was just a lot to prepare for."

Also falling under the umbrella of social-emotional/behavioral and educational functioning was a concern about Sedona's medications. Sedona left the hospital on a number of medications, which ultimately made her very sick at school. Mr. Franklin explained that he does not believe in medications "unless you're sick." So for him, getting Sedona proper psychiatric care was very important.

Regarding educational needs at discharge, Mr. Franklin minimized this as an area of significant concern. However, through ongoing discussion, it became apparent that he seemed to have placed more importance on this area of need than he may have realized. For example, Mr. Franklin initiated contact with Sedona's school to inform them of her situation, which contradicts his statement that educational needs were not a primary concern. This suggests that there must have been some implicit value placed on educational needs, but perhaps Mr. Franklin was not able to articulate what those needs were specifically. When asked why he initiated contact with the school, Mr. Franklin stated that he had to enroll Sedona and figured it might be good to share the hospitalization information with them. This somewhat confirms that Mr. Franklin placed some value on Sedona's educational needs, even if they were secondary to the social-emotional and behavioral concerns. Mr. Franklin's report of poor academic functioning prior to and post-hospitalization was confirmed by archival records, which suggests there was in fact a need for additional educational supports.

A possible explanation for why Mr. Franklin did not highlight educational needs as important may be that he was unaware of how the school could support Sedona upon re-entry. In other words, by minimizing educational needs in relation to her diagnoses, one of which was also minimized (depression), Mr. Franklin seemed to compartmentalize domains of functioning. He did not seem fully aware of how functioning in one area (e.g., social-emotional/behavioral) could adversely impact functioning in other areas (e.g., educational), which may have influenced his ability to effectively identify educational needs and advocate for educational supports.

Mr. Franklin also seemed unaware of the potential benefits of interagency communication on educational functioning. When enrolling Sedona in school after the hospitalization, Mr. Franklin said he “talked to the registrar and the counselor and we told them everything that Sedona had been through,” including the fact that she was on medications. Mr. Franklin stated he thought it would be beneficial for the schools to have information about Sedona’s medication, but when asked if he thought it would be helpful for the hospital to provide it, he said, “Yeah, I provided that to the school already though.” Per report, though, the hospital did not fully inform Mr. Franklin about the medications or side effects. As such, Mr. Franklin was responsible for advocating with only minimal medication information. When asked if he thought if it might be helpful for the schools to have other information about Sedona’s hospitalization, he said:

I don't know what information they would have found useful. She was in rehab, she was on drugs, she has an anger issue, plus, she's been through counseling sessions in Nevada before with her mother in the past. So all of that is record for any school that wants to look at it.

Despite his proactive efforts, Mr. Franklin did not seem to recognize the benefit of having information provided directly from the hospital to the school and seemed to have little insight regarding the depth of his own knowledge at the time.

Mr. Franklin also highlighted family and psychoeducational needs at discharge. He explained that there was a lot to do in preparation for Sedona's arrival and after she arrived, there was much conflict and time taken away from the other children. Mr. Franklin expressed he would have liked an outline of what the family needed to do post-discharge. The hospital did not provide Mr. Franklin with specific information at discharge, but Mr. Franklin also reported that he did not solicit this information. As such, he was left to conduct his own research on Sedona's conditions, with Google serving as his primary research tool. Specifically, Mr. Franklin's searches focused on drug addiction and anger management. Again he minimized the depression, explaining he did not research it because it was mostly related to issues Sedona had with her mother. He also did not research the educational impacts of the drug addiction and anger management problems, noting "I wasn't really looking for that....Education is not really, um, I mean, it was kind of secondary at the time." The need for psychoeducation was confirmed by Mr. Franklin conducting his own research. By minimizing the role of educational needs in his research, it seems that he may have further benefited from psychoeducation regarding the impact of Sedona's condition on educational functioning.

In general, Mr. Franklin seemed to place responsibility on the school for obtaining additional information about Sedona's psychological/psychiatric history, should they find it relevant. His belief appears reinforced by the fact that the hospital did not assist him in identifying educational needs. In fact, when asked about this in a follow-up interview,

Mr. Franklin explicitly stated that he felt it was the school's responsibility to obtain additional records and information. This may explain why Mr. Franklin's research on how to support Sedona post-discharge did not include educational impacts, why he did not solicit specific information from the hospital, and why he felt it unimportant to provide the school with such information. It may also be that Mr. Franklin simply did not know what types of questions to ask or what research to do.

### **Research Question #3**

Mr. Franklin did not appear aware of the range of possible supports the school could offer, and further, he seemed to be unclear about the connection between Sedona's hospitalization and school supports. His uncertainty was reinforced by the hospital not addressing educational needs and supports with him at discharge. When asked if he thought it would be helpful if the hospital had discussed Sedona's educational needs before discharge, Mr. Franklin responded, "Oh gosh, yeah!" but then further commented, "But I don't, I mean it's really hard to say. I don't know how they could tell me to make her better at school.....She wasn't hospitalized for a learning disorder or a mental thing. It was more substance abuse." Upon clarifying with Mr. Franklin, he then stated, "It would be nice if the rehab center had followed up with me and asked what school she was going to and you know, sent any of that information over to her counselor."

Mr. Franklin seemed to be genuinely confused about why the hospital would consider addressing Sedona's educational needs or how the behavior that led to her hospitalization might be educationally relevant. It follows, then, that Mr. Franklin may not have been aware of ways in which the school could support Sedona after her hospitalization. Mr. Franklin separated substance abuse from mental disorder, which he

seemed to imply might have more educational relevance. By compartmentalizing "drug problem" as separate from a mental disorder, Mr. Franklin struggled to find the connection between school and social-emotional/behavioral functioning, which suggests a general lack of understanding that schools can support students with these issues.

Although Mr. Franklin initially discounted the helpfulness of cross-agency communication, he eventually came forth with a statement indicating that direct contact may have been beneficial. It may be that Mr. Franklin did not see relevance at the time of discharge and perhaps talking about his disappointing experience with the school led him to see how this may have been a helpful form of support. Alternatively, repeated questioning about his experience with the discharge process may have cued him to respond in a socially desirable way.

Despite his uncertainty about school supports, Mr. Franklin initiated school contact post-discharge. He was not happy with the school's response, noting that he thinks "the counselor should have taken a more active role." Mr. Franklin said the counselor did not meet with Sedona and he felt the counselor should have sent him regular updates. He also stated that he thinks "schools should each have an anger management therapist....instead of delegating it to one counselor." Mr. Franklin stated that he also expressed concerns to the school psychologist but did not receive any helpful services or recommendations. Although he was unhappy with the school's response, he did not appear to know how to challenge it. Furthermore, it did not seem clear that he knew for what type of services to advocate (e.g., a transition plan outlining problematic behaviors, triggers, proactive strategies for managing behavior, reactive strategies, safe people/places/crisis plan, medication side effects). Although he stated that an email

update from the counselor would have been good, this was more of an afterthought and suggests that at the time of discharge, he put the onus on the schools for figuring out various support methods. This may also suggest that Mr. Franklin did not understand the importance of his parental role in working with the school. He did not advocate more strongly, perhaps, because he did not know how. Or perhaps Mr. Franklin did not feel it his responsibility to do so in the first place. At the same time, it does not seem that the school made vigorous efforts at involving Mr. Franklin.

It is also suspected that Mr. Franklin may have had unrealistic expectations for school supports. Although Mr. Franklin may have had a poor experience with the school and the counselor, the expectation for having an anger management specialist at every school seems lofty. Additionally, he seemed to have an expectation of school responsibility for developing intervention supports while minimizing his own role in this matter.

#### **Research Question #4**

A significant transition barrier faced by Mr. Franklin was the lack of information from the hospital. When asked about information received during the discharge planning process, Mr. Franklin reported, "Nothing about the discharge, nothing about after she gets out. Nothing, nothing, nothing." Mr. Franklin reported that he was only given a list of Sedona's problems and behaviors, along with a recommendation for continued counseling; however, there were no recommendations for how the family or school could more specifically support her needs post-discharge. They did not make a recommendation for him to notify the school post-discharge; Mr. Franklin facilitated that communication independently. He was not given any information about the side effects

for the plethora of medications Sedona was taking or how they might impact her educationally. Mr. Franklin took an active role in informing the school about his daughter's status, which is a transition facilitating factor. However, he lacked comprehensive information about Sedona's condition that could have been used to facilitate additional school support. Sedona likely faced several barriers to learning, including social-emotional/behavioral difficulties (e.g., depressed mood/irritability) and side effects from her medications (e.g., nausea). The inadequacy of information provided by the hospital seems to have outweighed his proactive efforts at initiating school contact.

Compounding the lack of hospital information were two other barriers – a lack of caregiver knowledge about the educational system and a perceived lack of school effort/unavailability of school resources. When asked about school supports, Mr. Franklin did not state an awareness of any special programming (e.g., IEP, 504 plan), but stated, “I think the schools should have more emphasis on the children. If that's what the schools are there for is the children, then shouldn't they be trying to coach them through life as well as just try to throw information at them?” He also pointed out that he felt the counselor did not play an active enough role in helping address Sedona's needs. Mr. Franklin reported that he felt the school's approach, a behavior contract, was not appropriate in addressing Sedona's needs. He was not aware that there are educational advocates to support caregivers. Although he researched supports post-discharge, Mr. Franklin did not research educational supports because he did not feel it was the biggest priority at that time.

Mr. Franklin demonstrated some insights regarding the role and function of the educational system with his comment about schools coaching children in life matters.

However, he was unaware of how schools should go about doing this, and even suggested having an anger management counselor in every school. Although this sounds like a good idea in theory, it suggests a lack of system knowledge in terms of what schools are able to realistically provide. This lack of systemic knowledge likely played a role in Mr. Franklin's failure to solicit specific information from the hospital to share with the school. Mr. Franklin was upset with the school's response, which serves as a barrier itself. However, he was unaware of educational advocacy resources, something that may have helped mitigate this barrier, had the hospital provided it.

The last observed barrier involved caregiver resources. It is suspected that the family faced financial burdens along with the stress of caring for four children, one of whom has significant mental health and behavioral problems. Mr. Franklin reported not knowing the family's annual income, but he is a stay-at-home dad and his wife is going to school and working part-time cleaning jobs. Additionally, all children are on Medicaid. When asked specifically if his financial situation was stressful at the time, he guardedly said, "Well, we got by." At the time of the transition, Mr. Franklin also appeared to be vulnerable to emotional stress, given his report of daily arguing with Sedona and some disagreement with the biological mother about aftercare services (e.g., meds, counseling). Mr. Franklin stated "there's only so much I can do with three other children," noting that he and his wife devoted a significant amount of time to Sedona's recovery without seeing much improvement. Mr. Franklin and his family also had to make accommodations for Sedona in their home after her hospitalization. This, coupled with daily conflict, which he indicated was in fact very stressful, likely impacted the overall family dynamic. There was also a physical barrier of the hospital being located in another state, making the

possibility of any in-person communications with the hospital difficult. This suggests time, physical ability, and emotional availability may have been limited resources, thus making it difficult to focus on supporting Sedona's needs.

## Case C

### Background Information

Alannah Cook is a 13 year old female who was hospitalized twice – once at age eight and once at age nine. She did not have psychiatric diagnoses prior to hospitalization, but received a diagnosis of oppositional defiant disorder (ODD) upon her first discharge. It was her extreme oppositional and defiant behavior at home that led to the hospitalizations; although, Alannah also displayed behavioral problems at school. Alannah has lived her entire life in Las Vegas and she was enrolled in the behavioral school at the time her mother was recruited as a study participant.

**Demographic information.** At the time of the hospitalizations, Alannah was in the second and third grade. Alannah's parents were never married and she grew up living with her mother, who was 24-25 at the time of the hospitalizations. Alannah's father lives in Las Vegas and has two other children, but she has not had a relationship with him or his family. Her ethnic background is African American and Caucasian. Alannah's mother, Ms. Cook, completed high school and was employed as an injury claims specialist. She still has this job and currently makes \$55,000 per year. The father's highest level of education was junior high school and he is unemployed. At the time of hospitalization, Alannah had health insurance.

**Family history and stressors.** Ms. Cook is a single parent and reported that Alannah did not have a relationship or contact with her father for most of her life. Ms. Cook reported, "He hasn't really been interested in her, her entire life." The father has other children, but Alannah does not see them. Ms. Cook reported a long history of a strained mother-child relationship due to Alannah's ODD diagnosis. Ms. Cook said Alannah "can be a handful on a daily basis." Some of her behaviors include yelling, screaming, temper tantrums, physical aggression, self-injury, threatening suicide, and running away. Despite this, Ms. Cook reported that they "get along fairly well," explaining, "It's normal for me to deal with temper tantrums and running away and stuff. But I mean, we try to have normal days." Despite her efforts at normalcy, Ms. Cook also indicated that the ongoing fighting with Alannah is quite stressful.

**Educational history.** Alannah is currently in the 7th grade and is going to be held back for failing all her classes due to suspensions much of the year. Alannah has never demonstrated any learning problems or required special tutoring or services, and Ms. Cook noted that "she's very smart." However, Alannah's behavior at school has been problematic since Kindergarten. By the time of her first hospitalization in the second grade, Alannah had been kicked out of school three times for disruptive behaviors and for acting disrespectfully. She reportedly likes school, but Ms. Cook suspects it is for the social aspect. Ms. Cook has requested an IEP or 504 accommodations at each of Alannah's schools, but reported being denied in all circumstances. These services were requested due to Alannah's significant behavioral difficulties at school. Alannah was sent to a behavior school, a short term intervention program for students who have committed

disciplinary infractions at comprehensive schools, once in the 6th grade and was enrolled in a behavior school at the time of the study.

Archival records of Alannah's educational history were available for review. Although grades were only available from 6th grade until present, there is an indication of a consistent decline in academic performance, with a GPA of 2.1 her first term of sixth grade and a GPA of .33 the last term of seventh grade, her most recent year. With grades of mostly Bs and Cs her 1st term of 6th grade, this confirms Ms. Cook's report that Alannah does not have any significant underlying learning difficulties. Behavior records indicate enrollment for her 7th grade year in a behavioral school due to ongoing behavioral infractions. Records indicate behavioral difficulties dating back to the end of Alannah's second grade year in 2008. Behaviors appear to have gotten worse over the years and have included unacceptable school behavior, theft, verbal abuse, inappropriate touch, hitting, threats to students, verbal confrontations, class disruptions, fighting with injury, campus disruptions, tardies, and harassment.

**Social-emotional, behavioral, and hospitalization history.** Problematic behaviors were reported beginning at age three, and Ms. Cook noted, "It gets worse as she gets older." Alannah was first hospitalized around age eight due to very violent behavior and threats to hurt herself. She was hospitalized for five days. She was re-hospitalized at age nine for grabbing a knife and trying to hurt one of the mother's friends. She was hospitalized for three days. Ms. Cook reported that Alannah has seen the school counselor at every one of her schools. However, Ms. Cook has not found these services helpful. Alannah has also seen outpatient counselors since Kindergarten, and again, Ms. Cook has not found these services helpful. Although Ms. Cook recently

switched Alannah to a new counselor, her previous counselor had been consistent for about five or six years and goes back to the time she was first hospitalized. Alannah took Vyvance (a stimulant) for attention problems for a brief period when she was nine. This was prescribed during her second hospitalization, but she was soon taken off of it because it did not seem to have an effect. Ms. Cook reported utilizing a variety of community resources to address Alannah's behavior, including community parenting classes, a Scared Straight-type program, and Boys Town's home-based behavioral intervention program. Alannah has a history of smoking pot, although Ms. Cook believes there was only one occasion and this was not prior to hospitalization. Alannah has been to juvenile detention about five or six times since February 2013, although she was never held longer than the 12 hour holding period. Holdings at the juvenile detention facilities were not pre-hospitalization, but confirm the increase in severity of Alannah's behaviors over time.

### **Research Question #1**

Ms. Cook had experiences with two separate hospitalizations. During the first, she was extremely disappointed with the overall experience, including discharge. Ms. Cook reported that there was no discussion of discharge until the day before. Further, she had made multiple attempts to speak with either a doctor or nurse in person and over the phone, but was never able to speak with someone. The doctors and nurses never spoke with her during visits and calls were not returned. Alannah was started on a medication without Ms. Cook's consent, despite being told upon admission that they would first call for consent. Additionally, the child psychiatrist told Ms. Cook, "Hopefully [Ms. Cook] could change her before she's 14, otherwise she'd become a drug addict prostitute." Ms.

Cook said she "clearly wasn't impressed." She was so dissatisfied with the process that she wanted to remove her daughter but was told she could not because it would be considered child neglect. Her first contact with the doctor was on the day he called to tell her Alannah would be discharged the following day. There was a discharge meeting in which Ms. Cook met with a team of people, although she did not know who everyone was at the meeting. The hospital addressed Alannah's social-emotional/behavioral needs by recommending family counseling and that Alannah not have contact with her father, which the staff believed was the source of Alannah's problems. Staff reported that they did not believe Alannah had a "mental disorder," but rather severe misbehavior. Ms. Cook did not find the discharge information to be helpful. She asked for specific recommendations for family therapists but did not receive them. When asked how the hospital could have better addressed Alannah's needs, Ms. Cook said:

It would have been nice if they would have given me some recommendations for family therapists. And it would have been nice if they would have given me some type of advocate or something with the school that would have helped me with her at school because by the time she had been to Treatment Center 1 she was eight and she had been kicked out of three schools.

Educational needs were not addressed by the hospital, although Ms. Cook asked about how she could get a 504 plan for her daughter. She said every school has told her that she would need a written statement from the doctor indicating the need for school accommodations, and Ms. Cook said the doctors here refused to do this for her.

At the second facility, Ms. Cook reported feeling better connected with the staff. Alannah was only admitted for three days, and the doctor notified Ms. Cook of the

release on the second day. Discharge procedures were 1:1 with the doctor, and Ms. Cook reported daily contact with the doctor, including returned calls. Although her overall satisfaction with this place was higher (five out of 10 versus zero at the first treatment facility), she attributed it to the contact with the doctor and prior notification of starting the medication. Although she was more satisfied at Treatment Center 2, Ms. Cook reported that the actual discharge procedures were no more helpful here than at Treatment Center 1. Recommendations at Treatment Center 2 included continuing with counseling, which Ms. Cook said was not working, and psychiatric care. No other specifics were given and educational needs were not addressed. Ms. Cook stated that she did not ask the doctor for a written statement to facilitate getting a 504 plan because she believed she would have gotten the same response as at the first hospital. At Treatment Center 2, the doctor did in fact contact Alannah's school teacher, but it was to assess her behavior in the classroom to see if a stimulant medication may be helpful for some noted inattention. Ms. Cook said that there was no discussion between the doctor and teacher about social-emotional/behavioral supports or recommendations for post-discharge supports.

For both places, Ms. Cook described the discharge plans as unhelpful because "they don't offer any solutions." Ms. Cook reported doing a lot of research on her own to try to find community resources for herself and Alannah. She would have used any resources offered by the hospitals at discharge, but none were given. Specifically, Ms. Cook would have liked recommendations for family therapists and an educational advocate to facilitate school supports for Alannah's severe behavioral problems. Neither

facility explained Alannah's diagnosis of ODD, how she might be impacted across settings, or how Ms. Cook could support her.

Although Ms. Cook's overall satisfaction with the second facility was higher, she reported many similarities between the discharge processes, except for the discharge approach (i.e., 1:1 meeting with parent vs. multidisciplinary (MDT) team approach). There was an overall dissatisfaction with both facilities in terms of discharge efforts. At the first facility, even though an MDT approach was used, the hospital did not make efforts at familiarizing Ms. Cook with several of the team members. Further, the hospital did not plan for discharge in a timely manner and tended to keep Ms. Cook unaware of what was happening. During the discharge meeting, the child psychiatrist made a rather harsh statement about Alannah, upsetting Ms. Cook possibly because of the implicit accusations on the quality of her parenting. The hospital failed to provide specific recommendations and blatantly refused to provide assistance with addressing Alannah's educational needs. As such, the first hospital appeared to make minimal efforts and assumed minimal responsibility for addressing Alannah's needs across all domains at discharge.

At the second facility, Ms. Cook felt like she had better communication with the doctor, but the discharge procedures were no more helpful than those at the first hospital. Although the doctor at Treatment Center 2 addressed medication issues by contacting the school, the doctor failed to initiate any conversations about supports post-discharge. The brief recommendations for counseling and psychiatric care were not deemed helpful, and, no educational needs were addressed outside of medication management for inattention. Of note, Ms. Cook's bad experience at Treatment Center 1 prevented her from

advocating similarly at Treatment Center 2, with her behavior reflecting a learned-helplessness. The lack of helpful discharge information and 1:1 discharge planning procedures are not consistent with effective discharge planning. Although this was a much shorter hospitalization than the first, the hospital still failed to involve Ms. Cook by engaging her with other staff and using an MDT approach to discharge. Additionally, specific information about Alannah's condition, potential impacts of her condition, and specific strategies for supporting her post-discharge were not offered. Although Ms. Cook felt more satisfied about her contact with the doctor at this hospital, their efforts at addressing Alannah's needs across all domains at discharge appeared minimal.

An alternative explanation for the lack of information received by Ms. Cook may be that the hospitals did provide her with more explicit and specific information, but given her lack of familiarity with mental health/medical language, was not able to understand the information and/or did not remember this information. Given the similarity of her experiences in both circumstances, however, it is suspected that there is validity to her personal accounting of what happened.

### **Research Question #2**

Ms. Cook reported a need for continued social-emotional/behavioral supports for Alannah post-hospitalizations. She noted the continued need for Alannah to follow up with counseling, but felt frustrated about the lack of recommendations for family therapists, particularly at the first facility. This was important for her because she felt like Alannah's counselor was not effective. She also reported feeling unaware of basic community resources. In general, Ms. Cook said she felt like Alannah "came out worse" from the hospitals because of the bad behaviors she learned and further explained the

hospitals seemed "more like a delinquent center." Ms. Cook also reported educational concerns. In the past she had tried to advocate for IEPs and 504 plans, but was told Alannah's problems were behavioral and not learning-related. Ms. Cook noted, "I tried to explain to [the schools] that, you know, her behavior problems are severe and that she does need to be handled differently than other children, but they still won't do it."

Archival educational records confirm that Alannah was not a student with inherent learning difficulties. However, behavior records indicate significant difficulties starting in the second grade and progressively getting worse over the years. Ms. Cook also identified needs related to psychoeducation and family support. She explained:

I've done so many programs just off my own research, trying to, you know, be consistent in helping. If they would have given me the information I definitely would have utilized it. Um, I can't say that it would have changed the outcome, but I would have found it helpful and used it.

Ms. Cook said the psychoeducational information she was given at Treatment Center 1 was not helpful. Specifically, the hospital told her they believed much of Alannah's behavior problems stemmed from anger towards her father. Ms. Cook explained, "I don't think that's where all of her anger comes from. I'm sure some of it comes from that, but I don't think all of it does." She also would have liked an educational advocate to help her navigate the educational system.

Some of Ms. Cook's most significant needs included social-emotional/behavioral and family supports. Alannah presented with chronic behavior problems at home and school, and years of counseling resulted in minimal gains. Her counselor was not effective, and neither were the other community resources utilized by Ms. Cook. As

such, she was desperate for assistance in obtaining specific recommendations, but was met with resistance. When she did not ask the hospital for help, this information was not volunteered. Additionally, Ms. Cook was in need of psychoeducational and educational information, particularly so she could better understand how to support Alannah's needs post-discharge. Alannah had a long history of behavioral difficulties at school, and Ms. Cook had not been able to successfully make headway in terms of obtaining supports. Although Ms. Cook was told that Alannah's difficulties seemed to stem from anger toward her father, who should be avoided, Ms. Cook found this unhelpful because Alannah had no contact with her father. Further, even though this information may have explained the source of some of Alannah's anger, it appeared only minimally relevant for determining post-discharge supports across settings.

### **Research Question #3**

Ms. Cook reported being aware that schools can provide IEPs and 504 accommodations, explaining that her younger brother had an IEP and her mother was very knowledgeable about the process. However, when other types of supports were explained, Ms. Cook said she was not aware that schools could offer support in this way. She also said, "I didn't even know the schools have a psychologist." When asked if she felt the hospitals should have addressed child's educational needs, Ms. Cook said "Yeah, that's one of [Alannah's] biggest problems - not doing well in school and nobody being able to get her an IEP or 504." She said for the hospitals, educational needs "didn't seem to be one of their concerns." Ms. Cook stated:

It would have been helpful if [the doctor] had assisted in getting Alannah set up on an IEP or 504 because every time I talk to the school about it, they say they

need something from the doctors stating that she needs special circumstances, or special treatment at school as far as her getting upset or getting agitated. But they won't. The doctors won't write anything or assist with that at all.

The only educational supports offered by either hospital was medication management to assist with fidgeting, outbursts, and agitation at school. However, Ms. Cook did not report the doctor having a discussion with her about side effects.

Ms. Cook was unaware of full range of supports schools can offer. Although she had some knowledge about formal supports (e.g., IEP, 504), she was unaware of other ways in which schools can offer support and thusly did not advocate for such services (e.g., a behavioral intervention plan). It is suspected Ms. Cook did not have had enough educational system knowledge to effectively advocate for Alannah's needs, which was worsened by the fact that the hospital did little to inform her about educational needs and supports. Given Ms. Cook's description of Alannah's behaviors and academic functioning, it seems as though she would have at least qualified for a 504 plan. However, this did not happen, and it is suspected that Ms. Cook was not aware of her rights in terms of challenging the school's response and/or filing a complaint. Conversely, Ms. Cook's request for assistance and recommendations from the hospital highlights her insight that hospital information is important and relevant for educational planning. Undoubtedly, both hospitals failed in providing even basic information to Ms. Cook, with Treatment Center 1 flat out refusing to provide a written statement of how Alannah's behaviors might impact her educationally. An alternative explanation for the doctor's refusal to write an educational impact statement is that the doctor did not see negative impacts at the time.

#### **Research Question #4**

A significant transition barrier was the general lack of information from the hospital. Ms. Cook made significant attempts at involving herself during Alannah's hospitalizations, which is a facilitating factor, but was ignored and rejected, particularly during the first hospitalization. For both hospitalizations, Ms. Cook was provided with little, if any information pertaining to her daughter's diagnosis, ways to support her post-discharge, and even community resources. Regarding discharge planning procedures, the hospitals did not refer Ms. Cook to a family therapist, despite making this recommendation and Ms. Cook asking for specific details. The first hospital generally did not keep Ms. Cook informed, and even placed her daughter on medications without her permission. Neither hospital incorporated specific information about social-emotional/behavioral or educational needs into the discharge plan. In fact, Ms. Cook even asked for a written statement from the doctor indicating Alannah's behavioral concerns and potential negative educational impact, but she was refused. She mentioned, "I asked them for referrals to other counselors, thinking maybe it was just her counselor that wasn't being effective, and they never gave me referrals for counselors or anything." She also asked for educational advocacy information, and the hospital did not provide it. Although the hospital provided some information regarding the genesis of Alannah's behaviors, Ms. Cook reported not finding this information very helpful. Ms. Cook noted, "I was very disappointed with the whole process, as far as when she was in there, they didn't keep me informed, they didn't update me, they just really didn't do anything until the discharge plan." One hospital contacted Alannah's teacher, but only for the purposes of assessing to prescribe medication. There was no communication about ways to

support her needs after discharge. Although Ms. Cook was generally more satisfied with the contact she received from the psychiatrist at this hospital, there was still no incorporation or discussion of educational needs in the discharge plan. Ms. Cook reported not asking for this kind of support because "I figured since the [first hospital] didn't have any suggestions or wouldn't help with it I figured it would be the same. So I honestly didn't even ask them." As such, Ms. Cook tried to advocate for her daughter's educational needs but was not provided with adequate information to facilitate this process better. Overall, both hospitals failed to provide adequate psychoeducational information, information on school/community resources, and recommendations for how Ms. Cook could support Alannah's needs post-discharge.

Ms. Cook also faced educational barriers, including an unavailability of school services/poor school effort and a lack of her own knowledge about the educational system. Educationally, Ms. Cook has tried to obtain school support in the form of IEP/504 but has been continually denied. Further, schools did not offer any other forms of support post-hospitalization other than notifying the mother that Alannah could speak to the counselor, if needed. Ms. Cook even noted going to the schools to get Alannah's homework, and that the schools were aware of Alannah's situation, but did not offer other forms of support. Alannah's academic record indicates a history of significant behavioral problems at school starting in second grade, which is about the same time she was first hospitalized. In fact, Ms. Cook reported that Alannah had been kicked out of three schools by the time she was first hospitalized. However, Ms. Cook was not aware of other school supports and resources, and she was not connected with any advocacy supports. The lack of hospital information, along with her lack of educational

knowledge, made it extremely unlikely that she fully advocate for her daughter in an informed way, especially when faced with resistance from the schools.

Lack of caregiver resources, such as emotional availability and physical resources (e.g., time) appeared to be another barrier. Ms. Cook has been a single parent for all of Alannah's life. As such, she has been the sole financial provider and person responsible for coordinating care for Alannah. Although she did not appear to be struggling significantly financially, as single parent, a lack of physical resources, such as time, could have made it more difficult for Ms. Cook to meet Alannah's needs. Ms. Cook seemed to have invested a great deal of time trying to obtain community supports, involving herself in the hospitalization process, doing research, and involving herself with the school. In addition, Ms. Cook and Alannah experienced significant interpersonal conflict for many years, with Alannah's behavior worsened over the years, which was reportedly a significant source of stress. Ms. Cook has struggled to find school/community resources that have been effective, despite investing much time in personal research and involvement in these endeavors. This stress, coupled with her limited time, put her at risk for emotional burnout, which Ms. Cook reported put a further strain on her relationship with Alannah and her ability to support Alannah's needs.

Alternative explanations to barriers include the possibility that Ms. Cook had more knowledge of the educational system than suspected, with her difficulties in obtaining services stemming mostly from the agencies involved.

## **Cross-Case Analysis**

### **Background Information**

**Demographic information.** In the current study, the children described in each case were of different ethnicities and from varying backgrounds. At the time of hospitalization, Sedona and Chad were similar in age, around age 15, while Alannah was much younger at ages eight and nine. Caregivers' educational histories ranged from high school dropout to college degree. Sedona's father is the only caregiver who was not employed at the time of hospitalization. All children were covered by health insurance at the time of hospitalization.

**Family history and stressors.** Family histories were remarkably different, but were fraught with an array of stressors across cases. Marital statuses included a single parent home; divorced parents, with a remarried father; and married parents, although the mother essentially functioned as a single parent. Each family housed some kind of ongoing interpersonal conflict, mostly between the hospitalized child and a parent, but at times between parents. Although this conflict was ongoing, it was particularly evident in each case immediately pre- and post-hospitalization. Families also experienced a variety of other stressors, including but not limited to chronic health problems in a child, suspected financial difficulties, unavailability of a spouse, marital stress, having multiple children in the home, and job stress.

**Educational history.** Chad's case was the only instance of prior special education services. However, in each case there was a reported history of behavioral problems at school and poor grades. For Alannah and Chad, these difficulties were observed in early elementary school, while Sedona's difficulties did not become

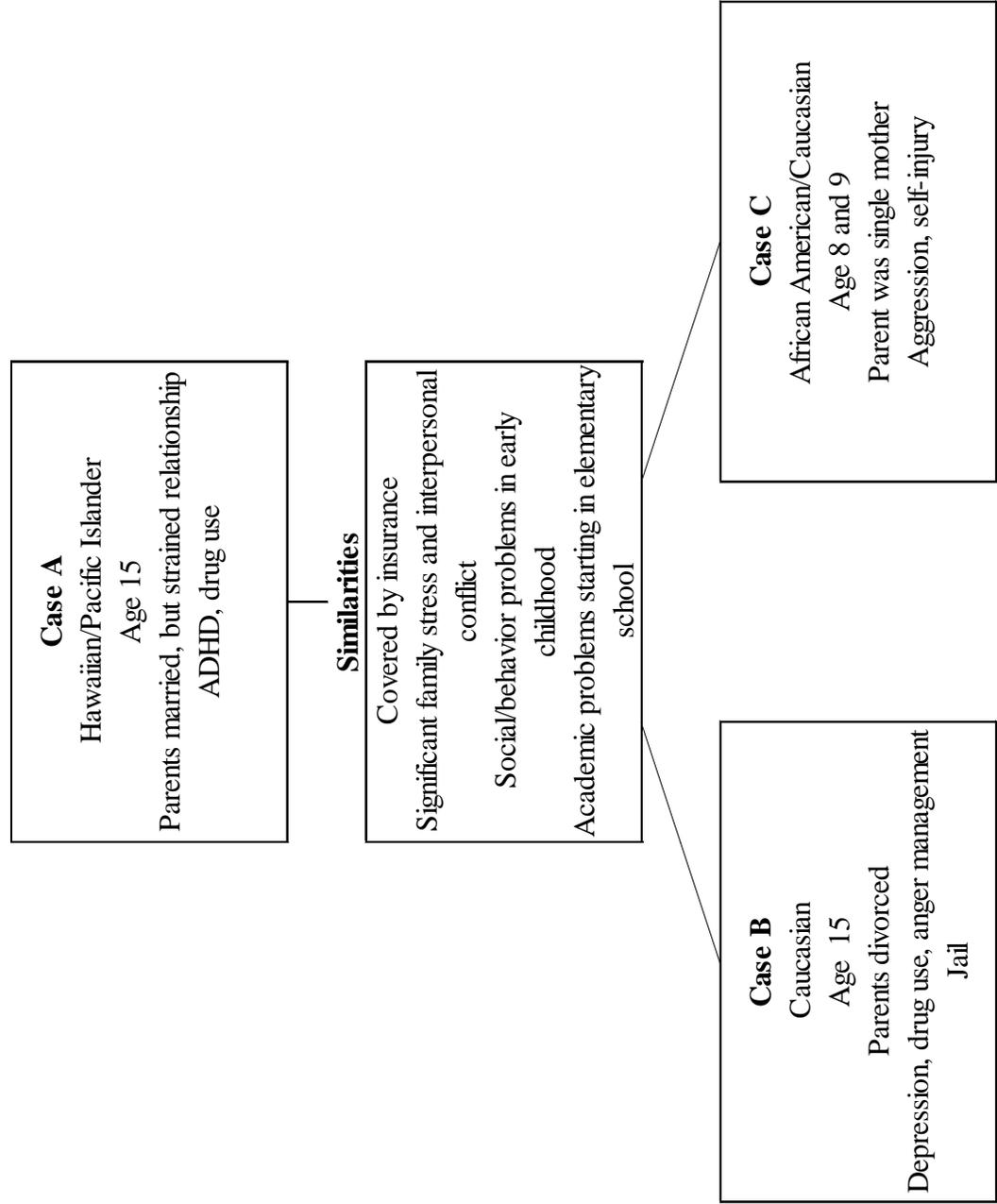
significant until later in elementary school. For all cases, academic and behavioral problems were clearly present prior to hospitalization, with an overall downward trend in functioning, especially post-hospitalization. Sedona was the only child reported eligible for honors programming, but she did not enroll due to her behavioral problems.

**Social-emotional, behavioral, and hospitalization history.** For each case, at least some level of social-emotional/behavioral disturbance was reported to have begun in early childhood. While Sedona and Alannah had histories of ongoing counseling prior to hospitalization, Chad's counseling history pre-hospitalization was more brief.

Utilization of prescription medications varied significantly across cases, with Sedona taking medications most of her life, Chad beginning medications in high school, and Alannah taking medications for only a brief period of time when she was nine.

Diagnoses and behavioral disturbances varied greatly across cases, including ADHD, oppositional defiant disorder, bulimia, substance abuse, depression, suicidality, self-injury, anger management problems, defiance, lying, stealing, physical aggression, bullying, and risky behaviors (e.g., having sex). Only Sedona had a history of involvement with the juvenile justice system prior to hospitalization, while Alannah became involved several years post-hospitalization. An overview of case similarities and differences is presented in Figure 2.

Figure 2  
*Case History Similarities and Differences*



## **Research Question #1**

Each caregiver had a very different experience with hospitalization and discharge planning, but all reported an overall dissatisfaction with the experience. Alannah and Chad's caregivers made significant attempts to involve themselves in the hospital experience. They were physically present and regularly solicited information from staff. They had similar experiences with staff interactions in that they both solicited information, but were often ignored. Provided information was deemed unhelpful. Sedona's caregiver could not be present because of the treatment center's location in another state, and it is suspected that financial burdens prevented him from being able to do so. However, Mr. Franklin had regular contact with the therapist. Despite this, he reported receiving a lack of useful information.

In all scenarios, it is clear that information provided by the hospitals was only minimally useful for caregivers. At discharge, each caregiver was given a list of their child's diagnoses and a recommendation for continued counseling. One was given a recommendation to seek out an IEP and another was told to continue with medication management. It turns out that these recommendations were vague, brief, and did not include psychoeducational information. Specifically, there was a failure to discuss each child's needs in depth, potential impacts on the child's functioning in various settings, specific intervention strategies for parents/schools, and recommendations for family support. Hospitals did not assist caregivers in developing a relapse-prevention and/or crisis intervention plans. There was no follow up with any caregivers post-discharge and no efforts at cross-agency communication, for example, with the schools.

For all cases, discharge planning procedures were not defined. The earliest anyone was involved in discussions about discharge planning procedures was two days prior to discharge. For the actual discharge, only Ms. Cook experienced an MDT meeting with hospital staff. However, she was unfamiliar with several of the team members. All other discharge meetings were one-on-one with caregivers. For Ms. Ives, this involved having several meetings with different staff and resulted in conflicting information from different staff. Overall, caregiver experiences with the discharge planning process across cases were not consistent with what the literature suggests makes for effective discharge planning. Hospitals made poor attempts at involving families in the process, failed to assist caregivers in identifying their children's critical needs, and did little to facilitate maintenance of skills gained during admission.

### **Research Question #2**

Across cases, the most significant area of need identified by caregivers was for psychoeducational material and family support. All caregivers expressed a desire for the hospital to have provided more information at discharge about the next steps in the process and ways they could support their children's needs. Ms. Ives and Ms. Cook expressed these needs most strongly. Mr. Franklin and Ms. Ives both felt like they could have benefitted from more explanation about what to do post-discharge, while Ms. Cook and Ms. Ives articulated a need for more specific resources. Ms. Ives felt lost, overwhelmed, and unclear about the steps she had to take post-discharge. She also felt like she did not understand what her child was going through or how she could support him. Mr. Franklin noted that the transition out of the hospital was a lot to prepare for, and he ended up having to conduct his own research on the internet. He would have liked

some guidance on how he and the school could support his daughter. Ms. Cook had previously conducted her own research in an attempt to find community resources but was continuing to see only minimal gains with her daughter. She specifically would have liked information about community agencies, therapists, and educational advocates.

Although each family dynamic was dramatically different, each faced stressful circumstances that validate a need for family support. Ms. Cook was a single parent, and Ms. Ives was essentially functioning as a single parent. Ms. Ives described the hospitalization experience as tearing her family apart, and she was also tasked with caring for a chronically ill child. Mr. Franklin described how he and his wife struggled to meet their other children's needs, due to spending so much time on Sedona with little improvement to show for it. All caregivers reported experiencing significant stress related to the hospitalization and strained relationships with their family members.

Another area of need identified by caregivers was for social-emotional/behavioral support. For Mr. Franklin, his biggest concern was obtaining proper psychiatric care for his daughter, while Ms. Cook and Ms. Ives identified a need for more information about understanding their children's condition and behavioral/counseling supports. Of note, Mr. Franklin only focused on certain aspects of Sedona's diagnoses (e.g., anger management, drug use), seeming to minimize the importance of her other diagnosis of depression.

A final area of need expressed by caregivers involved the educational concerns. This need was most strongly identified by Ms. Cook and Ms. Ives, and to a lesser extent Mr. Franklin. Ms. Ives had a strong desire to figure out how to make education more meaningful for her son. Ms. Cook, on the other hand, was more interested in obtaining

resources, such as educational advocates, to assist her in working with the school to obtain supports through an IEP or 504. Both Ms. Cook and Ms. Ives appeared to understand the relationship between social-emotional/behavioral well-being and academic functioning. Mr. Franklin, however, seemed to have difficulty understanding this relationship. Although he identified educational needs as “secondary” at the time of discharge, he independently initiated contact with Sedona’s school to inform them of her condition. This suggests he implicitly identified educational concerns as an area of need, but may not have known how to articulate them. With each case, school functioning continued to decline post-discharge, validating the caregiver reports of educational needs. Sedona and Alannah were eventually both placed in behavior schools, and Chad repeated the ninth grade four times, eventually dropping out of school altogether. Social-emotional/behavioral functioning appeared to be directly related to academic functioning in all scenarios.

### **Research Question #3**

Across cases, caregivers demonstrated minimal knowledge of the educational system. Caregivers were unaware of the full range of supports schools could offer, such as transition, crisis, and behavior support plans. While Ms. Cook and Ms. Ives were aware of formal supports such as an IEP and 504 plan, Mr. Franklin was not aware of them. In addition, although Ms. Ives and Ms. Cook were aware of these formal supports, they were not aware of advocacy resources to assist them in navigating the system. Both struggled to obtain school services, and Ms. Ives reported some confusion about eligibility for services. All caregivers reported dissatisfaction with school supports and services, but none seemed equipped with an understanding of how to challenge the

school's response or file for a complaint. Uniquely, Mr. Franklin seemed unclear about how social-emotional/behavioral functioning relates to school functioning. He also seemed to have some unrealistic expectations of school supports, criticizing the implementation of a behavior plan and recommending anger management specialists at every school. Additionally, Mr. Franklin seemed to put the onus on the schools for developing interventions and obtaining records, while minimizing his own parental role in the process. These findings further highlight his lack of awareness of school supports.

#### **Research Question #4**

The most notable transition barrier across cases was the lack of information provided by the hospitals. Ms. Cook and Ms. Ives both made significant efforts at involving themselves in the hospitalization process and asked questions, but were given little information. Ms. Ives was given conflicting information and Ms. Cook was denied answers to her questions and was uninformed about her daughter starting a medication. Regarding discharge process, the earliest any caregiver was informed about discharge was two days prior, with Mr. Cook receiving notice on the day of discharge. All caregivers reported basic recommendations for continued counseling services post-discharge, but nothing specific and no clear guidance on what to do next. They all reported only minimal to no utility of the information that was provided.

Another significant transition barrier was the lack of caregiver knowledge about the educational system. Although two caregivers had some knowledge of formal supports (e.g., IEPs and 504 plans), this knowledge was limited. The other caregiver was not aware of formal supports, and all caregivers lacked awareness of informal supports like transition, crisis, and behavior support plans. Only one caregiver was aware that

schools had a school psychologist. Furthermore, caregivers did not demonstrate an understanding of how to challenge a school's response or file a complaint. Mr. Franklin uniquely lacked an understanding of how schools can support students' social-emotional/behavioral needs, the schools' role and function, and his role in the transition process. This barrier appears to be exacerbated by the fact that caregivers were not provided with adequate information from the hospitals as well as the barrier, mentioned next, of inadequate school effort/unavailability of services.

Inadequate school effort/unavailability of services was another transition barrier across cases. All caregivers experienced dissatisfaction with either the school's effort and/or the availability of services and supports post-discharge. Ms. Cook and Ms. Ives reported denial of formal supports, and in both situations, caregiver reports of their child's behavior suggests the recommendation for formal supports was not outlandish. Furthermore, when services were denied, both caregivers indicated that the schools made no efforts to provide alternative means of support. Mr. Franklin did not seek out formal supports, but the schools did not recommend these services. Although in his situation the schools developed a behavior plan, the schools did not apparently do a thorough job of explaining the utility of this support, as Mr. Franklin brushed it off as inappropriate. Furthermore, the quality of the behavior plan is questionable, as Sedona's records post-discharge indicated a steady increase in severity of behavioral problems.

Another consistent transition barrier across cases was the lack of caregiver resources. Mr. Franklin was the only caregiver who appeared to be struggling financially. However, each caregiver lacked time, physical, and emotional resources. Each caregiver had to devote more time and physical effort toward their child who was

hospitalized, scheduling appointments, conducting research, and contacting the schools. However, Mr. Franklin's time and physical resources were further limited because he had three other children. Similarly, Ms. Ives had a chronically ill child and was operating as a single parent due to her husband's frequent travel. Ms. Cook was a single parent. Additionally, Ms. Ives and Mr. Franklin faced the physical burden of having the hospitals being located geographically far from home. All caregivers were dealing with a long history of behavior problems and interpersonal conflict in the home. This coupled with the time and physical barriers previously mentioned, took a toll on caregivers' well-being and likely strained their capacity to provide emotional support to their children.

A final barrier was the feeling of being disrespected by or disappointed in hospital staff. Ms. Ives reported being spoken to in a condescending manner, and at times felt as if she was being scolded about having a child with significant behavioral problems. Ms. Cook reported hospital staff making harsh and judgmental comments, leaving her feeling unimpressed with their approach. Mr. Franklin did not appear to face this barrier.

In contrast to the identified barriers, several transition facilitating factors were apparent. The first and perhaps most prominent facilitating factor was parent involvement with the hospitalization and discharge planning process. Each caregiver maintained contact with the hospital and even initiated contact. The second, also prominent factor was caregiver initiation of community/school resources. Across cases, caregivers initiated contact with their child's school to facilitate the hospital-to-school transition. Further, Mr. Franklin and Ms. Cook followed up with community resources for psychiatric and counseling services. A third factor was the caregiver seeking hospital recommendations. Ms. Ives and Ms. Cook both took active roles in seeking out specific

recommendations from hospital staff, while Mr. Cook did not seem to do this. A fourth factor, evident for Mr. Franklin and Ms. Cook, was conducting their own research on the child's condition and/or community resources. And the final factor, evident only for Ms. Ives, family involvement, specifically support outside of the nuclear family. See Table 1 for a summary of the main findings.

### **Summary**

The purpose of the study was to explore (1) caregiver experiences with the hospital discharge planning process, (2) caregiver perceptions of their child's and family's needs at discharge, (3) caregiver knowledge of the education system and hospital staff's role in providing information about the child's educational needs and potential supports, and (4) barriers to the hospital discharge planning/hospital-to-school transition process.

Results indicate an overall dissatisfaction with the discharge planning process across cases. Caregivers were provided with a lack of information in general, and a lack of helpful information. Hospital staff played only a minimal role in involving families in the discharge planning process, identifying the child's critical needs at discharge, and encouraging the maintenance of skills gained during admission. Furthermore, discharge planning procedures were not clearly defined and did not fall in line with what the research suggests makes for effective discharge planning.

Table 1  
*Summary of Main Findings*

Unsatisfactory Discharge Experience	Caregiver Needs Were Unmet	Limited Caregiver Knowledge of Educational System	Barriers Outweighed Facilitating Factors
-Solicited information ignored/not provided	-Psychoeducational information not provided	- Limited knowledge of formal and informal supports	-Caregivers showed initiative in seeking resources and supports, but were thwarted by inadequate hospital information
-Provided information not helpful	-Caregivers unclear about how to support child's needs	-Unaware of/unsure how to access educational advocacy resources	
-Recommendations were vague, brief	-Need for more information on post-discharge supports	-Unaware of procedures for challenging school/filing due process	-Inadequate hospital information and lack of educational knowledge limited
-Hospital discharge procedures unclear	-Families' needs not addressed		-Poor school effort/lack of services exacerbated by limited caregiver knowledge
-Functional impacts of behavior not addressed	- Educational needs inarticulately and inconsistently addressed		
-No discussion of specific interventions for parents, schools			-Lack of caregiver resources added increased strain on ability to meet child's needs
-No cross-agency communication to facilitate re-entry			

Regarding caregiver perceptions of their child's needs at discharge, the most prominent need was for psychoeducation and family support. Caregivers expressed a desire for more information about their children's functioning as well as ways they could support their children's needs post-discharge. The child's social-emotional/behavioral functioning was another area of identified need. Caregivers expressed a need for psychiatric and psychological care post-discharge. Educational needs were also a common concern, although one participant seemed to struggle understanding how these needs related to his child's social-emotional/behavioral functioning.

With respect to caregiver knowledge about the educational system, caregivers consistently demonstrated a lack of knowledge across cases. Knowledge in this area was significantly limited, with caregivers generally unaware of basic forms of support schools can offer. Findings indicate that hospital staff played a negligible role in educating caregivers about the children's educational needs and potential educational supports at discharge.

Finally, caregivers faced several barriers to the hospital-to-school transition process. Most notable was a lack of information provided by the hospital, including unhelpful information. Caregivers also consistently presented with a lack of educational system knowledge. Caregivers were faced with a lack of school effort or unavailability of services, which seemed to be related to the barriers associated with a lack of hospital information and lack of caregiver knowledge of the educational system. Another barrier was the lack of caregiver resources, mainly time, physical, and emotional resources. And finally, there was a feeling of being disrespected by or disappointed in hospital staff.

In contrast to the identified barriers, several transition facilitating factors emerged. Most significantly was that of caregiver involvement in the hospitalization process. Another factor involved caregivers seeking hospital recommendations. Caregivers also initiated school/community resources. One caregiver experienced significant family support beyond the nuclear family.

## CHAPTER 5

### DISCUSSION

#### **Overview**

This chapter will provide a brief overview of the purpose and procedures used in this study. Conclusions and assertions related to each research question will then be described. Implications and recommendations for policy and practice are presented next, followed by the study's significance, limitations, and recommendations for future research.

#### **Study Purpose and Procedures**

The purpose of the study was to explore caregivers' experiences transitioning a child from a psychiatric hospital setting back to school in an effort to develop recommendations for future policy and practice. The present study employed a multiple case study design whereby three separate cases were analyzed and convergent cross-case findings were sought. Cross-case interpretations and findings include a synthesis of background information as well as a synthesis of findings for each research question/theme.

#### **Interpretation of Findings and Assertions**

##### **Background Information**

Findings indicate variability across cases in terms of background information and histories. The children who were hospitalized in each case were of varying age and ethnicities. Caregivers were of varying ages and had different educational and

employment histories. However, each child had health insurance at the time they were hospitalized. Of note, although family histories and experiences varied significantly across cases, there was evidence of significant stressors impacting all families. Caregiver marital status was unique in each case, yet the presence of interpersonal conflict, often involving the child, was present across cases. Conflict within each case tended to be marked, with notable interpersonal strain around the time of the hospitalizations. Although differing in their nature, a variety of other stressors, such as financial, employment, and health, were experienced across cases. Although the age at onset somewhat differed, for all cases, academic and behavioral problems were clearly evident pre-hospitalization, with a downward trend in functioning, especially post-hospitalization. Similarly, early onset social-emotional and behavioral difficulties were apparent for children in all cases. The degree of impairment appeared similar across cases, despite the variability in the nature of these difficulties. Given the individual educational histories of each child, it is suspected that poor social-emotional and behavioral functioning accounts for a good portion of the poor academic performance observed across cases.

### **Caregiver Experiences with Discharge Planning and Transitions**

Overall, caregivers reported unfavorable experiences with the hospital discharge planning/transition process, experiences which were not indicative of what the literature suggests makes for effective discharge planning and transitioning experiences (Bull & Roberts, 2001; Guterman et al., 1989; Hedges et al., 1999; Leichtman & Leichtman, 2002; Leichtman & Leichtman, 2004; Rose & Haugen, 2010; Simon & Savina, 2010; Steffen et al., 2009; Tennier, 1997; Watts et al., 2006). Specifically, caregiver

experiences generally did not involve a multidisciplinary team (MDT) approach, clearly defined discharge planning procedures, and an ecological approach.

In all except one scenario, MDT approaches were absent, and for the situation in which an MDT approach was used, the process was inadequate. In the latter scenario, the caregiver was unfamiliar with several of the team members, which is not consistent with the recommendation for effective MDTs to have clearly defined roles among participants (Hedges et al., 1999). In general, information provided to caregivers was inadequate, unhelpful, and at times, contradictory. Caregivers reported feeling disappointed in and disrespected by hospital staff, which does not suggest a sense of trust and teamwork, as recommended in the literature (Bull & Roberts, 2001; Watts et al., 2006). Finally, there was no coordinator of services to assist families with discharge and transitioning.

All caregivers reported experiences that suggested a lack of clearly defined discharge procedures. There were reported feelings of uncertainty regarding the process, including when it would occur and what would happen next. Discharge plans were discussed at the earliest, only two days prior to discharge, giving caregivers little time to prepare and adding stress to an already overwhelming situation. Hospitals did not appear to make concerted efforts at involving families extensively in the process, and when caregivers asserted themselves, they were shut down. Hospital efforts at involving caregivers in discussions about coordinated services appeared limited to presenting caregivers with a brief recommendation for continued counseling, and in one case, seeking out an IEP at school. The one caregiver who reported receiving a paper copy of the discharge report did not experience this as helpful because the information was vague and similar to the verbal report. No caregivers reported hospitals assisting them in the

creation of a crisis plan or relapse prevention plan, which is seriously concerning since one case involved hospitalization for suicidality.

Discharge planning/transition experiences were not consistent with an ecological approach. In general, hospitals' efforts at encouraging the maintenance of skills learned during treatment were limited to recommendations for counseling post-discharge. One caregiver was actually given a list of potential providers, but reported feeling overwhelmed and confused about how to proceed. No caregivers were provided with psychoeducational information about their child's diagnoses and how to go about finding the right therapist. Although one caregiver was told to seek out an IEP for school supports, neither she nor the other caregivers were provided with information about how their child's psychological condition could potentially impact them educationally. Caregivers received no information about what to expect post-hospitalization or how they could support their child's needs in the home. All caregivers also reported no follow-up post-discharge, either with them or with other community agencies, including schools. As such, caregivers faced the transition process with minimal information and support from the hospitals. Hospitals' poor discharge planning/transition practices distanced caregivers from hospital staff and procedures, placed the transition burden on caregivers, left caregivers without the information needed to optimally facilitate the transition, and served in a minimal role toward stabilization and relapse prevention.

### **Caregiver Needs**

The greatest perceived need across cases was for caregiver psychoeducational information and family support. However, because hospital discharge planning procedures were inadequate, caregiver, child, and family needs were often left unmet. At

discharge, caregivers were left with little other than a list of diagnoses and recommendations for continued counseling. Diagnoses, expected impacts on functioning, strategies for managing behavior, warning signs for relapse, specifics about community resources, and medication side effects were left unexplained. In two of the cases, caregivers made significant attempts to solicit such information but were nonetheless left in the dark. Caregivers felt confused, overwhelmed, and frustrated about what to expect during the transition process. Compounding this issue in all cases was the presence of significant familial stressors and interpersonal strain. Each caregiver reported that the hospitalization and transition experience was extremely stressful for them and their families, validating the need for family support during this critical time of need. Despite this finding, caregivers were not given any recommendations or suggestions for promoting their own and other family members' mental health.

Another significant area of need identified by caregivers pertained to the social-emotional/behavioral functioning of their children. In all cases there was a recommendation for continued counseling, but caregivers were not provided with specifics about what type of counselors to solicit or what type of counseling approach would be helpful for their child's needs. The exception was the recommendation for family counseling, but again, this recommendation was limited and vague. One caregiver had significant concerns about his daughter's functioning on the medications, but he was only given a list of the medications, which he reported was not helpful as a means of support for his daughter.

Caregivers also expressed concern about their children's educational needs. While two of the three caregivers seemed to understand the relation between social-

emotional/behavioral and academic functioning, the other caregiver did not appear to demonstrate as much insight regarding his daughter's educational needs. Specifically, the latter caregiver did not seem to understand why educational needs would be of concern at discharge and thusly he did little to solicit more information in this area. This is noteworthy because as suspected, his poor discharge experience left him with the burden of facilitating the hospital to school transition with limited information. In essence, he "did not know what he did not know" and was not able to advocate for his daughter's needs as effectively as he could had he been armed with more information and supports. While the other two caregivers did in fact acknowledge the educational needs of their children, their advocacy efforts were thwarted by the poor efforts made by the hospitals.

In sum, caregivers were generally similar with respect to identified needs for their children and families at discharge. Those needs, however, were often left unmet, meaning caregivers struggled significantly to put in place all the needed supports post-discharge. This is not consistent with the ecological discharge approach previously outlined and puts children at risk for recidivism (Blanz & Schmidt, 2000).

### **Caregiver Knowledge of the Educational System and the Hospital's Role**

Consistent with prior research (Kaffenberger, 2006), caregivers presented with minimal knowledge about the educational system. They were unaware of the range of supports and services schools provide to students, including basic behavioral support plans, crisis plans, and transition plans. Although two caregivers were aware of special education and 504 supports, their knowledge was limited and prevented them from effectively advocating for their children's educational needs. Caregivers were unaware

of how to obtain educational advocacy supports or how to challenge a school decision. One caregiver did not understand how schools could students' social-emotional/behavioral needs and even minimized his own role in advocating for educational needs.

In all cases, hospitals played a negligible role in assisting families with identification of critical needs and potential educational supports, including advocacy resources. This finding is contrary to prior research describing the importance of educational supports in facilitating a successful discharge (Trout et al., 2010). Effective discharge plans have an overall positive effect on functioning (Steffen et al., 2009), and given the unique situation of children, it makes sense that educational supports, which at a minimum should include basic advocacy resources for caregivers, would be incorporated into these plans. Medical teams often do not know about the specific nature of school supports (Kaffenberger, 2006). Although they should not be expected to have this knowledge, hospital staff and medical teams can play a critical role in assisting families and schools in identifying children's critical needs, such as current areas of deficit and strength as well as interventions that have and have not been effective. This information can be used to facilitate a more seamless school re-entry plan. Although prior research has highlighted the importance of doing this (Simon & Savina, 2005), this study's findings suggest these recommendations were not a part of the participants' experiences.

### **Transition Barriers and Facilitating Factors**

Consistent with previous findings (AAP, 2005), not only were caregivers the primary agents facilitating hospital transitions, but they also struggled to gain access to

needed services, especially educational services. As anticipated, caregivers in the present study faced a variety of barriers interfering with the transition process. These barriers exacerbated the burdens caregivers faced in facilitating transitions and accessing needed services. In this study, the most notable barrier, previously highlighted by Keatinge et al. (2009), was the lack of information provided by hospitals. Consistently across cases, hospitals provided vague and unhelpful information. Information was not always timely, was sometimes denied when requested, and was even contradictory at times. This left caregivers feeling overwhelmed and confused about what to expect during and post-discharge, as well as feeling unarmed with the necessary information to support their children and obtain services post-discharge. This barrier stands in contrast to recommendations that help families feel more prepared for discharge/transition, such as beginning discharge planning well before actual discharge; inclusion of medication information, therapy, family supports, and other identified needs; and coordination of services (Leichtman & Leichtman, 2004).

Another current barrier previously found in the literature (e.g., Madan-Swain et al., 2004), was the lack of knowledge caregivers had about the educational system. This is problematic given the finding that the burden of facilitating hospital to school transitions was on caregivers. They did not demonstrate the depth and breadth of knowledge about their children's conditions to be able to effectively support and advocate for educational needs. Caregivers were also unaware of their rights to challenge schools' decisions. A similar barrier was evident, whereby caregivers were faced with unavailability of school services/poor school effort. In some situations, what seemed like reasonable supports were denied by the schools. In all scenarios, even basic supports,

such as the development of behavior, crisis, and relapse prevention plans were not offered. This barrier seemed directly related to caregivers' lack of educational knowledge, as well as the fact that hospitals provided inadequate information at discharge.

Another barrier consistent with prior research (e.g., Dryfoos & Barkin, 2006; Owens et al., 2008), included lack of caregiver resources. Time, physical, and emotional resources were taxed. Extra time was needed to participate in discharge/transition processes, coordinate care, and care for other family members. This was especially difficult for those caregivers whose time and physical ability to engage in these tasks were already limited due to pre-existing circumstances. All caregivers reported added stress and interpersonal strain as a result of the hospitalization. A final barrier involved feeling disappointed in and/or disrespected by hospital staff. This seemed to add to the stress of other barriers.

Conversely, caregivers presented with a range of transition facilitating factors. Most significantly, caregivers were involved in the hospitalization process, indicating a desire to support children's needs. Additionally, caregivers not only sought out recommendations from the hospital, but also followed-up with initiation of community supports. In fact, two caregivers went to great length to obtain hospital recommendations for specific supports and community resources. Finally, caregivers conducted their own research about their children's problems, suggesting a desire to know more about the presenting problems, ways to offer support, and availability of community resources.

## **Implications and Recommendations for Policy and Practice**

### **Current Practices and Needs**

Findings from the current study suggest a need for more effective psychiatric hospital discharge planning procedures for children. Aggregated findings of caregiver experiences with four different hospitals in three different states highlight similar needs. Hospitals are not currently employing MDT approaches, clearly defining discharge procedures, or engaging in practices that are ecologically sound (i.e., working within the child's systems to promote skill maintenance and discourage recidivism). Because of this, caregivers are burdened with facilitating hospital to school transitions, despite being faced with a variety of barriers negatively impacting the process. It is suspected that with changes in hospital procedures and improved coordination of care, these barriers will be reduced, hospital to school transitions will be more effective, and children's outcomes will ultimately improve. The following recommendations for future policy and practice were not only developed with consideration of prior research and currently identified needs, but also with the expectation that they will capitalize on the facilitating factors with which caregivers presented: The desire to be involved in the hospitalization experience, seeking specific hospital recommendations, seeking school and community resources, and seeking more information about their child's condition and strategies for post-hospitalization support.

### **Facilitating Transitions and Coordination of Care**

**Role of hospitals.** The first recommendation is for hospitals to employ an MDT approach for discharge. Use of this approach has the potential to improve communication and reduce the likelihood of contradictory information being given to

caregivers. Different staff members have different strengths and perspectives which may be valuable for developing appropriate recommendations and coordinating a variety of services. Critical to the MDT approach is the need for clearly defined roles and responsibilities (Hedges et al., 1999) and a coordinator of services (Bull & Roberts, 2001; Watts et al., 2006). One recommendation would be to include a member on the team who is knowledgeable in educational resources and advocacy services to assist caregivers in navigating the educational system. Understanding that this recommendation may be difficult to achieve due to financial constraints, hospitals should minimally consider consulting with local educational agencies and educational advocacy groups to develop an informational guide for caregivers.

This informational guide could include general information about common child mental health conditions, behavioral manifestations of these conditions, possible educational impacts, possible school accommodations and interventions, and medications and side effects. Educational resources with information about basic school services and supports (e.g., behavior, crisis, and transition plans), formal school supports (e.g., special education and 504 accommodations), and parent rights and advocacy can be provided in the form of local, state, federal, and online resources.

Additionally, because caregivers in the current study not only lacked information about the education system but also the nature of their children's difficulties, it would be beneficial for a member of the hospital MDT to contact the child's school to share information. This direct interagency communication will allow school staff to ask questions for which caregivers may not have the answers. Although it is important for caregivers to be empowered with information about their children's situations, hospital

staff who worked directly with the child may be better able to explain current levels of functioning, potential impacts at school, and strategies for intervention and support (e.g., the child's triggers, proactive and reactive strategies, and warning signs of decomposition/crisis).

The second recommendation is for hospitals to have clearly defined discharge procedures. For each step of the discharge process, hospitals will need to take care to specifically identify participants and their roles. Current findings suggest discharge procedures should minimally include discussion of initial discharge plans with patient, discussion of coordinated services, assistance with the transitions home and to school, encouraging family involvement, and development of a relapse prevention and crisis plan. Discussion of discharge should begin soon after the child is admitted and should include identification of the child's potential needs post-discharge, identification of caregiver and family needs, identification of potential services with which to coordinate, and developing a tentative timeframe and plan of action. These discussions should be ongoing, and could involve obtaining necessary permissions and releases to coordinate with various community agencies, including schools. This would allow for those involved in coordination efforts, such as community agencies and schools, to have more opportunity for collaboration and preparation. Hospitals should encourage family involvement at all stages of the hospitalization and should make concerted efforts to keep caregivers updated on their child's progress, medication changes, plans for discharge, and any critical events.

Hospitals should include a relapse prevention and crisis plan within the discharge plan. Developed collaboratively with the caregiver, this plan should identify critical

issues, including a description of diagnoses; describe ways in which such issues were manifested prior to treatment, are currently presenting, and could impact the child in various settings, including school; identify warnings signs that problems are returning; identify triggers for social-emotional/behavioral problems and ways in which such problems can be dealt with effectively, including what to do in case of emergency; outline recommendations for how others can help the child; and outline specific behavioral expectations and consequences for home.

It is of great importance that hospital communications are clear and specific to the child's circumstances. Prior research (Keatinge et al., 2009) and current findings suggest that hospitals often provide inconsistent, unclear, and unhelpful information. Keatinge et al. recommend providing information in plain language that is in both verbal and written formats. Johnson and Sanford (2005) also highlight the need for information to be comprehensive, yet provided in a format that caregivers can understand. This can include verbal, written, electronic, and multimedia communications, which increase the likelihood that information will be retained.

A final recommendation for hospitals is to employ practices consistent with an ecological approach. This should involve taking efforts to assist children in maintaining skills learned during hospitalization; working with families throughout the child's hospitalization, during the transition to home and school, and after the child is released; and identifying the critical needs and subsequent coordination of critical social-emotional/behavioral and educational supports needed to facilitate transition, promote stabilization, and prevent relapse. To facilitate maintenance of learned skills, hospitals should follow the previously mentioned guidelines for discharge procedures. Hospitals

should also work closely with families throughout the hospitalization process and when possible, with other agencies involved in the child's care.

Caregivers in the current study reported difficulty obtaining recommendations and records from the hospital, which inhibited the ability for caregivers to initiate the necessary supports in the community and at school. Hospital staff who worked directly with the child should be available should the caregivers or outside agencies have questions or concerns post-discharge. Hospitals can also assist caregivers in identifying the child's needs and appropriate community resources. Caregivers in the current study reported receiving very little information about the condition of their children at discharge and having a poor understanding of how to obtain resources and navigate various systems of care.

#### **Role of schools.**

*School level responsibilities.* NASP (2008b) advocates for the provision of coordinated, comprehensive, and culturally competent mental health services in the schools. Recognizing that not all student services may be provided in the school, such as psychiatric hospitalization and post-discharge counseling, NASP encourages school psychologists to make effective linkages with various community resources to ensure continuity of community support when necessary. This position merges well with the recommendations for the hospital's role in discharge planning. Regarding the use of an MDT approach, school psychologists can serve as the school representative on the hospital teams. As such, critical information can be communicated across agencies and incorporated into transition plans, with school psychologists serving as the liaisons facilitating the school re-entry.

Schools can also serve a critical function in the hospital's discharge procedures. The recommendation for clearly defined procedures involves coordination of care, assistance with transitions, developing a tentative timeframe, and development of a crisis and relapse prevention plan. School involvement in the discharge process can facilitate a more seamless transition by improving the quantity and quality of communication between service providers. This communication may help parents feel more aware of what is going to happen next, thus reducing anxiety and confusion. Involvement in the development of a relapse prevention and crisis plan should undoubtedly involve school personnel, as this plan should be followed at school. The school psychologist can incorporate this information into the school's own re-entry plan, which would be shared with staff that have a critical need to know about support strategies for the student.

The recommendation for an ecological approach to facilitate maintenance of learned skills during hospitalization will logically require school supports. Knowing what interventions worked and did not work will be critical for school staff in terms of intervention and progress monitoring. School involvement may also help caregivers feel supported, which in turn could empower caregivers and reduce feelings of being overwhelmed. By doing so, increased collaboration is achieved and ultimately, the child's well-being is promoted and likelihood for relapse reduced.

NASP (2008b) also recommends that school psychological services can include "consultation; the formulation of behavioral intervention plans and behavior management; provision of direct mental health services for individual and small groups; assessment; development, implementation, and evaluation of prevention and intervention programs; crisis intervention; and referral processes" (p.2). One approach for supporting

children's social-emotional/behavioral functioning is within a tiered service-delivery model, which Burns (2011) explains is critical for prevention efforts. This type of system not only allocates school resources efficiently, but also attempts to proactively prevent problems, prevent problems from worsening, and identify those students most at risk. Within this type of model, services range from system-wide prevention efforts for all students, to intensive, individualized support for those struggling most significantly (NASP, 2009). Furthermore, effective multi-tiered models employ evidence-based strategies; use a systemic, multi-tiered problem solving and data-based decision-making approach to meeting students' needs; focus on prevention efforts promoting positive behavior, social-emotional learning, and academic functioning; and are culturally responsive.

The multi-tiered model proposed by NASP (2009) involves three tiers. At Tier 1, universal supports are provided to all students. At Tier 2, targeted supports are provided to the approximately 10-15% who continue to struggle socially, behaviorally, or emotionally despite the provision of Tier 1 supports. At Tier 3, intensive, individualized supports and progress monitoring are provided to those who were unsuccessful with Tier 2 interventions. These students may require wraparound services, collaboration with various community agencies, and an integrated plan for intervention. Some students may even require support through special education with an IEP or accommodations through a 504 plan. For children making the hospital to school transition, school teams will need to decide at what level supports are most appropriate. Within this model, school psychologists are in an important position to serve as facilitators of the problem-solving teams; collaborate with individuals within the school, family, and community; coordinate

and prevent fragmentation of services; assist in designing, delivering, and evaluating interventions; advocate for mental health needs by through provisions of universal screenings and targeted interventions; advocate for evidence-based practices that are culturally competent; and advocate for school reform that promotes equitable and effective outcomes for all students.

*District level responsibilities.* According to NASP's (2008a) position on the role of school psychologists in ensuring high quality pupil services, school psychologists are "trained to deliver a broad spectrum of psychological services, develop and provide system-wide prevention activities, develop and monitor program services, direct intervention services, provide case consultation, and interpret data for program planning" (p. 2). Because they often serve in a consultation role, Burns (2011) suggests that school psychologists be aware of the change process and how it affects the systems within which they work. Specifically, school psychologists are in a position to promote institutional change for the well-being of students. Therefore, school psychologists have the capacity to serve not just within their assigned schools, but at a departmental or even district level to promote change and use of evidence-based strategies. This may be of critical importance for school psychologists working in areas in which there are no departmental or district level policies on dealing with hospital to school transitions. Working at the administrative level, school psychologists can advocate for implementation of new policies and procedures and can facilitate program evaluation to assess their efficacy. For example, this could involve assisting in the development of school-based and district-level crisis teams, including the creation of crisis plans, school re-entry plan templates, and formalized procedures for interdisciplinary collaboration.

Adelman and Taylor (1997) propose a phases of change model to bring about systems level change, an excellent resource for school psychologists and other key school district players that want to advocate for organizational reform. The four phases include (a) creating readiness, (b) initial implementation, (c) institutionalization, and (d) ongoing evolution. Although the authors present this model in a context of comprehensive educational restructuring at a district level, a more practical option may be for school psychologists and key players to use this model to address changes within specific programs or departments, particularly those directly involved in facilitating hospital to school transitions (e.g., departments of school psychological and/or related services).

### **Significance**

Qualitative inquiry is shaped by the researcher's paradigms or worldviews (Creswell, 2007). This multiple-case study embodied a paradigm of advocacy in which the researcher brought attention to an important social issue and injustice (i.e., systemic barriers interfering with hospital to school transitions), gave voice to participants' experiences with the issue, and developed recommendations for policy and practice in order to encourage change to occur. While studies have shown both that schools are an important source of social-emotional and behavioral support for students and specific practices result in effective hospital discharge planning, few have explored the incorporation of educational supports into psychiatric hospital discharge plans for children. Further, caregiver experiences with the discharge planning and the hospital to school transition process were largely unknown. This study contributes to the body of research by explaining caregivers' experiences with the hospital discharge

planning/hospital to school transition process, as well as identifying the critical needs of children at discharge, in order to facilitate recommendations for change in policy action and practice.

### **Recommendations for Future Research**

The current study was a multiple case study with a small sample size. Although this is not necessarily a significant limitation, and analyses of diverse case experiences resulted in similar findings, a larger multiple case study, quantitative study, or mixed methods study could increase the generalizability of research findings if they are similar to those in the present study.

The focal point of this study was on caregiver experiences with the discharge planning and transition process. Future research efforts may involve more of a focus on hospital and/or school roles in the discharge planning/transition process, with attention being given to the identification of children's specific needs (e.g., educational needs) and coordination of care. These efforts could involve program evaluations and needs assessments to identify strengths and weaknesses of services and supports.

Although the focus of the present study was on caregiver experiences, a secondary finding for children in all cases was a progressive downward trend in social-emotional/behavioral and/or academic functioning post-hospitalization. Future research may wish to explore the long-term outcomes of children who were hospitalized for psychiatric reasons in an effort to connect these outcomes with the quality of discharge planning/transition procedures and coordination of care.

## **Limitations**

A notable limitation involves generalizability of results. Although the goal of qualitative research is not necessarily generalization of results to the wider population, this study was designed with the intent that findings would be situated within the context of the study's conceptual framework. This study's findings are consistent with this conceptualization, and thus provide a vehicle by which transferability to future cases can occur (Yin, 2009).

Another limitation involves participant interviews. Marshall and Rossman (2006) point out that because interviews require human interaction, there is the possibility that participants were unwilling to cooperate or were uncomfortable sharing all that the interviewer hoped to explore. Conversely, interviewees may have demonstrated a response bias (Yin, 2009) in which they presented information in a socially desirable way. Additionally, due to a lack of familiarity with the participants and their culture, the researcher may not have asked questions that elicited long narratives, which could limit the utility of the data (Marshall & Rossman, 2006; Yin, 2009).

Another limitation involving interviews deals with the issue of transcribing. Marshall and Rossman (2006) suggest that these tasks are not merely mechanical tasks. Rather, they involve judgment and interpretation. In transcription, what is said during the interview is transformed into text. Because the way we speak is different from the way we write, the transcription process can be muddled by the task of trying to determine where to add appropriate punctuation. Furthermore, visual cues we rely on to interpret the speaker's meaning is lost in transcription, meaning a critical part of communication is gone.

Finally, there is the possibility of reporting bias, or the unknown bias of the author (Yin, 2009). This could have impacted the interpretation of interviews, archival records, and overall analyses of the data.

### **Conclusion**

The present study explored caregiver experiences with hospital to school transitions. Psychiatric hospital discharge plans rarely include school supports for children, despite schools serving a critical role in supporting the social-emotional/behavioral needs of children. Caregivers are often responsible for transitioning their child back to the school setting, despite being faced with barriers that impede the process. Results from this multiple case study indicated poor discharge/transition experiences, with hospital discharge practices generally not falling in line with best practices. Caregivers were generally responsible for making transitions, all while experiencing a range of barriers making the discharge/transition process more burdensome. Study findings of family experiences informed a discussion about recommendations for future policies, practice, and advocacy.

APPENDIX A

**Background Survey-Interview**

***Family Data***

Child Information:

Today's date: \_\_\_\_\_

Child birthday: \_\_\_\_\_

Grade: \_\_\_\_\_

Sex: \_\_\_\_\_

Age: \_\_\_\_\_

Parent/Guardian and Family Information:

Mother/guardian  
age: \_\_\_\_\_

Father/guardian  
age: \_\_\_\_\_

Marital Status of Parents:  Married  Divorced  Separated  Not Married but Living Together  
 Other \_\_\_\_\_

If any siblings live outside the home, list ages: \_\_\_\_\_

What is the primary language spoken at home? \_\_\_\_\_

What is the estimated annual family income? \_\_\_\_\_

Does your family have health insurance? \_\_\_\_\_

What is the mother/guardian's highest education level? \_\_\_\_\_

What is the father/guardian's highest education level? \_\_\_\_\_

What does the mother/guardian do for work? \_\_\_\_\_

What does the father/guardian do for work? \_\_\_\_\_

List all family members living in the home:

Relationship to Student

Age

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Please describe how the members of your family get along with each other:

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***Prior Hospitalization Data***

Please list all prior hospitalizations for your child:

<u>Date/Length of Stay:</u>	<u>Grade:</u>	<u>Name of Hospital:</u>	<u>Reason for Hospitalization:</u>

Please describe the reasons for your child's hospitalization, including how long these difficulties were present prior to hospitalization:

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Please describe any clinical diagnoses your child may have:

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Please describe any social-emotional, behavioral, and/or educational difficulties your child had after being hospitalized:

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***Educational Data***

Current GPA/grades: \_\_\_\_\_

Days of school missed: \_\_\_\_\_

Does your child have difficulty with:  Reading  Arithmetic  Spelling  Writing  
 Other subjects (which ones?)

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If yes, when did these problems begin?

\_\_\_\_\_

Does your child have difficulty with:  Memory  Attention  Learning new things

Does your child like school? \_\_\_\_\_

Is your child presently receiving special education services or have an IEP or 504 Plan?

\_\_\_\_\_

If yes, do you know what type of disability your child has? \_\_\_\_\_

If yes, how long has your child been receiving these services? \_\_\_\_\_

Has your child ever been retained/held back a grade? \_\_\_\_\_

If yes, what grade? \_\_\_\_\_

Has your child ever received any special help or tutoring? \_\_\_\_\_

If yes, please describe:

\_\_\_\_\_

Has your child ever received physical, occupational, or speech therapy? \_\_\_\_\_

If yes, please describe:

\_\_\_\_\_

Has your child ever attended summer school programs? \_\_\_\_\_

If yes, please describe:

\_\_\_\_\_

Has your child ever seen a psychologist or counselor? \_\_\_\_\_

If yes, please describe:

\_\_\_\_\_

## APPENDIX B

### Sample Interview Questions

1. Tell me about your experience with the discharge planning process at the hospital.
2. What type of supports and community resources were incorporated into your child's discharge plan?
3. How did the hospital incorporate your child's educational needs into the discharge plan?
4. Do you think a hospital should include educational needs into a discharge plan? If so, how would this be helpful to you? If not, please explain.
5. How did the hospital incorporate your child's social-emotional and behavioral needs into the discharge plan?
6. Do you think a hospital should include social-emotional and behavioral needs into a discharge plan? If so, how would this be helpful to you? If not, please explain.
7. Who was involved in the discharge planning process? How were you involved in the process?
8. At what point during your child's hospitalization were you first consulted with about the discharge planning process?
9. What was your level of satisfaction with the discharge process?
10. What were your child's educational/social-emotional needs at the time of discharge?
11. What were your family's needs at the time of discharge?

12. What did you like about the process/what made the process effective? What things made the discharge planning/transition process more difficult/what would you want to change?
13. Do you feel that you and your family were treated respectfully during the discharge planning process?
14. Before your child was discharged from the hospital, were you aware of any type of support your child's school could provide? If so, what were they and how did you know them?
15. Is there anything else you would like to tell me about your experiences with the discharge planning process?

## APPENDIX C



### Social/Behavioral IRB – Expedited Review Approval Notice

**NOTICE TO ALL RESEARCHERS:**

*Please be aware that a protocol violation (e.g., failure to submit a modification for any change) of an IRB approved protocol may result in mandatory remedial education, additional audits, re-consenting subjects, researcher probation, suspension of any research protocol at issue, suspension of additional existing research protocols, invalidation of all research conducted under the research protocol at issue, and further appropriate consequences as determined by the IRB and the Institutional Officer.*

**DATE:** October 12, 2012  
**TO:** Dr. Paul Jones, Educational Psychology  
**FROM:** Office of Research Integrity - Human Subjects  
**RE:** Notification of IRB Action  
Protocol Title: **Hospital to School Transitions for Children: A Multiple Case Study of Family Experiences**  
Protocol #: 1207-4214  
Expiration Date: October 11, 2013

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This memorandum is notification that the project referenced above has been reviewed and approved by the UNLV Social/Behavioral Institutional Review Board (IRB) as indicated in Federal regulatory statutes 45 CFR 46 and UNLV Human Research Policies and Procedures.

The protocol is approved for a period of one year and expires October 11, 2013. If the above-referenced project has not been completed by this date you must request renewal by submitting a Continuing Review Request form 30 days before the expiration date.

**PLEASE NOTE:**

Upon approval, the research team is responsible for conducting the research as stated in the protocol most recently reviewed and approved by the IRB, which shall include using the most recently submitted Informed Consent/Assent forms and recruitment materials. The official versions of these forms are indicated by footer which contains approval and expiration dates.

Should there be *any* change to the protocol, it will be necessary to submit a **Modification Form** through ORI - Human Subjects. No changes may be made to the existing protocol until modifications have been approved by the IRB. Modified versions of protocol materials must be used upon review and approval. Unanticipated problems, deviations to protocols, and adverse events must be reported to the ORI – HS within 10 days of occurrence.

If you have questions or require any assistance, please contact the Office of Research Integrity - Human Subjects at [IRB@unlv.edu](mailto:IRB@unlv.edu) or call 895-2794.

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### Work Experience:

2013-present *School Psychologist*, Clark County School District, Department of Student Threat Evaluation and Crisis Response, Las Vegas, NV. My duties include assessment and management of lethal threats of violence made by students; assessment and management of student suicidality; assisting schools with managing critical events and providing post-crisis responses; development of school re-entry and safety plans post-hospitalization; individual student and family counseling; and regular collaboration and consultation with schools and various community agencies to ensure continuity of care.

2013-present *Independent Contractor/School Psychologist*, Innovations International Charter School, Las Vegas, NV. My duties include conducting comprehensive psychoeducational evaluations for special education eligibility and provision of recommendations and interventions for school and community supports.

2011-2013 *School Psychologist*, Clark County School District, Las Vegas, NV. My duties included conducting psychoeducational evaluations for elementary, middle, and high school students; collaborating with parents and teachers to address students' learning, behavioral, and social-emotional needs; intervention development and implementation; individual, group, and parent/family counseling; suicide risk assessment; and individual program evaluation.

Publication:

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Dissertation Title: Hospital to School Transitions for Children: A Multiple Case Study of Family Experiences

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