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## **A Case Study of Landau Kleffner Syndrome: a Look at Strategies, Experiences, Challenges, and Perceptions of Teachers, Family, and Support Personnel**

George Mathenge Wairungu  
*University of Arkansas, Fayetteville*

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Teachers, Family, and Support Personnel

A Case Study of Landau Kleffner Syndrome:  
A Look at Strategies, Experiences, Challenges, and Perceptions of  
Teachers, Family and Support Personnel

A dissertation submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy in Curriculum and Instruction

by

George Mathenge Wairungu.  
Moi University- Kenya  
Bachelor of Education, 1997  
Drake University  
Master of Science in Education, 2006

May 2015  
University of Arkansas

This dissertation is approved for recommendation to the Graduate Council.

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Dr. Marcia B. Imbeau  
Dissertation Director

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Dr. Michael Wavering  
Committee Member

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Dr. Christian Goering  
Committee Member

## **Abstract**

There is an unprecedented increase of rare low-incident severe disabilities in today's classroom. Some of them pose classroom management challenges due to concomitantly appearing behavior challenges. Landau Kleffner Syndrome is one such disability. It was cited for the first time in 1957 (Zhang, & Gregory, 2010) and is characterized by a typical language and cognitive growth that retrogresses after three to nine years of age (O'Hare, 2008). Behavioral regression is exhibited by students being physically and verbally aggressive (Ekinici, Isik, & Melek, 2012). Children also depict abnormal electroencephalographic (EEG) traits, especially when sleeping (Slyke, 2002). Other concomitant characteristics include attention deficits and severe auditory verbal *agnosia* (Slyke, 2002).

This research was conducted to collect, analyze, and consolidate experiences of adults who served a particular child with Landau Kleffner Syndrome from elementary school to high school. By the end of the research, the subject was nineteen years old and in high school. Challenges, strategies, and concerns of the participants were successfully consolidated and documented for future consultation.

## **Acknowledgements**

This edition of *A Case Study of Landau Kleffner Syndrome* is dedicated to the team of University of Arkansas professors who served on my committee. They went out of their way to do more than they dutifully owed me. Given my challenges, they exhibited the patience of a vulture.

**Dr. Marcia Imbeau**, my dissertation director, thank you very much. You not only provided me with detailed instructions, but also directed my whole dissertation journey. God bless you abundantly for smoothing the rough rocky journey for me. I always saw some light at the end of the tunnel, but I was never sure a train was not coming toward me. Your words were always reassuring.

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**Dr. Christian Goering**. Thank you very much for introducing me to scholarly writing. Through your student oriented teaching strategies, I learned how to critique articles written in high-tier journals. I also learned that some research articles are written “for” and not “about.” Never again shall I read a research article with the esteem of religion, no matter the author.

## **Dedication**

By the time I started conducting my research, I intended to dedicate my work to my deceased parents, Boniface Wairungu Murebi and Zaveria Wanjiru Wairungu. Unfortunately, my beloved sister Elizabeth Wangari Wairungu passed on just months before my graduation; she would have definitely joined me for graduation. Therefore, I dedicate this work both to my two parents and to my beloved sister, all who worked tirelessly to see me through this rough journey.

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## I. Chapter One: Introduction

According to I.D.E.A (Individuals with Disabilities Education Act), children with disabilities are entitled to free appropriate education in the least restrictive environment (Turnbull, Turnbull, & Wehmeyer, 2010). I.D.E.A was signed into law in 1975 and, except for a few modifications, the principles remain the same to date (Hammel & Hourigan, 2011). This act governs and advocates for the rights and conditions under which education should be appropriately provided to individuals with disabilities. Some severe disabilities are rare, unique, and challenging to manage. This is especially so with the current trend towards inclusion. Inclusion refers to teaching students with disabilities among typical peers (Olduyurt, 2013). Landau Kleffner Syndrome is an example of a rare severe and challenging disability. The syndrome is also known as Aphasia-Convulsion syndrome, or acquired epileptiform aphasia (Mikati & Shamseddine, 2005). Little research exists about its causes, effective intervention strategies, and transition planning.

Landau Kleffner Syndrome is a rare childhood neurological disorder usually affecting children from ages three to eight (Malvestio, 2010). These children develop age appropriate speech but suddenly experience language regression. This is usually accompanied by verbal auditory *agnosia* (failing to make meaning of verbal expressions), behavior disturbance and sometimes overt seizures (Mikati & Shamseddine, 2005). Other features include sub-acute aphasia and abnormal EEG (the brain's electrical activity), which is usually detected through a child's scalp (Deok-Hee et al., 2012).

Landau Kleffner Syndrome was first described in 1957 by two researchers, Doctors William M. Landau and Frank R. Kleffner, after which the syndrome is named. They conducted research on six children diagnosed with language regression (Bogaert et al., 2012) and

discovered that children with Landau Kleffner Syndrome usually experience a sudden onset of severe language disturbance and a pattern of frequent electroencephalograph (E.E.G.) abnormalities that appear either predominantly or exclusively during sleep. The Syndrome is considered to be on a continuum of epileptic encephalopathy that generally involves epileptiform abnormalities (that take place during sleep) that are also associated with negative change of cognitive function. Medically, “epileptiform” means seizure-like (Kuriakose, 2012).

To serve students with severe disabilities such as Landau Kleffner Syndrome effectively, teachers must differentiate instructions in order to address deficiencies associated with the Syndrome (Chapman, et, al, 1998). Differentiation of instructions refers to classroom practices that place emphasis on the individual student and the content of the course under study (Tomlinson, & Imbeau, 2010). While accommodating students with Landau Kleffner Syndrome, teachers should aim at modifying instructions to accommodate aphasia, agnosia, behavior problems, and cognition deficits usually characteristic of Landau Kleffner Syndrome. If done effectively, differentiation allows children with severe disabilities such as Landau Kleffner Syndrome to learn through direct instruction and through interaction with typical peers (Downing, 2010).

Lack of resources and pedagogical challenges are a barrier to effective differentiation for children with Landau Keffner Syndrome. This paper outlines a research project aimed at investigating, consolidating, and documenting experiences of teachers, family, and collaborating personnel who serve a child with Landau Kleffner Syndrome (Malvestio, 2010).

### **Research Problem**

One of the most distressing conditions that parents can face with their children is the regression or loss of previously acquired cognitive functions, especially language skills (Kuriakose, 2012). Language regression is described as the loss of language skills after acquiring

more than a five-word vocabulary (Ekinici, Isik & Melek, 2012). Children with Landau Kleffner Syndrome experience cognitive and linguistic regression after a typical growth. The syndrome was first cited in 1957. In this rare, but severe, disability, a child's language regresses after the age of three to nine years, with a mean range of five to seven years (Malvestio, 2010). This language regression is accompanied by low cognitive development and verbal and physical aggression. According to the Individuals with Disabilities Education Act, all children with disabilities are entitled to free appropriate education in the least restrictive environment, regardless of the severity of the disability (Hammel & Hourigan, 2011). Determining the least restrictive environment calls for understanding the characteristics, challenges, and appropriate strategies for an equal education (Chapman et al., 1998).

Currently, not much literature is available on Landau Kleffner Syndrome (Malvestio, 2010). There is an urgent need to look at this disability from the perspective of family education practitioners. Another challenge posed by Landau Kleffner Syndrome is its closeness to other disabilities that lead to common misdiagnoses. For instance, it is usually misdiagnosed as Rett syndrome, epilepsy, and autism. Developing a vast knowledge base is important in order to help teachers identify, recognize, and effectively serve individuals with this severe disability (Chapman et al., 1998). This is one of the goals that my research seeks to achieve.

### **Purpose of Research**

This research investigates how and what it is like to teach and serve an individual diagnosed with Landau Kleffner Syndrome (Chapman et al., 1998). As will be noted from the literature review to follow, children with Landau Kleffner are potentially aggressive, oppositional, and pose significant challenges for classroom management (Malvestio, 2010). To improve classroom practices and to serve individuals with Landau Kleffner Syndrome better, it is

important to seek information from family and professionals who have successfully worked with individuals with Landau Kleffner Syndrome. The main purpose of this research is to gather, consolidate, and document experiences of teachers and support personnel who served a specific individual with Landau Kleffner Syndrome. This research aims to compile these experiences, turn them into a consumable text (Hatch, 2002), and contribute to the knowledge base of people with Landau Kleffner Syndrome (Chapman et al., 1998). This research will be a good resource for consultation by teachers and other supportive personnel (Stake, 2010) and will also seek to distinguish Landau Kleffner Syndrome from Rett syndrome, epilepsy, and autism (Chapman et al., 1998).

### **Benefits of the Research**

First, by exploring the perceptions, challenges, and experience of family, teachers, and supportive professionals, the research presented here will act as a resource for teachers, family, and practitioners. The literature will be used to design effective intervention strategies that are needed for language, motor, and social skill challenges (Chapman et al., 1998). Respondents in this research include experts in various areas (Turnbull et al., 2010). Their responses will set standards, form a guide, and set expectations to be followed by future teachers and personnel (Mercer et al., 2011). Responses from parents will be helpful for teachers, therapists, and other professionals to learn what parents expect of them as they serve children with Landau Kleffner Syndrome as collaborators (Friend 2000). Other team members will also know what is expected of them in collaboration (Chapman et al., 1998).

### **Research Interest**

Both personal and professional experience influenced my decision to conduct this study. Circumstances exposed me to the syndrome when I was hired to teach in a school district in the

mid-west region of the United States. The school district had previously tried educating the student with other severely disabled peers in a 1:10 classroom, but due to physical aggression she was moved to a class with 1:6 ratio. This did not work. She was eventually moved into a class of her own. I was hired to teach her one-on-one.

I did not have any experience teaching severe disabilities. Her language challenges and verbal and physical aggression were unbearable. Research on the internet was frustrating since not much literature on teaching challenges and strategies was available. Only after working in tandem with behavior analysts, psychologists, administrators, and other teachers was I able to contain the behavior. It is mainly out of this experience that I developed an interest in conducting this research.

### **Research Question**

As noted from the literature review above, Landau Kleffner Syndrome is a rare but very challenging neurological disability. Students with the syndrome tend to be physically and verbally aggressive to other students and adults (Chapman et al, 1998). The students' cognitive abilities and language communication skills are also negatively affected by seizures. In this research, I seek to investigate the experiences and challenges of professionals who serve a particular individual with Landau Kleffner Syndrome. I will also investigate the concerns they have, the challenges they face, and the strategies they use to overcome those challenges. My primary question is, "What are the experiences, strategies, challenges, concerns and perceptions of teachers, parents and support staff serving an individual diagnosed with Landau Kleffner Syndrome?" This question is further broken down into the following:

- 1. What challenges are faced by family, teachers and support personnel serving a child with Landau Kleffner Syndrome?*



2. *What strategies are applied by family, educators, and support personnel in addressing the challenges faced while serving a child with the Landau Kleffner Syndrome?*
3. *What concerns do teachers and support staff have in their past and present experiences serving a child with Landau Kleffner Syndrome.*

### **Definition of Terms**

Terms specific to the study are Landau Kleffner Syndrome, aphasia, differentiation, and EEG. Landau Kleffner, also known as acquired aphasia with convulsive disorder, is both a rare and idiosyncratic syndrome (Slyke, 2002) that affects an individual's receptive and language abilities (Zhang et al, 2010). Aphasia is defined as a language impairment that affects the production or comprehension of speech and the ability to read or write. Aphasia is always the result of brain injury and impairs a person's ability to use and comprehend language.

Differentiation refers to modification of instructions to fit the learning needs of individual students (Turnbull, Turnbull, & Wehmeyer, 2010). An EEG (electroencephalogram) is a test that helps diagnose epilepsy. During an EEG, electrical signals of one's brain are recorded.

Electrodes detect electrical activity in the brain as they are placed on the patient's scalp. They are then transmitted to a polygraph that records the activity.

### **Limitations and Delimitations of Study**

One major limitation of this study is the ability to generalize the findings. This is a study about one student with Landau Kleffner Syndrome (Slyke, 2002). Needs differ across disabilities. They also differ across individuals with the same disabilities. In other words, interventions that work for one particular individual with Landau Kleffner Syndrome may not work for others with the same disability (Green, 2006). Therefore, the findings of this research apply specifically to the student under study. Another limitation is the researcher's inability to

track and reach all potential respondents. This research was designed to interview and investigate respondents who have taught and served the child of interest from the time she started schooling in elementary. While many teachers and supportive personnel were interviewed, not all potential respondents were available for an interview. Three teachers had already died before they could be interviewed, and others had moved to other districts. Finally, I have been a teacher to the student under research for three years. Every effort was in place to remain objective, but there exists no guaranteed way of achieving this without a margin of error.

## II. Chapter Two: Literature Review

Marinac and Harper (2009) define Landau Kleffner Syndrome as a “rare childhood disorder” characterized by a sudden onset of a severe language disturbance and a pattern of very frequent encephalograph abnormalities (either exclusively or predominantly at night). The syndrome is known by several names: Worster Drought Syndrome, Acquired Epileptic Aphasia, Infertile Acquired Aphasia, and Aphasia with Convulsive Disorder (Sharma, Sharma & Yeoleker, 2011). This syndrome is a condition acquired by children usually between the ages of 3 and 10 with the peak range being 5 to 7 years (Fandino et al., 2010). However, symptoms have been described in patients as young as eighteen months and as old as nine years according to Malvestio (2010). This condition attacks the *Brocas* and *Wernickes* areas of the brain; the Brocas and Wernickes areas control speech and comprehension, respectively (Malvestio, 2010).

Landau Kleffner Syndrome typically appears first as a moderate or abrupt auditory agnosia in children of previous normal development before the onset of the illness (Sharma, Sharma, & Yeolekar, 2011). Auditory agnosia refers to the loss of the inborn ability to interpret sensory stimuli, such as common sounds. The syndrome is generally characterized by aphasia symptoms that can develop suddenly or over a period of time (Hurley, 2011). EEG examination demonstrates dominant epileptiform activity which contributes to the deterioration of ability to auditory process. Epileptiform resembles epilepsy. Electroencephalography (EEG) records the brain’s electrical activity, which is usually detected along the skin of the head. EEG measures voltage fluctuations resulting from ionic current flows within the neurons of an individual’s brain (Fandino et al., 2010). With the increased EEG during sleep, it is suspected that persistent convulsive discharges result in the functional ablation (damage) of brain areas concerned with linguistic communication (Bogaert & Paquier, 2009).

In 90 % of the children, a receptive aphasia appears first. Then a rapid and severe reduction of spontaneous speech occurs. Language abilities in Landau Kleffner Syndrome is usually characterized by remission and exacerbations. After a period of time, depending on the individual and lasting from a few months to several years, the aphasia stabilizes and usually improves before adulthood. Remission is a period during which disease symptoms lessen or symptoms disappear. Exacerbation represents the aggravation and worsening of a condition (Fandino et al., 2010).

A case reported by Sharma and others (2011) of a 13-year-old boy who developed Landau Kleffner at 8<sup>th</sup> grade notes that Landau Kleffner Syndrome began with a progressive loss of speech and seizure disorder. The boy was developmentally normal before the onset of the illness. Two months prior to the illness, the boy experienced subtle trauma to the head. He started communicating with signs, followed by paucity of speech, and eventually progressed to complete aphasia and abnormal behavior in the form of bursts of aggression and hyperactivity (Sharma, Sharma, & Yeoleker, 2011). The very first manifestation of language problems was the inability to understand what others said to him, a condition known as ‘word deafness or auditory verbal agnosia’. The boy was unable to recognize familiar noises, but alertness and response to sound remained normal (Sharma et al., 2011).

The boy’s receptive language, comprehension, and speech productions were seriously impaired but his reading and writing abilities were initially preserved. He also had a speech disturbance which included use of jargon or nonsense, paraphrasia (unintended garbling of speech while consciously attempting to speak), disorder of syntax (characterized by difficulties using and/or comprehending the structural components of sentences), and verbal stereotypes. With time, he developed some difficulty identifying the differences between nonverbal based

sounds such as dog barking or door bell ringing (Sharma et al., 2011). This is in line with literature from Malvestio (2010) that suggest that the first manifestation of the condition is noted by children being unable to recognize familiar sounds, such as whistles, bells, barking of a dog, or a ringing phone. Speech became garbled, and he started communicating mainly through signs. Language deterioration occurred over months. With time, abnormal behavior and attention deficit were also noticed. The EEG revealed repetitive spike and wave activity on the skin of his head (Sharma et al., 2011).

### **Characteristics of Landau Kleffner Syndrome**

General characteristics of Landau Kleffner Syndrome can be summarized as abnormal loss of receptive and expressive language abilities with possible seizures. Children with Landau Kleffner Syndrome have low to above average abilities and strong visual learning skills (Chapman, Stormont, & McCathren, 1998). The epileptic effect is believed to lead to cognitive behavioral impairment in childhood (Bogaert & Paquer 2009). Psychomotor and behavioral problems are also observed (Sharma et al., 2011). Regarding gender, Landau Kleffner Syndrome affects more boys than girls in the ratio of 2:1. Children with the syndrome can comprehend meaning well when they use sense of sight, but they comprehend very poorly when they listen (Chapman et al, 1998).

Children with Landau Kleffner Syndrome are at risk of developing social behavioral problems inclusive of verbal and physical aggression. This is observed in as many as 78% of individuals (Malvestio, 2010). Children with the syndrome are also described by Sharma et al. (2011) as having the potential to develop hyper activity, to experience a decrease in attention span (in as much as 80%), to exhibit aggressive and oppositional behavior, including raged attacks, and intellectual deficits according to Malvestio (2010). Raged attacks and aggression

may be the result of frustration with the loss of comprehension. A child with the syndrome may also develop neuropsychological symptoms, and the child's intelligence quotient may be adversely affected (Malvestio, 2010).

Children with Landau Kleffner Syndrome in most cases have eating and sleeping problems. Other concerns include difficulty following directions and refusing to participate in classroom activities. The refusal may be related to failure to understand instructions due to poor auditory receptive language skills (Chapman et al., 1998). The appearance of this syndrome occurs during a critical period of language development. Speech production is affected just as badly or even as worse as language comprehension (Malvestio, 2010). While the above problems are evident, children with Landau-Kleffner Syndrome have been described by many researchers as friendly when not emotionally aggrieved (Chapman et al., 1998).

Individuals with this syndrome may sometimes exhibit autistic-like behaviors such as avoidance and echolalia (automatic repetition of vocalizations made by another person), echopraxia (the involuntary repetition or imitation of another person's actions), hyperlexia (precocious ability to read words without prior training in learning to read, typically before the age of 5), and even psychotic like disturbances. These symptoms can lead to the misdiagnosis of autism (Chapman et al., 1998). This makes EEG examination crucial as a confirmatory test for Landau Kleffner Syndrome (Pedro & Leisman, 2005). Autistic children experience language regression in as many as 39 % of the cases; they have communication deficits and show abnormal development of a spoken language. Some may also have seizures and some may have EEG abnormalities. While the above similarities exist, there are also some distinguishing differences between Landau Kleffner Syndrome and autism. The majority of language regression in autism happens before three years of age. Those who have Landau Kleffner Syndrome

experience this regression from age five to seven years. Since speech is more developed in older children the changes that occur in with Landau Kleffner Syndrome are more drastic (Malvestio, 2010).

As the first researchers of the syndrome, Landau and Kleffner studied a group of six children aged 5 to 15. They noted that the onset of the disorder was gradual in some children and sudden in others. Language improvement occurred in all the six cases studied. Two of the six children had a complete recovery of their previously acquired language skills without any systematic or planned speech therapy. As noted earlier, since the original case series in 1957, only around 350 cases have been described in published reports internationally (Kuriakose, 2012), but disagreements on this number exist: Malvestio (2010) puts it at 200 and Slyke (2002) puts it at 170. These figures, however, show the incidence of the disability is a low one.

In order to teach students with Landau Kleffner Syndrome effectively, strategies must be devised that help accommodate cognitive and behavioral deficits. According to Downing (2010), in the past children with severe disabilities like Landau Kleffner Syndrome were considered incapable of learning. They were placed in secluded institutions where they only learned basic care and safety. Only after pressure from parents, advocacy, and activism, has legislation emerged that requires countries to provide access to education for individuals with disabilities (Downing 2010). Unlike past perception, where educators and the general population assumed that students with severe disabilities were incapable of learning, current instructors and the general population support the fact that all individuals are potential learners (Downing, 2010). It is imperative that education practitioners be aware of the characteristics and strategies of Landau Kleffner Syndrome (Sharma et al., 2011). This can be achieved through increased research on the disability.

## **Teaching Strategies**

To support and teach students with Landau Kleffner Syndrome effectively, modification and differentiation of instruction must be done to meet their needs (Tomlinson & Edison, 2003). Teachers must also have a positive attitude. Negative attitudes are a significant barrier to effective teaching. Teachers' beliefs influence their teaching practice because a link exists between their theoretical orientation and instructional practices (Berry, 2006). Teachers should have a positive perception toward the learning abilities of students with severe disabilities (Downing, 2010). This includes setting high expectations and standards for these students (Berry, 2006).

Students with Landau Kleffner Syndrome need intervention strategies that target their impaired abilities to receive, process, and express language (Chapman et al., 1998). When students struggle with expression and reception of language, adverse behavior may result (Lierheimer & Stichter, 2011). This may include physical aggression, verbal aggression and/or becoming easily distracted, which ultimately affects classroom management. Although students with Landau Kleffner Syndrome sometimes have challenging behaviors, they also have strengths that educators could foster to differentiate instruction to the advantage of students. Landau Kleffner Syndrome students are described as friendly by many authors and are also known to have strong visual skills, including visual memory (Chapman et al., 1998). These skills can be utilized toward effective learning, especially in an inclusive setting.

One major step toward effective intervention for students with Landau Kleffner Syndrome is structuring the learning environment (Buron & Wolfberg, 2008). This helps organize time and space for maximum learning. Students with severe disabilities like Landau Kleffner Syndrome tend to be disorganized and could benefit from external organization (Buron,



& Wolfberg, 2008). Structured teaching includes individualized schedules, routines, and activities. Each student's schedule should be planned and content taught based on the individual's learning style, interests, and personality. Another way of structuring instructions for individuals with Landau Kleffner Syndrome is to use task analyses and work systems. Work systems and task analyses are strategies that have successfully been applied in teaching children with severe disabilities (Kagohara, 2011). In his research, Kagohara (2011) found that students with developmental disabilities were able to learn how to operate an iPad when the learning task was broken down into short component chunks through task analyses. Teaching the task incorporated video modeling to enable students to review the steps of the work system repeatedly until mastery was acquired (Kagohara, 2013). This would be helpful for Landau Kleffner Syndrome students who are known to be strong visual learners (Chapman et al., 1998).

Work systems involve breaking a task into many sub-steps where students attempt to complete them chronologically. Tasks are presented in a way that allows students to see what tasks he or she is being asked to complete from the very beginning (Buron & Wolfberg, 2008). Students are also instructed on how to tell if they are making good progress towards completion. In situations where the activity does not involve concrete material, time passage is visually represented. This helps the students to monitor and understand how long they have been working.

Daily classroom and school routines are also part of structured teaching. An example of a simple routine is when a student enters class, deposits a winter coat and back pack, and then proceeds to settle at a designated work table every morning (Buron & Wolfberg, 2008). This should be practiced until it becomes automatic. Students should always be aware of what is

expected of them throughout the day; anticipated changes should be planned for and explained in advance.

Most Students with Landau Kleffner Syndrome tend to have attention deficit hyperactivity disorder (AD/HD) as a co-morbid diagnoses (Chapman et al., 1998). Strategies that target attention imbalances should be effected because attention imbalance can hinder teaching and learning for students with Landau Kleffner Syndrome (Patterson & Watson, 2011). This could also lead to social impairment and challenges in communication. According to Patterson and Watson (2011) attention is an individual's gaze to the target stimulus, and the gaze exists in three aspects: orienting, shifting, and sustaining attention. Potential difficulties arise if any of the above aspects are impaired (Patterson & Watson, 2011). Orienting attention refers to the initial physical adjustment toward a stimulus. When teachers and therapists are work with students diagnosed with Landau Kleffner Syndrome, they may get frustrated if a student is unable to orient attention to the target stimulus in order for a lesson to start.

Sustained attention refers to ongoing attention on an object. Some students get fixated at gazing at one stimulus even when they are no longer required to do so. Sustained attention in students with Landau Kleffner Syndrome may be affected by ease of distractibility of students with Attention Deficit/Hyperactivity Disorder (Turnbull, Turnbull, & Wehmeyer, 2010). AD/HD makes students impulsive easily distracted. This negatively affects effective teaching and learning. Effective intervention for disruption would include modification of teaching arrangements to minimize disruptions. For example, sitting students near the teacher or next to attentive students is an effective strategy towards this. Another strategy is minimizing the work given to a student with impulsivity and high distractibility. Teachers should only focus on the essential aspects of the task. Breaking the task into small chunks with verbal, visual, and physical

cues used to redirect students to stay on task is an effective strategy (Turnbull, Turnbull & Wehmeyer 2010).

Shifting attention is another critical aspect that affects students with Landau Kleffner Syndrome. Shifting attention is characterized by students' disengaging from one stimulus and reorienting with another (Patterson & Watson, 2011). When this fails to take place, students are exhibiting the inability to change focus. Challenging behaviors may be exhibited when the student does not want to transition from one activity or station to another (Chapman et al., 1998). Finally, another important aspect of attention is joint attention. This refers to both the teacher/therapist and student jointly paying attention to one common stimulus at the same time. For joint attention to effectively take place, all the other aspects of attention must be used effectively.

There are several ways of redirecting attention for students with Landau Kleffner Syndrome (Chapman et al., 1998). Therapeutically, attention can be encouraged through contingent reinforcement where the student is rewarded for paying attention to the target object (Patterson & Watson, 2011). Attention can also be maintained through prompting. Prompting is done through visual, tactile, or auditory cuing. Linguistic mapping has also been used to maintain or initiate attention. In this, the speech therapist or the teacher talks or initiates a conversation through what the child is presently doing (Patterson & Watson, 2011).

To serve these students effectively, teachers and therapists should pace their instruction for individual students' learning and cognitive abilities in mind (Tincani, 2012). The teacher's pace must reflect the students' ability to communicate. A student's communication skills are affected by sensory, motor, cognitive and social capacities. Impairment in any of these developmental skill areas may interfere with communication (Johnson & Parker, 2013).

Effective teachers must address the need to receive and process information for students with Landau Kleffner Syndrome (Johnson & Parker, 2013). One way to do this is by adjusting the instruction wait time. Wait time, according to Johnson and Parker (2013), increases positive responses in students with delayed development and communicative abilities. By utilizing a wait time of at least five seconds, parents and educators may be able to see an increase in appropriate responses from their children with severe disabilities (Johnson & Parker, 2013). Wait time helps the individuals process information, respond to instructors, minimize off-task behaviors, and improve the student's overall performance (Tincani, 2012).

Manipulating aspects of instruction such as pacing, response latency, feedback delay, inter-trial interval, and pace of vocal delivery of instruction or question can improve student's reception and response. Response latency which is controlled through teachers wait time refers to the duration between presentation of a discriminative stimulus such as teachers question or instruction and a student's response to that stimuli (Tincani, 2012). Students with severely low intellectual abilities have been noted to benefit from a slower instructional pace by some researchers according to Tincani (2012). Inter-trial interval, or the duration from one student response until the next teacher delivered instructional stimulus, increases the rate of accuracy when utilized with children who have severe disabilities. This interval also reduces rate of off-task and disruptive behaviors (Tincani, 2012).

Another a barrier to effective learning with children diagnosed with Landau Kleffner Syndrome is their impaired social skills. Their ability to interact positively with their peers is critical to learning and deriving satisfaction with everyday school experience for both special needs and typical students (Hughes et al., 2013). Some challenging behaviors exhibited by students with this syndrome can be attributed to the inability to interact with peers successfully

(Lierheimer & Stichter, 2011). Teachers should target interventions that improve the ability to understand their emotional states and those of others. One way of doing this is by involving typical non-disabled peers in social interaction activities with students with Landau Kleffner Syndrome. This strategy is more effective than teaching social skills directly to students (Hughes, 2012). To effectively involve peers, teachers must train the peers on interactive skill.

When peer tutoring takes place, teachers should prompt, guide and reinforce the typical non-disabled peers as they interact with Landau Kleffner Syndrome peers. Even experienced peer interveners need occasional prompt according (Hughes et al., 2013). Adults should meet occasionally with peers to teach them strategies to adapt in classroom assignment, provide instructional and behavioral support, and promote communicative interaction as they provide peer tutoring to them. According to a research by Hughes et al., (2013) individual training of three general Education students which combined goal setting, suggestions for interacting with a specific student, and self-monitoring was associated with a specific increase in students' social interaction with high school classmates diagnosed with developmental disabilities ( Hughe, et, al., 2013).

Naturalistic interventions has also been used to assist students improve their ability to interact. In this, the social interaction skills are taught in an informal setting as opposed to classroom setting. It is more effective for it leads to more generalization of skills (Ingersoll, et. al. 2012). Within naturalistic interventions are Behavioral perspectives and the Developmental perspective. Naturalistic behavioral interventions are based on the application of the learning theory. These interventions use direct prompting and reinforcement within natural contexts to teach specific social communication skills. Naturalistic developmental interventions are largely based on the social pragmatic model of language acquisitions. Naturally, there is an association

between the parent's level of responsiveness and the child's joint attention and language development over time (Ingersoll, et, al., 2012). The interventions are focused on increasing the adult's responsiveness to the child and establish balanced turns between the child and the adult. The interventions are done within meaningful activities in the natural environment such as play and daily routines. Teaching materials and activities are selected by the child. Main difference between the two approaches is the degree in which the adult uses prompting to directly elicit specific child behaviors and facilitative strategies to encourage adult responsiveness (Ingersoll, et, al., 2012). A third approach involves combining the two above approaches. The resulting combined interventions is known as the Milieu enhanced teaching. This according to Ingersoll and others has been shown to be quite effective with people with developmental disabilities (Ingersoll, et. Al., 2012).

Finally, Discrete Trial Teaching has been effectively used to teach individuals with developmental delays. It utilizes skinner's principle of operant conditioning. Discrete trial teaching utilizes simple but structured steps. Instead of teaching an entire skill, the skill is broken down and then built up through trials and reinforcement for correct responses. A teacher first provides an antecedent, for example he may say, 'point at an orange', and the student responds by pointing at the orange. If the child does not respond positively, he may be prompted further. This could be through physical guidance or otherwise to minimize errors. If the child responds correctly then the behavior is reinforced with a praise. Teacher poses for 1-5 seconds (inter trial interval) before presenting the child with the next antecedents. Each trial has a duration of 5-2-seconds and provides many learning opportunities. This is useful for teaching many numerous behaviors such as speech sounds, motor skills and new discrimination according to Wightman et al (2012).

Consequence for correct response is a verbal praise or through a token system. This is known as reinforcement. It is delivered after every single correct answer. Consequence of incorrect answer is a correction. Finally, inter-trial interval comes after consequences. Whether response is correct or not as the name suggest, it is an interval that comes between trials and signifies ending of that trial (Wightman et al., 2012).

### III. Chapter Three: Methodology

Chapter one covered the purpose and importance of carrying out this research (Stake, 2010). Chapter two provided some literature review on the Landau Kleffner Syndrome disability, challenges, and strategies (Chapman, et. al., 1998). This chapter describes the research question, rationale behind using qualitative research design, researcher's paradigm inclination, participants, the researcher's interest and experience and how data was collected (Yin, 2009). Finally, trustworthiness, ethical issues and procedure used to analyze the data in order make meaning for effective consumption is discussed (Hatch, 2002).

#### **Purpose of Research**

The purpose of this research was to explore, evaluate and consolidate the experiences (Creswell, 2013), of teachers, administrators, family, and support personnel serving a child with the Landau Kleffner Syndrome (Chapman et al., 1998). It was intended that this experience would then be consolidated to one document for future consumption by family and education practitioners (Hatch, 2002). As noted in the literature review, not much resources on nature, challenges and appropriate strategies currently exist on the Syndrome (Chapman et al., 1998). This research aims at ameliorating this situation (Creswell, 2013).

#### **Research Question**

The major research question is, “*what are the perceptions, challenges, concerns and strategies used by family, teachers and support personnel serving a child with Landau Kleffner Syndrome?*” In order to effectively achieve an in depth description of the participants' experiences (Berg, 2009), and increase the efficiency and quality of data collection (Creswell 2013), the research question was broken down into the following three minor questions (Yin, 2009):



- 1. What challenges are faced by family, teachers and support personnel serving a child with Landau Kleffner Syndrome?*
- 2. What strategies are applied by family, educators and support personnel in addressing the challenges faced serving a child with the Landau Kleffner Syndrome?*
- 3. What concerns do teachers and support staff have on their past and present experiences serving a child with Landau Kleffner Syndrome.*

### **Rationale for Qualitative Research**

According to Hatch (2002), Qualitative researchers seek to understand the world from the perspective of individuals who live in it. Accordingly lived experiences of real people in real settings form the objects of qualitative study. Further, when research settings are modified in any way or are manipulated for research purposes, as done in traditional research, the findings of the research indicate more how individuals act but in a narrowly defined, inherently artificial contexts. In qualitative research the intent is to investigate human behaviors within the contexts of their natural uninterrupted occurrence (Hatch, 2002). This research as reported earlier is designed to investigate how a targeted group perceive their experience serving a child with Landau Kleffner Syndrome (Yin, 2014). The perceptions experiences, challenges and intervention strategies of this targeted group was investigated with minimal or no obstruction (Hatch, 2002).

According to Yin (2009) a qualitative single subject case study design can be selected for several reasons. One of these include situations where the case represents an extreme, rare or an unusual case that deviate from every day occurrences (Yin, 2014). Landau Kleffner Syndrome is a rare, extreme, unusual and uncommon developmental disability. This study perfectly fits in the category. Subject of study has been a major behavior challenged to the district for more than

fourteen years. She was described by administrators as the most challenging and expensive case the district has ever had. To get an insight of the case, qualitative study is the most convenient method (Yin, 2009).

Another rationale for using a qualitative case study design according to Yin (2014) is revelatory case. In this, a researcher has access to a situation previously inaccessible to empirical study (Yin, 2014). This case again fits in this description. It is only for the fact that the district was unable to instruct Grace among other students that the researcher was hired to work with her. She belongs to a protected section of the society (Hatch, 2002). The researcher had a long history serving children with disabilities but this was an extreme and revelatory case. Qualitative single subject case study was inevitably the most appropriate option to for this revelatory case research (Yin, 2014).

Finally, in qualitative research, a researcher has an opportunity to use lengthy open ended interview strategy. This include many follow up questions to collect data from members of a target group (Creswell, 2013). In this particular research, individuals who had worked with the subject for more than a decade were targeted. Some had left the district and had to be tracked down. To seek insightful views of participants and review archival documents for information dating more than fourteen years, qualitative research was best fit (Yin, 2009).

### **Research Design and Paradigm Inclination**

According to Yin (2009), a research design represents a logical set of statements. The design satisfies trustworthiness, credibility, conformability and logical tests of data dependability. On the same note, researchers go to the field guided by some theoretical frameworks. Merriam (2009) defines theoretical frame work as the assumptions, concepts, underlying structure, scaffolding or frame of a research study. This is qualitative, in-depth

description and analysis of one bounded case where the researcher adopts a constructivist paradigm and framework approach (Yin 2009). The researcher sought to constructively achieve an in-depth understanding of target group (Creswell, 2013) by investigating how it perceives its experiences serving a child with the Landau Kleffner Syndrome (Creswell, 2013).

According to Hatch (2002), a world of universal absolute reality is unknown to researchers who approach research with a constructivist framework (Hatch, 2002). They use individual perspectives as their objects of inquiry. Constructivists acknowledge that elements are often shared across many social groups. However, they argue that multiple realities exist (Yin, 2013). In the field, constructivist researchers spend extended time interviewing participants or making observations. This is aimed at reconstructing the ‘constructs’ used by participants in making reality (Hatch, 2002). In this research, extended amount of time was spent interrogating participants and reviewing archival records spanning more than fourteen years.

### **Participants and Sampling**

Children with severe disabilities are protected section of the society (Hatch, 2002). Before recruiting any participants, measures were taken to minimize potential legal implications. A meeting was held between the researcher, district special education supervisor, and an administrator in the superintendent’s office. Confidentiality measures were discussed and conditions of conducting the research were given in writing (Yin, 2013). Most importantly, parents had to consent to allow school district employees to participate. Both parents had to sign a consent form for each participant.

After the discussion, written consent was then required of parents (Creswell, 2013). Apart from giving consent, parents helped identify some potential participants. Grace had been in the school district for over period of fourteen years. Several potential participants had left the

district, and snow balling (Hatch, 2002) or chain sampling recruitment was done (Berg, 2009). By the time of the research, the researcher was a teacher in the high school where the subject of the study was a student. Most teachers who had taught Grace in lower schools were then teaching in same high school. There was already a good working relationship between the researcher and the potential participants. The researcher easily recruited them to participate (Creswell, 2013). They formed an accidental sample or sample of convenience (Berg, 2009). Participants included support staff, such as occupational therapists, speech therapists, nurses, and teacher's aides who had served Grace in the last fourteen years. Other participants included administrators, teachers, and family. Psychiatrists and medics participated indirectly through their reviewed archival records (Hatch, 2002).

### **Researcher's Experiences, Role, and Participation**

The researcher was hired to work with the subject after the subject became difficult to serve amongst other students due to behavior challenges. The researcher is a trained special education teacher with more than ten years of experience. The case under study proved an extreme challenge to the researcher (Chapman et al., 1998). There were limited resources on the strategies and the nature of Landau Kleffner Syndrome (Chapman et al., 1998). He was verbally and physically assaulted. Collaboration was perfect but unhelpful (Friend, 2000). It was after experiencing challenges working with the subject that research interest was developed. Were it not for the quality support from family, teachers, and administrators, the researcher would have quit within months. Despite receiving physical and verbal aggression, the researcher desired to create a knowledge base and resource for future teachers, the reason for this study (Stake, 2010).

According to Stake (2010), researchers can appropriately study their own places or units supervised by themselves, but a better design, length of time, and more triangulation would be

necessary (Stake, 2010). Great effort was put towards achieving this objective. The researcher did not directly participate in the research as a respondent (Hatch, 2002). However, his experience was fundamental in designing research questions and posing probing questions (Creswell, 2013). Additionally, his experience made it easy to recruit participants and get consent from parents who confessed they would not have done so under normal circumstances.

### **Data Collection**

According to Yin (2014), case study evidence can come from many sources. Multiple sources, instruments, and strategies were utilized in this research (Yin, 2009). They are explained below. Protocol used to collect information from various participants is included in Appendix B of this report (Stake, 2009).

**Interviews.** According to Stake (2009), interviews are used to achieve many goals. Among them is obtaining information or interpretation held by the person being interviewed. They are also used to find about a “thing” that the researcher was unable to observe themselves (Stake, 2009). Both written and oral interviews were conducted in this research. Oral interviews included individualized one-on-one oral interviews and two focus group interviews (Hatch, 2002).

**Individual interview.** There were both individual written and oral interviews (Creswell, 2013). Written interviews were given first to all participants via e-mail (Yin, 2009). Their written responses were reviewed and analyzed. Responses from the interview were then used to design and moderate individual oral interview questions (Hatch, 2002). All recipients were invited for oral interview at different times depending on their availability. Members were asked to clarify and expound on any unclear responses from their written interviews. Because respondents were diverse in occupation, the time they spent serving Grace, and the capacity of their roles,

questions were person specific (Hatch, 2002). After completing the one-on-one interviews, participants were invited to participate in the focus group interview (Creswell, 2013).

*Focus group interview.* According to Hatch (2002), while focus group interviews that were developed in sociology and marketing may be independently and effectively used in self-contained studies in education, many qualitative researchers use focus group techniques as supplemental sources of data. They collect this data, along with others, that might include observation, individual interviews, and unobtrusive data (Hatch, 2002). In this research, focus group was used to supplement and clarify data collected through archival records and individualized oral and written interviews (Yin, 2009). According to Hatch (2002), several advantages accrue in using focus group interviews. First, a focus group interview has the capacity to produce a concentrated data on the precise topic of interest. This is because the groups are selected with one particular focal topic in mind. Such focus can generate much data in a short period of time. A focus group interview is also captures the dynamics of group interaction that are unavailable in an individual interview. On the same note, being interviewed in groups gives members a sense of security. Some members express themselves better and freely in topics they may perceive beyond expectations of the researcher. Finally, a focus group offers the advantages of giving participants a say in how the direction of the interview ought to go (Hatch, 2002).

Two focus group interviews were conducted (Creswell, 2013). Administrators had their own focus group interview while teachers and other support personnel had a separate focus group interview. Those who sat in the same focus group interview with teachers included a librarian, teacher's aide, and a speech therapist. The focus group interview effectively provided

insightful perceived inferences and explanations by administrators, support personnel, and teachers (Yin, 2009).

*Archival records.* According to Hatch (2002), archival records are an unobtrusive data source. Also, several advantages are associated with it. The data source is considered non-reactive because it is not filtered through the perception, interpretation, and possible biases of research participants. These can be powerful indicators of the value systems operating within institutions. They can also give the researcher a sense of history related to the contexts being studied (Hatch, 2002). Several archival records were studied and analyzed. Due to confidentiality and legal reasons, parents requested the confidential records from the school district first. They then handed them over to the researcher. This procedure had previously been agreed upon by the researcher, special education supervisor, and the responsible assistant superintendent in a precautionary meeting held before research was approved. As noted earlier, individuals with disabilities form a protected section of the society (Hatch, 2002).

The confidential records covered a period of fourteen years with some medical records spanning throughout Grace's life. When studying the documents, parents and former teachers sought clarification. Archival records were also utilized in formulating oral and written interview questions. Among the documents studied and reviewed were psychological reviews, individualized education programs, functional behavior analyses, and medical records (Turnbull, et al., 2010). Psychological reviews are usually completed by a school psychologist every three years. The review is usually accompanied by assessment from other support specialists, such as a speech therapist; it is aimed at reassessing change in needs. An I.E.P is completed every year and is like a road map for provision of services for the particular child that year (Mercer et al., 2011). A formal study of these documents and their evaluations provided a significant source of

information in this case study (Hatch, 2001). Finally, the researcher's impressions and short field notes, perceptions, and tentative interpretations recorded during the research were analyzed (Merriam, 2009).

Documents being unobtrusive, and not necessarily kept for the particular study, played a great role both in information and triangulation in this research (Hatch, 2002). Apart from advantages mentioned earlier, archival records were stable, exact in information and subject, and were reviewed many times during the research (Yin, 2014).



## **Data Analysis Methods**

To make research findings make sense to potential consumers, textual representation reflecting the data was created. Data collected via interviews and study of archival records were analyzed to seek meaning from them (Hatch, 2002). According to Hatch (2002), there is no universal manner in which qualitative data is analyzed. It is an idiosyncratic and complex process (Hatch, 2002). The analysis of case study evidence is the least developed and most difficult stage of a case study (Yin, 2009). In this research, data analysis was done concurrently with data collection (Creswell, 2013) in order to establish efficiency and accuracy with transcribing and interpreting data; the researcher's memory was still fresh. This was also necessary so that clarification from participants would be done when their memory was still fresh as well (Yin, 2013).

An inventory of all data collected was continuously kept (Yin, 2013). The inventory included notes on archival records reviewed, who was interviewed, and whose responses were transcribed. Duplicates of notes and transcripts were kept before the analysis started (Merriam, 2009). (This was a precaution against loss of information.) Open coding was done by assigning some short-hand designation to the main aspects of data (Merriam, 2009). Each interview set and field notes were coded in a unique manner for ease of access and identification. Because participants were varied in role and occupation, pseudonyms were used to identify and differentiate their responses (Hatch, 2002).

Transcribing of audial recording data was done immediately after field data collection (Hatch 2002). This was necessary to ensure that it happened when mind and memory were still fresh (Merriam, 2009). This also helped to modify questions for future respondents depending on how clear the questions were answered by participants under review (Hatch, 2002). Questions

that were misunderstood by the participants were rephrased for future participants (Yin, 2014). Responses that were not clear were clarified by consulting the respondents as soon as possible. This ensured clarification took place when their memories and that of the researcher were still sharp (Merriam, 2009).

During the analysis, category construction was done. Most dominant concepts were established (Yin, 2013), and this was achieved by reading transcripts repeatedly, jotting notes, and writing comments in order to establish mutually exclusive themes and categories (Creswell, 2013). Finally, the categories were further sorted to come up with the least indivisible forms of categories (Hatch, 2002). The final categories were marked as research themes; a category qualified as a theme if it was responsive, sensitive, conceptually congruent, and mutually exclusive compared to others (Merriam, 2009). As observed by Hatch (2002), determining when to stop analyzing qualitative data is hard. This is mainly because qualitative research data is ambiguous and abundant in nature (Creswell, 2013). New themes kept emerging. According to Hatch (2002), when analyzing qualitative data, it is prudent to confine oneself to what data answer the research question. In this research, data analysis was stopped when it became possible to tell a coherent story, account for data disconformities, and clearly explain the analyses (Hatch, 2002). When patterns, identities, and themes in answering the research questions were fully established, the analysis process was stopped (Yin, 2009).

### **Triangulation and Trustworthiness**

To increase the soundness and trustworthiness of data collected from this research, member check was done after transcribing data (Creswell, 2013). According to Yin (2011), member check has several advantages, for corrections and changes can be made that may increase validity. Sharing has a great role in increasing collaboration and promoting ethical

relationships (Yin, 2011). Each participant was given a complete written transcript of their interview to review and confirm its authenticity. They confirmed the accuracy and also clarified any discrepancies between what was written and what was initially said (Yin, 2011). Apart from this, trustworthiness was further sought through triangulation of data sources as explained below (Merriam, 2009).

According to Berg (2009), researchers obtain a better substantive picture of reality by combining several lines of sight known as triangulation. Triangulation provides not only a richer, more complete array of symbols and theoretical concepts, but also a means of verifying many of these elements (Berg, 2009). This single-subject case study triangulated knowledge by consulting multiple sources of information (Merriam, 2009). The sources with converging inquiry lines included study of archival records, individual written and oral interviews, and two focus group interviews (Yin, 2004).

Reviewing archival records has several advantages (Merriam, 2009), the main advantage being that archival records are unobtrusive. Additionally, the records are not kept purposely for the said research and, hence, are objective. Furthermore, they can be studied and reviewed many different times during the research (Yin, 2004). In this research, documents reviewed were written and filed by diverse experts for a period exceeding fourteen years. Some of the documents reviewed include I.E.P. and psychological reviews (Turnbull et al., 2010). Psychological reviews are done every three years while I. E.P.s are prepared annually by a committee of inclusive teachers, family, and support staff. Psychological reviews are accompanied by assessment from occupational and speech therapists, depending on the disability and needs of the student. Since Grace has been in the district for over fourteen years, records

reviewed were written by many different individuals, primarily due to staff turnover. This increases the diversity of data sources.

Some disadvantages exist for using archival records. They cannot be interrogated, and there is no guarantee that they were accurately kept (Hatch, 2002). To counteract these disadvantages, oral and written interviews were conducted (Merriam, 2009). Individual oral, written, and focus group interviews were conducted (Creswell, 2013). As noted earlier, interview questions were modified on an ongoing basis. Responses to written interviews informed the designing of questions in one-on-one oral interviews. Responses to individual oral interviews were analyzed, and they informed the designing of focus group interview questions (Hatch, 2002). Triangulation was further achieved by conducting two separate focus group interviews (Yin, 2009). Participants in one focus group were administrators only. Those who participated in the second one were teachers, teacher's aides, librarians and speech therapists. All of the participants not only contributed to triangulation, but also increased the trustworthiness and soundness of data collected (Merriam, 2009).

### **Ethical Issues**

According to Yin (2014), every researcher has a duty to conduct research with utmost care and sensitivity (Yin, 2014). This research involved a member of a protected section of the community. People with disabilities are considered vulnerable groups and are legally protected (Stevens & McCool, 2011). This research respected all ethical requirements of standard research. Before the research, an I.R.B. form was filed, and approval was granted by the University of Arkansas Institutional Review Board (see Appendix A). A written consent to conduct the research was sought from the parent and the school district. Parents gave their informed consent (in writing as required by law), approving participation of individuals by providing separate

informed consent forms. All participants signed an informed consent form. The participants were made to understand that their participation was voluntary and confidential and anything shared or developed during the research would be destroyed after the research (Yin, 2014). All information gathered from the participants was kept confidential throughout the research. All transcripts developed from focus group and oral individual interviews were destroyed at the end of the research (Hatch, 2002).

#### **IV. Chapter Four: Results**

In Chapter Three, methods applied in gathering data for this research was discussed. The methods include the study of archival records and conducting both individual interviews and two focus group interviews. One of the focus groups consisted of teachers and support staff, while the second was comprised of school administrators. Archival records reviewed include behavior plans, psychological reviews, individualized education plans, and evaluation and assessment records from speech and occupational therapists. Relevant informal communication records by educators and parents were also analyzed. In this chapter, data collected on the lived experiences of 15 participants serving a child with Landau Kleffner Syndrome are presented. The first part of this chapter presents the student's social background and disability. The last part of this chapter presents data collected from oral, written, and focus group interviews. A summary of themes emerging from the interview responses is first presented in table form, followed by a narrative that expounds upon the themes.

##### **Research Question**

This research was designed to answer the following research question: "What are the perceptions, challenges, and strategies applied by family, teachers, and support personnel serving a child with the Landau Kleffner Syndrome?" For ease and efficiency of data collection, the question was broken down into three sub-questions as follows:

- 1. What challenges are faced by family, teachers, administrators and support personnel serving a child with Landau Kleffner Syndrome?*
- 2. What strategies were applied by family, teachers, and support personnel to address challenges faced serving a child with the Landau Kleffner Syndrome?*

*3. What concerns do teachers and support staff have on their past and present experiences serving a child with Landau Kleffner Syndrome?*

### **Student's Disability and Social Background**

Grace is a twenty one year old high school student described in her Individualized Education Program as a Super Senior (SS). According to her high school administrators, "Super Senior" refers to a student who has already graduated from high school, but has returned to the school system with an exit date after her twenty first birthday. Social history records indicate Grace lives with her parents and two older brothers. Her hobbies include playing with her dogs, looking at photographs on electronics, singing, and dancing. When not agitated she was described as people loving, willing to help, and empathetic. When agitated she was described as strong willed, illogical in her reasoning, egocentric, mean, un-empathetic, and potentially violent.

Grace's Individualized Education Program and psychological review indicate that she is diagnosed with multiple disabilities. She is primarily diagnosed with the Landau Kleffner Syndrome, among others. She is concomitantly diagnosed with Attention Hyper-Activity Disorder (AD/HD), anxiety disorder, seizure disorder, and Epileptic Encephalopathy. Psychological reviews indicate that Grace receives special needs under a category known multiple disability. This is as defined by the Individuals with Disabilities Education Act (I.D.E.A). Records indicate that she has previously received services under a separate category known as "Other health impairments." According to her psychological review records, multiple disabilities are impairments that are concomitant in occurrence but whose combination causes such severe educational impairments that they cannot be accommodated in a special education

program solely for one of the impairments. In all her psychological reviews, Grace is cognitively described as very low with an I.Q. below forty, equal to that of a three year-old.

Neurological assessments indicate that Grace is a product of a pregnancy complicated by thyroid disorder that necessitated her mother to continue taking synthroid medication. Other medical records indicate that Grace's mother fell on ice when she was expectant. Her birth was reported to have been complicated by placental abruption, which led to excessive loss of blood during delivery. She was placed in the hospital's intensive care unit for four days. Records indicate that Grace developed normally for the first two years until she experienced a seizure episode at the age of twenty months. She had three seizures within twenty four hours; afterward, she completely lost her spoken language abilities. Records indicate that she peddled a tricycle at age three with little motor development thereafter.

### **Family's Disability and Medical History**

There is no history of Landau Kleffner Syndrome in the family. There is however a history of Attention Deficit Hyper-activity Disorder (AD/HD). Grace's father and one paternal uncle are diagnosed with AD/HD. On the same note, Grace's mother reported that both of Grace's brothers are diagnosed with AD/HD. According to Grace's mother, "There are two categories of AD/HD, one with hyperactivity and one without. Grace's elder brother has one with hyperactivity while the younger brother has one without. Grace has the one with hyperactivity." Medical Records indicate that Grace has also recently been diagnosed with diabetes. Her father is also diabetic. Developmental disability records indicate that Grace was diagnosed with a mixed seizure disorder at the age of two. According to her mother, this was her first experience ever with seizures. She reported, "I never experienced seizures before, but I definitely knew that was it when I saw it. I heard my daughter screaming and I ran to her room. I



found her body shaking hard. We rushed her to the hospital, it was a partial atonic seizure. Half of the body had lost tone but the rest was okay.” Archival records indicate that Grace takes Depakote for seizures, a drug that had successfully eliminated seizures for almost ten years. As research was going on, Grace started experiencing seizure episodes again. Her mother believes that the Depakote level in the blood stabilized in such a way that a dosage increase is needed to help fight back the seizures.

Medical records indicate that Grace has experienced many different categories of seizures in the past. These include myoclonic head drops, tonic falls, and myoclonic jerks of the upper extremities, causing her to drop objects. Archival records indicate that she has once experienced nine seizure episodes in twenty four hours. She has also had a fever of 104 degrees or higher for longer than 24 consecutive hours. Similarly, records indicate that Grace has a history of ear infections that was treated with antibiotics. When she was young, she was reported to have had challenges with her balance and was also tremulous. One of her recent teacher aides indicated that occasionally Grace loses balance and falls while walking or playing. Her hand muscles also shake uncontrollably when she is anxious.

### **Speech and Language Ability**

Each psychological review is accompanied by speech language evaluation. All Grace’s speech evaluation records have consistently reported major language and speech deficits. Grace has significant delay in both receptive and expressive language abilities; she does not process verbal information effectively as expected of her age. She is unable to follow lengthy verbal directions which go beyond two steps. Also, she does not comprehend abstract information and has a moderate delay in conversation. According to the most recent evaluation, Grace treats words in a sentence as separate entities hence losing the context of the sentence. Her pragmatic

and social language skills are also delayed. In conversation, Grace does not wait for her turn to speak—she interrupts continuously and at times asks questions unrelated to the topic of conversation. After asking a question, she does not wait for an answer before proceeding to another question. Her topic maintenance is described as minimal in all speech evaluation records. She skips syllables in words, too.

Compared to typical peers, Grace is unable to express cause and effect. She also rarely adjusts her speed to improve understanding. Only those familiar with the context of the conversation would understand Grace in a conversation. Another concern in Grace's speech is her pitch and voice volume. She tends to be too loud while talking and her pitch is higher than normal. The pitch is also described as immature for her age in her evaluation records. Further, while her fluency and rate of speech are adequate, her prosody (elements of rate and intonation) is described as choppy and lacking affect/intent. Records also indicate that Grace has serious deficits in her verbal receptive language abilities. Based on the most current evaluation, her ability to understand common nouns, adjectives, and verbs is equivalent to that of a three years and three months-old. Her expressive language ability for naming common nouns, verbs, and adjectives is rated by her speech therapist as equivalent to that of a child aged 2 years 11 months. Records indicate that in the past, it has been difficult to test Grace's receptive and expressive language skills in the area of word meaning (semantics), word and sentence structure (morphology and syntax), and the recall and retrieval of spoken language (memory) because Grace has been unable to follow instruction in the tests.

### **Occupational Therapist's Evaluation Records**

Grace is assessed by an occupational therapist every three years to help plan for appropriate placement or to review changes in her occupational needs. Assessment usually

occurs during tri-annual psychological reviews. Based on assessment records on file, Grace is described as having motor challenges exhibited through shakiness. Records further indicate that she has tremors in her upper extremities. Tremors in her bilateral upper extremities are noticed both in rest position and in motion. The tremors increased when Grace engaged in fine motor activities, but the tremors increased more rapidly as she moved her hand away from her trunk. Records indicate that Grace experiences challenges when maintaining her balance and sometimes falls or misses steps while running, walking, or playing.

Furthermore, according to assessments records when Grace is given objects to work with, she experiences difficulty manipulating them by hand. She also has difficulty with large eye to hand coordination, such as hitting a ball with a hammer. Similarly, she demonstrates severe deficits in visual motor skills. In one of the assessments, she was unable to isolate eye movement with head movement. Grace also experienced difficulty tracking a slow-moving manipulative cue from left to right, right to left, up to down or diagonally. Divergence of bilateral eyes beyond three feet was also noted. During all tracking activities, her eyes were noted to tear and turn red. Excess eye rubbing when tracking the figure eight was also noted.

Grace also experiences difficulty controlling her muscles while writing. She holds her pen in a manner that makes it hard for her to control the pen. When holding her pen, she assumes a modified tripod grasp; she places the pen perpendicular to the paper and rests it on the web space of the thumb. Her thumb is wrapped around the shaft of the pen with the palm of the proximal phalange in contact with the pen. This grasp typically limits the control of the pencil by decreasing the web space between the thumb and the index finger. The result is poor proportion of line management in the larger muscle group controlling the pen. Therefore, Grace is unable to keep letters on the lines, and as her hand progresses to the right, she is unable to control the pen

as well. This results in a tighter grip and an increase in force of muscle tremors. This makes her handwriting shaky, nonlinear, and illegible.

### **Behavior Assessment Records**

Archival records indicate that Grace has exhibited behavior challenges throughout her school life. Her behavior plans (documents indicating challenges and intervention methods to respond to and prevent behavior escalation) describe her challenges as physical aggression, verbal aggression, and nonverbal threats of harm. According to archival records, behavior challenges are most common when Grace is agitated, transitioning, seeking attention, sick, when there is a change in medication, or when she experiences an abrupt change in her routine. Regarding issues with transitioning, records indicate that Grace is not always prompt when moving from one activity or setting to another. Behavior challenges are experienced mostly when transitioning from an activity of interest to one that is not as interesting. While resisting transition, she crawls around the room like a baby, may sit and remain in the same position refusing to comply, may engage the teacher in an off-topic conversation, and may start talking loudly and exhibit non-compliant behaviors. Her lack of compliance is also characterized by shouting “no,” even before she is done listening to the directives. She is also reported to use profanity, disrespectful language, and to make verbal threats to avoid transitioning.

Her physical aggression includes hitting, kicking, pushing, pulling hair, spitting, and stabbing. If engaged verbally when annoyed, she enters into a power struggle with the engager which leads to more agitation and a possible tantrum. Her behavior plan has documented several predictors of potential behavior. These predictors include transitioning between activities with high levels of verbal prompting, making demands with high levels of verbal prompting, seeking attention by calling names, hitting the table to get attention, and asking off-topic questions

continuously. When Grace makes a request, she expects to get a positive answer all the time, and she gets irritated when she is told “no.”

According to her high school teacher, there are identifiable signs of escalation that teachers should watch. These signs include shakiness, increased verbal call out, profanity, and refusal to comply with tasks or directives. Grace’s behavior plan describes her as a student who tactfully evades work. She raises physiological concerns to avoid participating in learning activities and transitions between activities and seeks negative attention. The physiological concerns include stating, “I am not feeling well,” “I have a headache,” “My stomach hurts,” or “I did not sleep well last night.” According to her parents, these ailments actually occur at times, but most of the time she will use them to evade or for the sake of getting attention.

Grace’s behavior specialists recorded several challenging behaviors that were caused by her setting. Physiological imbalance, hunger, fatigue, and lack of sleep the previous night all are included in the setting. The most recent behavior plan describes physiological imbalances as her menstruation cycle, satiation, new medicine, and seizure activity. Grace’s parents and her teacher’s aide also noted that when her blood sugar level is either very high or very low, Grace is more prone to exhibit behavior challenges. Her behavior plans have highlighted a number of antecedent triggers of aggressive behavior. They include increased task demand, transitioning from preferred activity to a non-preferred activity, and physical blocking (when Grace tries to walk away from or toward a targeted student during aggression), and seeking social interaction with peers and attention from teachers/audience. Grace also gets easily distracted by noise, movement, and visual objects; she has challenges remaining focused and maintaining attention.

## **Summary**

This section highlighted behavior, disability and related challenges as provided for in archival records with supplemental information from oral interviews. Among the records reviewed in this section are psychological reviews, I.E.P.s, and evaluation records by speech therapists and occupational therapists. Grace has several disabilities: Landau Kleffner Syndrome, attention hyper-activity disorder (AD/HD), anxiety disorder, seizure disorder, and epileptic encephalopathy. She also has behavior challenges inclusive of verbal and physical aggression. She is unable to consistently remain attentive and focused and is easily distracted by noise, visual objects, and movements.

Grace's behavior challenges are primarily prompted by physiological changes, hunger, and insufficient sleep. She employs certain tactics to avoid transitioning, work, and to get attention. Grace has speech and language challenges that inhibit her ability to receive and express verbal language. She is described as a child with mortal control challenges in her occupational evaluation records.

### **Oral and Written Interview Responses**

The above section presented social history, personality, disability, speech, and mortal and behavior challenges. This section presents an analysis of data collected from oral and written interviews. In this section a table of the findings is presented, followed by a narrative explanation of its contents. In the table, the first column represents the titles of the participants while the rest presents the results of the three research questions. As noted in the methodology section, the research question was broken down into three minor questions for ease and efficiency of data collection. Column two presents the challenges experienced by the respondents as they served a child with the Landau Kleffner Syndrome. This was what the first research questions investigates. The second column highlights the strategies applied to address the above questions.

This is what question two investigates. Finally, column four presents the concerns that participants had based on their lived experiences serving a child with Landau Kleffner Syndrome. This is what question three investigates.

**Table representing the perceived challenges, strategies and concerns by respondents who served a child with the Landau Kleffner Syndrome**

<b>Participant</b>	<b>Challenges</b>	<b>Strategies</b>	<b>Concerns</b>
Parent	Economic, Physical/Verbal aggression, Anxiety, Attention, Manipulation, Family conflicts, Empathy issues, Invasion of space, Medical, Anger/Mood swings, Obsession, Inappropriate language/Profanity, Seizures, Shakiness, Sleeping patterns, Time constrains, Unclear Triggers, Diabetes Seizures,	Collaboration, Speech intervention, Routine and structure, Verbal redirection, Positive reinforcement, Age appropriate language, Avoiding crowded places	Decorum/Administrative, Future placement of student, Use of medication to control behavior, Generalization by experts, Camera supervision
Occupational therapy	Motor control, Proprioception, Distraction, Missing of sessions, Physical/Verbal aggression, Task Avoidance, Screaming, Over interaction with strangers, Demanding reinforcement not yet earned, teacher aide	Weight jacket, Magnetic pencil, Rapport building, Collaboration, Behavior plan, Separate room, Long wait time, Staying calm, Simple and clear directions, Collaboration, Consistence, Wrist weights	Student has not been able to communicate in writing a decade down the line, Role of teacher aide during therapy sessions
Speech therapist	Impaired Attention, Distraction, Irregular Sleeping patterns, Missing of sessions, Syntax errors, Decreased vocabulary, Comprehension challenges, Word retrieval difficulty, Perseveration, Difficulty following directions, Delayed processing,	Regular breaks, Structured setting, Tactile, auditory and visual activities, Language Modelling	Future placement of student Role of teacher aide during therapy session



	Difficulty in topic maintenance, Abstract thoughts. Anxiety, Coherence of speech, Inappropriate language, Assessment challenges, Low Motivation		
Nurse	Seizure, Physical /Verbal aggression, Screaming, Collaboration challenges	Collaboration, Social stories Positive reinforcement	no concerns
Teachers 1	Phy/Verbal aggression, Unclear triggers, Sleeping patterns, Selective respect of authority, in coherence of speech Empathy issues, Impaired attention, Vulgar language Stimulation challenges, Screaming, Cussing	Collaboration, Rapport building, Verbal redirection, Physical manipulation, Positive reinforcement Isolation,	Least Restrictive environment
Teacher 2	Phy/Verbal aggression, Imbalanced attention, Escaping, Classroom management challenges, Sleeping patterns, Insufficient physical facilities, Curriculum/Placement, Cognitive abilities, Distractibility, Unclear triggers, Obsession with food, Incoherence of speech, Inappropriate questions, Invasion of personal space	Be swift, Discrete trial, Proactivity, Clear room for safety, Simple activities, Slower instruction pace, Break activities into smaller chunks, Positive reinforcement	Least restrictive environment, Parents had not yet filed appropriate social security paper work.
Teacher 3	Turn taking in conversation, Placement and curriculum, Distractibility, Inexperience, Invasion of space, Sleeping patterns, Limited administrative	Collaboration, Behavior plan, Physical/Verbal redirection, one on one teacher aid, Giving attention appropriately	Insufficient support from administration  Is positive reinforcement enough?

	support, Low cognition, No sense of wait, Phy/Verbal aggression, Seizures, Unclear Triggers, Shakiness, Time constraints	Attention, Isolation, Positive reinforcement	
Teacher 4	Phy/Verbal aggression, Attention, Placement issues, Sleeping patterns, insufficient physical facilities	Positive reinforcement Verbal redirection, Being proactive	Which is appropriate Least restrictive placement?
Teacher 5	Obsession with items, Phy/Verbal aggression, Attention challenges, Unclear Triggers Failing to follow directions, Crying, Irregular Sleeping pattern, Anxiety, Low Cognition, Overstimulation Screaming, Empathy issues, Speech incoherence	Being Proactive, Clearing for safety, Consistence, Discrete trial, choices, Hands on activity, Wait time, Plastic items /Limited furniture, Positive reinforcement, One on one aide, Repetition, Routine, Social story, Age appropriate language, Cultivate trust	Misunderstanding of reinforcement Contradictions by Behavior analyst
Teacher 6	Curriculum, Yelling, Inappropriate language, Avoidance, Escaping from class	Positive reinforcement	Inexperience
Teacher Assistant 1	Distractibility, Cognition, Empathy issues, Escaping, Inappropriate questions Personal space, Low cognitive abilities, Manipulation ,Obsession Perseveration, Shakiness Short attention span Sleeping patterns Tantrums	Brief directions, Collaboration, Discrete trial, Language mapping, Wait time, Medication, One on one aide, P.C.M, Prompting, Quite environment, Minimized movement, Verbal	Insufficient support from administrators More effective collaboration

		Redirecting, Short lessons, breaking activities into small chunks, Visual aides	
Teacher Assistant 2	Attention seeking, Disruption, Shakiness, Phy/Verbal aggression, Inappropriate language	Clearing class for safety, Positive reinforcement, Verbal redirection	Training, Bribing the student for peace
Teacher Assistant 3	Antagonism, Crying, Escaping from class, Inappropriate questions, Low Cognition, Personal space, Turn taking, Obsession, Dependency, Phy/verbal aggression, Body coordination, Attention, Transition, Verbal expression, Staying on topic, Shakiness, Perseveration, Attempted self-injury, Sleeping pattern, Language and Speech	Be firm, Structure, Regular routine Avoid power struggle, Be proactive, Break activities into small chunks, Wait time, Surveillance camera, Calendar time, Collaboration, Avoid crowds, Discrete trial, Minimize noise, No eye contact, Be proactive, Remove hard objects from environment, Repetition, routine, Slow pace of instructions	Training, surveillance by camera, Least restrictive environment, Relationship with ADM
Teacher Assistant 4	Physical aggression Verbal aggression, Escaping from class, Inexperience, Sleeping patterns, Transition challenges, Shakiness, Distractibility, Manipulation, No sense of time Speech incoherence	Calmness, Patience, Collaboration and team work, Consistence ,Eye contact, High expectations, P.C.M, Tally marks, Visual cues	

Teacher Assistant 5	Phy/Verbal aggression Distraction, No sense of time, Trigger issues, Manipulation, Anxiety Escaping, Speech incoherence, Following Directions, Transition challenges	Visual aids, Verbal redirection, Modeling, Cultivation of trust, Structure, routine, Wait time, Slow pace of instruction	Training
Focus group 2: Teachers	Triggers issues, Shakiness Phy/Verbal aggression T.A roles, Personal space, Low cognitive abilities, Physical size n strength, Shakiness, Selective cooperation, Lack of empathy, Manipulation, Attention seeking Curriculum and placement, Distractibility, Low motivation, Teacher aid roles	Behavior chart Decreased day length, Isolation, Let her be independent, Positive reinforcement, Visual aids, Long Wait time, Weight on wrist, Weight jacket, Sensory diet, Work program, Behavior plan	Least restrictive environment, Inappropriate use of camera, Insufficient help from behavior analyst, Positive reinforcement concerns, Parents late filing Social security paper work, Late untimely Training
Focus group 1: Adm	Economic, Administrative, Overstimulation Phy/Verb aggression Poor com skills, Poor socialization skills , Collaboration challenges Language and speech	Collaboration, educating Parents, Minimize talking when agitated, Know the student, PC.M, Personality match, Proactive, Video, Visual prompts	Communication and expectations of teachers

## Challenges

The first Question in this research aimed at investigating the challenges experienced by educators, family, and support personnel serving a child with the Landau Kleffner Syndrome. In the table above, column 2 summarizes the challenges as perceived by family, educators, and

support staff. In this section, the various emerging themes are presented and discussed. Five major thematic categories of challenges emerged: speech and language challenges, behavioral challenges, economic challenges, motor control, and social skill challenges. They are analyzed in the following section.

**Communication, speech, and language challenges.** One of the most commonly mentioned challenges was Grace's inability to process or express spoken language. According to Grace's parents, Grace lost her speech language abilities after an unprecedented seizure episode when she was twenty weeks old. Grace's mother reported that "Grace was a very effective communicator until the seizures happened. She was comparatively ahead of her two brothers in speech, motor, and language development. After the seizure episode, she would only communicate in gestures. She also misunderstand our spoken language increasingly often." Most teachers and administrators reported that language and speech communication challenges contributed to behavior challenges. According to one high school administrator, "At times we understand Grace, but other times her ability to communicate shuts down. When she is agitated, she is unable to verbalize her communication. She instead uses single words and phrases that at times do not make sense. She also uses self-devised gestures. If not understood, she results to violence." Grace's speech therapist reported that Grace has challenges following verbal directions with more than two steps. Some teachers reported that only people familiar with context would understand Grace's communication. Her teacher reported that "Grace at times mumbles and makes statement that do not make sense. Grace has no sense of time and tenses. She refers to the future as present and the past as the future, today and yesterday respectively. It is hard to understand her." She also skips syllables when talking.

**Behavioral challenges.** Behavioral challenges were a dominant theme throughout this research. According to Grace's mother, "Behavior challenges began after the seizure episode that left her unable to verbalize her communication. She would point at items, and we kept guessing what she wanted. She would get irritated when we made wrong guesses." All respondents described Grace as verbally and physically aggressive. They reported that she uses profanity and issues verbal threats when agitated. All participants reported that she would pull hair, spit, destroy property, kick, hit, and use obscene gestures when agitated.

According to her occupational therapists, "Grace is very particular in her verbal threats. I have heard her threaten to hit the belly of an expectant teacher's aide. A teacher's aide said, "Grace screams and at times cries like a little baby when agitated. She attempts to run away from class, and she hits those who block the door to stop her." All teachers reported that they have been physically assaulted by Grace at one time or another. According to her teacher, "Grace mostly attacks with rage but can also scheme for it. There is a time she waited for me to turn my back towards her then she pulled my hair. This was unusually well schemed. Any other time, she confronts directly." The majority of the respondents reported that Grace targets severely disabled students in wheel chairs. One of her high school teachers reported, "I had to clear my class each day. I had several wheel chairs and this was cumbersome. Administrators would come running to my class every time I signaled. This seemed to reinforce Grace's inappropriate behavior. She would flip computers and throw items at us as we moved."

**Economic challenges.** Taking care of Grace was described as expensive, both at home and at school. According to one high school administrator, "Grace is the most expensive student in the district. We have provided her with a class of her own, she rides a bus by herself to her work program, and she has a highly qualified teacher and a teacher's aide all to herself."

Administrators also reported that they have spent money treating injuries, paying substitute teachers, and repairing destroyed furniture and technology.” An administrator also reported that they have funded an expensive professional crisis management course for their teachers, and the training has to be renewed every year. The school would not have sent any staff for the outsourced training were it not for Grace. The family, too, reported that Grace is expensive to maintain. According to her mother, money has been spent on diagnoses, medication, and replacing destroyed furniture. She also noted that every time Grace experiences a seizure she gets sick soon after. Grace has a high pain tolerance and usually complains when it is too late. This leads to more expensive treatment than would otherwise be required.

**Social skills challenges.** Most of the respondents reported that Grace has deficient social skills. They reported that she invades other people’s conversations, intrudes in personal space while conversing, shares very personal medical and hygiene concerns in public, does not respect boundaries, and asks people embarrassing questions. Grace’s mother reported that “Grace is very particular about her personal space and her personal effects, but she does not respect ours. We are also worried of her safety because she trusts strangers too fast. She hugs them intimately and opens up too quickly. She also asks inappropriate questions to acquaintances and friends.” According to a former teacher’s aide, “Grace asks her peers to allow her to listen to music on their electronics, but she does not give them back when it is time. This usually leads to a behavior tantrum.” According to her summer school teacher, “Grace asks very personal questions. If someone appears like she is pregnant to Grace, she publicly ask them whether they are. This embarrasses many people, especially if they are just acquaintances.”

**Empathy issues.** The majority of the teachers reported that Grace does not empathize with victims of her aggression. According to the teachers, Grace picks her target from vulnerable

students in wheel chairs, mostly the severely disabled. According to her elementary school teacher, she once bit the ear and toe of a child in a wheel chair, making him bleed. The teacher reported, “I walked to the teachers’ lounge and left my two aides to watch the class. When I came back, Grace pointed at the student in a wheel chair and said, ‘I made him cry.’ The student was still bleeding and crying. Grace was not in any way disturbed by his crying or bleeding.” Participants in the focus group reported that Grace once hit a blind autistic kindergartener as they rode the bus to summer school. As one teacher observed, “She was unconcerned that this child was blind and severely disabled. She was completely helpless but this did not bother Grace.”

**Attention deficit.** The majority of the respondents described Grace’s attention span as short. Grace is unusually easy to distract. According to the majority of the teachers, Grace struggles with focusing and is easily distracted by noise, movements, and visuals. According to Grace’s mother, as well as archival records, Grace is diagnosed with AD/HD. Grace gives selective attention to targets, and she pays undivided attention to intrinsically interesting targets. If an activity is not interesting to her, her mother notes that she struggles with paying attention. A speech therapist reported that Grace has challenges attending to tasks. According to her, “It is at times difficult to make Grace visually attend to a task. A lot of energy and time is wasted in redirecting her attention. She gets distracted easily by noise, movement, and visual distractors.” One high school teacher’s aide reported that “too much time is wasted redirecting as opposed to instructing. She is distracted by almost anything.” Her teacher observed, “In my autism class, she would be distracted by repetitive noise from autistic children. I could not do anything about it, but Grace could hardly concentrate. She would yell and scream at them. This at times contributed to her aggressive behavior.”



**Transitioning and avoidance challenges.** All teachers reported that Grace has difficulties transitioning from an interesting activity to a less interesting one. A teacher reported that “After P.E., Grace would refuse to walk to class. She would remain in the gym to wait for another class to join her.” One administrator reported, “Grace likes cheer leaders. After P.E she would remain in the gym hoping they would come next.” Grace was also reported as refusing to walk back to class after visiting the bathroom. A teacher’s aide said, “At times she would sit in the hallway and refuse to move. She would attempt to engage passers-by in conversation.” In the classroom, teachers reported that Grace would refuse to transition from preferred activities to non-preferred ones. According to one high school teacher, “She would plead for more time in the interesting activities. If the time is granted, she would refuse to honor her part of the bargain. She would remain seated in the same position and start engaging teachers in out-of-topic conversations.” According to one teacher’s aide, Grace would use profanity, become aggressive, and induce fear into teachers and teacher’s aides to avoid transitioning.” The majority of the teachers reported that most aggression was related to transitioning. According to them, Grace would run out of class to avoid transitioning. She would also feign sickness or claim to be sleepy.

**Manipulation.** The majority of the respondents indicated that Grace is manipulative. According to her mother, Grace twists other people’s words or statements in a conversation, making them commit to favors. She then “acts up” and starts demanding the purported promises immediately. According to one of her teachers, “She will say anything, put words in your mouth, and distort statements to get favors. She will make you commit to doing something, and the next thing you realize is that Grace is throwing a tantrum about it.” Her 1:1 high school teacher’s aide reported, “Grace will use a language that will make a person sympathize with her situation. She

will then let you do everything for her as she pretends to be unwell.” An administrator also said that Grace asks questions and demands that “No” should not be answer. She claims that hearing “no” annoys her. The administrators noted that this usually limits the way the teacher responds and could lead to a behavior tantrum. A number of teachers reported that Grace also uses the strategy of intimidation and inducing fear to manipulate others. According to one of her teacher’s aides, Grace sometimes makes dishonest statements to manipulate the system.

**Placement and curriculum challenges.** Some teachers complained that having Grace in their class was a misplacement. According to them, a big challenge was getting material to instruct her. Documentary evidence shows that Grace is below forty in her I.Q. Teachers needed materials that are hard to get, especially in secondary school. For this reason, it was hard to make a curriculum for her. Grace was in class with other highly functioning students. The majority of them reported that they had to plan for instructions twice. One for Grace and one for the rest of the class. A middle school teacher reported, “I had 14 other students who were cognitively high compared to Grace. She looked lost as far as academics were concerned. Other students would listen to me teach and would write short notes. They would participate in group activities. Grace could hardly write her name. She would engage in inappropriate behavior to get attention. It was also extremely difficult to find material for her.” Similar challenges were reported by a high school teacher. “Grace was in my class by mistake. She had no idea what was going on academically. She could not read while all my other nine students could. They could manipulate calculators and do some budgeting. I had nothing for Grace. She intimidated other students in her efforts to get attention, which would then disrupt my class.”

**Sleeping pattern challenges.** Grace’s family and teachers reported that Grace had an irregular sleeping pattern. One high school teacher reported, “Grace asked to sleep a lot.

Sometimes she would do so first thing in the morning. At times she looked very tired. Some other times she would ask to sleep less than five minutes before the end of the day. She would become irrational when I told her that it was time to go home.” According to her elementary school teacher, “She would ask to sleep the first thing in the morning. Other times it would be during the day. It was irregular. We would always let her sleep to avoid tantrums.” A former teacher’s aide also reported that Grace would wake up in the middle of sleep and become violent without provocation. She believed that this may have been caused by some seizure effect or a bad dream. Her 1:10 high school teacher observed, “She asked to sleep a lot. We did not have anywhere for her to sleep. I let her use the changing room but she would be disrupted when students needed to be changed. This would often lead to behavior challenges.” Her 1:15 middle school teacher reported, “She was really sleepy. I thought it was because of medication. If we stopped her from sleeping she would turn violent.” Her mother reported that “Grace sometimes wakes up in the wee hours of the night when everybody else in the family is sleeping.”

**Anger management challenges.** Family and teachers also described Grace as easily irritable and quick to anger. They noted that while she easily loses her temper over simple things, it takes a long time for her to calm down. Most respondents described her as illogical when annoyed. According to her mother, “She may be watching a movie on a DVD and after realizing it is scratched, she would be annoyed with everyone.” Her mother noted too that the escalation is usually too fast that there is no time for intervention. The majority of the respondents observed that Grace could change from a happy mode to an irritated one with no provocation. According to her most recent bus driver, “Grace would be easily irritated if the bus was late. She does not like waiting. She would also get angry after chatting with the bus aide if the bus aide turned away from Grace to attend to another child.” Her summer school teacher described her as

illogically easily angered. According to her, “This minute she would be laughing loudly and all of a sudden she would turn around and start cussing and hitting.”

**Seizures and other health challenges.** Archival records indicate that Grace has a seizure disorder. According to her mother, “Grace experienced her first seizure at the age of twenty months. She experienced three consecutive seizures in less than twenty four hours. After the first seizure episodes, Grace’s early life was dominated by frequent seizures. Grace would always get sick shortly after the seizures. It seemed like the seizures affected her immunity. The seizures were, however, controlled by medication. After beginning medication, we didn’t experience a single seizure episode for ten years. Unfortunately, they have started striking again.” Records indicate that Grace has once experienced nine consecutive seizures. Grace’s mother also reported that Grace recently was diagnosed with diabetes. According to her current teacher’s aide, Grace’s blood sugar level affects her behavior. She reported that when Grace’s sugar level is high, the chances of exhibiting behavior tantrums are usually higher. Her school nurse made the same observation. Managing Grace’s sugar level is difficult due to her low cognitive abilities as noted by her mother. She does not always eat what is appropriate.

**Anxiety and obsession challenges.** Archival records indicate that Grace is diagnosed with anxiety disorder. Teachers and family described Grace as a student with anxiety and obsessive tendencies. According to her mother, Grace is obsessed with food, and she worries too much about upcoming events, including, but not limited to, holidays, family birthdays, and wedding ceremonies. As her mother reported, “She obsesses with topics of interest. She asks the same questions over and over again. No matter how many times you answer her, she will keep on asking and asking. This has led to behavior tantrums several times.” Her mother also reported that Grace gets overly anxious in crowded places due to her anxiety disorder. Her summer school

teacher reported that “Grace gets obsessed with people and objects. Currently, she is obsessed with her teacher and her teacher’s car. She talks about them over and over again. She has given a name and human properties to the teacher’s car.” Her elementary school teacher reported that Grace was obsessed with her music teacher. Due to a high degree of obsession Grace’s behavior was effectively controlled by using a visit to the teacher as a positive reinforcement.

**Proprioception.** According to her occupational therapist, Grace has challenges recognizing her position in space. The therapist reported that when Grace walks in the hallway, she walks too close to the wall to avoid falling. She is worried about falling because she cannot effectively sense her position in space. Grace’s current teacher’s aide mentioned that Grace has fallen several times after missing steps on the bus. Related to this, the occupational therapists reported, “Normally, sensations from joints, muscles, and connective tissues lead to body awareness. Evidently, this is delayed in Grace’s body. Interventions are necessary to help her overcome this.” Grace’s parents reported that when Grace was young she regularly lost her balance. Some teachers reported that it is common for Grace to lose balance when playing or walking. Medical records indicate that when Grace was young she frequently lost her balance.

**Administrative challenges.** Current and former administrators described Grace as the most challenging student they have ever served. According to the administrators, it has been a challenge balancing Grace’s needs, legal requirements, and administrative logistics. One administrator reported, “I know I am obliged to place Grace in the least restrictive environment. According to her I.E.P., this includes a half school day and a one-on-one teacher’s aide. Unfortunately, not very many people want to work for half days, especially when subjected to Graces aggression.” According to the administrator, it is hard to get someone willing to work with Grace, given her conditions. At the same time, a teacher’s aide hired to work with Grace has

every right to ask to be transferred to another assignment. She can technically work for a week and demand a safe environment according to the administrator. “She cannot be fired or be forced to work with Grace,” he reported. Another administrator lamented that changing placement and accommodating teachers’ needs has been hard in the past. According to her, “When Grace becomes violent in a teacher’s class, the teachers demand that she be removed immediately. This is not always possible, but some teachers are not understanding. Some decisions have to be made in the superintendent’s office. Sometimes meetings with the superintendent are needed because it might be necessary for committees to be formed.”

**Experiential challenges.** Throughout this research, teachers, support staff, and administrators reported that they did not have any prior experience serving a child with Landau Kleffner Syndrome. This put many of them in a difficult situation, especially during collaboration. According to one high school teacher, “We would consult one another but to no avail; none of us had solutions to some of Grace’s challenges, and our administrators were no better. We had to rely on trial and error.” In this research, only one teacher reported to have experienced similar challenging behaviors. According to her, she preferred the previous student to Grace. She reported, “The main difference between Grace and the other student was cognition. The other student was cognitively higher and logical. I could reason with her. She would also participate in activities with other students. Grace could barely write her name, and I could never reason with her. She was illogical. She reasoned like a three year old. She was unusually strong and aggressive, which made her more dangerous.” Grace’s middle school principal reported, “I have taught for more than twenty years, and I have never experienced a child with behavior and language challenges like those of Grace. I am almost certain I never will again.”

**Other family challenges.** Records indicate that Grace has two older brothers. Grace's mother reports that she appreciates the positive concern that all family members have towards Grace. However, she reports that the relationship between Grace's brothers and her can be a challenge at times. She reported, "I sometimes disagree with my husband on many issues. This includes cause of behavior change and appropriate interventions. The biggest source of conflict is with the way my sons relate to Grace. They sometimes forget the disability and look at her as a typical attention-seeking younger sister. They forget that she must be handled in a certain way or she would escalate to a full blown tantrum." Grace's disability has also limited the degree with which the family can participate in social activities and interact with the rest of the community. According to Grace's mother, most of their events involve close family members. The majority of them appreciate Grace's behavior and she is also free with them. According to her mother "We do not interact a lot with other families during special holidays. We normally do things as a family. I am sure this would have been a big challenge if we were doing things differently. We would find it hard to interact with other families given Graces anxiety and behavior challenges."

**Summary of challenges.** This section summarizes the challenges experienced by family, teachers, and support staff serving a child with Landau Kleffner Syndrome. Grace's challenges thematically fell in four main categories: economic, speech and language, social skill deficiency, and inability to effectively control body muscles. Grace was described as expensive by both family and school. The school system has spent a lot of money hiring a highly qualified teacher and a teacher's aide for her, providing her with a one-on-one class, replacing destroyed property, and hiring substitutes when teachers are injured. Training staff and treating injured students and teachers were also described as expensive. The family reported that a lot of resources have been spent to diagnose and understand Grace's disability, to treat her when she is sick, and to replace

broken property. Speech and language challenges were also mentioned to have inhibited effective communication both at home and at school. She is unable to express herself and process spoken language effectively. Grace is also verbally and physically aggressive to peers and adults, and she sometimes destroys property and occasionally attempts to hurt herself.

Respondents reported that Grace has challenges with attention and needs frequent redirection to remain focused. She is easily distracted by noises and movements. Too much time is wasted redirecting her to stay on task. On the same note, she has challenges transitioning, and she evades work at times. Grace is also manipulative and will use manipulative skills to control the system. Other challenges include an inability to effectively control muscles, lack of experience by educators, and curriculum and placement challenges.

### **Strategies and Interventions**

This section presents responses to the second research question which sought to investigate and document strategies applied to solve the above challenges. The research question was, “What strategies were applied by family, teachers and support staff to address challenges experienced while serving a child with Landau Kleffner Syndrome?” Based on their responses, the following major themes emerged.

**Accurate data collection.** The majority of participants reported that effective interventions are dependent on accurate data collection. According to the participants, information on how frequently a behavior occurs and about the antecedent events, triggers, and consequences of behavior must be accurately documented. One teacher’s aide reported, “We collect data when behavior is taking place. Waiting until end of school day is ineffective. This is subject to forgetting.” One high school administrator reported “You cannot plan for any intervention if you do not know the triggers of a behavior, the setting of events, and the



frequency of the behavior. You also need to determine why the student is behaving that way. They do not just act up; rather, they communicate with the behavior and they aim at achieving something.” Grace’s mother also reported that she sent data to schools on a modified form that includes information about Grace’s blood sugar level, sleep, or any other physiological concerns. She reported, “I fill her blood sugar level, sleep issues, physical complains, general mood, verbal behavior and physical behavior.”

**Rapport building and positive working relationships.** All respondents were in agreement that educators should cultivate a good working relationship with Grace and her family. According one middle school administrator, “It is very important that Grace trusts her teachers and teacher’s aides. If Grace does not trust a member of our staff, she is anxious and gets nervous.” Another administrator noted, “We encourage teachers to develop a positive working relationship with both the family and student. In the past we have seen increased behavior challenges when Grace’s personality conflicted with that of an aide.” Administrators also reported that they occasionally visit Grace to cultivate a relationship. Her summer school teacher reported, “It was challenging working with Grace the first year. She never understood me and I didn’t understand her. I talked to her former teachers and family. I learned that she likes talking about dogs, her family, and her teacher. I engaged her in these topics repeatedly. I brought my dog to school one day, and I let her spend time with it. Our interaction has never been the same since.” Finally, Grace’s 1:6 teachers commented that “Anxiety is defeated by a good working rapport between the student and the teacher.”

**Positive behavior reinforcement (token system).** All respondents reported that Grace lacks intrinsic motivation to participate in school work. A token system was reported to have reinforced positivity in Grace throughout her school life. According to one high school

administrator, “Grace needs immediate realistic rewards for motivation. In her class, there is a transparent tube with distinct markings. It has four marks of different colors. In this reward meter, teachers insert light colored balls (tokens) every time Grace makes an appropriate choice. If she earns enough balls, she earns free time with her iPad. As the tokens accumulate, she earns more valuable items like listening to music, going for a walk, or Skyping.” Grace’s mother observed that “The token system has worked miracles for us at home and at school. Grace is able to Skype her teacher at 5 o’clock every evening if she has an incident-free day at school. Since she leaves school at twelve o’clock, she has conduct herself well at home between then and her 5 o’clock appointment with her teacher. This motivates her to behave well after school.” Teachers also reported that Grace responds positively to verbal praise. However, they noted that she gets accustomed to rewards quickly, so inventing more rewards is necessary.

**Speech and language interventions.** According to her mother, the family requested that the family doctor recommend early speech intervention when Grace was twenty months old. She reported that this helped Grace recover her speech by age three. All her past and present individualized education plans require 100 minutes of speech per week. According to her current speech therapist, Grace has worked and progressed well in her general, social, and pragmatic language skills. She reported using language modeling, language mapping, and repetition and redundancy as strategies. The speech therapist reported, “I like modeling age-appropriate speech. I rephrase what Grace says, making it age appropriate. Grace will normally speak like a three year old. We have always encouraged her to speak at an age appropriate language. I also build on Grace’s topic to achieve my objectives.” Grace’s mother also reported that Grace has a one-hour speech session from a private service provider each weekend.

**Visual aids.** Records indicate that Grace has difficulty understanding and expressing spoken language. Teachers observed that visual aides have been used to counter the inability to process language effectively. According to Grace’s speech therapist, “Where verbal instructions are used, they should be heavily supported by visual illustration.” An elementary teacher supported this. “Grace has incredible visual skills. In contrast she does not effectively comprehend spoken language. She sometimes exhibits behavior tantrums when frustrated by verbal communication. I strongly made use of visual supported teaching strategies.” According to her mother, “Grace has very strong visual abilities. I encourage everybody to take advantage of this during instruction. She is able to see and remember very fine details in an object or a picture. She has good visual memory too. We always visually illustrate as we talk to her.” A teacher’s assistant reported, “Grace’s classroom schedule is visual, her social stories heavily illustrated with pictures, and her class is demarcated with colored tapes. We have utilized the board maker computer software to identify visual icons for most common words.” Grace’s behavior plan also recommends use of visual cues and illustrations as much as practically possible.

**Video modeling.** Teachers reported that video modeling and video self-modeling have been used as a strategy in class. A teacher’s aide reported that these two modeling approaches have helped Grace learn both social and functional skills. We let Grace watch a clip of an adult successfully performing skill. We also let her watch herself doing the same at times.” Video self-modeling was also reported to have been used to teach appropriate behavior after a major tantrum. A teacher’s aide reported that “Every time Grace has calmed down after a tantrum, we have a learning moment. We review the inappropriate behavior choices and discuss replacement behaviors. During such times, video self-modeling is an effective strategy.”

**Surveillance cameras.** Administrators and teachers reported that there is a surveillance camera installed in Grace's class. After exhibiting a behavior tantrum, the video is reviewed for a behavior analysis. According to one administrator, "The camera can be reviewed many different times, and we can also use it for training."

**Shortened school day.** Archival records indicate that Grace's school day is shortened as a behavior intervention strategy. Her school day starts at 7:30 a.m. and ends at noon. A high school administrator reported that a special programming conference was held, and the I.E.P. committee opted to cut Grace's day in half following excessive episodes in the afternoons. According to one of her teacher's aides, "We used to have behavior tantrums in the afternoons mostly. It was also observed that Grace is usually active in the mornings as compared to afternoons. This is why we opted to have her here in the mornings and not afternoon." An administrator reported that there are intentions to increase Grace's time at school contingent upon continual behavioral improvements. The administrator also reported that there has been a drastic reduction of tantrums. According to her, "Data is continuously being collected to help review her school day in the near future. If data is favorable, the length of her time at school will be adjusted incrementally."

**Denying audience during behavior episodes.** The majority of the teachers reported that Grace is more violent when she has an audience. According to her teacher's aide, "When Grace becomes violent, she looks around for an audience. We discourage audience participation, and we deny her eye contact when she is making inappropriate choices." According to Grace's mother, "Grace hates being ignored. She destroys more property and hits and kicks more aggressively if there is a third party watching. We have learned to pay no attention in such situations. However, we give her extra attention when she makes appropriate choices." The

administrators also observed that watching Grace in moments of aggression reinforces the wrong behavior. They recommended that teachers give her attention during positive behavior.

**Slow instruction pace.** Records indicate that Grace is cognitively delayed. As aforementioned, her I.Q. is below forty. Her cognitive abilities are described by teachers as that of a pre-kindergarten child. According to her teachers, this makes her information processing slow. The majority of the teachers recommended a slow pace of instruction. According to them, “This gives Grace an opportunity to process her information slowly given her delayed cognitive abilities.” According to her tenth grade teacher, “Grace benefits from a slow instructional pace. She does not need to be hurried. We do not want to frustrate her.” Her 1:6 teacher concurred. Another high school teacher observed, “Grace needs not only a long wait time, but also a slow instructional pace, too. This gives her an opportunity to process information efficiently given her intellectual disability.”

**Repetition and redundancy.** The majority of the teachers recommended repetition and redundancy as an effective teaching strategy for Grace. Her 1:6 teacher repeats the same information many times until it is mastered. She may also engage her in the same task until the concept is mastered. Grace’s mother also recommended repetition but warned that it should be done with caution. “I have always repeated things for Grace to ensure she understands. She has a very poor short-term memory but an incredible long-term memory. We have to look for a strategy to send information to the long term memory. Unfortunately, Grace hates monotony, and she is easily irritable. This can lead to a tantrum.” Similarly, Grace’s elementary teacher recommended repetition and redundancy but warned that it should be done with wit. She stated that Grace has always reacted negatively to sameness and monotony.

**Discrete trial.** Archival records indicate that Grace is diagnosed with an anxiety disorder. She is also described in her psychological reviews as a child with attention deficit challenges. Grace's mother reported that Grace becomes anxious when overwhelmed with multiple objects in a task. This negatively affects her concentration and behavior. According to her 1:10 high school teachers, "Grace should definitely not be overwhelmed with choices. Too many choices are disruptive. If she is, for example, required to compare and contrast several items, she should be provided with two first. After comparing and contrasting the two, one should be substituted and the process should be repeated." According to her speech therapist, "If Grace is given many items to compare or contrast at once, she gets overwhelmed. She starts asking questions about the items but outside the task objective. The best thing is to give her two items at a time and then replace each as the activity progresses."

**One-on-one teacher's aides.** Grace's I.E.P. indicates that she needs a one-on-one teacher aid throughout her school day. According to Grace's mother, Grace needs concentrated help in everything. She needs to be redirected, observed in case of seizures, and motivated during moments of laxity. In situations where some administrators have defied the I.E.P. requirement, increased behavior tantrums result. A school administrator commented, "We always try to match Grace's personality with that of the teacher's aide. When hiring, we look for certain qualities. In the past, an aide invaded Grace's personal space, which regularly led to behavior escalation. She did not have mutual respect for her. She discussed her with other adults in her presence which led to mistrust."

**Being proactive.** The majority of the teachers and administrators strongly advocated for proactivity as an effective way of addressing behavior challenges. According to Grace's middle school administrator, "We do not want to put out fires. We want to prevent them in the first

place. Most of her episodes can be prevented or intervention can take place in a timely manner before escalation if teachers are proactive.” According to Grace’s 1:10 teacher, “Teachers should treat Grace as potentially irritable all the time. They should study her visual and body language continuously. The raising of her voice, shaking of hands, and/or being antagonistic and hitting the table are major warning that there is a potential escalation.” The majority of the teachers reported that they succeeded in working with Grace, mainly by being proactive. According to them, this helped to modify the immediate environment and, at times, to remove fragile students before they are in danger. Behavior plans name the following setting events for teacher to watch: fatigue, lack of sleep, physiological changes in Grace’s body, and changes in medication. Behavior plans recommend modification of environment to prevent escalation.

**Use of social stories.** Archival records indicate that social stories have been used successfully throughout Grace’s school life. Grace’s behavior plan requires that a social story be regularly read to remind her of expectations. According to her current teacher’s aide, “We read a social story before going to the restroom, leaving for home, and doing an activity on the work table to remind Grace of her expectations.” According to Grace’s behavior plan, the social stories should be illustrated with visual icons to ease Grace’s understanding. The stories should also be short, precise, and simple in language.

**Structure and predictable routine.** Grace is diagnosed with an anxiety disorder according to her current psychological review. Her behavior plan indicates that she becomes anxious and disoriented when confronted with an abrupt change of routine. Her mother supported this. She reported, “Grace does not like being surprised with changes of routine and structure. If a change is expected, she needs to be prepared in advance.” Most teachers observed that Grace becomes excessively anxious when a routine change takes place by surprise. This

includes going home early due to inclement weather, cancelling of school, check out for medical reasons, and fire and tornado drills. Administrators reported that Grace's classroom structure is maintained at a fairly constant structure. She reported that "Grace's classroom is structured and demarcated with specific sections designed for particular usages. The sections which are distinctly marked with colored tapes are the dining table, activity table, bed area, living room, and teacher's desk. There is a place for everything." He noted that the organizational structure has greatly reduced Grace's behavior tantrums.

**Collaboration and teamwork.** All respondents reported that collaboration and team work have played a great role in serving Grace. According to Grace's teacher, "Nobody can do this alone. We need one another to serve Grace sufficiently. We need the behavior analyst, the psychologist, the occupational therapist, and the speech therapist to address their areas of specialty among others. It is a team, not many individuals." High School administrators also observed that collaboration is important. They describe Grace as a complex student and a "school unto herself." One of them reported, "We always aspire to bring everybody's views on board. We believe that everyone's opinion matters. In most of our I.E.P. committee meetings, we ensure every member is invited. Our policy is that everyone matters."

**Student advocacy.** Advocacy is a major theme that emerged in this research. Teachers commended Grace's family for their advocacy. It was noted by some teachers that Grace would not be in the school system if her parents were not aggressive with their teaching methods. Grace's mother reported that there has been unscrupulous administrators who have attempted to access Grace's medical records without her permission. Another one would try to manipulate the I.E.P. committee. According to Grace's mother, at one time "Grace was about to be referred to an institution for people with mental challenges. This would have removed her from the school



system against my wishes. I contacted a neurologist and developmental disability specialist for an assessment. They returned with a diagnosis of Landau Kleffner Syndrome. The assessment was expensive, but I had to advocate for Grace.” Grace’s mother believed that this stopped Grace from being removed from the school system. “They could not refer her since what the diagnoses returned was a communication disorder and not a mental sickness.” Grace’s 1:10 high school teacher also reported that she advocated for Grace to the school administrators. She stated, “Before Grace reported to high school, I received her thick folder from junior high school. It had several indicators of a challenging behavior. I brought it to the administration’s attention. When Grace finally reported to senior high school, the administration was fairly prepared to serve her.” Most teachers reported that they advocated for Grace’s needs to behavior analysts, speech therapists, occupational therapists, psychologists, and administrators accordingly.

**Raising of expectations.** While Grace is cognitively impaired, the majority of respondents reported that she needs challenging activities in class. When the bar is set too low, Grace takes advantage of this to evade work. According to her teacher, “Grace is able to manipulate digital cameras, access priority music on YouTube, and manipulate Skype. These are challenging tasks that demonstrate how capable she is. There is no reason as to why she should not be challenged with other activities.” Grace’s current teacher’s aide reported, “If we really want Grace to be independent, we must set high standards. We need to help her succeed. We must remind ourselves that we are not caretakers but educators.” One middle school administrator observed that “Grace knows far much more than we think she does. She needs challenging tasks with increased motivation.” The majority of her teachers supported the idea of raising expectations with minimal help and increased motivation.

**Educating parents.** Most teachers and administrators reported that occasionally there is a breakdown in communication between schools and home. They believed that parents need to be educated on their expectations of collaboration. As one high school teacher observed, “We make parents sign a lot of paperwork without effectively explaining to them the implication of their signatures. Sometimes they do not care; they want to leave the meeting as soon as possible. They then learn of implications later.” As one high school administrator explained, “We need to educate parents on transition opportunities for their children after school. We also need to educate them about changing laws.” Another senior high school teacher reported that she educated Grace’s parents on the importance of signing state social security paperwork. This teacher said, “I know there is usually a long waiting list before a child with a disability benefits from the social security system. I learned the parents were ignorant of it, so I brought it to their attention. They signed the paperwork, and now they are in the system.”

**Sensory diet and occupational therapies.** Archival records indicate that Grace has challenges maintaining balance and sensing her position in space. According to some teachers, this has led to several accidents and injuries when running or playing. According to Grace’s occupational therapist, her proprioceptive awareness is atypically delayed. In order to address her proprioceptive challenges, her occupational therapist designed a sensory diet. The therapist stated, “Proprioceptive input, which refers to sensations from joints, muscles, and connective tissues, lead to body awareness and can be obtained via several means. These include putting pressure on joints by pushing, pulling, and lifting one’s own weight or other weights.” According to Grace’s teacher’s aide, Grace’s sensory diet includes a swing, a big bouncing ball, a weight jacket, and some wrist weights. The teacher’s aide noticed that “Grace sits on a bouncing ball or uses a swing the first five minutes of her arrival in school. While doing her

school work on the work table, she wears her weight jacket for the length of time of the activity. She also wears her wrist weights when writing.” This tends to regulate her alertness and minimizes disruptive sensory seeking.

**Use of work system strategy.** According to one of her high school teacher’s aides, Grace is not independent and lacks self-motivation in most tasks, but she is usually very proud of her independent accomplishments. Similarly, her mother reported that Grace is proud of her final products. Some teachers reported that this trait has been utilized in a teaching technique known as the “work system.” Grace’s teacher’s aide reported,

With work systems, we give Grace tasks that have several discrete steps to accomplish.

The major task is usually broken down into small chunks or steps. All tasks are illustrated by some pictorial directions. An example is packaging jewelry. This activity has four to six steps. In the first step, Grace walks and brings a box with jewelry to the table as the first step, she opens the box and counts five empty plastic sacks as the second step, she counts five pieces of jewelry as the third step, puts them in each sack as the fourth step, puts them back to box and returns them to where she got them as the fifth and sixth steps.

The teacher’s aide reported that Grace is positively reinforced for each step.

**Seizure protocol.** Grace’s family has collaborated with schools to address challenges related to seizures. This is done through establishing seizure protocol. Archival records indicate that sharing has been done yearly with doctors, renewing the seizure protocol annually. Based on the seizure protocol records reviewed, information about family doctors and contacts are provided. Teachers are instructed on how to assist Grace effectively during a seizure. For example, if the seizure exceeds four minutes in duration, the teachers are required to inform the nurse and call an ambulance. The protocol also describes the common type of seizure Grace

usually experiences, mainly head drop seizures, which last 1-2 seconds. Grace sometimes experiences partial atonic seizures, which last 1-2 minutes. According to the protocol, Grace may rest in the nurse's office following a seizure, and she may return to class after resting. A seizure record must be sent home with the student. Seizure protocol requires teachers to turn students on the side and keep the room quite during an episode.

**Summary of strategies and intervention.** To address Grace's behavioral, speech, social, and academic challenges, several strategies have been devised. One strategy is shortening her school day. Grace's day starts at 7:30 a.m. and ends at noon. The school has also hired a speech therapist who assesses Grace's delayed speech and language challenges. During the weekends, Grace participates in one-hour interventions via a private speech therapist. She receives 100 minutes of speech therapy every week. Additionally, teachers have modified their instructions to fit Grace's low cognition and attention challenges. They use a slow instructional pace and give Grace a long wait time. Teachers also collect timely and accurate data on behavior to help plan for additional intervention methods. Video modeling and self-modeling have been used to teach Grace functional and social skills. They are reviewed for her several times until she masters the concept under study. In order to address Grace's anxiety, family reported that they avoid crowded places. For example, they do their shopping at night when grocery shops are not very crowded. Also, Grace does not attend pep rallies school, nor does she attend parades. To address Grace's seizures and medical challenges, the family has shared her seizure protocol with the school's nurse. Grace enjoys a sensory diet in addition to services from an occupational therapist. This helps address motor control challenges. The sensory diet includes a swing, a bouncing ball, weight jacket, and a wrist weight.

## **Concerns**

This section addresses concerns that family, administrators, teachers, and supportive staff have based on their lived experiences serving a child with Landau Kleffner Syndrome. Research Question 3 sought to document the concerns expressed by family, teachers, support staff, and administrators as they served Grace. The research questions is, “What are the concerns that family, teachers, administrators, and support staff have in their experiences serving a child with the Landau Kleffner Syndrome?”

**Use of digital surveillance cameras.** As noted in the strategy section, a digital camera was installed in Grace’s class to help investigate and analyze triggers and settings that prompted Grace’s aggression. The aim was to analyze the footage after each episode. There were some complaints from Grace’s teacher’s aide that the intended use of the digital surveillance camera was abused. According to her, the teacher and the teacher’s aide in that class were subjected to unfair digital supervision unlike other employees. She reported, “There is an incidence when Grace became physically aggressive against us. We physically restrained her for our safety. Unfortunately, we had never received any training and neither did we receive any after the incident. We were reprimanded afterward.” According to her, the fear of being reprimanded led to them taking a hands-off approach in managing Grace’s behavior. As a result, her behavior worsened. According to the teacher and teacher’s aide, “Both of us had, at one point, to visit a doctor’s office with injuries.” The family also had some of the same concerns. As Grace’s mother said, “We feel the camera investigated the teacher and her aide and not Grace as objectively intended. Their intervention strategies were the ones being monitored not behavior triggers and setting.” In her opinion, it was a mistake to have installed the camera. Grace was eventually suspended from school because the teacher and teacher’s aide lost classroom authority.

**Temporary solutions to problems.** Teachers were concerned that Grace remained a challenge despite being in the same district for over fourteen years. The majority of the teachers felt that the school district did not seek long-term solutions for Grace's challenges. As one teacher reported, "The school hired an external behavior analyst. She would pop into class and observe Grace for a few minutes. She was never there for consultation. She wrote e-mails instead of communicating face-to-face most of the time." A middle school teacher reported, "When a behavior analyst walks into class, she immediately changes the classroom dynamic. Grace starts interacting with her and mostly does not exhibit her regular challenging behavior. She should be observed in many different settings and for a longer time. This cannot be effectively done by a visiting analyst working across buildings." One teacher observed that "The district dressed the wound instead of stitching it." Teachers also complained that Grace's change of placement was random and uncoordinated. According to them, when Grace progressed from junior high school to senior high school, she was placed with nine other students without any evidence supporting that her behavior had improved. She had been in a class of her own in junior high school. She was violent and had to be placed back in her own class after showing signs that including her in a classroom with nine other students was the wrong decision.

**Untimely/insufficient training.** While the school provided access to a course on professional crisis management, some teachers felt that this came a little too late. Records indicate that the first training took place when Grace was already in twelfth grade. According to the majority of the teachers, the training should have been provided earlier. One teacher reported, "I think it was dangerous to have waited until a major episode occurred before offering any training. The district endangered our lives by exposing us to an aggressive student with no training." Another teacher's aide reported, "I really learned a lot from P.C.M. training. I wish I

had known all of that when I worked with her. I would not have suffered a bloody nose and lost two pairs of spectacles.” A former 1:1 teacher’s aide complained that she was not trained when other teachers and aides were trained. This was despite her being the current 1:1 teacher’s aide. She reported, “They took my teacher for training and left me out. This did not make sense because some of the strategies applied in the PCM program requires two people to work together as they physically immobilize the student.”

**Insufficient support from administrators.** Some teachers thought that administrators were not supportive enough. One teacher reported,

My class had fourteen other students of diverse abilities. We were placed in an isolated class in the far end of the building. My class had students with major behavioral challenges. Some had been to jail at least once. Grace was a behavior challenge and cognitively very low. She did not really care about classroom regulations, unlike the others. She made my classroom management a ‘nightmare.’ I consulted my principal for help but I was disappointed. She told me that I am the 1:15 teacher, and I needed to think outside the box. She had told me earlier not to be sending my behaviorally challenged students to her office because the office did not know what to do with them.

The teacher also reported that Grace did not have a one-on-one support despite her I.E.P. requiring her to have one. Other teachers felt that the administration would have done more, especially advocate for more effective behavior analysis support.

**Foregone opportunity for social skills development.** Teachers acknowledged that having Grace in a class of her own was a positive move. However, they were concerned that Grace was denied an opportunity to learn how to make friends. Grace’s elementary teacher reported, “We completely denied her opportunities to socialize. She is soon exiting the school

system. It is very unfortunate that she is joining the society without these skills. We addressed the behavioral challenges but ignored the social skills challenges.” The majority of the teachers felt that Grace will find it extremely hard to fit in with society. They were concerned that more energy and resources were spent on maintaining the status quo than improving it. One of Grace’s 1:1 teacher’s aides regretted that no peer tutor was allocated to Grace despite continued advocacy. According to this aide, “We repeatedly made requests for peer tutors. The administrators kept promising, but this never happened for the three years.” Other teachers thought that Grace should have been integrated with typical peers in some classes. They gave an example of agriculture. According to them, Grace likes animals and the greenhouse. This would have improved her social skills as she interacted with typical peers.

**Role of the teacher’s aide during therapy sessions.** Both occupational and speech and language therapists raised some concerns about the role of teacher’s aides during therapy sessions. They lamented that the aide redirected students when they were giving them therapy sessions. In their opinion, this took authority away from them. They also felt that it resurrected negative classroom dynamics that were there before therapists came. This made Grace defiant. According to the speech therapist, “When working with Grace, I prefer to be the only authority. I do not like it when I ask Grace to perform an activity and the teacher’s aide interjects before Grace can respond.” The therapist further noted, “I cannot redirect the aide in front of the student. I work across buildings and rarely meet with the aide in absence of the student.” Grace’s speech therapist had similar concerns. She expressed, “I do not appreciate it when I ask Grace a question and then a teacher’s aide rephrases it for her. This makes the question lose context. I want to be the only authority in the classroom during my therapy session.” She preferred that the aide remain quiet throughout the session unless invited by the therapist to participate.



**Against generalization.** Parents and teachers observed that each child with a disability is unique. Some teachers were concerned that the school administration does not seem to appreciate this. According to teachers, some expectations from administrators are not very realistic. One teacher reported, “[Administrators] are guided by behavior theories, but this is not what happens on the ground.” The majority of the teachers noted that just because a training has taken place it does not mean the children with behavior challenges will be transformed overnight. As one teacher reported, “Although I appreciate the P.C.M. training, I have found that most of its techniques do not apply to Grace. She is cognitively too low to respond positively to reinforcement, and at times she enjoys being physically restrained for her own sensation seeking. In that case, the P.C.M. training does not work for Grace the way it works for other students. Unfortunately, most administrators and behavior analysts do not appreciate this. They want us to deliver as the theories promise.”

Regarding generalization, Grace’s family had some concerns. Grace’s mother states, “I do not appreciate a behavior analyst walking to Grace’s class, observing her for fifteen minutes, and then generalizing her behavior. I would prefer that Grace is observed longer and in many settings.” On the same note, Grace’s parents preferred that any expert purporting to address Grace’s challenges should talk to her parents first. She was wary of experts intervening with Grace’s challenges without consulting her parents first. She felt that family input is important to the whole evaluation.

**Dishonest administrators.** Grace’s family raised concerns that some of the administrators were dishonest. They were particularly offended by one administrator, who they accused of attempting to access Grace’s medical records without family consent. The family also lamented about a special education administrator who often came to meetings with preconceived

notions. He would then manipulate the I.E.P. committee to endorse them. Regarding this, Grace's mother lamented, "What is the need of a meeting if my views will not change anything? This is my child with disability; I should have the greatest say." Grace's mother reported that at one time the administrator attempted to manipulate the I.E.P. committee to refer Grace to an institution serving individuals with mental challenges. To save Grace from being forced out of the school system, the family financed an expensive assessment that returned with the diagnosis of Landau Kleffner Syndrome. "With Landau Kleffner Syndrome diagnosis, a communication disorder, the district had to continue serving Grace as provided by law," she reported.

**Grace's future placement.** The majority of the people interviewed were quite concerned about Grace's future after exiting the school system. They were worried that she is too aggressive for any institution around to admit her. They also noted that she was too aggressive for her aging parents. Teachers were also concerned that Grace's family took too long to complete the necessary state social security paper work that would fund Grace's staffing. They reported that long waiting lists exist for people needing to benefit from such funding. Grace's mother was equally concerned about Grace's future. Her mother states, "I have always been in a state of denial. I have never wanted my child to be taken care of by anybody else. Unfortunately, reality is sinking in. I have recently resigned from my job on medical grounds. Grace has grown bigger and stronger but remains illogical when annoyed. Soon, I will be unable to handle her challenging behaviors. Grace has to go somewhere but I do not know where. We do not have very many institutions with facilities and staff trained to serve Grace's needs." Grace's parents also worried that some institutions might use medication to manage Grace's violent behavior. She intimated, "I do not want medicine used to subdue Grace. I have seen it before, and I do not have the heart to see her in that state again."

**Inconsistencies by support staff.** The behavior analysts advise teachers to be consistent when serving children with severe disabilities. However, the teachers lamented that the analysts do not always model that. The analysts would bribe the students to win their favors. One teacher reported that she saw Grace physically assault the behavior analyst outside the school bus. The behavior analyst then gave Grace some candy, after which Grace stopped being violent. According to the teacher, this reinforced the wrong behavior. She stated, “Our behavior analyst has always complained that we bribe Grace with rewards against the principals of behavior management and positive reinforcement. Truly, we would take her for a walk, paint her fingers, and let her listen to music after a violent behavior in the past. By this time we had not been trained, but we are now trained. On the same note, Grace is cognitively too impaired to understand positive reinforcement. Sometimes we just wanted other students to be safe.” One teacher wondered, “What is the difference between me and the behavior analyst who rewarded hitting with a bag of candy?” In conclusion, teachers noticed some inconsistencies between what the behavior analyst said and what she did. The teachers wished the analysts would model the appropriate behavior.

**Summary of concerns.** This part summarizes the family’s, teachers’, and administrators’ concerns serving a child with the Landau Kleffner Syndrome. The family lamented unsupportive and dishonest administrators. They believed that one of them attempted to access Grace’s medical records without their permission. They also reported that an administrator often came to meetings with premeditated decisions. He would then manipulate the I.E.P. committee to endorse it. Grace’s teachers and family were concerned about what would happen to Grace upon exiting one school and transitioning to another. They believe she is too aggressive to continue staying with parents. She is also too aggressive for many service providers. Teachers were finally

concerned that Grace does not have appropriate friendship initiation and socialization skills. They thought that this would prove a big challenge when Grace joins the general community upon completion of school. There were also some concerns that a behavior analyst gave Grace a reward to stop her from physically assaulting her. This, the teachers reported, was against appropriate response measures.

## **V. Chapter Five: Summary, Conclusions, Implications, and Recommendations**

The purpose of this qualitative research study was to investigate and document perceptions, experiences, challenges, strategies, and concerns of families, educators, and support staff serving a child with Landau Kleffner Syndrome (Yin, 2009). Landau Kleffner Syndrome is a rare neurological disorder that negatively affects expressive and receptive spoken language abilities. Children with this syndrome begin with normal language abilities but usually lose them after a seizure episode, usually between ages of three and seven (Pedro & Leisman, 2004). Grace, the child under investigation, experienced a seizure episode at the age of twenty months, resulting in the complete loss of her language abilities. She later regained part of her abilities at age three after an early speech language therapeutic intervention (Iacono, Chan, Waring, 1998).

### **Review of the Problem**

In this error of inclusion, there has been an increase in American schools (Pedro & Leisman, 2005). In most cases, Landau Kleffner Syndrome appears concomitantly with behavior challenges (Chapman et al., 1998). This poses a major classroom management challenge to special educators as well as general education teachers (Urton, Wilbert, & Hennemann, 2014). As noted in the literature review, there is a lack of sufficient information on characteristics, teaching, and behavior management strategies for the disability (Pedro & Leisman, 2005). On the same note, there are common cases of misdiagnoses of Landau Kleffner syndrome for autism, epilepsy or Rett syndrome (Chapman et al., 1998). This research aimed at investigating and documenting lived experiences of family educators and support staff (Yin, 2009). Findings of this research will provide a formidable knowledge base for teachers, support staff, and families serving children with Landau Kleffner Syndrome (Chapman et al., 1998). With the No Child Left Behind law, every child is entitled to free appropriate education. For effective provision of

service, it is important to have enough knowledge and strategies for this rare disability (Urton, Wilbert, & Hennemann 2014).

### **Research Question**

The major research question was “What are the perceptions, challenges and strategies applied by family, educators, and support staff serving a child with Landau Kleffner Syndrome?” In order to increase the efficiency and quality of data collection (Yin, 2009), the question was broken down as follows:

1. *What are the challenges experienced by family, teachers, and support staff serving a child with Landau Kleffner Syndrome?*
2. *What strategies do teachers, family, educators, and support staff use to address challenges experienced while serving a child with Landau Kleffner Syndrome?*
3. *What concerns do family members, educators, and support staff have on their lived experiences serving a child with Landau Kleffner Syndrome?*

Chapter three of this research presented and discussed the various methods used to collect data in this qualitative research (Creswell, 2013). They include individual one-on-one oral and written interviews, focus group interviews, and a study of archival records (Yin, 2009). Chapter Four is organized into three themes and presents the analysis of data collected. These themes include: challenges, strategies, and concerns (Creswell, 2013). In this chapter, the conclusion of the study findings and implications for various stake holders in special education are discussed. These stake holders include teachers, parents, policy makers, administrators, teacher’s aides, and parents (Whitby & Marx, 2013). The first part of this section presents a summary of the research findings.

## **Findings**

This research sought to investigate and document challenges, strategies, and concerns of family, educators, and support staff serving a child with Landau Kleffner Syndrome. In this section, the challenges are presented first, strategies next, and finally the participants' concerns (Creswell, 2013).

**Challenges.** There were four thematic challenges reported by respondents in this research. They include behavioral challenges, challenges with motor control, social challenges, and obstacles with language and speech (Chapman et al., 1998).

***Behavioral challenges.*** According to the majority of the respondents, ameliorating adverse behavior was the biggest challenge experienced (Pedro & Leisman, 2004). Grace breaks classroom rules without considering the consequences (Dupaul & Jimerson 2014). She was described as physically and verbally aggressive by all respondents (Fiedler, & Haren, 2009). She portrays high levels of aggression and defiant behaviors both at home and at school (Dupaul & Jimerson, 2014). She also acts non-compliantly and destroys property (Voorhees, Walker, Snell, & Smith, 2013). This was noted to impair her social and academic performance and made it difficult for teachers to manage their classes (DuPaul & Jimerson, 2014). Her challenging behavior was reported in archival records to be triggered by transition, physiological imbalances, anxiety, nervousness, frustration, sickness, and noise. According to teachers, Grace targets the most vulnerable students, especially the ones in wheel chairs, when she's agitated. Much instructional time was reportedly wasted redirecting her behavior and clearing classrooms for safety.

***Speech language challenges.*** Grace experiences challenges expressing herself in or understanding spoken language (Pedro & Leisman, 2004). When speaking, she occasionally

mumbles incomprehensible garble (Chapman & Stormont, 1998). Language challenges were reported to be partially connected to her aggression. When she fails to understand others verbally or to be understood by others, she gets frustrated and results to verbal and physical aggression (Chapman et al., 1998). On the same note, it was reported that when agitated her ability to speak or understand spoken language decreases. Grace also has no sense of time or tense in her speech. Additionally, her speech is characterized by single words and simple phrases. Dysnomia (difficulty finding and articulating words), paraphrasia (i.e., using the word “cut” for “scissors”), and reversing her compounds (saying “light” for “stoplight”) are common speech incongruities for Grace. She skips syllables while talking and pays attention to single words in sentences as if they were single entities. This leads to the loss of context and meaning in the sentence (Chapman et al., 1998). Her speech therapist also reported that Grace has challenges following verbal directions that go beyond two steps.

**Anxiety.** Anxiety was also reported as a challenge by the majority of the respondents (Wichstrom, Belsky, Berg-Nielsen, 2013). Archival records indicate that Grace is also diagnosed with an anxiety disorder (Dupaul & Jimerson, 2014). She becomes overly anxious when faced abrupt changes in routine, unfamiliar situations, or crowded places (Pedro & Leisman, 2005). Similarly, when anticipating interesting events in the future, she becomes anxious and nervous, repeatedly obsessing over the same topic. This raises her emotions and may lead to a tantrum (Chapman et al., 1998).

**AD/HD.** Archival records indicate that Grace is also diagnosed with AD/HD (Pedro & Leisman, 2004). She gets easily distracted, struggles to remain focused, has a short attention span and is hyper active (DuPaul & Jimerson 2014). When focusing on an interesting activity, she acts as if she cannot hear when people talk to her (McCathren et al., 1998). She is also easily



distracted by noise, movement, and visual distractors. Grace also tactfully evades work and has challenges transitioning between activities (Pedro & Leisman, 2004), particularly from those that are more interesting to less interesting. To avoid transitioning, she engages in unrelated conversation, refuses to move, asks for extra time, procrastinates, becomes violent, and repeatedly calls teachers names (DuPaul & Jimerson 2014).

***Social skills challenges.*** Grace exhibits pervasive social skills impairment that affects her capability to interact with others appropriately (Kagohara et al., 2013). According to Kagohara et al. (2013), some children with disabilities, regardless of their language and cognition capabilities, may not possess the skills necessary to participate in social situations or appreciate social norms that govern how people interact with one another (Kagohara et al., 2013). Grace is unable to make and maintain friends or sustain meaningful conversations with them. She invades space, does not respect boundaries, and inadvertently asks embarrassing questions. She also stands high chances of being rejected by peers due to her hyperactivity (Dupaul & Jimerson 2014).

***Economic challenges.*** Grace's schools and family both reported that Grace is a major economic challenge. When agitated, she destroys property and has injured others (Chapman et al., 1998). Money has been spent by schools to replace destroyed furniture and technology, hire staff, treat injured victims, and hire substitute teachers to replace injured teachers. The district has also sponsored teachers and paraprofessionals for expensive professional crises management training (Brock & Carter, 2013). The family also reported as having to spend money on furniture replacements, medical treatments, and disability diagnoses (Chapman et al., 1998).

***Curriculum and placement challenges.*** Intellectual capacity deteriorates in some Landau Kleffner Syndrome cases due to seizures (Pedro & Leisman, 1998). Archival records indicate that Grace is cognitively very low; her I.Q. is below forty. In some of her classes, she was

amongst other high functioning students. Even then teachers found it challenging to get instructional materials for her. Unlike her, other students would work in groups, listen to teachers, and write notes, but Grace could barely write her name. She was also incapable of sitting still due to her AD/HD, and she frequently disrupted teaching (Pedro & Leisman, 2004). Teachers planned for instruction twice, once for Grace and once for the rest of class. Some teachers reported staying after school due to time constraints (Albrecht, Johns, Mounstevan, & Olorunda, 2009). Teachers also complained that Grace's placement from school to school was random and poorly coordinated. It was not based on documented behavior improvement. That is why she continued being a challenge in all of her schools.

***Irregular sleeping pattern.*** Grace's sleeping pattern was described as irregular (Chapman et al, 1998). She slept odd hours in class, interfering with instruction, and she would become irrational if denied permission to sleep. This led to tantrums. She was also reported to go to sleep peacefully and wake up violent. Teachers suspected that it was due to bad dreams or seizures. Grace's family reported that she would wake up in the wee hours of the night.

***Motor control challenges.*** Grace's hands were reported to be shaky, especially when agitated (Chapman et al., 1998). This was also common when she tried to use her fine motor skills. Tremors were noted both when resting and also when moving her hands (Pedro & Leisman, 2004). Her occupational therapist noted that her inability to control her muscles effectively makes it difficult for her to hold a pen properly. She then had a difficult time to write in a straight line.

***Untimely training.*** Teachers reported that they did not receive timely training when they worked with Grace (Brock & Carter, 2013). According to the majority of the teachers, the first

training ever conducted by the district was done when Grace was in twelfth grade. Teachers believed that they would have given better service to Grace if they had received training earlier.

***Insufficient support.*** Some participants were concerned that they did not get sufficient support from administration and behavior analysts due to staff shortage. The behavior analyst worked across buildings, and teachers and parents felt she did not observe Grace in enough in environmental settings to understand her behavior fully (Chapman et al., 1998). Some teachers also thought the behavior analyst was not very familiar with Landau Kleffner Syndrome. Some teachers also complained that they did not get enough support from administrators. This was due to inexperience, but they regretted that the administrators did not advocate for them in situations where they were unable to help (Fielder & Haren, 2015).

***Seizures and other medical challenges.*** Archival records indicate that Grace is diagnosed with a seizure condition (Pedro & Leisman, 2004). Though the seizure had been medically contained for almost ten years by the time of this research, it started striking again toward end of the research (Pedro & Leisman, 2004). According to her family, every time she would experience seizures she would become sick almost immediately. They believed seizures weakened her immune system. She was also recently diagnosed with diabetes. The family finds this as a challenge because Grace is cognitively too impaired to manage her own diet. (Chapman et al., 1998). She eats what she craves for raising her sugar level at times. The family also believed that a high sugar level increases the chances of tantrums.

***Inexperience.*** All participants reported that they had never experienced the disability before. Collaboration was therefore a challenge because all members were equally ignorant (Friend, 2000). One teacher reported having worked with a student with similar challenging

behavior (Chapman et al., 1998). However, she preferred the former student to Grace. Unlike Grace, the former student had the ability to understand reason (Pedro & Leisman, 2005).

***Manipulation.*** Grace's family and teachers reported that Grace uses words and fear induction to manipulate the system to her benefit. At times she acts sick and helpless to have others do things for her. She may also make dishonest statements or twist someone's statements to achieve her immediate goals.

***Strategies.*** Question two sought to investigate and document strategies applied by practitioners to overcome the aforementioned challenges (Yin, 2009). Findings of this research will provide a resource for best practices to apply while serving children with Landau Kleffner Syndrome (Dupaul & Jimerson, 2014). The following are the thematic strategies that emerged.

***Collaboration.*** The most important strategy cited by all respondents was collaboration and teamwork (Friend, 2000). Teachers, support staff, and administrators worked together and consulted as equals while serving Grace (Diehm, Brandes, Chesnut & Haring, 2014). As a team they wrote an individualized education program (I.E.P.) and deliberated on other matters important to provision of services to the child (Diliberto & Brewer, 2012). An I.E.P. is a roadmap to special education services and is quite crucial in planning appropriate learning goals and functional education for students with severe disabilities. When discussing I.E.P.s and collaborating in other matters, every collaborator's voice is given equal weight (Friend, 2000).

***Building a good rapport and working relationship.*** Teachers reported that they ensured there is a good working relationship between them, students, and parents. As administrators noted, parents and teachers must work harmoniously to eliminate any discontinuity between home and school (Narayn et al., 2009). On the same note, Grace exhibits tantrums when dealing with people she does not trust (Chapman et al., 1998).

***Collection of accurate data.*** According to administrators and the majority of the teachers, effective intervention strategies are informed by accurate and precise data collection (Simmons & Ellis, 2014). Teachers reported that they collect data in an ongoing base. According to Adamson and Mankato (2014), the observing teacher provides immediate and quantifiable data pertaining to student behavior. Unlike students who internalize behavior through anxiety, social withdrawal, and somatic problems, Grace externalizes hers through classroom disruption, off task behaviors, and both physical and verbal aggression. These are observable and can be easily documented (Adamson & Mankato, 2014). For forms used to collect various data, see Appendix C-L.

***Appropriate instruction methods.*** Grace cognitive ability is low (Chapman et al., 1998). She experiences a delay when processing information and has a slow reaction time and delay of certain components while responding to both nonverbal and phonological stimuli (Pedro & Leisman, 2005). To help Grace more effectively, it was important to give a long wait time and avoid using verbal instructional commands. Instead, commands/instructions should be illustrated. Additionally, a wait time gives Grace an opportunity to process information and is also known to reduce behavior challenges (Lamella & Tincani, 2012). Discrete trial, which uses Skinnerian principles of operant conditioning, was reported to have been successfully used. This method employs highly structured drill-like activities which involve shaping, prompting, prompt fading, and tangible reinforcement strategies (Tsiouri, Simmons, & Paul 2012). Teachers also recommended repetition and redundancy because of Grace's low intellectual capabilities.

***Social stories.*** The use of social stories was mentioned as a major intervention strategy for Grace's poor social skills (McGill, Baker & Busse, 2012). Social stories are designed and customized to Grace's learning style because they have major pictorial representations with few

simple phrases. They are also read to her during transitioning, meeting people, and beginning activities in class. Another method is Board Maker, a computer software that matches words with pictorial representations. Members observed that the stories have increased pro-social behaviors and has reduced problem behavior (McGill, Baker, & Busse, 2012).

***Behavior intervention plans.*** Grace has a behavior intervention plan that is part of her I.E.P. This plan identifies Grace's behavior triggers as noise, frustration, or change of routine (King & Kostewicz, 2014). The plan also recommends environmental modification and the use of Skinnerian positive reinforcement to manage behavior (Tsiouri, Simmons, & Paul 2011). Another recommendation is the reading of social stories to remind Grace of her expectations during transition and activity time. Having her schedule represented visually is key (Meadan, Ostrosky, Triplett, Michna, & Fettig, 2011). According to the plan, all her activities must also be timed. A visual timer with a beeping sound is recommended.

***Managing anxiety.*** Anxiety disorders are characterized by disproportionate fear and reaction to relatively non-detrimental environmental stimuli (Lang, Register, Lauderdale, Ashbaugh, & Haring 2010). To minimize the anxiety, Grace has a regular classroom structure and routine. She is also advised in advance before there is change of routine. Grace is also excused from participating in crowded school parades, including pep rallies. Parents also reported that they do shopping at night when stores are not crowded. Teachers are also encouraged not to mention special occasions to Grace too soon in advance.

***Managing AD/HD.*** As noted earlier, Grace is also diagnosed with AD/HD (Chapman, Stormont, McCatherine, 1998). She displays developmentally delayed levels of inattention, distractibility, impulsivity, and hyperactivity (Dupaul & Jimerson, 2014). To alleviate these challenges, noise and movements are minimized. She is also verbally and physically redirected

to stay on task regularly. Visual barriers are also utilized to help her focus by blocking the visual distractors. A technique known as “the work system” is in place to encourage independence in accomplishing tasks (Hume et al., 2012). This breaks lengthy activities into small chunks and provides visual information and organization (Hume & Reynolds, 2010). She also receives positive reinforcement for accomplishing each step (McVilly, Webber, Sharp, & Paris 2013). In order to manage her transition challenges, she is given activities with minimal transition. Grace is also informed of transition in advance. Visual timers with beeping sounds are also used to signal that a transition is about to occur (Meadan et al., 2011).

***Proactivity.*** Respondents observed that teachers are proactive and not reactive to behavior. They adopt evidence-based practices that reduce challenging behavior (King & Kostewicz, 2014). Administrators recommended that teachers consistently conduct a functional behavior analysis to identify physiological and environmental triggers of behavior and consequences (McVilly, Webber, & Paris 2013). The majority of the teachers reported that manipulating consequences have helped reduce Grace’s adverse behavior challenges. This is done mainly through positive reinforcement (King & Kostewicz, 2014). Finally, parental involvement has been used proactively to manage behavior challenges (Mueller & Buckley, 2014)

***Professional crises management (P.C.M).*** According to administrators, this is a four-day intensive training. Teachers are trained on how to qualitatively and functionally analyze behavior to understand it (King & Kostewicz, 2014). Teachers are also trained on the appropriate time and how to educate a child after a tantrum. Similarly, this training armors teachers with skills to physically restrain students without hurting them. Teachers reported that this is done only as a

last result. Finally, teachers are trained on how to manipulate behavior consequences through positive reinforcement (McVilly et al., 2013).

**Digital surveillance cameras.** Evidence shows that digital surveillance cameras can be helpful. There is a digital surveillance camera installed in Grace's class (Palmer, Wehmeyer, Davies, & Stock, 2012). After a major tantrum, the video is reviewed critically for functional behavior analysis (Adamson & Wachsmuth, 2014). Observations help make decisions on appropriate environmental and instructional modifications (King & Kostewicz, 2014). This footage also helps in collaboration because several people are able to watch the images from different locations via internet connection (Friend, 2000), after which they can provide their feedback to the whole team.

**Shortened school day.** Grace's I.E.P. provides for a shortened school day. Grace's day begins at 7:30 and ends at noon. This is aimed at minimizing behavior and tantrums that commonly occurred in the afternoons (Adamson & Wachsmuth, 2014). The I.E.P will continuously review the length of the day as behavior improves. The committee plans to change the length of the day incrementally based on data collected.

**One-on-one teacher's aide.** Throughout her stay in school, Grace has a one-on-one teacher's aide to redirect negative behavior and reward good behavior, collect data, and model behavior for her (King & Kostewicz, 2014). While hiring, administrators said they look for a personality match between Grace and the teacher's aide. In the past there was a teacher aide whose personality conflicted with that of Grace, and Grace then became regularly antagonistic and aggressive toward the aide (Pedro & Leisman, 2005). It is required that the aide respect student's personal space and avoid power struggles with her. Instead, she should involve Grace in conversations with third parties and should avoid discussing her in her presence. These



challenges were noted to have been a problem previously. She should also be ready for on-the-job training (Vuran & Gul, 2012).

**Therapists.** Grace has benefited from the services of occupational and speech therapists. The occupational therapist intervenes with her muscle control challenges, while the speech therapist intervenes with language and speech challenges (Chapman, Stormont, & McCatherine, 1998). Currently, her occupational therapy is seen on a consultation basis. According to the therapists, Grace's progress reached a plateau and services were discontinued. For language impairment and speech intervention, Grace benefits from a 100 minute therapy session every week (Steele & Mills, 2011). The family also reported that Grace benefits from a one-hour private speech therapy session each weekend.

**Sensory diet.** The occupational therapist has also designed a sensory diet for Grace. This includes the use of a swing, weight jacket, wrist weight, and a bouncing ball. Grace uses the swing or sits on a bouncing ball every day, first thing in the morning for five minutes. She also has the option of using a swing instead. She puts on the weight jacket when she receives instruction. On the same note, when an activity involves writing, Grace puts on her wrist weight.

**Video modeling and video self-modelling.** Video modeling and video self-modeling have been used to teach Grace behavioral and functional skills. According to Kagohora et al. (2013), video modeling entails showing a student a video segment and demonstrating how to perform a skill or behavior correctly. The student is expected to observe and learn from the positive performance (Kagohara et al., 2013). On the other hand, video self-modeling involves a student viewing herself positively performing a skill (Williamson, Casey, Robertson, & Buggiey, 2012). For both modeling, a mobile device, usually an iPad, is utilized. As noted earlier, Grace enjoys working with electronics and this has been motivating for her.

**Concerns.** Question three sought to investigate and consolidate concerns that family, educators, and support staff have with past and present experiences serving a child with Landau Kleffner Syndrome (Yin, 2009). Open-ended questions were posed to respondents to help investigate what participants thought could have been done differently (Creswell, 2013). This section addresses the concerns based on who raised them.

**Occupational therapists.** Occupational therapists were particularly disappointed that Grace could not express herself in writing after more than a decade of intervention. Much energy and time have been spent on intervention since elementary school. Because Grace stopped making marked improvements, occupational therapy services were discontinued after her motor control ability progress reached a plateau (Pedro & Leisman, 2005). On a different note, the therapist was concerned that the teacher's aide interrupted his therapy sessions inadvertently. The aide's attempts to verbally redirect Grace when receiving therapy services took authority away from the therapist. He believed that this made Grace defiant by introducing dynamics that were there before therapist arrived. In his opinion, teacher's aides should refrain from intervening unless requested to participate. Due to time constraints, the therapist never had time with the aide outside of working with the student, so they could not discuss the matter. Consequently, boundaries were never established.

**Speech therapists.** Like the occupational therapist, the speech therapist was also concerned that the teacher's aide verbally redirected the student when she was receiving therapy. The speech therapist was also concerned that the aide rephrased statements spoken by Grace, making them lose context. Like the occupational therapist, the speech therapist preferred that the aide remain an observer unless otherwise requested to participate.

**Teachers.** Teachers were concerned that Grace remained a behavior challenge to the school district despite having been in the same district for more than a decade (Chapman et al., 1998). They believed that the district never sought long-term solutions to Grace's behavioral challenges. They were particularly concerned that the district did not have a behavior analyst of its own until Grace was in twelfth grade. They hired someone externally, leading to a shortage of consultation time with teachers. Teachers also observed that Grace's placement from school to school was not well coordinated; the placement was random and was never based on documented behavior improvement indicators (Adamson & Wachsmuth, 2014).

Another concern by teachers was insufficient and untimely training (Vuran & Gul, 1998). Teachers reported that by the time they received professional crisis management training, Grace was already in the twelfth Grade. They believed they would have served Grace better if it was done earlier. They also felt that this unfairly subjected them to a dangerous working environment due to Grace's aggression (Pedro & Leisman, 1998).

Teachers were also against generalizations and assumptions made by administrators on behavior management. Although the school did a great job training teachers on how to effectively manage behavior using professional crisis management courses, teachers observed that no strategy worked universally for everybody. In their opinion, the administrators assumed that since the training has taken place, then it should be implemented and the child would be fixed automatically. The teachers believed this was an unrealistic expectation.

**Family.** Parents were concerned that some administrators were also unprofessional and dishonest (Helton & Ray, 2009). One tried accessing Grace's medical records without consent, another attempted to manipulate I.E.P. committee decisions, and another one attempted to kick Grace out of the school system and commit her to another facility. Grace's family also

transferred Grace from her first kindergarten school due to an unsupportive principal and designee. They believed this was against the principles of collaboration (Fiedler & Haren, 2009). They reported that they felt disrespected and wished the administrators would have acted professionally (Fiedler & Haren, 2009).

Grace's family was concerned that at times behavior analysts generalized Grace's behavior after observing her for only a short time in class. According to her family, fifteen minutes is not enough time to observe a child and understand her behavior. They believed the analysts should have spent more time with students and in different settings. However, reports have shown that there is a shortage of behavior analysts and, hence, time constraints. At the same time, they thought that enough time should have been allotted to consult with the family; the family felt their opinions were important and would have prevented generalization.

*Administrators.* Administrators were concerned about regular communication breakdown between them and teachers. Following behavior challenges (Pedro & Leisman, 2005), teachers demanded that Grace be removed from their classes immediately. According to them, some decisions are beyond them. Committees met and decided on certain matters—they found it difficult to balance I.E.P. requirements with reality in the field. They described it as an ethical dilemma (Fiedler & Haren, 2009). Grace's I.E.P., for example, requires a one-on-one teacher's aide and a reduced school day. Hiring someone who is willing to work half days and be subjected to Grace's violence is a difficult task. Similarly, once an individual is hired, she is entitled to demand a change of placement any time she feels unsafe. She cannot be fired or be forced to continue working with Grace. This means that administrators start searching for another teacher's aide. For everyone involved, this is a frustrating and vicious cycle.

## **Implications and Recommendations**

The current study holds some value for special education practitioners (King & Kostewicz, 2014). The main aim of the research was to create a documented resource for families, educators, and support staff (Creswell, 2013). The findings of this research, if effectively applied, will improve service provisions for people with Landau Kleffner Syndrome. As noted in the literature review, not much literature exists on Landau Kleffner Syndrome (Yin, 2009). This research attempts to add to that field of study. As reported by parents and administrators earlier, no one can serve Grace effectively alone. Professionals need to collaborate and work as a team (Friend, 2000). This section provides implications of this research to various stake holders in the special education field.

**Implications for policy makers.** Policy makers play a pivotal role in special education services. They not only make new policies, but also modify existing ones to meet the needs in the field. Effective policy making should also respond to existing challenges in the field (Ireland, Hall-Mills, & Millikin, 2013). Most of the challenges and concerns reported in this research reflect these needs.

**Economic support (funding).** Grace was described as expensive to her school district. The district has spent money hiring a teacher and teacher's aide for her, paying for substitute teachers, replacing broken assets, and treating injured students and teachers (Pedro & Leisman, 2005). Ultimately, policy makers should allocate more money to support students with Landau Kleffner Syndrome.

**Effective teacher training.** Policy makers should also ensure that training institutions include in their curriculum studies of rare disabilities like Landau Kleffner Syndrome. Based on the participants' responses, most training institutions seem to pay more attention to high-incidence disabilities at the expense of rare disabilities. In the spirit of inclusion, severe

disabilities must also be given equal emphasis in training institutions (Urton, Wilbert, & Hennemann, 2014). This will arm teachers with effective strategies for managing and serving children with Landau Kleffner Syndrome amongst other students. Furthermore, institutions must teach collaboration, parental involvement, and behavior management strategies to both general and special education teachers (King & Kostewicz, 2014)

***Training more therapists.*** Findings in this research indicate a shortage of occupational, speech, and behavioral therapists. Individuals with Landau Kleffner Syndrome require interventions from all of the above concurrently (Chapman et al., 1998). Policy makers should devise ways of encouraging more people to become therapists for efficient services. This may include campaigning, better salary packages, and student loan forgiveness. Students with Landau Kleffner Syndrome need several therapists, such as behavior analysts, occupational therapists, and speech therapists. (Chapman et al., 1998). Institutions should devise strategies of encouraging more applicants to enroll for these courses. While training therapists, it is important to take into consideration that many Landau Kleffner Syndrome students have concomitantly appearing disabilities, so therapy intervention needs to include strategies to help with speech, occupational, and behavioral challenges.

***Improving working conditions.*** One administrator reported that it was difficult to hire a one-on-one teacher's aide for Grace (Brock & Carter, 2013) primarily because of poor pay, Grace's aggressive behavior, and few working hours due to Grace's shortened schedule. This led to a high rate of staff turnover in the last four years. To encourage employees to work with students of severe behavior challenges, policy makers must improve their working conditions (Albrecht, Johns, Mounstevan, & Olorunda, 2009). This should include better payments, compensation for injuries, counseling services in case of life threatening injuries, protective gear,

and better insurance packages. Sadly, it was reported that there are no special days off for teachers if they sustain any injuries. Teachers and their aides are charged for them if they do not have any remaining sick days. Modifying this is essential to attracting more teachers and therapists.

***Training teacher's aides.*** Teacher's aides play a very crucial role in serving children with special needs (Brock & Carter, 2013). Severely disabled students like Grace need a skilled one-on-one teacher's aide throughout their day (Hume & Reynolds, 2010). Students like Grace need appropriate behavior management, someone who can collect meaningful data, parental involvement, and collaboration among all individuals involved (McVilly, Webber, Sharp & Paris, 2013). One of the teacher's aides was reported to have increased behavior escalation due insufficient skills. Another one inadvertently invaded therapist and parental boundaries. This indicates lack of professional skills (Helton & Ray, 2009). Policy makers should facilitate professional training for aides.

***Teaching materials and ample planning time.*** Teachers complained that they could not get enough planning time or appropriate teaching materials for Grace (Naryan, Bruce, Bhandan, & Kolli, 2009). Policy makers should ensure that teachers are allocated more time for instructional planning (Albrecht, Johns, Mounstevan, & Olorunda, 2010). In obtaining appropriate teaching materials, policy makers should ensure that accessible materials exist in each school building or in a centralized office in the district for teachers

***Enhancing collaboration.*** Therapists complained that they did not have any time with teacher's aides outside therapy sessions. The therapist and teacher's aide were always in the presence of the student, which made it difficult for the therapist to maintain authority. To remedy this, policy makers should enhance and facilitate professional training opportunities for

collaborators in the same setting (Vuran & Gul, 2012). This should also be aimed at relationship and team building between various collaborators (Brock & Carter, 2013).

**Implications for districts and school administrators.** Districts and school administrators play a key role in collaboration (Friend, 2000). They are central to providing effective special education services for children with severe developmental and behavioral disabilities like Grace's (Fiedler & Haren, 2009). Findings of this research will help them serve teachers and families more effectively.

**Parental involvement.** Parents know their children better than anyone else (Diliberto & Brewer 2012), so there should be a reciprocal partnership between school and home. Administrators, parents, and students need to work as a team in all the child's social, educational programming decisions, and behavioral aspects (Mueller, & Buckley, 2014). According to Mueller and Buckley (2014), while some districts encourage communication between family and schools, their approach is usually top-down with the school maintaining the greater authority. (Mueller & Buckley, 2014). For efficient provision of services, should this situation change they should henceforth correspond as equals.

**Advocacy.** Educators and support staff are routinely called upon to advocate for the rights of children with disabilities. They must speak, write, and act positively in support of families of students with disabilities (Fielder, & Haren, 2009). Each school district should empower its personnel by training them and giving them specific directions for advocacy (Dupaul & Jimerson, 2014).

**Increased quality support for teachers.** In this research, some teachers reported that they did not get enough support from the school administrators. A teacher's aide also reported that she had been given several promises that a peer tutor would be partnered with Grace but to no avail.



Administrators should give sincere and timely support to teachers when they ask for help (Albrecht, Johns, Mounstevan, & Olorunda, 2009). If administrators are ever in a position to help, they should.

***Respect I.E.P. requirements.*** During this research, a parent complained that a principal failed to hire a one-on-one teacher's aide for Grace. The I.E.P is a legal document which must be respected (Diliberto & Brewer, 2012). If administrators need to change it, they should then engage the whole I.E.P committee for modifications. Violating the provisions in an I.E.P requirement is unprofessional.

***Respect professionalism and ethics.*** Administrators should act with respect and proper decorum (Helton & Ray, 2009). They should conduct themselves with integrity while serving parents and children with severe needs (Fiedler & Haren, 2009). Grace's parents complained that an administrator attempted to access Grace's medical records without the parents' permission. According to Fielder and Haren (2009), ethical principles of maintaining integrity calls for the safeguarding of confidential information. Manipulation of I.E.P committee decisions was also reported. Administrators should be professional and respectful.

***Enhancing collaboration.*** Grace's parents also complained that were not able to meet with supportive professionals who served Grace in the last decade (Muller & Buckley, 2014). Grace's mother in particular wished that they would have tried to get the family's input. Effective administrators have a duty to create opportunities and device strategies for team members to meet and exchange ideas. With state of the art technology, a Google group, or communicating via Skype might have been helpful (Palmer, Wehmeyer, Davies, & Stock, 2012). While doing this, they should be guided by the principle of giving equal respect and worth to all collaborators (Fiedler & Haren, 2009).

***Expedited services.*** Teachers and administrators observed that protocol issues delayed implementation of decisions. Administrators should respond swiftly to teachers' requests (Albrecht, Johns, Mounstevan, & Olorunda, 2009). They should also advocate for teachers to those outside the building (Krooks & Walsh, 2013).

***Hiring enough support staff.*** A shortage of speech therapists, occupational therapists, and behavior analysts was reported in this research (Brown, Rodger, & Roevers, 2005). In order to effectively serve students with Landau Kleffner Syndrome, it is necessary to hire enough occupational, behavior, and speech therapists. The biggest challenge was reported to be behavioral in nature. Ironically, the district reported not to have hired a behavior analyst of its own for more than a decade. The only time an analyst was hired was when Grace repeatedly slammed her head against the wall in the hallway as many general education students watched.

***Planning time and teaching materials.*** Teachers complained that there were time constraints when planning for Grace's instruction (Albrecht, Johns, Mounstevan, & Olorunda, 2009). It was also reported that appropriate and effective teaching materials were not easily available (Narayan et al., 2009). Administrators should increase planning time for teachers (Chapman, Stormont, McCatherine, 1998). If teachers stayed after school for purposes of planning, there should be a way of compensating them. On the same note, administrators should work with experts to provide materials and consultation services for teachers. They should also consider relieving special education teachers of other school duties so that they could get more planning time.

***Coaching teachers on effective behavior management skills.*** In this error of inclusion, all teachers need behavior management skills (McVilly, Webber, Sharp, & Paris, 2013). Administrators should provide experts to coach teachers on behavior analysis. Identifying

triggers and designing appropriate intervention strategies requires skills that most teachers do not readily have (Voorhees, Walker, Snell, & Smith, 2013).

**Implications for teacher training institutions.** Teacher training institutions should prepare teachers for children with special needs. Findings of this research will improve the way they train their teachers.

***Including rare disabilities studies in the curriculum.*** All respondents had not heard of or studied about Landau Kleffner Syndrome in their colleges. This is a big concern, considering some of them had been to college for both bachelor's and master's degrees. For this reason, teacher training institutions should include rare disabilities, such as Landau Kleffner Syndrome, in their curriculum. The institutions should also indulge in research that helps understand rare disabilities (Chapman, Stormont, & McCatherine, 1998). There seems to be more concentration on high incidence disabilities, such as autism, at the expense of the rare disabilities.

***Teaching behavior intervention strategies.*** Training teachers how to address children's challenging behaviors should be a priority (Voorhees, et al., 2013). Both special education and general education teachers need skills on how to conduct functional behavior analysis, collect accurate data, set behavior goals, and write effective behavior replacement plans.

***Teaching advocacy and collaboration.*** All educators must serve as advocates for students with disabilities and their families (Fiedler & Haren, 2009). Teachers must also work collaboratively with support staff and families to promote continuity between home and school. Teacher training institutions should thus include these skills in their teacher training curriculum, (Diehm, Chesnut, & Haring, 2014). The curriculum should include internship opportunities to work with families and support staff (Mueller & Buckley, 2014).

**Implications for teacher's aides.** Teacher's aides play a crucial role in serving children with severe disabilities. Grace, for example, needs a teacher's aide throughout her school day. Continued research of one-on-one interaction between a student with Landau Kleffner Syndrome and her aide could help future teacher's aides improve their services in the following areas:

***Professionalism.*** It is important that the aides be professional and ethical in discharging their duties (Fiedler & Haren, 2009). At times, Grace's teacher's aide took Grace's behavior personally. Aides should always perform functional behavior analysis to understand what the student is communicating during a tantrum (King & Kostewicz, 2014). It was also reported that the aides interfered with speech and therapy sessions by attempting to redirect students verbally as they received therapy. A speech therapist complained that some teacher's aides rephrased the questions she asked Grace during therapy sessions (Hua, Woods-Grove, Ford, & Nobles, 2014). According to the therapist, intervening made the questions lose context and made understanding hard to achieve. Ultimately, the therapists wanted the teacher's aide to be absent from the session unless otherwise requested to participate.

***Respecting students.*** Regardless of cognitive abilities, students must be treated with respect. Administrators complained that sometimes a teacher's aide caused behavior tantrums by invading Grace's personal space, entering a verbal power struggle, indulging in conversation with other adults while leaving Grace out, and discussing Grace in her presence. Teacher's aides should refrain from such behavior and treat students with dignity as they serve them.

***Being an educator, not a care taker.*** It was reported in this research that an aide did almost everything for Grace, denying her an opportunity to practice independent living skills. Teacher's aides should be educators and not care takers. While assisting students they should do

“with” and not “for.” They should also provide opportunities for students to practice living independently by teaching them how to do things for themselves (Hume et al., 2012).

***Implications for Support Staff.*** Support staff play a crucial role in collaboration (Diehm et al., 2014). As noted earlier, Grace was served by a number of support staff. They included behavior analysts, occupational therapists, and speech therapists. Support staff would benefit from implementing the following:

***Modeling.*** Support staff must model what they teach. One teacher complained that a behavior analyst gave candy to Grace after Grace physically assaulted her. Giving candy just encouraged the inappropriate behavior. Support staff should behave consistently and follow what they teach. Rewarding improper behavior is against the principles of positive behavior reinforcement. On the same note, speech therapists reported that the teacher always rephrased Grace’s speech to make it age appropriate. Therapists who work with Grace should have focused on teaching her to act like typical peers by modelling appropriate speech and redirecting her when she behaves like a pre-kindergartener.

***Welcoming parental involvement.*** It is important that all support staff involve parents as they serve their children. A parent complained that she was not effectively involved by some support staff (Ihuma et al., 2014). It is important that support staff regularly communicate with parents and involve them in their service to students. Failure to do this could lead to a festering of mistrust between school and home (Iacono et al., 1998). Support staff should respect that parents know their children more than anybody else.

***Advocating.*** Special educators and support staff are routinely the first people who are called upon to advocate for children with severe disabilities (Fielder & Haren, 2009). This includes advocating for effective and appropriate intervention strategies by peer experts (Dupaul

& Jimerson, 2014). They should also advocate for changes in intervention strategies that are not effective.

**Implications for teachers.** According to Fiedler & Haren (2009), teachers have a more direct and immediate impact on the quality of education for children with severe disabilities. They know students better than most collaborators, and they also interact with them for the better part of the day. Teachers should consider the following:

*Effective communication and building relationships.* According to Abrams (2014), the communication that teachers have or don't have with parents can truly strengthen or weaken the bond between school and home (Abrams, 2014). No matter what administrators do to strengthen relationships, teachers form the bridge between home and school. There should be regular two-way, meaningful communication between teachers and parents (Mueller & Buckley, 2014). Similarly, teachers should be effective communicators to students as well. In this research, it was reported that abrupt changes affected Grace due to her anxiety. Teachers must effectively communicate to both students and parents if changes are expected in the future. This will help prepare students like Grace in advance.

*Collecting of accurate data.* Collection of accurate data is the most crucial part of behavior management (Adamson & Wachsmuth, 2014). Effective teachers should collect data when the behavior occurs, not at the end of the day. Teachers need to be creative and devise easy-to-use teacher-friendly forms that help them collect data accurately and with timeliness. The forms should also allow collection of data on multiple objective goals. At the end of each school day, teachers should document that day's behaviors and analyze it next to all previously entered behavior data for future planning and intervention. Data should be analyzed on a continual basis for it all to make sense.

***Effective teaching strategies.*** Grace is diagnosed with AD/HD, an anxiety disorder, and an intellectual disability. Teachers should use strategies that accommodate all those challenges (DuPaul & Jimerson, 2014). Due to her low intellectual capabilities, teachers must give a long wait time in between answers. They should also avoid using abstract language (Lamella & Tincani, 2012). Due to her AD/HD, Grace also needs minimal noise and verbal distractors in class. Her teachers should then verbally and physically redirect her on regular basis (DuPaul & Jimerson, 2014). Since she is not intrinsically motivated to work, positive reinforcement should be continuously applied (King & Kostewicz, 2014). Furthermore, since she has anxiety disorder and is easily overwhelmed by learning tasks, discrete trial methods should be used the majority of the time (Tsiouri, Simmons, & Paul, 2012). Visual aids should also be used with minimal or no speaking due to spoken language processing challenges (Chapman et al., 1998).

***Proactivity in behavior management.*** Behavior challenges is the primary barrier preventing inclusion with most Landau Kleffner Students (King & Kostewicz, 2014). Effective teachers should avoid being reactive; instead, they should act in a timely manner to *prevent* escalation. To be proactive, teachers should use positive behavior reinforcement to encourage good behavior continuously (Diliberto & Brewer, 2012). To determine whether a tantrum is imminent, teachers should look for indicators, such as body language, the raising of the student's voice, and other common setting events and triggers (Chapman et al, 1998). To manage anxiety, routines and structure should be maintained constant (Lang, Regester, Lauderdale, Ashbaugh, & Haring, 2009).

***Classroom safety.*** Physical aggression was a dominant challenge in this research (Chapman et al., 1998). Classrooms were reported as needing to be cleared frequently when Grace became physically aggressive (for safety concerns). In situations where classes have to be

cleared for safety, an evacuation plan should be devised; this would avoid accidental injuries or stampedes. (Grace was known to throw items at people.) Rooms must be clear of unnecessary items that could be used as weapons. Items with no teaching purposes should be removed, and plastic materials should be utilized when necessary.

***Use of visual aids.*** Speech therapists reported that Grace has challenges understanding and expressing spoken language (Chapman et al., 1998). Effective teachers should minimize the use of spoken language (Pedro & Leisman, 2005) while instructing Grace through visual aids (Meadan, Ostrosky, Triplett, Michna, & Fettig, 2011). Pictures, charts, and other visuals should be used with minimal words.

***Managing anxiety.*** Grace is diagnosed with anxiety disorder (Chapman et al., 1998). Parents reported that Grace gets overwhelmed by large crowds or being in unfamiliar places, such as school pep rallies (Wichstrom, Belsky, Berg-Nielson, 2013). Parents also reported that Grace worries too much about future events. Teachers should avoid discussing events too far in advance. Finally, teachers should communicate routine changes before they occur (Diliberto & Brewer, 2012).

***Educating parents and teacher's aides.*** Several teachers and administrators reported that parents need to be educated for several reasons. First, they need to know about transition opportunities for their children after school. Second, they also need to know about available funding and the benefits of such funding (e.g., social security benefits). Third, they need information about new special education laws and parental consent requirements. Finally, parents need to be educated of what is expected of them during collaboration (Friend 2000), and teachers have a duty to educate parents accordingly. Educating teacher's aides on what is



expected of them as they serve students to help the students but also to prevent over-interaction with the parents during non-urgent situations.

**Advocacy.** It is necessary that teachers advocate for both the rights and needs of students (Whitby, Marx, McIntire, & Wienke2013). As noted earlier, teachers hold a central position in collaboration (Friend 2000) because they spend more time in the day with student than any other collaborator. For this reason, they know students' needs more than anyone else, sometimes more than the parents. At times, parents do not know what services their children need (Krooks & Walsh, 2013). Teachers should advocate for the students to behavior analysts, speech therapists, and psychologists. On the same note they should advocate for teacher's aides to the administration when necessary.

**Implications for Parents.** Parents play a very crucial role in providing special needs services to their children with severe disabilities. Much of the time, no one knows the child better than the family. What parents do or fail to do greatly affects the quality of service given to their children. The findings of this research could benefit families in the following areas:

**Collaboration.** Collaboration is key to success in special education (Iacono et al. 1998). Research indicates that there is a direct connection between parental involvement and academic and positive social and emotional outcomes (Mueller & Buckley, 2014). Parents must be actively involved in writing I.E.P.s for their children with special needs as well. Individualized education plans describe the needs of a child and the way they should be addressed. Parents need to participate and give their input since they know the child better (Diliberto & Brewer, 2012). During this research, it was reported that some administrators were insincere and manipulated I.E.P. committee decisions. This is one reason why it is of utmost importance that parents be

present in all meetings. Parents must also positively and actively respond to requests by support staff and other collaborators to enhance service delivery.

***Behavior intervention plan.*** According to King & Kostewicz (2014), a behavior plan outlines environmental and physiological triggers of behavior and how they can be manipulated for a desired outcome. Parents should assist teachers in identifying positive reinforcement for behavior management. Parents know students better and should be able to give appropriate suggestions. They also need to highlight behavior challenges and desired replacement behaviors, as well as to implement the same conditions in the behavior plan at home.

***Managing family conflicts.*** Parents reported that family conflicts arose at times while serving Grace. Some involved the mother and father while others involved Grace and her brothers. For the parents, it was reported that they are able to resolve the differences by researching information about Landau Kleffner Syndrome. The more difficult conflicts to resolve are the ones between the siblings. Parents must ensure conflicts are avoided as much as possible and that they are solved amicably when they arise. This includes educating children without disabilities how to accommodate behavior challenges of the one with disabilities.

***Advocacy.*** Advocacy has also emerged as a major theme in this research (Krooks & Walsh, 2013). School districts made several attempts to unfairly remove Grace from the school system. One particular administrator attempted to manipulate I.E.P. committee decisions to fit his preconceived wishes. In cases like this, parents must stand firm and question suspicious decisions. They must also ask the experts questions when they need help. According to some teachers, children with less challenging behaviors are no longer in the school system; instead, they receive “home bound” services. Grace has, however, remained in the school because her parents advocated strongly for her.

## **Reflection**

This research has been an educational eye opener and a challenge to me at the same time. I have learned a lot on how to conduct an effective qualitative study and how not to. On the same note, I will no longer wonder which method of research is better than the other, qualitative or quantitative. It is now very clear to me that it depends with what one is investigating. I do not see how I would have gathered information on people's experiences using any other method other than qualitative. Unfortunately, it is too time consuming and more challenging than I thought. A lot of time was spent reading archival records, interviewing people, and transcribing. My batteries on a voice recorder also ran out in middle of an interview, and I didn't have any replacements. I should have been more organized than that.

There were other challenges in the field, too. Due to fearing legal ramifications, some potential participants signed the informed consent forms but became evasive thereafter. I also faced a challenge with my focus group interviews. The groups would often go off topic, and it was a challenge redirecting them back. At times, they differed on opinions and this wasted time. Bringing participants together for a focus group interview was also a challenge. They had different availability and were equally busy.

The one-on-one interviews proved challenging as well. Some teachers were brief in their responses, for they, too, feared legal ramifications. I had to engage them verbally in off-topic talks as the interview proceeded to encourage them to have confidence in me. Unfortunately, this wasted time and my audio recorder taped unnecessary material. Transcribing was also a big challenge because it was done manually and took too long. Also, some people would stray off topic. This wasted time in both the field and during transcription. Background noise also

disrupted the recording. Depending on where the interview was done, I strained a lot to hear some participants as I transcribed data.

There were also some emotional moments during the interview. Some information that I gathered in archival records that were difficult for me to process. For instance, some questions posed to the parents were quite sensitive and personal. This included the history of pregnancy, experiences during and after delivery, and the impact of the disability on the family. While Grace's parents were composed, I was emotionally affected when listening to their responses.

Lastly, three potentially resourceful participants had died by time the research began, two of them within last two years of research. According to the parents, these other participants knew Grace well and would have changed the quality of this research.

### **Limitations**

A major limitation of this research is its specificity. This is a single-subject case study that investigates challenges, strategies, and concerns of respondents who served an individual with Landau Kleffner Syndrome. Therefore, it is difficult to assign the findings of the research to another setting or another child with the syndrome; every student is unique.

Another limitation is the relationship between me (the researcher) and Grace. I was Grace's special education teacher for four years. While I applied extra effort to minimize the likelihood of bias, there can never be a fool-proof method of accomplishing this goal. This research would have been more fruitful if I were actually an interviewer. I would have contributed a wealth of information more objectively. Finally, there are three crucial potential participants who were deceased by the time the research began. One was an elementary school teacher, another was a middle school teacher, and the third was Grace's junior high school teacher. I believe their participation would have contributed much to the quality of this research.

## **Recommendations for Further Research**

This research successfully investigated the perceptions, challenges, strategies, and concerns of family, educators, and support staff serving a child with Landau Kleffner Syndrome. Investigating what other families of children with disabilities think of having Grace in the same class with their children was important. Similar research on the perspective of medical professionals who have served Grace should also be conducted. Due to confidentiality reasons, it was not possible to interview Grace's psychiatrist and family doctor. Their experiences would have added more quality and advice in serving children with Landau Kleffner Syndrome.

It is also necessary to investigate what policy makers think about serving Grace and children with similar challenges. Should the cost per child matter? Suppose a school district had one hundred children like Grace...would it be realistic to hire teachers and teacher's aides for each child and give them a class of their own? How far can we go with the least restrictive placement? Some teachers also observed that there were some students who were less aggressive than Grace who received their services from home. Policy makers should be asked questions like this.

## Summary

This chapter looked at the conclusion of the entire research. The findings were summarized, implications to stake holders given, challenges of research discussed, limitations given, and recommendations for further studies proposed. Grace is an expensive student for the school district and her family. She has a class, teacher, and teacher's aide of her own. Additionally, a lot of money has been spent on repairing destroyed furniture, technology, and medical treatment to name a few. Similarly, she is a physically and verbally aggressive child who has injured many teachers and students. Her main challenges are the inability to understand and express herself verbally. This is indirectly related to her aggressive behavior. Grace was also described as manipulative, egocentric, and insensitive to the feelings of her victims. She has attention deficit hyperactivity disorder, anxiety disorder, and challenges transitioning from one activity to another.

Among the strategies used by the teachers include, the use of visual aids is vastly superior because it minimizes distractors like noise. Other successful strategies include repetition, discrete trial, behavior intervention plans, and Skinnerian reinforcement of behavior and collaboration. Respondents also had some concerns. Parents were concerned that some administrators were dishonest. One of them would come to I.E.P. meetings with preconceived decisions and would try to manipulate the standing I.E.P. Others tried to access Grace's medical records without parental approval. The limitations of the research include inability to generalize the results. This is a one subject case study, and findings are person specific. Children with disabilities are diverse in their needs, so the findings in this study can not necessarily be applied to all children with Landau Kleffner Syndrome. Having been a teacher of the subject of more than three years, I was in a good position to remain objective. Doing this was necessary, but there is no guarantee that it

will happen. On the same note, three teachers who would have been abundantly resourceful had already died by time of the research. Further research needs to be done, including getting the parents' perspectives, interviewing psychiatrists and other medical professionals, involving the tax payers as a possible funding resource, and imploring policy makers to provide more incentives for teachers and teacher's aides.

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## Appendix A



Office of Research Compliance  
Institutional Review Board

April 21, 2014

### MEMORANDUM

TO: George Wairungu  
Marcia Imbeau

FROM: Ro Windwalker  
IRB Coordinator

RE: New Protocol Approval

IRB Protocol #: 14-04-658

Protocol Title: *A Case Study of Landau Kleffner Syndrome: A Look at Strategies, Experiences, Challenges, and Perceptions of Teachers, Family and Support Personnel*

Review Type:  EXEMPT  EXPEDITED  FULL IRB

Approved Project Period: Start Date: 04/18/2014 Expiration Date: 04/17/2015

Your protocol has been approved by the IRB. Protocols are approved for a maximum period of one year. If you wish to continue the project past the approved project period (see above), you must submit a request, using the form *Continuing Review for IRB Approved Projects*, prior to the expiration date. This form is available from the IRB Coordinator or on the Research Compliance website (<http://vpred.uark.edu/210.php>). As a courtesy, you will be sent a reminder two months in advance of that date. However, failure to receive a reminder does not negate your obligation to make the request in sufficient time for review and approval. Federal regulations prohibit retroactive approval of continuation. Failure to receive approval to continue the project prior to the expiration date will result in Termination of the protocol approval. The IRB Coordinator can give you guidance on submission times.

**This protocol has been approved for 15 participants.** If you wish to make any modifications in the approved protocol, including enrolling more than this number, you must seek approval *prior to* implementing those changes. All modifications should be requested in writing (email is acceptable) and must provide sufficient detail to assess the impact of the change.

If you have questions or need any assistance from the IRB, please contact me at 210 Administration Building, 5-2208, or [irb@uark.edu](mailto:irb@uark.edu).

210 Administration Building • 1 University of Arkansas • Fayetteville, AR 72701  
Voice (479) 575-2208 • Fax (479) 575-3846 • Email [irb@uark.edu](mailto:irb@uark.edu)

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## Appendix B

### General Interview/Data Collection Protocol

#### Teachers: Academic

1. What motivates Grace to participate in classroom activities? What discourages her from participating in classroom activities?
2. Comment on Graces academic challenges and how they were addressed.
3. Describe Graces receptive and expressive language abilities. How does she communicate? Any challenges? How is it addressed
  - How did this affect her learning?
  - Comment on Graces auditory comprehension deficits. How has this been addressed in classroom?
5. Comment on Graces verbal expressions challenges. How did this affect her learning?
  - Comment on Grace Communication in relation to *Dysnomia* (example, saying hammer for shovel,).
  - Comment on Graces semantic *paraphrasia* (example, saying Cut for scissors)
  - Comment on her language as pertains use of reverse compounds (example saying light stop instead of stoplight).
  - What interventions were there for the three language problems above?
6. Comment on Grace's Language comprehension skills, (example use of word order and sequence to interpret sentences rather than use grammatical structure of the sentence)
  - What Strategies were used to intervene in this?
  - What strategies worked?
  - What strategies did not work?
7. Comment on Grace's mathematic skill as pertaining.
  - Counting skills
  - Addition skills
  - Subtraction skills
  - What interventions were used to help her in Mathematics?
  - Which interventions worked?



- Which interventions did not work?
6. What attention impairments were evident in Grace during learning activities?
- How long is her attention span?
  - How did attention impairments affect Grace's learning?
  - What interventions were used to attend to her attention deficits?
  - Which strategies worked?
  - Which strategies did not work?
7. How does motor control problem (shaking) affect Grace's participation in classroom activities?

What strategies were used to intervene with this?

8. Comment on Grace's visual learning skills.
- Visual memory
  - Association
  - Recognition
  - Comprehension
  - Detail identification
  - Perception
  - Analysis
  - How did this affect her learning either positively or negatively?

**Teacher: Social**

1. Describe how Grace relates with peers.
2. How does Grace rate in the following
  - Taking turns while talking with others?
  - Maintaining personal space with friends?
  - Asking appropriate questions?
  - Responding to appropriate questions with appropriate answers?
  - Remaining on topic while chatting with friends.
  - Asking appropriate questions to friends and acquaintances.
  - What strategies have been used to intervene with the above concerns?
  - Which ones worked and which ones did not?

## **Teacher's Behavior**

1. What behavior and emotional concerns does Grace have?
  - What triggers her aggressive behavior?
  - How does aggression affect her learning?
2. What emotional and anxiety concerns does Grace have?
  - How does that affect her learning?
3. Comment on Grace's obsessive behavior with food and other items.
  - How does it affect her learning and her health?
  - How is it addressed?
4. Describe any concerns with Graces sleeping pattern?
  - How does this affect her learning?
  - How was it addressed?
5. What was the role of collaboration when working with Grace? Describe your experience working with other collaborating staff.
6. In your opinion, what should the classroom environment be like for Grace to participate effectively?
7. In your opinion what role should be played by administration in supporting parents, teachers and student when serving a childlike Grace (with LKS)?
  - What in your opinion should the administrators have done differently?
8. What are your concerns with Grace as a student with a disability?
  - Which teaching techniques did you utilize while serving Grace?
  - Which techniques worked best and which did not work.

## **Speech Therapist**

1. Comment on Graces speech and language challenges as follows.
  - Speech Syntax
  - Semantics
  - Coherence in speech
  - Inappropriate initiation
  - Stereotyped language
  - Use of context
  - Nonverbal communication
  - Pragmatic language
  - Social interaction
3. Comment on her attention span and distractibility, how did it affect her learning? How did you handle it?
4. What are the main challenges that you faced serving Grace? How did you address them?
5. In your opinion what is the best classroom environment for Grace?
6. What are your concerns as a speech therapist with Grace as a student with a disability?
7. What teaching techniques did you utilize while teaching Grace? Which technique worked best, which one was a challenge, which did not completely work and why?

## **Occupational Therapist**

1. Introduce yourself and briefly explain how long you have worked with Grace and in what capacity?
2. What warranted Grace to require an occupational therapist?
3. What were the challenges working with her?
4. Were there any shaking or muscle abnormalities? How did this affect her learning? How did you address them?
5. Were there any concerns with Grace's sleeping pattern? How did this affect her learning or you working with her?
6. What role did collaboration play in working with Grace? What kind of communication is necessary between occupational therapist and other personnel serving a childlike Grace?
7. Do you relate the challenges of working with LKS to any other disability in your career, is it any different?
8. What are your concerns as an occupational therapist with Grace as a student with a disability?

## **Parent**

1. At what age was Grace diagnosed with LKS.
2. Comment on history of various disabilities in the family in relation to Grace's diagnoses.
3. Briefly explain the trend of events that led to the diagnoses.
4. Briefly comment about Grace's life before and after diagnoses.
5. Briefly explain the main behavior concerns with Grace
6. What interventions have been used to manage Grace's behavior
7. Do you have any concerns about Grace's anxiety? What are they? How does anxiety affect her behavior?
8. What teaching strategies /techniques have you seen yielding progress with your daughter's social and academic performances at school and at home?
9. Comment about Grace's muscle control concerns/shaking of hands. What triggers it? How is it handled?
10. Describe Grace's obsessions with food or any nutritional concerns? How does this affect her?
11. What have been your greatest concern/fears in Grace's entire school life? How about when she is at home?
12. What has been your experience working with supportive staff such as social workers, occupational therapists and speech therapists?
13. Briefly explain your challenges as a mother/father of a child with LKS.
14. Comment on any concerns about Grace's sleeping patterns if any.
15. What is the role of collaboration when working with Grace?
16. What are the transitional plans on future residential matters?

## **Administrators**

1. Introduce yourself capacity and duration in which you worked with Grace.
2. What are the challenges you faced as an administrator serving Grace? How were they addressed?
3. What is the role of collaboration in serving Grace?
4. What really used to trigger Grace's physical and aggression behavioral problems?
5. What was the implication of having Grace in your school?
6. What role have you played in supporting Grace?
7. How has Grace's behavior affected other students in your school?
8. How has Grace's behavior affected teachers and other adults in the building?
9. What have been your concerns having Grace in your school?
10. What were the physical classroom arrangements for the student?
11. In general how was her school routine and time of attendance, etc.? How did you arrive at it?
12. Were there any legal concerns or fear of them?
13. Have you had any other child with LKS in your school before?

### **School Nurse**

1. Introduce yourself and explain your role in Grace's life.
2. What health concerns did Grace have?
3. What other concerns did you ever notice while working with Grace?
4. What exactly did you do for her?
5. Describe challenges working with her parents.
6. Describe challenges working with Grace.



## Appendix C

Forms for collecting behavior data.

Goal: Escaping from class

**Behavior:** Grace attempts to leave the classroom, and/or remains out of the classroom after leaving

**Directions:** Mark + if behavior is observed, continue with plus if student successfully leaves the classroom. Mark o if not observed, or when behavior ends. Each interval, or empty square, is one minute; each row represents a half hour time period.

Time	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	Comments
7:30-8:00																															
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