Parents as Change Agents in Their Schools and Communities: The Founding of Families for Early Autism Treatment (FEAT)

Bethany Kristin Mickahail

University of Denver

Follow this and additional works at: https://digitalcommons.du.edu/etd

Part of the Disability and Equity in Education Commons, Education Policy Commons, Oral History Commons, and the Special Education and Teaching Commons

Recommended Citation
PARENTS AS CHANGE AGENTS IN THEIR
SCHOOLS AND COMMUNITIES: THE FOUNDING OF FAMILIES FOR EARLY
AUTISM TREATMENT (FEAT)

———
A Dissertation
Presented to
the Morgridge College of Education
University of Denver

———
In Partial Fulfillment
of the Requirements for the Degree
Doctor of Philosophy

———
by
Bethany K. Mickahail
June 2010
Advisor: Dr. Ellie Katz
Abstract

A qualitative research highlights how parent driven “communities of support” create lasting change in schools and communities, through the unique blend of the two methodologies, oral history and educational criticism and connoisseurship.

In recent years, schools and communities are unusually impacted by an escalating wave in the diagnosis and treatment of persons with Autism. In 2010, the Center for Disease Control’s Report stated 1 in 110 U.S. children are diagnosed with Autism. Yet long before this official report, parents and professionals affected by Autism and other disabilities were busy during the last half of the 20th century, seeking out ways to treat, cure and increase the quality of the children’s lives. They were part of the disability advocacy movement that forged legislation in special education, pre-school early identification/education and pioneering therapeutic treatments.

Among these pioneering early groups in the Autism community, are the parents and professionals who founded FEAT (Families for Early Autism Treatment), in 1994. Their intent was to promote high quality school programs and services for children with Autism. Their creative efforts serve as a model for parents of children with disabilities everywhere. Through perseverance and concerted action, they channeled their personal
loss and grief into a positive force, creating a community of support advocating for change in their schools and community.

This research discovers valuable information about parent organization efforts, perspectives of FEAT’s strategies, along with practical applications for a model which may be useful for other parent organizations seeking to change their schools and communities.

A hybrid research methodology was implemented. Building on the qualitative design of oral history; this research records and interprets living disability rights history. Utilizing Eisner’s educational criticism and connoisseurship, it also illuminates research results with an enlightened pen, through poetic representation. These two qualitative methodologies, oral history and educational criticism and connoisseurship, guide the data collection, analysis, interpretation, and literary presentation of this research. The parents and professionals, as the five founders of FEAT were interviewed three times and tape-recorded. The tapes were transcribed, studied, analyzed and poetic representations of their personal insights were written and displayed.

Answers to the research questions were gleaned through analysis, highlighting the founders' challenges, resources, the impact of their efforts, and a detailed list of recommendations for other parents, community leaders and educators.

Through the technique of educational criticism and connoisseurship, research findings were further analyzed. The themes emerging from this study are: direction for advocacy, building for change and impact of legacy. The founders' insights and
perspectives of their life experiences provided study implications focusing on the autism
related issues of urgency, advocacy, effective treatment, public awareness, research,
policy planning and communities of support. Resulting recommendations hold
significance for those who work with and advocate for persons with autism and/or for
those who make policies that guide autism research, services and programs.
Acknowledgements

Open minds, open hearts which
open doors, and open up
once unopened roads
to unopened lives.
- B.K. Mickahail

In contemplating who to acknowledge for their contribution to this research, I
must first express sincere gratitude to the FEAT founders, those who have spent years of
personal toil and self sacrifice as “pioneers” in the wilderness of advocacy for children
with Autism. Without their efforts and life stories I would have no topic to drive my
research.

Special thanks are extended to my dear friends and family; to my loving husband Al
who always expressed enthusiasm for my work, my daughter Kristina who along with my
friend Gail Reiger served as an extra pair of eyes and ears to ensure the manuscript’s
accuracy. Acknowledgements must be made to my committee members; to my advisor,
Dr. Ellie Katz, who’s gentle encouragement and interest in the topic facilitated the
completion of this work, and Dr. Bruce Uhrmacher, Dr. Nick Cutforth and Dr. Roger
Salters, for their valuable guidance.

I dedicate this work to my wonderful husband and children and the beloved memory
of my late mother, Dr. Beverly Malmstad. Lastly, I express gratitude for my effervescent
son, Dimitrius, who is my daily inspiration to do justice, love mercy, walk humbly and
give thanks (Micah 6:8, Psalm 28:7).
# Table of Contents

Abstract ..................................................................................................................................................... ii

Acknowledgements ................................................................................................................................... vi

Table of Contents ..................................................................................................................................... vii

Chapter One: Introduction to the Study ................................................................................................. 1
  Significance of the Study ......................................................................................................................... 3
  Purpose of the Study ............................................................................................................................... 4
  Research Questions Guiding the Study ................................................................................................. 5
  Overview of the Literature .................................................................................................................... 6
  Overview of the Research Method ........................................................................................................ 8
  Organization of Research Project ......................................................................................................... 10
  Definition of Terms ............................................................................................................................. 13

Chapter Two: Literature Review ............................................................................................................ 15
  Overview ............................................................................................................................................... 15
  The Who of Change: Parental Involvement ......................................................................................... 18
    Paradigm Shift .................................................................................................................................... 23
    Parents as Community Organizers .................................................................................................... 26
    Parents as Change Agents: The Ultimate Stakeholders ................................................................. 26
    Impact of Parent Involvement ........................................................................................................... 28
    Parent Leadership Models ................................................................................................................ 30
    Partners in Policy Making ................................................................................................................ 31
    The Council of Parent Attorneys and Advocates (COPAA) .......................................................... 31
  The What of Change: Pioneering Efforts ............................................................................................. 33
    Early Advocates for Special Services in Public Schools ................................................................. 33
    Advocacy and Legislation in the Disability Movement .................................................................. 34
    Summary of the Literature on Parents as Change Agents .............................................................. 35
    Recent Legislative Efforts for Autism Research .............................................................................. 38
    The Children’s Health Act of 2000 ................................................................................................. 40
    A Brief History of FEAT .................................................................................................................. 42
    Summary of the Literature on the Why of Change ....................................................................... 43
  The How of Change: A Conceptual Framework to Study Change .................................................. 43
    Kotter and his Change Model ............................................................................................................ 44
    Educational Policy Implications ....................................................................................................... 46
  Summary of the Literature Review .................................................................................................... 47
Appendices ..........................................................................................................................234
  Appendix A: Conceptual Framework .................................................................234
  Appendix B: Interview Protocol .................................................................235
  Appendix C: Informed Consent Form ........................................................239
  Appendix D: Letter of N. Fellmeth .............................................................243
  Appendix E: Interview Guidelines .............................................................244
List of Figures

Figure 1. Conceptual Framework. .................................................................19

Figure 2. Kotter's Eight-Stage Change Model for Interviews .........................20
Chapter One

Introduction to Study

Personal inclination made me an historian. Personal encounter with public policy made me an activist. —Paul Longmore

Autism is a brain disorder that affects an individual's ability to communicate, reason, and interact with others. It usually manifests around the age of 12-18 months in young children with a range of developmental and social delays. In most cases it is a debilitating condition that requires early intervention, continuous special education services, and lifelong adult support services. Autism, once a rare and largely unknown disability, is on the rise. The number of children diagnosed with this serious disability is growing. Recent reports in the media have informed the general public about what some are calling a hidden epidemic, which is monitored by the Centers for Disease Control and Prevention (CDC, 2009; MSNBC, 2005; Newsweek, 2005, 2006; UPI, 2009). The number of children diagnosed with Autism and the Autism Spectrum Disorders (ASDs) has grown from an estimated one in 2,500 to 5,000 children in the 1970s (Autism Society, 2009), to one in 110 (CDC, 2009). It is estimated that as many as 1.5 million Americans currently have some form of Autism. According to statistics from the U.S. Department of Education and other governmental agencies, Autism is growing at the
alarming rate of 10% to 17% per year. Based on these data, the Autism Society (2009) estimated that the number of Autism cases could reach 4 million in America over the next decade.

In 2009, the CDC's *Morbidity and Mortality Weekly Report* found "an average of one in 110 U.S. children age 8 have an Autism spectrum disorder. One-in-70 U.S. boys and 1-in-315 girls have an Autism spectrum disorder—an average 60 percent increase for boys and 48 percent for girls" (UPI, 2009). The latest statistics released by the CDC in December 2009 highlighted new data on the prevalence of ASDs, which translates to over half a million persons with ASD in the United States alone. This ratio is, actually, higher than the aforementioned estimate of one child in 110 having some form of ASD, as reported by Stein (2009). Autism is the fastest growing developmental disability; its numbers have increased by 57% in the last 4 years (CDC, 2009; DeNoon, 2009).

Despite the prevalence of numerous medical, psychosocial, emotional, and physiological theories, there are no conclusive answers available related to cause, prevention, or cure of this modern affliction. Publicly funded medical research institutes such as the Medical Investigation of Neurodevelopmental Disorders (M.I.N.D.) Institute at UC Davis and many legislative initiatives such as the Combating Autism Acts of 2005 and 2006; the Individuals with Disabilities Act (IDEA) of 1975, 1997, and 2004; California's Lauterman Act of 1969 and 1974; and President Obama's campaign commitment of $1 billion of annual federal spending on Autism by 2012 have been forged by strong parent advocacy efforts to fight, treat, and research the causes of developmental disabilities and ASDs.
Autism is not retreating. It cannot be ignored. It is impacting the ways in which schools and communities serve, educate, and embrace people who have this disability. The disability rights movement in the United States has been instrumental in initiating and perpetuating the socially progressive goals of school inclusion, community support, integration, and meaningful participation and contributions by people with disabilities. Parents of children with disabilities share these values and work hand in hand with disability advocates from all segments of society.

It is the vital efforts of parents of children with Autism that this research sought to interpret, record, and preserve for posterity. It is through the study of their history, in the context of the continuing struggle of the disability rights movement, that we can learn, understand and appreciate the evolving social and educational progress in America. Valuable public policy discoveries and considerations have emerged through this research as well.

**Significance of the Study**

The implications of this research for educational policy, as well as practice, are manifold. As the number of school children diagnosed with ASD continues to rise, policy makers, school administrators, concerned community members, and teachers, together with parents, will continue to seek best practices to meet the growing needs of children with Autism. Schools and communities are required by law to respond constructively and proactively. Parents of children with ASD relentlessly seek out programs and solutions to help their children learn and normalize. In turn, parents need organizational models such as Families for Early Autism Treatment (FEAT) to empower their efforts. This research
sought to answer some of the larger questions still remaining: How can schools and communities positively and constructively respond to an Autism health crisis, as the numbers continue to rise? How can FEAT serve as a model of positive social action for other parent organizations seeking to become change agents in their schools and communities? And how can these research findings serve as a model to empower other parent social-action organizations in the realm of public education?

**Purpose of the Study**

The purpose of this study was to explore the primary research question: What has been the experience of parents of children with Autism who are also founders of the parent organization FEAT? This question was examined, through several secondary research questions, parental involvement and advocacy efforts and the history of disability rights in the context of social action theory.

This study was based on a comprehensive review of the literature about parent involvement, parents' role in advocating disability legislation related to special education programs, service delivery and support, along with oral history projects related to the disability rights movement in the 20th century. Most research on disability rights focuses on advocates who are physically disabled, deinstitutionalization, independent living, and accessibility issues such as access to public buildings, including schools. The bulk of disability-related legislation and recognized advocacy efforts took place on the heels of the Civil Rights Movement in the late 1960s and 1970s.
Recent research into positive parent advocacy efforts for their children is related to their role in lobbying for specific educational and entitlement legislation, such as PL 94-142, and the establishment of service agencies, such as the ARC (UC Berkley, 2004). This research built on the history of parent advocacy efforts that established public school programs for children with special needs. It extends and describes the living experience of parents of children with Autism and their roles as change agents for improved special education interventions and programming in their schools and communities through the parent organization FEAT.

Research Questions Guiding the Study

The research questions related to parent involvement and advocacy efforts were as follows:

1. How did a particular group of parents establish the advocacy organization Families for Early Autism Treatment (FEAT)? These parents advocated for change in school programs that benefited the development of their children who have Autism. Their efforts have also significantly contributed to the establishment of FEAT, as well as to the M.I.N.D. Institute at UC Davis, which has the purpose of conducting research into the prevention, causes, and treatment of children with Autism and other brain-related disabilities.

2. How did FEAT parents create change in their schools' programming and services for children with Autism through their advocacy efforts? How did their efforts become a catalyst for school change in their community of Sacramento, California? What factors contributed to their success in working with schools, teachers, and administrators?
How have they maintained their strong membership and activity levels over the past two decades, since they organized themselves in 1993?

3. What is the import of their experience? Of what benefit might FEAT experience be to other parent advocacy groups? What advice do they give to other parents who advocate for change in their schools and communities?

An extensive framework was designed to structure these research questions into, at least three, interviews, based on Kotter’s Eight-Stage change model. A discussion about the research-interview process is presented in Chapter Two (Figure 2).

**Overview of the Literature**

The review of the literature is rooted in the research into parent engagement, community leadership, disability legislation, and the recent health crisis of Autism, which has spawned a wave of extraordinary parent advocacy efforts to change public policy, schools, and communities. Little has been written to date about the role of parents as change agents and their significant contributions to shaping the public policy that drives the educational and service-delivery models for children with Autism. This study was also directed and shaped by its conceptual framework of the Who, What, Why, and How of Change. It is summarized in Figure 2: Conceptual Model for the Literature Review.

The literature review begins with research into the Who of Change: parents of children who have Autism and other disabilities, and their involvement in their schools and communities. A dearth of research exists regarding the early history of parental engagement in special education for their children. However, the existing research indicates that a major paradigm shift occurred, over the last few decades, in the general
and special education fields' perceptions of parents and their involvement. New perceptions of parents evolved as the education professionals developed an appreciation for family-centeredness, partnerships, and collaborative supports in the education of typical children and children with disabilities. Parents, once viewed as passive observers, now are often encouraged actively to participate.

The literature highlights the radical shift, which now supports parental engagement as a vehicle for positive change in schools and communities. The role of parents as community organizers, change agents, and models for quality and leadership are presented through examples in the literature.

The What of Change is examined in the literature through an overview of what parents accomplished as early pioneering advocates for special services in public schools. As they learned from their friends in the Civil Rights Movement of the 1960s, they became not only change agents, but also models for the next wave of parent for school change in the 21st century. The work of parents as citizen advocates for high quality disability services and support in our democratic republic is chronicled.

The research on parent participation indicates that, as parents engage in public-education advocacy, they are empowered to become leaders, promoting important educational programming, best practices, and legislation related to their children's educational progress and the research into the treatment of their disabilities. To pursue these goals locally and nationally, parents formed groups. The early pioneers in the 1950s and 60s served largely through volunteer neighborhood basement gatherings. Some of these volunteer groups were later funded by private and federal money as their important
roles as educators, partners, resources, and advocates were affirmed by the legislation they forged (e.g., the IDEA of 1973, 1998, and 2004).

The literature further delves into the Why of Change through research on the rising numbers of Autism cases. Some disabilities remained relatively constant in numbers, while Autism incidences increased from one in 10,000, some 15 years ago, to the present ratio of 1:110 schoolchildren (CDC, 2009). In response, parents of children with Autism are another wave of volunteer parent advocates, establishing their own grassroots support groups as springboards for significant activism in educational programming, health care, and political arenas. The uniqueness of FEAT stands out among these groups. It emerged early within the Autism community to become not only an effective parent organization over the last 15 years, but also a vehicle for forcing significant changes in school communities and state public policies. FEAT is fueled by the enthusiasm and hard work of volunteer parents of children with Autism.

The How of Change is addressed through Kotter's (1996) change model, as a conceptual framework for studying planned change. Among many existing change models such as those proposed by Senge (1990), Wheatly (1992, 1997), and others, Kotter's (1996) model is the most appropriate for studying strategic change. The Kotter change model was, therefore, the tool chosen to study FEAT as a force of change in local schools and communities, which is the focus of the present study.

**Overview of the Research Method**

This study used a hybrid qualitative research design, which combined the formal approaches of educational criticism and connoisseurship (Eisner, 1998) and oral history
to record the personal life insights of the founders (Mears, 2005). This methodology facilitated the identification of themes and motifs as they emerged from the founders' living memories.

Oral history was the most appropriate venue through which the intricately woven accounts of the founders were collected. The strength of qualitative research was heightened by the oral history approach with its emphasis on the perceptions, or stories, of the parents' views, experiences, and situations (Berg, 1989).

A representative, purposive, nonrandom sample of four parents and a professional was chosen for this research. These founders are all members of the original FEAT group, established in 1993, to improve the early-intervention and service-delivery system for children with Autism in the Sacramento area schools and communities. The founders had the opportunity to participate in three individual interviews. Each interview was approximately one hour in duration, with the second and third interview were completed within the initial 30 days of the study. The interviewees' stories revealed the meaning of their lived experience (Yow, 1998) as advocates and change agents for children with Autism.

The interview question protocol followed Kotter's (1996) Eight-Stage change model (Appendices A), beginning with Stages 1, 2, and 3. The second interview covered Stages 4, 5, and 6. The third interview addressed Kotter's Stages 7 and 8 and also included questioning into the founders' reflections on the past and future work of FEAT. Through the hybrid qualitative research design of oral history and educational criticism and connoisseurship (Eisner, 1998), this researcher applied an *enlightened pen or poetic*
representation (p. 31), for artful presentation and to express the aesthetic (literary) meaning of the interviews. The interviews constitute the data of this research.

The interviews of participants were conducted according to the requirements of the Institutional Review Board (IRB) and the oral history guidelines (UC Berkeley, 2005; Yow, 1994). The founders as interviewees were asked to sign an Informed Consent Forms (Appendix B), granting permission for tape recording and protection during the interview. The founders decided whether they wanted to remain anonymous or be identified. After each interview was transcribed and displayed in the poetic representation format (Glesne 1997), each founder was asked to review the data and make appropriate corrections for accuracy and member-checking purposes. Then, the data were analyzed by using the methodology of Eisner's (1998, p. 88) educational criticism and connoisseurship, and the dimensions of educational criticism (i.e., description, interpretation, evaluation, and thematic) were applied.

**Organization of Research Project**

This study is presented in seven chapters. Chapter One discusses the significance and purpose of the research. In chapter Two, a detailed review of the literature related to parental engagement and advocacy with the disability movement is presented. Research methods and concerns with Institutional Review Board (IRB) compliance are outlined in chapter Three. Each founder is introduced and his or her interview is displayed as poetic representation in chapter Four. In chapter Five, the original research questions are examined through evaluative and interpretive research perspectives. Themes and
significant meanings are further explored in chapter Six. In the last chapter, chapter Seven, implications of the research and conclusions are discussed.


**Definition of Terms**

For the purposes of this research, the following terms were operationally defined as follows:

**Applied Behavioral Analysis (ABA):** A science that studies how principles of behavioral conditioning can be applied to learning, pioneered by Dr. O. Ivar Lovaas in the 1970s at UCLA (Siegal, 2003). The ABA is the science of understanding the functional relationship between behavior and conditions. Therapists use data to develop hypotheses about why a behavior occurs in a particular situation without attention given to cause or etiology. In this way, the ABA is a therapy approach for systematically modifying of the behavior of children with Autism to improve their communication, adaptation, and social skills (Jensen & Sinclair, 2002; Simpson, 2001).

**Autism:** A neurodevelopmental disorder that now affects an average of one in every 110 children in the United States or 1% of the U.S. school-age population (CDC, 2009). Commonly diagnosed by the age of 3 years, it is characterized by varying degrees of impairment in communication skills; social interactions; and restricted, repetitive, and stereotyped patterns of behavior. Several treatments are in use, but there is no definitive
cure for Autism. Children with Autism can exhibit symptoms that run from mild to
severe, with widely differing symptom profiles. Research indicates that Autism may
result from an innate challenge in the ability to utilize and control expressive movement.
As a result, the autistic individual in severely challenged in his or her ability to keep body
movements, including sensory responses, under control. These sensorimotor problems
make it difficult to respond normally, consistently, and productively to others and to the
environment (Autism National Committee, 2009).

_Autism Spectrum Disorder (ASD):_ A diagnosis of Autism that occurs anywhere
along the spectrum of the disability, from milder forms such as Asperger's syndrome or
Pervasive Developmental Disorder (PDD) to more severe manifestations of the disability.

_Disability Rights Movement:_ The struggle of people with disabilities to gain
access to the mainstream of American life. Disability advocates' efforts resulted in the
passage of landmark disability rights legislation (begun on the coattails of the greater
Civil Rights Movement of the 1960s). Additional groundbreaking legislation included the
passage of Section 504 of the Rehabilitation Act, in 1973, the nation's first civil rights
law for persons with disabilities; Mills v. Washington, DC, Board of Education, in 1972,
which laid the foundation for the Education for All Handicapped Children Act (EAHCA)
of 1975, which was later amended and renamed the Individuals with Disabilities
Education Act (IDEA), in 1990. Also in 1990, the landmark civil rights law Americans
with Disabilities Act (ADA) was signed into law by President G. H. W. Bush.
Educational criticism and connoisseurship: A research method that emphasizes the perception of qualities, the interpretation of significance, and the giving of public form to the content of consciousness (Eisner, 1998).

Enlightened pen (researcher): A way of presenting analyzed research data (as gleaned from interviews) in aesthetic poetic representation. This concept is similar to the appreciation an art critic experiences when viewing and reviewing visual art, as described in Eisner's (1998) book The Enlightened Eye.

Medical Investigation of Neurodevelopmental Disorders (M.I.N.D.): Founded in 1998 at UC Davis, the M.I.N.D. was established through the initiative and fund-raising efforts of four fathers who had children with Autism. UC Davis established the institute with a unique interdisciplinary focus to study neurodevelopmental disorders (e.g., Autism, Fragile X syndrome, and other brain-related disabilities). The M.I.N.D. Institute is a collaboration of parents, community leaders, volunteers, researchers, and clinicians who combined their available resources at UC Davis and the greater University of California system to study three major areas of related to brain disorders: research, treatment, and education.

Oral History: The oral history method involves interviewing people who have shared or participated in some experience, location, or moment in the past, so they can tell their experiences, perceptions of events, details of their recollections, and understanding of these memories.
Poetic representation: In this research study, poetic representation (Glesne, 1997; Miles & Huberman, cited in Mears, 2005) is a way of showcasing and artfully organizing analyzed data (collected through interviews) for meaningful literary appreciation.

Social action: Weberian types of social action (antipositivism, a.k.a. humanistic sociology), are identified by the mode of orientation: "We can accomplish something which is never attainable in the natural sciences, namely the subjective understanding of the action of the component individuals" (Weber, 1924, p. 24-25).

The Children's Health Act of 2000: The first federal legislation addressing Autism. It established the Interagency Autism Coordinating Committee (IACC) to coordinate all efforts within the Department of Health and Human Services concerning Autism, including activities carried out through the National Institutes of Health (NIH) and the CDC.

The Combating Autism Act of 2005 and 2006: The Act provided grant programs for every state to develop Autism screening, early diagnosis, and intervention programs for children: Medical News Today (2005) reported that the Act provides the following:

Twice the number of NIH Centers of Excellence Programs for research on Autism. Expansion of the National Institute of Child Health and Human Development Collaborative Programs of Excellence in Autism. Funds for CDC epidemiological surveillance programs. Establishment of Centers of Excellence regarding environmental health and Autism. Reauthorization of the Interagency Autism Coordinating Committee (IACC), established in the Children's Health Act of 2000, to coordinate all efforts within the Department of Health and Human Services concerning Autism, including activities carried out through NIH and the CDC.

The Lauterman Act 1974, California: In 1969, AB 225 (Lauterman Mental Retardation Services Act) established a statewide system of regional centers based upon
pilot projects. In the first 3 years of operation, there were seven regional centers statewide; since then, the number of regional centers has grown to the current number of 21. In 1974, additional legislation (AB 846-Lauterman) went into effect, which expanded the clientele served by the regional centers to include persons with cerebral palsy, epilepsy, Autism, and other significantly handicapping conditions found to be closely related to mental retardation. Regional Centers currently serve approximately 207,000 people with disabilities in the state of California.
Chapter Two

Literature Review

Overview

Before delving into the research of parents as change agents, it was necessary to examine the existing literature on the Why, Who, What, and How of Change as it relates to this topic. What is the Why of change for this research focus? It is the crisis of Autism. Autism is occurring in alarming numbers. A recent briefing by the CDC (2009) reported that Autism is occurring in one of every 110 school children.

Who could possibly be more impacted by this crisis than even the primary Who, the children with Autism, but their parents? The parents of children with Autism and their quest for quality services and support in their schools and communities is the second area of this review of the literature. The What of Change touches upon my original research questions: What has FEAT (as a group of active and informed parents) accomplished? Another primary concern of this research was the How of Change. How have FEAT parents accomplished the necessary and effective changes in their schools and communities to meet the needs of their children with Autism?

This review examined the Why, Who, What, and How of Change as it specifically relates to the Autism crisis and the parents and children impacted by this crisis, and it studied groups that have forced positive change in the educational disability community. Thus, not all aspects of the literature could be explored. This literature review focused on
research and other pertinent literature from various fields that have examined the links and collaborations that promoted change as outlined in the Conceptual Model (Figure 1).

Following is a description of the pictorial representation in Figure 1, which shows how the literature review is organized:

1. The Who of Change: Parent Involvement—from passivity to change agent
   - Paradigm shift from power-over-parents to parent engagement
   - Parents as community organizers
   - Parents as change agents—a definition
   - Impact of parent involvement
   - A parent leadership model
   - Parents as policy makers
   - The Council on Parent Attorneys and Advocates

2. The What of Change: Pioneering Efforts
   - Early advocates for special services in public schools
   - Advocacy and legislation in the disability movement
   - Parents as change agents—a 21st century democratic model for institutional (school) change

   - Recent legislative efforts for Autism research
   - The Children's Health Act of 2000
   - Parents and the Autism crisis: A brief history of FEAT
4. The How of Change: A conceptual framework for studying planned change

- Kotter's Eight-Stage change model
- Educational policy implications

**The Who of Change: Parental Involvement**

Historically, the education community did not perceive parents as potential sources of information about their children's disabilities. There was an apparent failure to acknowledge the important role of families as experts on their children. Perhaps, this was due to the traditional hierarchy of power and knowledge in special education. However, this paradigm counters the increasingly accepted principle of family-centered services and collaboration in recent decades.
Figure 1: Conceptual Framework
What has been the experience of parents of children with autism who are also founders of FEAT (Families of Early Autism Treatment)?

Overarching question: What has been the experience of parents of children with autism who are also founders of FEAT (Families of Early Autism Treatment)?

1. How did they establish the dynamic advocacy organization, Families for Early Autism Treatment (FEAT)? What does advocacy mean to them?

2. How do they create change in their schools' programming and services for their children? When successful, what factors contributed to their working with schools, teachers and administrators?
   a. Have they maintained their strong membership? What has been their activity level over the last decade since they were first established in 1994?

3. What's the import of their experience? Of what benefit would the FEAT experience be to other parent advocacy groups?
   a. What advice do they give other parents of children with disabilities?

**Figure 2:** Kotter’s Eight Stage model as Framework for studying planned change
Paradigm Shift

Until recently (and still prevalent in resistant corners), there was strong emphasis on unidirectional education from professionals to parents in special education. This conflicted with one of the key components of the principle of family centeredness—a strengths perspective (Allen & Petr, 1996, p.68). The strengths perspective acknowledges the expertise of parents and other family members and their contribution in working with education professionals. The vital resources parents provide to professional and community partners cannot be dismissed. This collaboration enhances the child's and his family's quality of life.

More research is needed that focuses on validating parents as providers of education to other parents and professionals, as it relates to meeting the needs of children with disabilities. Some recent research findings indicated that parents who use parent-to-parent services benefit from the contact with other parents. Such contacts help parents feel better able to cope with their child and family situation. Parents, as a result, view their child and family circumstances in a more positive light, and their child as making progress on important goals (Singer, 1996). Parents also reported that they found parent-to-parent assistance particularly helpful because of perceived likemindedness, similar parenting experiences, and opportunities for learning through the exchange of ideas and mutual support (Ainbinder et al., 1998).

A push to focus on parent-professional partnerships in education now exists. This includes an effort in the early-intervention special-education community to work collaboratively with local and state parent-to-parent programs. Parent-to-parent funding
and support from Part C (federal preschool early intervention funds) have expanded to underwrite the valuable educational resources that develop from family–professional partnerships in the provision of education for children with disabilities. As educational professionals learn to value parents as resources and community members, it is necessary to build a system that supports parents to take on this additional educational role (Sanders, 2000; Santelli, Turnbull, Marquis, & Lerner, 1997; Siegal, 2003).

The federally funded Parent Training and Information Centers, also provide educational support to families. These centers seek to enable parents to secure their rights under federal and state laws. Parent Centers are located throughout the nation and provide comprehensive educational resources that can form the basis of family-professional partnerships. Some of these centers are specifically developed to provide information to families about the IDEA, which mandates that children with disabilities receive a "free and appropriate education in the least restrictive environment" (IDEA, 2004). Examples of Parent Training and Education Centers are located at the PACER Center in Minneapolis, Matrix in the North Bay area of greater San Francisco, and the PEAK Parent Center in Colorado Springs.

Experts on early intervention have routinely advised schools about the need to provide positive avenues for parental involvement (Baker & Soden, 1998; Ballen & Moles, 1994; Epstein, 1995; Henderson & Berla, 1994; Radclif & Nathan, 1994; Swap, 1993). This includes the sharing of authority for school management and decision making, as well as their contribution to the learning community.
The No Child Left Behind (NCLB) Act of 2001 further mandated parent involvement in education at large (Adams, 2002). The NCLB sought to empower parents. Parents would have more information about the quality of their child's school. Students in persistently low-performing schools were given choices. Adams wrote, "This also involves a system of greater accountability and higher teaching standards for all students, including those with disabilities" (p. 35). Title II of the NCLB further stated, according to Adams,

[The NCLB] empowers Parents with Teacher Quality Information. Parents have a right to know if their child's teacher is effective. Local districts, upon the request, are required to disclose to parents information about the quality of their child's teacher, as defined by the state. (p. 35)

Some projects that promote parent involvement were the networks of the Parent Teacher Association (PTA, 2005), which have been the usual vehicles for parent involvement over the past several decades. The PTA has over 800,000 members and a history of child advocacy and parent training. The PTA works to support and speak on behalf of children and youth in the schools, in the community, and before governmental bodies and other organizations that make decisions affecting children; to assist parents in developing the skills they need to raise and protect their children; and to encourage parent and public involvement in the public schools of this nation. (PTA, 2005, p.1)

Parents as Community Organizers

Parents can be encouraged to contact other parents with similar concerns to form their own community organization group. Home meetings can be vehicles through which children's school problems can be discussed, and parents develop strategies that best address these issues (Toseland & Rivas, 1995). In addition, parent groups help to set
priorities for action and a strategy for approaching school staff, petitioning the school board, and speaking out at school board meetings (Interfaith Education Fund [IEF], 1998).

Some parent programs have distinguished between parental involvement, which is passive and tends to maintain the existing school culture, and parental engagement. "Parental engagement views parents as citizens in the fullest sense—change agents who can transform inner-city schools and neighborhoods" (IEF, 1998, p. 333). Finding ways to expand parental involvement requires creativity and collaboration of both parents and schools.

**Parents as Change Agents: The Ultimate Stakeholders**

Few exact and specific definitions exist in the literature for what is meant by *parents as change agents*. However, the general concept of change agent in the business sector is described by McCalman and Paton (1992) as someone who "facilitates change in the particular area in which it is needed" (p.144). Other researchers identified change agents as those with expertise (in this case parents who are also experts about their disabled child's needs), which includes 15 competencies in five overarching groups. These competencies are articulated by Buchanan and Boddy (1992), as (a) goals (sensitivity, clarity, flexibility), (b) roles (team building, networking, tolerance of ambiguity), (c) communication (communication, interpersonal skills, personal enthusiasm, stimulating motivation), (d) negotiation (selling, negotiating), and (e) managing up (political awareness, influencing, having a helicopter perspective).
Other researchers in the management field reflected similar, if less elaborate, perspectives (Butcher & Atkinson, 2001; Cripe, 1993; Werner & Lynch, 1994). An effective change agent must not only have limitless energy, confidence, intelligence, common sense, and a dedicated work ethic, but also possess the ability to increase dissatisfaction with the status quo and meet resistance or rejection with persistence. A parent as change agent embodies what Helen Keller (1991) described when she said, "To keep our faces toward change and behave like free spirits in the presence of fate, is strength undefeatable" (p. 122). In other words, the most qualified change agent is uniquely gifted to lead and never give up. Many parents, on the path to improving their children's future, seem to embody these descriptions of the term change agent.

**Impact of Parent Involvement**

The positive effects of parental involvement for children are well documented; less is known, however, about promoting their productive participation or which practices schools might use to maximize their investment in family-school connections (Baker & Soden, 1998; Singer et al., 1999). Some U.S. Department of Education studies found that, more influential than family attributes (e.g., marital status, family size, level of parents' education, student grade level, or even socioeconomic status) is how schools encourage parental participation. The latter is more useful to predicting whether parents will get involved (Dauber & Epstein, 1993). When school administrators and staff demonstrate a sincere interest to involve parents (by considering their needs), parent involvement rises correspondingly (Collins, Cooper, & Whitmore, 1995).
Research indicated that parent involvement in the education of their children, regardless of any disabilities, is essential for their success in school (Green & Nathan, 2005; Henderson & Berla, 1994; Seligman & Darling, 1997). However, some barriers exist that hinder full parental engagement. Often, poor school communication to families limits trust on the part of parents, who might feel humiliated by their children's lack of educational progress, especially the parents of children with disabilities. These barriers to parental involvement need to be addressed to promote the learning potential of all children (McWilliam, Maxwell, & Sloper, 1999).

When it comes to partnering with parents in primary and secondary education, sustaining family involvement requires a commitment to open, continuous, two-way communication with families. Most schools have established methods of one-way communication with parents, but the need for more two-way communication cannot be emphasized enough. It is important for educators to take the time to listen to parents. The attitudes and practices of teachers and principals make a difference in the extent of parental involvement and in the achievement of students (Dauber & Epstein, 1993; McWilliam et al., 1999). Sometimes, educators overlook what they can learn from families. Families are rich sources of information that can be used in the classroom. Parents have interacted with their children, and they know many of their learning styles as well as their strengths and weaknesses. Partnerships with families require that all participants share the responsibility for educational outcomes. This perspective represents a major shift for schools from merely delivering services to students to the families' taking active, integrated roles that validate the importance of family (Sanders, 2000). To
succeed in this partnership role, the staff needs to ask parents for their ideas, meet with parent and community representatives to define goals, and develop a plan for parent and community involvement.

The ways schools can promote parent involvement should include accommodating the parents' work schedules by arranging meetings at a time when parents can be available. They should also include providing ways that both mother and father can participate in the education of their child. It is clear that, when parents engage in partner learning activities (such as homework and shared reading assignments) with their children, all parties benefit. According to Ballen and Moles (1994), some educational interventions, which both schools and parents can implement to increase communication and involvement, include training teachers to work with parents and to view them as partners in the education of their children; arranging contacts in neutral settings; offering informal classes in parenting, ESL, GED, or other topics of interest; arranging transportation for parents to attend school meetings; hiring a home-school coordinator to develop programs and act as a liaison between teachers and families; encouraging mothers and fathers to attend and speak out in steering committees and task forces; and promoting an active PTA and other parent groups.

Finally, more research is needed to understand what types of parental involvement are most beneficial. It is not clear, for instance, what the optimal level of participation is, at what point levels of involvement become less beneficial, and how the impact of involvement can affect parents' feelings about their children and their self-esteem.
Even without the answers to all these questions, it is clear that students achieve more when parents are actively engaged in their education, whether they are able or disabled. Parents can also work together with school officials to improve school policies and educational programs.

**Parent Leadership Models**

The Intercultural Development Research Association (IDRA), for example, has done work in creating a parent-centered model and a process for developing parental leadership in their children's education. The IDRA outlined four types of parental involvement with schools: (a) parents as teachers, (b) parents as resource, (c) parents as decision makers, and (d) parents as leaders and trainers (Montemayor & Romero, 2000). Each type values and acknowledges the assets that families from all cultural backgrounds, socioeconomic groups, and geographical areas bring to their children's education.

Such training models can help educators and family members take on new roles that are needed for more effective partnerships. Ongoing partnerships need evaluation and frequent checkpoints to see if their goals and objectives are being met and also if those goals and objectives are still appropriate. Keeping programs flexible helps everyone adjust to changes within the student body, families, the school staff, and the community.

**Partners in Policy Making**

Partners in Policy Making (PIP, 2007) was founded in 1987, in Minnesota, by the Governor's Council on Developmental Disabilities. It is one of the most forward-thinking
ventures. The PIP is a leadership training program for adults with disabilities and parents of young children with developmental disabilities. The program has two goals: to teach best practices in disability, and to develop the competencies of influencing public officials.

Partners programs have been implemented in 46 states, the Northern Mariana Islands, the Netherlands, the Virgin Islands, and the United Kingdom, since the PIP was conceived. PIP graduates number more than 13,000 and are part of a growing national and international network of community leaders serving on policy-making committees, commissions, and boards at all levels of government.

Partners in Policy Making (2007) was the first training venture in the curriculum of the Governor's Council, in 1987. It has since expanded to meet current needs with courses that can be completed in 3-8 hours online, titled Partners in Time, Partners in Education, Making Your Case, Partners in Employment, and Partners in Living.

The Council of Parent Attorneys and Advocates (COPAA)

Another groundbreaking group was the Council of Parent Attorneys and Advocates (COPAA, 2006). This independent nonprofit organization has as its main goal "to secure high quality educational services for children with disabilities." According to its Web site, the COPAA pursues the following objectives:

To enable parents to work more effectively with school personnel to plan meaningful educational programs for their children with disabilities.
To enable parents to work more effectively with advocates and attorneys to plan and obtain effective educational programs, thereby reducing the costs of representation of children with disabilities.

To encourage more attorneys and advocates to undertake representation of parents of children with disabilities in their efforts to plan and obtain effective educational programs.

To provide attorneys and advocates with the basic practical resources and information required to plan and obtain effective educational programs for children with disabilities.

To increase the qualitative level of representation for children with disabilities by establishing methods to obtain and exchange necessary information, training, and consultation relevant to planning and obtaining effective educational programs.

The COPAA (2006) also promotes collaboration with other associations and coalitions that share its values and support its work. For example, the COPAA is a member of the Consortium for Citizens with Disabilities (CCD), a national coalition of approximately 100 associations dedicated to the improvement of disability policy. Its work is also with CCD centers around its Task Force on Education.

Another, more recent COPAA (2006) collaboration took place with the University of Southern California's University Center of Excellence in Developmental Disabilities Research, Education, and Service. This project is funded by the U.S. Department of Education. The project's mission is to develop a curriculum for advocacy training, provide training to advocates at two field sites (the states of California and Pennsylvania),
and determine the feasibility of establishing national certification standards for special education advocates. This collaborative effort intends to improve the quality of advocacy training and develop a growing force of trained advocates.

The What of Change: Pioneering Efforts

Early Advocates for Special Services in Public Schools

Parents have been instrumental in shaping the special education laws and service delivery programs in their schools and communities. Parents of children with disabilities have pushed for changes in the public education system to obtain much-needed special education services and support for their children. The passage of PL 94-143, the Education of Handicapped Children Act (EHCA) of 1975, which later became the Individuals with Disabilities Act (IDEA) and Part C PL 105-17 of 1997, and the Lauterman Act of 1974 did not happen without parents' concerted and organized engagement in the political process to bring about significant and effective legislation for children with disabilities. Pioneering parent advocates, such as Gunnar Dybwad (UC Berkeley, 2004), fought the injustice of exclusion, which institutions for the disabled embodied. Dybwad was inspired by the strides that could be made and participated in the civil rights movement for persons with disabilities, known as the Disability Rights Movement.
Advocacy and Legislation in the Disability Movement

The Civil Rights Movement and related legislation of the 1960s, inspired parents' efforts to work in changing their schools and communities. However, now they also knew societal change and the elimination of prejudice would be slow. Essentially, attitudes cannot be legislated, and education is the next wave of any sweeping effort for reform.

The noted educator Paulo Freire (1970) promoted education as a means to transform society for the better. Freire wrote:

> Education either functions as an instrument which is used to facilitate the integration of generations into the logic of the present system and bring about conformity to it, or it becomes 'the practice of freedom', the means by which men and women deal critically and creatively with reality and discover how to participate in the transformation of their world. (p. 72)

Advocates for disability rights, which include parents of children with disabilities, have continued their efforts to effect change in society by engaging in what the famous sociopolitical theorist Max Weber (1968) called social action. Weber's social action theory is summarized in his own words, "We can [through social action] accomplish something which is never attainable in the natural sciences, namely the subjective understanding of the action of the component individuals" (pp. 24-25). Hannah Arendt (1998), a noted political writer and contemporary of Weber, asserted,

> Action would be an unnecessary luxury, a capricious interference with general laws of behavior, if men were endlessly reproducible repetitions of the same model, whose nature or essence was the same for all and as predictable as the nature or essence of any other thing. (p. 8)

Thus, it is through education and social action that parents of children with disabilities (and the parents and professionals of FEAT) hope to change their schools, communities, society, and the world.
Summary of the Research on Parents as Change Agents

Parents as citizens of a democratic republic effected change in their schools and communities by, first, defining the needs of their children with disabilities and, then, determining what policy issues needed to be raised in order to address these needs. With government funds and organizational training, they progressed over the last century from passive onlookers to active and vocal advocates. They and their allied networks lobbied U.S. government representatives for the legislation and needed appropriation to make their vision of support a reality for their children (i.e., the IDEA).

In sum, parents continued to pass on training methods and skills to the next generation of parents as change agents, who are continuing the wave of political involvement and organization continually to meet the needs of children with Autism and other disabilities in the 21st century. Lawyer advocates Peter and Pam Wright (cited in Knapp, 2006) contended:

The real catalysts for change are parents. Parents are the enforcers of IDEA, the special education law [the Individuals with Disabilities Education Improvement Act of 2004]. Parents represent their children’s interests so, in effect, they are the consumers of services. And it doesn't take an army of parents to begin to educate school board members and superintendents—or even to run for school board, and change the system at that level. . . . By the time you get 10 people together, you are becoming a powerful group. By the time you reach 25 or 50, you are a powerful organization and 'we'd better meet with you'. (p. 1)

The Why of Change:

Autism and its Rapid Increase—A New Health Crisis?

Less than 2 decades ago, Autism was an "orphan disease" (Wing & Potter, 2002, p. 152), a rare and largely unknown disability affecting one in every 10,000 children. At present, the CDC (2009) has declared Autism to be a spectrum disorder, which affects
one in every 110 school children. There is no doubt that the numbers of children diagnosed with this serious disability are increasing. Recent reports in the media, based on information released by the CDC (2007, 2009), alerted the general public to the growing health crisis manifesting as the current Autism epidemic (California Department of Developmental Services [CADDS], 2003; MSNBC, 2005; Newsweek, 2005; Wallis, 2009). In addition, researchers from the Harvard School of Public Health and the Mount Sinai School of Medicine found evidence that Autism might be linked to a wider silent pandemic caused by the pervasiveness of environmental pollution (Grandjean & Landrigan, 2006).

Nationwide, the number of identified children diagnosed with Autism and the Autism Spectrum Disorder (ASD) has grown from an estimated one in 2,500 – 5,000 children, in the 1970s (Autism Society, 2005) to one in 110, in 2009 (Paddock, 2010). In the state of California alone, the number of Autism cases has risen from 2,273 in 1987 to 20,377 in 2002 (California State Legislative Blue Ribbon Commission on Autism, 2006). Two decades later, there were over 30,000 more cases diagnosed (CADDS, 2006).

The U.S. Department of Education reported 1,700% more schoolchildren with Autism nationally in 2002 than in 1992 (Autism Society, 2005). It was estimated in 2005 that, every day, 50 children in the United States were diagnosed with some form of Autism, according to the Autism Society of America (2005), an advocacy organization in Bethesda, Maryland.

New medical, psychosocial, emotional, and physiological theories are released almost monthly, and yet there are no conclusive answers as to cause, prevention, or cure
of this modern affliction. Publicly funded medical research institutes (e.g., the M.I.N.D. Institute at UC Davis) and legislative initiatives (i.e., the Combating Autism Acts of 2005 and 2006; the IDEA of 1975, 1998, and 2004; and the California Lauterman Act of 1969 and 1974), have been forged by strong parent advocacy efforts to fight, treat, and research the causes Autism and other disabilities.

Often, obtaining special education services that should be given to children with Autism or other disabilities is problematic. Even though federal laws (PL 94-142; Part C of the IDEA; PL 105-17 of 1997 and 2004) mandate free and appropriate education services, the goals, methods, and resources available to families of children with Autism vary from state to state and from school district to school district. This presents a need for research into the composition and extent to which parents of children with Autism are receiving needed family-centered services (National Academy of Sciences [NAS], 2001).

Autism is impacting the ways in which schools and communities serve, educate, and embrace people who have this disability. Disability rights organizations (e.g., Centers for Independent Living, United Cerebral Palsy and the Down Syndrome Congress, Autism Now, and Autism Speaks) are working together to create quality support and services for children with disabilities in public schools and communities. They emphasize integration, meaningful participation, and the contributions of people with disabilities. Working together with parents of children with disabilities, they share these values with disability advocates from all segments of society.

This study recorded and interpreted the efforts of advocating parents of children with Autism. As their history is recorded for posterity, others struggling with similar
concerns will benefit and learn from these pioneers. We can all learn from their efforts to
force social, educational, and public policy changes to better the lives of people with
Autism. The efforts of active parents who created change in their schools and
communities are a legacy for many to emulate.

**Recent Legislative Efforts for Autism Research**

The rising wave of Autism cases has created an urgency to develop public
policies that specifically address this population's needs. Front running states such as
California, Washington, Colorado, and Kentucky and others, have established specialized
Autism task force committees to develop legislative public policy recommendations for
immediate emergency funding and implementation (Caring for Washington Individuals
with Autism, 2006; Kentucky ASD Comprehensive State Plan, 2006).

These efforts seek to meet the needs of the burgeoning population of persons with
Autism and aid in alleviating the potential strain on state educational, community,
vocational, housing, medical, and developmental-disability systems. These task forces are
uniquely composed of established advocacy and public-agency leaders from Vocational
Rehabilitation, Easter Seals, school districts and universities, medical research institutes,
Autism Speaks, Cure Autism Now, the California Department of Developmental Services
(CADDS), and FEAT. Each member brings his or her expertise and insights to the table
to develop groundbreaking public policy recommendations. In December 2006, the
California State Legislative Blue Ribbon Task Force identified gaps in California state
policy related to the provision of comprehensive services to adults with ASD.

Consideration was given to the following issues:
• Adequacy of transition planning by schools, regional centers, and other service systems for youths with ASD transitioning into adulthood;

• Coordination between multiple service systems in an integrated systems approach to serving adults with ASD;

• Effectiveness of current program models for persons with developmental disabilities (i.e., residential, employment, day program, self-directed, and other services) in meeting the unique needs of persons with ASD;

• Availability and accessibility of well-trained service providers for ASD statewide;

• Adequacy of funding to meet the current service needs of adults with ASD and anticipated fiscal impact to the state to meet future needs;

• Eligibility of high-functioning persons with Asperger's syndrome or Pervasive Developmental Disorder Not Otherwise Specified for regional center services; and

• Services that are culturally competent for persons of different racial and ethnic groups.

**The Children’s Health Act of 2000**

Nationally, parents of children with Autism have been particularly busy in recent years working for the passage of legislation to diagnose, treat, and prevent Autism. The Children's Health Act, the first federal legislation addressing Autism, was passed in 2000. In April, The Combating Autism Act of 2005 was passed by the U.S. Legislature. The
Act provides grant programs for every state to develop Autism screening, early diagnosis, and intervention programs for children. The Act provides:

Twice the number of NIH Centers of Excellence Programs for research on Autism.
Expansion of the National Institute of Child Health and Human Development Collaborative Programs of Excellence in Autism.
Funds for CDC epidemiological surveillance programs.
Establishment of Centers of Excellence regarding environmental health and Autism.
Reauthorization of the Interagency Autism Coordinating Committee (IACC), established in the Children’s Health Act of 2000, to coordinate all efforts within the Department of Health and Human Services concerning Autism, including activities carried out through the NIH and the CDC (Medical News, 2005, para. 5).


In 2006, two additional significant legislative victories were achieved by the Autism community: The first was the passage of the Combating Autism Act (S. 843), in December. It has been hailed by policy makers as the most sweepingly specific legislation ever enacted, declaring war on Autism by the U.S. government. The Combating Autism Act authorized nearly $1 billion over the next 5 years to fight Autism through research, screening, early detection, and early intervention.

The second effort culminated in persuading Congress to include $7.5 million specifically for Autism research in the FY 2007 Defense Appropriations bill. This established biomedical and other research funds to discover the causes and possible treatments for Autism, specifically for the benefit of affected military families and others affected in the Autism community.
In 2007, many Autism advocates set ongoing legislative priorities for the first session of Congress. The Autism Speaks (2007, para 2) Web site listed the organization's legislative goals as follows:

1. Implementation of the Combating Autism Act. To seek full implementation of the Combating Autism Act, including necessary appropriations.


3. Autism Services Legislation. To work with Congress to develop and secure passage of a law.

The passages of the Combating Autism Acts of 2006 and 2007 could not have occurred without the concerted activism around the United States of hundreds of thousands of active parents and concerned Americans. Upon President Obama's inauguration, the Web site of the White House (whitehouse.gov) pledged further support for helping people with Autism and their families. Autism tops all others and is given priority in Obama's presidential agenda. President Obama mandated the following, as reported by Shute (2009):

1. Increased funding for research, treatment, screenings, public awareness, and support services for ASDs.

2. Life-long services for people with ASDs, as children and as adults. Many parents struggle to find and pay for screening and treatments for their children, but there is even less coverage and capacity for adults with Autism-based impairments.
3. More funding for the 2006 Combating Autism Act, as well as improving state and federal Autism programs.

4. Universal screening of all infants for Autism disorders, as well as rescreening for all 2-year-olds.

A Brief History of FEAT

FEAT was founded in 1993 by a group of Sacramento area parents and professionals seeking to improve the early intervention services for children with Autism. Since then, over 100 children in Northern California have participated in workshops and clinic programs sponsored by FEAT and several providers of ABA services. This grant and continuing fund raising, along with advocacy efforts, have been the source of funding for ABA services provided to families by FEAT. That same year, FEAT honored Dr. Bernard Rimland, PhD, Director of the Autism Research Institute.

Since 1993, FEAT has maintained numerous community activities. The M.I.N.D. Institute (a government-funded medical facility dedicated to researching, treating, and discovering the causes of Autism), was started at UC Davis by several FEAT members, who sought out government grants to establish the institution. At present, several founding members of FEAT are serving on the California State Legislative Blue Ribbon Commission for Autism to work on a public policy that best serves the growing Autism population. In the last 2 decades, FEAT parents and professionals have made remarkable gains for a group of volunteers, dedicated to helping children with Autism.
Summary of the Literature on the Why of Change

It is evident that parents and their allies are the driving force behind all significant medical research on disability and legislation since the Civil Rights era of the 20th century. Without their efforts, special education would have found neither funding nor support by federal and state governments. Without their efforts, children with Autism would go largely undiagnosed and untreated, and they would flounder in a web of misunderstanding and misery. In the beginning of the 21st century, we are witnessing an unprecedented surge of parent advocacy in our democratic republic. The media and government representatives have taken notice of their power, and the result is sweeping legislation and money to combat Autism and related ASDs. State governments have begun to acknowledge that they cannot formulate appropriate policies without the input of parent advocates.

In California, FEAT representatives sit on all three State Legislative Blue Ribbon Autism Task Force committees. These committees are ongoing and meet to update public policies related to programs and funding support for California's surging Autism population. FEAT has been at the forefront of efforts to improve the quality of life of children with Autism.

The How of Change: A Conceptual Framework to Study Change

None of the pioneering successes of the early advocates of disability rights could have been achieved without planned and concerted effort. Many parent organizations were essentially formed to push for changes the parents knew would require advocacy (e.g., United Cerebral Palsy [UCP], ARC, The Down Syndrome Congress, FEAT, and
others). Their intentions were deliberate and planned, and for this reason Kotter’s Eight-Stage change model served as a relevant conceptual framework to study the work of FEAT in particular.

**Kotter and his Change Model**

Kotter (1996), a Harvard Business School professor, and his work have impacted the business and educational communities and many other organizations for nearly two decades. Kotter is renowned in these circles through his studies and writings about leadership and change. In *A Force for Change*, Kotter made the case for distinguishing between managers who manage even when it is not adequate for an organization and leaders who, though rare, are much needed for change to happen. He asserted that noteworthy changes will never happen if corporations and organizations continue to put managers into leadership positions. Kotter argued that "management skills do not lead to change" (pp. 7-8). Since the release of his book, the terms manager and leader are no longer synonymous.

Today, the focus of many progressive organizations is systems change. Researchers in health care reform, higher education, and many other fields have found Kotter's (1996) model useful for mapping out their organizational change strategies (Eddy, 2003; Eiken, 2004). Kotter's (1996, 1998, 2002 and 2006) ideas trickled into the field of education as policy makers sought ways to address the perceived deficits in the American educational system. His writings aided in shaping and defining effective leadership impacting the education and business arenas. In his works, *Leading Change* (1996); *Winning at Change* (1998); *The Heart of Change* (2002), written with Cohen; and
Our Iceberg is Melting (2006), written with Rathgeber and Mueller, Kotter outlined his noted Eight–Stage change model (Figure 2-1). This model promoted a strategic, planned, and linear approach to problem solving, which many in business, education, and other organizations have affirmed as effective. Other models for planned change exist, which include specific stages to follow (Rowley, Lujan, & Dolence, 1997; Trahant, Burke, & Koonce, 1997). However, Kotter's (1996) change model stands out because it does not begin Stage 1 with developing a vision. The vision stage follows after the leaders have created a sense of urgency for change and built a coalition that will drive the change.

Kotter's (1996, 2002) model of planned change is singularly relevant to this study of the development of FEAT. It is articulated in his book Leading Change and in his later work The Heart of Change. The Eight-Stage linear framework is a clearly identifiable road map for change. Although the first book addresses primarily the corporate sector, it provides a conceptual framework that is well-suited to studying grassroots parent organizations as change agents in their educational surroundings. Therefore, it was the model of choice for studying FEAT.

This research highlights FEAT's strategies as they follow Kotter's (1996) model and, then, to apply them to specific organizational growth situations and challenges. Kotter's Eight-Stage process for change proposes the following stages:

1. Establishing a sense of urgency.
2. Creating the guiding committee.
3. Developing a vision and strategy.
4. Communicating the change vision.
5. Empowering broad-based action.
7. Consolidating gains and producing more change.
8. Anchoring new approaches in the culture.

Kotter's (1996) model, as mentioned earlier, does not start with a vision. The vision emerges only after an organization's leaders have established a sense of urgency for change and built a coalition to help them push for change. Kotter warned that, omitting the first two stages could lead to failure. Cultural change in Kotter's model is placed at the end of the change process, rather than at the beginning, even though it is critical to long-lasting change. According to Kotter, cultural change follows after successful change of action.

Since FEAT grew out of the members' intentional efforts to promote specific changes in their schools and communities, the application of Kotter's (1996) model (as a guiding framework for FEAT parent interviews) provided an opportunity to apply this change theory to practice and analyze the results (Figure 2). By recording and reconstructing the memories of FEAT parents and a professional, and their roles as change agents for the rights of their children with Autism in their schools and communities, this research preserves their legacy and extends the social action model for other parent advocacy groups to consider.

**Educational Policy Implications**

This study sought to provide answers to some urgent questions with implications for how to effect educational policy change: How can schools and communities
positively and constructively respond to a health crisis such as Autism, as the number of cases continues to rise? How can these research findings serve as a model to empower other parent social-action organizations in the realm of public education?

**Summary of the Literature Review**

This review of the literature outlined a major paradigm shift in how parents and their active involvement are perceived in the fields of general and special education. The perceptions of parents have evolved as education professionals began to develop an appreciation for family centeredness, partnerships and collaborative supports in the education of typical children and children with disabilities. Parents were once viewed as passive observers and encouraged to limit their participation on the fringes of school life, (e.g., holding bake sales and other fund-raisers). Recently, a radical shift occurred that supports parent engagement as a vehicle for positive change in schools and communities.

As parents engage in public education, they are empowered to become leaders in promoting important legislation related to their children's education and the treatment of their disabilities. To pursue these goals locally and nationally, they have formed groups. At first, they served mostly in volunteer neighborhood basement gatherings. Some of these volunteer groups were later funded by private and federal money, as their important roles as educators, partners, resources, and advocates (e.g., the UCP, the ARC, and more), were affirmed by the legislation they forged. Some disabilities have remained relatively constant in numbers, while the prevalence of Autism increased dramatically. In response, the parents of children with Autism became a new wave of volunteer parent advocates, establishing their own grassroots support groups, which, in turn, became
springboards for significant activism in health care and the political arena. The uniqueness of FEAT stands out among these groups. It has become not only an effective parent organization over the last 17 years, but also a vehicle forcing change in schools and communities. FEAT is fueled by the enthusiasm and hard work of volunteer parents of children with Autism.

Among the many available change models (e.g., those proposed by Senge, 1990, Wheatley, 1997, and others) Kotter's (1996, 2002) model is the most suitable for studying planned strategic change, as forged by these effective parent groups. Therefore, Kotter's change model was the tool of choice to study FEAT as a force for change in local schools and communities, which is the focus of this research.
Chapter Three

Research Methods

Every social action group should at the same time be an adult education group, and I go even as far as to believe that all successful adult education groups sooner or later become social action groups.
— Eduard Lindeman, 1945
The Sociology of Adult Education

Oral History

This research sought to illuminate the experiences of parents of children with Autism by focusing on the original founding members of the parent organization FEAT. This small group forged groundbreaking advocacy efforts, which ultimately benefited all children with Autism in California and beyond. Telling their story required a thorough investigation into the sweeping impact of Autism and how affected parents and families rendered significant the social, economic, educational, political, medical, and environmental repercussions of this innately modern crisis. By gleaning from their experience valuable lessons and perspectives, others might be inspired to make profound changes in their schools, communities, and public policy.

Through the venue of oral history, the rich and detailed data of the stories of parents were collected. Oral history provided these parents with a voice and a forum from which many others can learn. Oral history was the most appropriate method to build upon the strengths of traditional qualitative methods; its emphasis is on understanding and
interpreting how respondents construct the world around them (Glesne & Peshkin, 1992). Oral history further highlights the strengths of qualitative research with its focus on the perceptions, or stories of participants' views, experiences, and situations (Berg, 1989).

Oral history serves the purpose of acknowledging and hearing the stories of those who have been "traditionally marginalized" (Munro, 1998, p. 12). In this research, the traditionally marginalized groups are not only the parents of children with disabilities, but also the children themselves and their stories, most of which can be told only by those close to them because of the limitations imposed by their disabilities. Oral history was uniquely suited for this research about parent involvement, advocacy, and change. The noted oral historian Allesandro Portelli (1997) wrote, "One of the two things that distinguish oral history from other disciplines is the search for a connection between biography and history, between individual experience and the transformations of society" (p. 6).

**Oral History, Validity, and Reliability**

The oral history method offers opportunities for data validation. Frisch (1990) wrote, "Oral history is unique in that it creates its own documents, documents that are by definition explicit dialogues about the past, with the 'subject' necessarily triangulated between past experience and the present context of remembering" (p. 188).

To address validity issues related to this type of qualitative research, the practice of member checking was employed. The participants who had been interviewed were given the opportunity to read through the interview answers to ensure that the information as stated was what they had intended to convey.
Reliability concerns were addressed through thematic consistency. The researcher inquired: Is there consistency in the themes that emerge from interview data when textual analysis is performed? Do the data support the themes that surface? Noted oral historian Paul Thompson (2000) commented on the reliability of oral history through recording,

> Recording is a far more reliable and accurate account of an encounter than a written record. All the exact words are there as they were spoken; and added to them are social clues, the nuances of uncertainty, humor or pretence, as well as the texture of dialect. (p. 126)

**Data Collection**

The method of data collection for this oral history was accomplished through in-depth interviews with seven volunteer participants in compliance with the oral history interview procedure guidelines (UC Berkeley, 2005; Yow, 1994). The qualitative researcher Berg (1989) wrote,

> The interview is an especially effective method of collecting information for certain types of research questions and for addressing certain types of assumptions. Particularly when investigators are interested in understanding perceptions of participants or learning how participants come to attach certain meanings of phenomena or events, interviewing provides a useful means of access. (p. 72)

The oral history method employed the prolonged interview, which comprises multiple interviews with each participant and the interviewer (Denzin, 1970). Yow (1994), a researcher of oral histories, stated, "This is the great task of qualitative research and specifically oral history interviews: to reveal the meanings of lived experience. The in-depth interview offers the benefit of seeing in its full complexity the world of another" (p. 25). Seidman (1998), further, saw little distinction between oral history interviewing and in-depth interviewing.
To facilitate the emergence of essential meanings and the effectiveness of data collection during the interview process, it was necessary for the researcher to develop a rapport with the participants (Berg, 1989; Glesne & Peshkin, 1992). When participants were made to feel comfortable and relaxed, they were better able to relate their stories to the interviewer. This researcher adhered to the guidelines set forth by Fraenkel and Wallen (1993) to establish rapport with the participants in this study (Appendix E).

Semistructured and open-ended interviews were also implemented. According to Patton (1990), semistructured and open-ended interviews have several advantages: Semistructured interviews increase comprehension of the data, and the interviews are primarily contextual and conversational. Open-ended interviews allow respondents to answer the same set of questions more freely, thereby increasing response comparison. Analysis of the data was more easily organized, and interviewer bias was reduced as a result of adhering to the aforementioned guidelines.

To assure consistency in the open-ended question format, Kotter's (1996) Eight-Stage change model was utilized as an interview framework for data collection (Figure 2). All the interview questions sought to elaborate on the overarching research question: What has been the experience of parents of children with Autism who are also founders of FEAT? There were at least three separate interviews with five of the founding members of FEAT, who were part of a purposive, nonrandom sample (Miles & Huberman, 1994). Two other important later members of FEAT, Rick Rollens and Nancy Fellmeth, were also interviewed. Their perspectives represented the successive waves, after the founders' early accomplishments, regarding FEAT's continued successes. The
data from their interviews was used to understand FEAT's influence in founding the M.I.N.D. Institute and understanding the future of FEAT, as outlined in later chapters.

The first group of interview questions follows Kotter's (1996) Eight-Stage change model sequentially, beginning with Stage 1: How did FEAT create a sense of urgency to help children with Autism? followed by Stage 2: How did you attract leaders and promote teamwork? through Stage 3: How was the vision for FEAT created? How was it planned? (Figure 2)

The second interview followed up with Kotter's (1996) next two stages, Stages 4 and 5. The Stage 4 questions were: How did others become involved? What attracted you? Stage 5 asked: What changes were a FEAT priority? What risks were taken? What new ideas were implemented?

The third interview addressed Kotter's (1996) Stages 7 and 8. Stage 7 questions asked: What was learned? Who or what was celebrated? Stage 8 questions concluded with: How were FEAT's goals perpetuated and its successes anchored?

**A Hybrid Research Design**

Specific aspects of the two established forms of qualitative methodology were adapted: oral history, to record and collect the founders’ lived experiences, related to change they forged in their schools and communities, and educational criticism and connoisseurship, to uncover the themes, patterns, and implications that those experiences revealed.

Therefore, a hybrid qualitative research design of oral history and educational criticism and connoisseurship (Eisner, 1998) was the research method chosen for this
study. The two qualitative traditions combined to communicate the data with the most appropriate lens for researchers, and other interested parties, who have not participated in the systems change process. To further understanding of the founders’ insights, poetic representation of the interviews, gave a new perspective to the data (interviews). In the spirit of Eisner, the poetic data display provides the reader with a greater appreciation of the founders’ experiences.

Since oral history was discussed in the previous sections; this section, will delve into educational criticism and connoisseurship as a research methodology used in this endeavor. Educational criticism and connoisseurship is the qualitative research method that emphasizes the perception of qualities, the interpretation of significance, and the giving of public form to the content of consciousness (Eisner, 1998).

The researcher’s role in Eisner’s (1998) educational criticism and connoisseurship method is that of a critic and appreciator of the visual arts, with an enlightened eye. By utilizing the approach of poetic representation of the analyzed data (Glesne, 1997; Miles & Huberman, cited in Mears, 2005; Richardson, 1992, 2002), this researcher assumed the role of literary connoisseur with an enlightened pen. The researcher with the enlightened pen utilized poetic representation for artful presentation and expressed the aesthetic literary meaning of the founders’ interviews. Since this research is social- action and historic in scope, poetic representation was the chosen method to best communicate the life stories of the founders. Had the data rich interviews been only summarized and/or codified, the importance of the founders’ insights may have been lost. In Old Norse tradition, the skald, or poet, had a unique societal role to fulfill—a concept that is related
to the social-action focus of the present study. Hillman (1999) wrote, "The poet's task is to bring the community to its senses and wake it up" (p. 62). The use of poetic representation in this research also captures the Old Norse skald's spirit of collective community consciousness raising.

**Data Analysis**

Upon the completion of transcription and study of the interview transcripts, the data were displayed in poetic representation form (for the reader’s appreciation), which reflects the aesthetic appreciation aspect of Eisner’s educational criticism and connoisseurship research method. Poetic representation, *the enlightened pen*, also best preserved and communicated the founders’ life experiences, by displaying the interview data with *their words*. The meticulous process of writing poetic representation, (as opposed reliance on the traditional analysis coding and/or summary approaches), became an intrinsic part of the data analysis, whereby vital themes emerged for research discovery and discussion. As themes surfaced through the analysis process, a color code was employed to sort and organize the prominent information. Carolyn Mears, who has pioneered this research hybrid research method asserts,

While oral history gives educational critics tools for researching impacts and long-term consequences of educational experiences (e.g. pedagogical approaches, school reform, classroom design), educational criticism gives oral historians a method for discovering and disclosing meaning and significance beyond the immediate situation and related events. It also gives oral historians a framework for analyzing interview data through interpretation, evaluation, and thematics. (Mears, 2008 p.418)
Qualitative Research and Subjectivity

In qualitative research, the issue of researcher subjectivity is often discussed. Qualitative research as a method allows for the researcher to be an interpreter of emergent themes in the research (Eisner, 1998). By definition, the qualitative researcher qualifies, sorts, analyzes, and synthesizes research data in accordance with his or her professional judgment.

Oral history interviews (i.e., the data collection method) were derived from relevant research questions about the parent's and/or professional's role in the history of founding FEAT. The interviews were analyzed and displayed through poetic representation or descriptive prose (Eisner, 1998). The organization of data (interviews) was done according to Eisner's emergent themes for meaningful discussion.

Educational Criticism and Connoisseurship

The oral history interviews were conducted in accordance with Eisner's (1998) dimensions of educational criticism: description, interpretation, evaluation, and thematics. These four dimensions are discussed in more detail in the following sections.

Description is the participant's expressive language, or heart story, which emerged from several guided research interviews. Instead of Eisner's (1998) usual description and collection of data for research through observation, the description and collection of data for the present study was done through in-depth interviews, using established oral history guidelines (UC Berkeley, 2005; Yow, 1994). Eisner (1998) wrote,

The presence of voice and the use of expressive language are also important in furthering human understanding . . . it is called 'empathy'. . . . To read about people or places or events that are emotionally powerful and to receive an
eviscerated account is to read something of a lie. Why take the heart out of the situations we are trying to help readers understand? (pp. 36-37)

Interpretation addresses matters of meaning (Eisner, 1998) for the data collected and described. Here, it not only accounts for and communicates meaning from the recorded interviews, but it also allowed this researcher, a parent of a child with Autism (and also connoisseur of disability history, experience, Autism, and advocacy), to offer an interpretation that penetrates the essence of participants' heart stories through the enlightened pen of poetic representation.

Evaluation intends to assess participants' experiences as change agents in their schools and communities. Portelli (1997) explained,

Narrators (participants) articulate memory, evaluation, and anecdote in the dialogues with interviewers who are trying to reconstruct a broader framework and therefore invite them to highlight the encounter between history and their lives, private worlds and events of general interest. (p. 97)

Thematics involves "identifying the recurring messages that pervade the situation. A theme is like a pervasive quality [that] . . . permeates and unifies situations" (Eisner, 1998, p. 104). As both a critic (as discloser, not judge) and connoisseur of the research topic, this researcher delved into the experiences of participants and gleaned some unique generalizations or themes, which might have practical application to the greater educational, parent support, and disability communities. Grele (1985) wrote,

By showing people trying to make sense of their lives at a variety of points in time and in a variety of ways, by opening this individual process to view, the oral history reveals patterns and choices that, taken together, begin to define the reinforcing and screening apparatus of the general culture and the ways in which it encourages us to digest experience (p. viii).
The Participants

This researcher interviewed five founding members of the original FEAT group. The questions following Kotter's (1996) Eight-Stage change model were presented in three separate interviews (Interview Protocol in Figure 2-1). This sample was a purposive, nonrandom sample, as described by Miles and Huberman (1994).

Consistent with the expectations for a purposive, nonrandom sample, this researcher had knowledge of these participants and their relationship to the founding of FEAT, along with privileged access as a parent of a child with Autism. As a parent and advocate for her son, this researcher was given the privilege of trust by these participants, who openly shared their unique experiences in developing a groundbreaking organization to advocate for children with Autism. Due to this gift of access, this researcher was privileged to listen and hear their stories. Had this researcher not been a member of this Autism group, her access to such candor and insights would most likely have been barred. As a trusted member of the group and as a researcher, this researcher met the challenge to be as objective as possible in listening to and conveying the meaning of their life stories for this research project.

Parents in Crisis: A Brief History of FEAT

Families for Early Autism Treatment (FEAT) was founded in 1993 by a group of Sacramento area parents and professionals seeking to improve the early intervention services for children with Autism. They collaborated, volunteered, and wrote several grants, raising enough money to provide intensive early intervention training in Applied Behavioral Analysis (ABA) for parents and local professionals. That same year,
therapists from the UCLA Clinic for the Behavioral Treatment of Children started coming to the Sacramento area and providing training workshops to help the families in FEAT to get started. These early workshops led several professionals in the Sacramento area to run ABA programs, which currently help children with Autism and their families.

Over 100 children in Northern California have participated in workshop and clinic programs sponsored by FEAT and several other providers of ABA services, since 1993. The goal of providing ABA programs to young children is to assure that all young children with Autism have the opportunity to maximize their potential. As a result of this concerted program, many of the children are now attending regular public schools, most with the assistance of an aide and many school districts are now funding ABA treatment for children with Autism. FEAT's initial ability to provide these ABA workshops was made possible by a grant of $75,000 from the Sierra Health Foundation, in 1993. This grant and continued fund-raising, along with advocacy efforts, have been the source of funding for ABA services provided to families by FEAT.

FEAT has held its Annual Night of Caring Fund-Raising Dinner and Auction every year since its inception. In 1994, FEAT sponsored State Autism Awareness Week and held its second Dinner Dance. The guest of honor was the noted Dr. O. Ivar Lovaas, PhD, Director of the UCLA Clinic for the Behavioral Treatment of Children. That same year, FEAT honored Dr. Bernard Rimland, PhD, Director of the Autism Research Institute. The Annual Night of Caring continues to be FEAT's main social and fund-raising event each year.
A lending library was established, in 1995, to provide information and materials to families involved in early intervention programs to treat Autism. Since 1993, FEAT has maintained numerous community activities. These activities include monthly resource meetings, which are designed to provide continuing information, education, and support for families of children with Autism; a FEAT quarterly newsletter; and a Handbook for Parents (FEAT, 2009). As FEAT's efforts expanded, some parents and professionals sought out additional government grants, which led to the establishment of the M.I.N.D. Institute, a government-funded medical facility at UC Davis, dedicated to researching, treating, and discovering the causes of Autism.

What FEAT parent and professionals have accomplished in the last two decades is remarkable for a group of volunteers, dedicated to helping children with Autism. Their efforts, activism, and energy deserve attention and are the main focus of this research study. Their advocacy serves as an inspiration for other parent groups that seek to help their children with disabilities by changing school policies, programs, and their communities.

The Interview Process

Each selected participant received a letter describing this research study and its intentions to record their responses. The letters were followed by a phone call to arrange for the place and time of the interview. During the first interview, each participant was given an explanation of the focus of the research and an introduction to the oral history method. The Informed Consent paperwork was presented and signed. The first interview covered the Interview 1 section, outlined in the Interview Protocol in Figure 2-1.
Information about the first days and months of FEAT's formation were discussed, as well as insights these participants had achieved, which had motivated them to action as a parent of a child with Autism.

The second interview dealt with the questions in the Interview 2 section of the Interview Protocol in Appendix B. Information from the previous session was summarized for clarification purposes. Then, information relating to the progress and maintenance of the organization was explored.

The third and final interview dealt with the questions in the Interview 3 section of the Interview Protocol in Appendix B. In addition to clarifying information from the previous session and the interview protocol, questions related to the meaning and significance of their efforts were asked. Also, questions pertaining to the future of their advocacy and the future of FEAT were posed, and their personal recommendations for others, who might be inspired by their efforts to become change agents, were solicited.

**Informed Consent**

The interviews with participants were conducted in accordance with the requirements of the Institutional Review Board (IRB; Appendix B) and the oral history guidelines (UC Berkeley, 2005; Yow, 1994). Participants were asked to reconstruct the history of their lived experience and share recollections about their role in the formation and development of FEAT.

The participants were volunteers and informed consenters to the research, as outlined in the IRB process. They did not choose anonymity, although they were given that option. Ethics concerns and participant protection were observed in accordance with
IRB guidelines, which include the participants' informed consent and the option to withdraw from the study at any time (Appendix B: Informed Consent).

**Assumptions**

1. The experiences of parents with disabled children, especially with Autism, are different from those of parents with typical children.

2. Parent engagement and advocacy are necessary for children with disabilities to obtain needed services, programs, and support in their school and community.

3. Parents of children and concerned community professionals were integral to the founding of FEAT.

4. Autism is a growing national health and educational programming challenge, which must be properly addressed.

**Delimitations**

1. This study focused on a small group of parents and professionals and their experiences in founding Families for Early Autism Treatment (FEAT).

2. This study did not attempt to provide a comparison of the experiences of FEAT parents and professionals with those of other parent and/or professional groups.

3. This study also acknowledged the researcher's experience as a parent of a child with Autism.

4. This study did not attempt to endorse or document treatments for Autism.

5. The literature review covered related and necessary publications through January 2010.
Role of the Researcher

As a doctoral candidate and student researcher in the University of Denver Educational Leadership and Policy program, this researcher is grateful to have the opportunity to study educational change through this doctoral thesis. She is uniquely qualified for this research topic and the chosen methodology. First, she has experience in oral history research through her work as a researcher for the United Nations Department of Public Information Division's Oral History project. She understands the merits and demerits of this research approach and finds it extremely appropriate for her research topic. She is not only an experienced and certified educator of children and adults, but also an advocate for her twenty-two-year-old son, who has Autism. She presented at several conferences, serves on California's Blue Ribbon Legislative Task Force for Autism (Transition Issues), and has become personal friends with some of her interviewees. These participants granted her privileged access to their thoughts, insights, and personal stories because she is a trusted member of their group. Although she has specific perspectives on this topic, as a researcher, she endeavored to be dispassionate in her final analysis and conclusions.
Leaders mobilize people to face problems, and communities make progress on problems because leaders challenge and help them to do so. —Ronald Heifetz, 1994

**Conclusion**

By recording and reconstructing FEAT founders' recollections and their roles as change agents for the rights of their children with Autism in their schools and community, this research sought to contribute to the greater body of knowledge regarding the history of disability rights and Autism. The noted oral historian Grille (1985) wrote, "Oral history should be a way to get a better history, a more critical history, a more conscious history which involves members of the public in the creation of their own history" (p. viii). In the pursuit of a more critical history, this research also sought to extend and contribute to the History of Disability Rights Oral History project, based in the Bancroft Library Archives of the University of California, Berkeley. This research highlights the role of parent advocacy, and parents' subsequent contributions to shaping landmark legislation, research, and programs in their schools and communities; It also offers practical insights for equally concerned parent and community groups.
Chapter Four

The founders of FEAT and their stories

What creates the tireless energy that is needed to grow a parents’ advocacy organization from its inception? Is there a special formula for change? This chapter will introduce the stories of the individuals who made up the powerful small group that established FEAT. Five poetic representations or narratives of interviews with three mothers, one father and a dedicated professional are introduced. The detailed poetic displays feature each participant’s personal perspective of the journey. Each person describes their inner motivation, the group’s dynamics and view of the organization’s past, present and future. They also share useful advice to other parent advocates who are growing their own group and support network to help their children. When confronted with the daunting challenge of raising a child with autism, these individuals exhibit grace under pressure and forged a creative force of support, advocacy and systems change, when others in their circumstances would have succumbed to hopelessness and depression.

The following are the poetic narrative stories of these champions of determination. Each poem is written for the purposes of historic preservation. Yet each is also treated as raw data for analysis in the next chapter. The original “free verse” poetic narrative goes beyond the more traditional qualitative interview, expanding the simple narrative’s
typical boundaries of prose. Poetic representative prose, by expressing the fullness of each individual’s story, preserves the vivid “live color” of the storyteller’s experience.

The qualitative researcher Reason (1988) has articulated, interpretative research processes (such as poetic representation), urges researchers to trust their own intuitive interpretation of their data. It is this researcher’s aim to be congruent with the expressive research agenda set forth by Eisner (1981) and Finley & Knowles (1995). In many aspects, a poem can be viewed in much the same way as the actual qualitative interview from which they were derived, as an exploration of the lived experience of the research participant. This is affirmed by other aesthetic-educational, qualitative and oral researchers (Eisner, 1998; Glesne & Peshkin, 1998; Portelli, 1997) as well.

In the past, data re-presentation was often viewed as something separate from the research. Richardson (1992) has suggested that methods of data re-presentation are integral to the research process. By using experimentation with the data in poetic forms, this research seeks to stimulate like experimentation and attention to strategies of data representation. Poetic representations, according to Richardson (2003), are as important as prose in representing social research knowledge.

**Introducing the founders**

Each poetic representation in this chapter is the “Salafah” of the individual. The “Salafah” is a pre-Islamic narrative genre used by the inhabitants of the Arabian Peninsula to carry the oral history of important past events (Sowayan, 1992). Each poetic narrative or representation in this research is an individual “Salafah” to herald the teller’s unique experience of living the history of the organization FEAT.
Visually the poetic representations flow as cascading streams. They drip with intricacies and meander like persistent waterways, changing the landscape as they flow forward. Later (in the final chapter of this research), the individual water paths meet to forge a waterfall of surging ideas and symbiotic energy. The waters flow--- forcing, pushing and molding change, powering forth into rapidly expanding moving waters.

Presenting four parents and a professional; the stories of Linda Mayhew, Joni Price, Carl Haynie, Tina Hendrix and Dr. Ron Huff, the founding members of FEAT.

**Linda**

Linda Mayhew was a challenging appointment to schedule. She had left the Sacramento area years before and lived with her husband and daughter, Kristina in Bakersfield. She also works as an airline stewardess and helped to run the family bookstore in her spare time. So when she came to Sacramento to be the keynote speaker for the FEAT Capitol Conference, I was quick to schedule a face-to-face interview with her. She was often the bold “front line” person speaking publicly to the media for FEAT in the early years. However, Linda's own commentary of her contributions appears modest by her own assessment. At the FEAT Capital Conference they were honoring her as a driving force in the founding of FEAT. We found a free hour prior to her keynote to record the initial interview. This was followed by two other phone interviews and emails. Her excitement about her work with FEAT and her daughter’s development is evident in as her story unfolds…

Kristina was diagnosed with autism at two and half years.
At that time, we were told there was nothing we could do to help her.

It was a life-long disability—she would never talk….. because of her severe behaviors, she would have to be institutionalized by the time she was a teenager.

When we got that diagnosis, it was very different from other parents. Two weeks prior the doctor’s first diagnosis was -- a brain disorder she was going to die!

So, we were very happy it was only autism.

I never even accepted or thought that there was nothing we can do my husband and I did whatever we could for Kristina.

She didn’t like being touched at all. She didn’t like being held- She would scream bloody murder tried to throw herself out of our arms if we did pick her up.
We started doing, what we found out later to be called a “Holding Therapy” we were just parents knowing our child needed to be held touched and loved. Together my husband and I would hold her and rock her... ....tell her that we loved her and we weren’t going to be going anywhere. By doing that consistently, all the time- we broke down that first barrier—that wall. She started wanting us to touch her and hold her.

**Direction for advocacy**

Lovass. When she was 3 1/2, our caseworker told us of a speech about autism at Sacramento State. We went to see what he had to say we thought anything about autism we needed to learn. Dr. Lovaas- My husband and I were sitting in the back of the auditorium, amazed watching the video clips of the children how they were improving.... We were seeing there was something we could be doing now. I thought, “This is crazy. I’ve lost a year of time with my daughter.” I was raising my hand for about 45 minutes Dr. Lovaas finally called on me, I asked him, “How can I help my daughter here in Sacramento?” He said, “there was no program in Sacramento, and at the age of three and a half. my daughter was too old to get help at UCLA.
That upset me,
   I spoke with a Dr. Huff who worked with the Regional Center.
       what could he could do for us?

After Dr. Lovaas was done,
   I went up to speak with Dr. Huff,
       and then we were approached by other families
       who were there to listen to Dr. Lovaas

I set up an appointment with Dr. Huff to meet Kristina
   and the other families and I stood there
       for two hours talking with each other,
       and we even had a chance
           to go to a reception
           and meet Dr. Lovaas.

We didn’t want to leave.
   We just kept talking…..
       we needed to talk to each other
       and hear other stories

We had never met any other families with autism.

We decided we needed to start
   a support group.
   We wanted to keep talking to each other
       we knew that there were other families
           who would enjoy sharing stories.

On the way home, I told my husband
   I was going to call
       the Sacramento Bee
           and the Pennysaver.

We put ads out looking for parents
   with autistic children.
       That’s what we did.

A few people answered the ad.
   From there we started our meetings.

I am only a high school graduate.
   I have never attended college,
       My whole life, all I ever wanted to be was a mom.
       The type of parent that I am,
           the type of person that I am…
               I’ve never accepted “no” as an answer.

If I thought that there was something to be done,
   I did it!
My daughter educated me.
   Reading books and then meeting the other parents
   and Dr. Huff and also Dr. Linda Copeland—
   they were my education.
When I heard there was something I could have been doing
   with my daughter, and nobody told me …
   I didn’t want any
   other parent to go through that
   and waste time.
I thought it was wrong.
   I also met a mom that day who was doing program
   in her home with her daughter
   and she happened to have a lot more money
   so she was able to help her daughter
   with her own money.
And I didn’t feel that that was right
   a parent can help a child out with autism
   because they had money
   but people who didn’t have money
   couldn’t help their children.
And so it was more a spirit of right and wrong
   needing to change that and knowing that it wasn’t correct
   and something had to be done.
   When we started this with Kristina
   I felt very lucky to have her
   I raised two other children prior.
By the time she came around,
   they were still young, but I got to watch them grow
   and it was very fast.
   They learned to walk,
   to sit up,
   they learned to talk.
They were going to school so fast.
   Everything was so fast, and you missed a lot of it.
   With Kristina, I got to see
   every single aspect
   of her growth.
It was like watching a rose open in slow motion
   because it was so beautiful
   truly inspired me to keep going.
We got the first words,
   and we got two words together,
   and then we got three word sentences.
   Kristina was a late talker.....
I remember-
we were told
she would never talk.

Seeing her face
when she learned
something new…..
She had
so much excitement---

We had a book
of different pictures
of buildings
and we would point to it and say.
“What is it?”
She would tell us by memory ---
everything!

She continued teaching me things
through our trials and errors.

She kept me going.
She kept me inspired.
When she learned her “ABCs”
her Dad would come home,
and not even take off his tie.
He’d put down his brief case --
jump on the floor with her flash cards
and start doing “ABCs.”

He was so excited
not only was she talking,
now that she was learning!

So it was her.
Watching her grow,
teaching us things …
we needed to know
to teach her –
That just truly inspired us.

Challenges
The challenges were
there was nothing around
at that point in time.

The services from Regional Center
were respite care,
babysitting, and diaper service.
I can’t remember any other services available.
Not knowing and trying to find out what she needed and then trying to find those services were the biggest challenge.

The school system was also a challenge.
When Kristina was three, she started going to school. But she never learned there— it was more of a babysitting time — for me to take a breather.

She enjoyed the bus ride. She really liked getting on the bus and going to school.
So, when we started doing program at home, and started teaching her. At this time she was in special education. They had put a lid on her and didn’t think children with autism could learn. I didn’t see any learning!

By the time Kristina was five, we had been doing programming, and we never did a full program with her services weren’t included.

It was Applied Behavior Analysis but it was not a strict Lovaas program.

We didn’t have that training yet, but it was working. It was helping her. She was learning. We were excited.

She was getting her first words. And with her words, her behaviors started decreasing. She was a very violent child. We would have to subdue her a lot.
She would actually attack me.
    I have scars on my face from her.
    She always wanted
        to pull my eyes out for some reason.
I would have to huddle on the ground,
    covering my face,
        and she would be on my back,
    pulling my hair,
        trying to get me off the ground.

We found out later
    it was all because she didn’t know
        how to communicate.
She was very angry.
    She didn’t understand anything we said
        and she couldn’t talk.
So she didn’t know how
    to get her needs met.
        As we started being able to
            communicate with her,
                her behaviors started decreasing.
Back at school,
    she was learning to talk,
        and she was learning her ABCs
            and her numbers at home
                and they did not even know at school
                    they never asked her to speak.
They never tried to get her to talk
    because they didn’t think
        she could talk.
And so what we did was start
    video taping her at home.
When I thought she was ready
    to go into the
        regular kindergarten classroom
            where she would have role models,
I took the videotape to an IEP meeting
    and showed them
        what Kristina was doing at home.
They were silent and crying.
    And when we were done--
        they said they could not
            believe that she was able to talk and to learn.
They said that we could
put her into a kindergarten class.
I started searching for classes.

I found an amazing school
with an amazing teacher
who I observed letting the children
help each other while she was teaching.

The teaching style was called
brain-based teaching
where they use multiple ways of teaching.
It wasn’t just a strict learning on paper.

This was what Kristina needed.
We brought her into a classroom
with Mrs. Giffin.
With the brain-based learning
they also stayed in
the same classroom
with the same teacher
and the same students
for three years.

She did kindergarten,
first and second grade
with the same class of students
who became her friends and Ms. Griffin.

She had an aide,
the school started allowing her tutors
to be hired by the school
to be her aides in the school
They saw that with training,
it was much better for her.

They were home tutors.
Ms Griffin called me after a week
She found that Kristina was
wonderful to have in the classroom.

Even though she was different,
she was actually helping the other children
to do better.

The kids that were having problems
were attracted to Kristina.
It made them feel better
helping someone else
instead of concentrating
on not being able to do something.

So, Miss Giffin was a wonderful teacher.
We had an amazing relationship working together to help Kristina through school.

We ended up moving to Salinas, and it was amazing
I was going out to Salinas to check on schools and classroom.
I was not going to let her go into a classroom again without knowing the teacher and making sure it was the appropriate setting.

Her school district, Dry Creek School District, called and said they were not going to allow Kristina to leave without making sure that she would continue to succeed.

They sent her teacher and her aide with me to Salinas to check out the classroom and make sure that she got the appropriate education.

When I had called Salinas, I had a reputation through the years in Sacramento as a parent that didn’t accept “no’s” and fought for my child.

The school district in Salinas, found out who I was so they were a little bit on eggshells when I went to observe.

I was amazed. They had a room full of people to have our first meeting and I thought I was just going to look at some classrooms.

I went in the meeting with Kristina’s teacher and aide and we started talking.

We were taking a break and Kristina’s teacher said, “Linda, let me talk to these people for a minute while you’re outside.”
I went outside
and she told them to relax.
   I was only there because I loved my child
   and I was the most involved parent
   that she’s had ever known.

All I wanted to do was work
   with them,
   not against them,
   and if they did that,
   it would be a wonderful experience
   for them as well.

So she really opened the
doors for me in Salinas, too.

**Building for change**

**FEAT**
   It’s the heart
   we really care.
   We’re not just workers or volunteers.
   We care about what’s going on with the children.
   When you do something out of your heart,
   instead of for money
   you get better results.

Before the “waves,” as Scott Price, called them
   the founders started it,
   and then we carried the ball down the field
   as long as we could.
   And then new people stepped in
   and took the ball
   and kept running.

Everybody has shared in the responsibilities
   of making FEAT.

What I did, in the beginning, is nothing
   compared to what the people
   who have come after me had done.

We started it with an idea
   and started the support group
   and the fundraising….
   but people that have come since then
   and just carried on
   to make it even more effective.
I was very angry in the beginning, 
not because of the autism, 
but because of the lack of information-- 
the lack of response from the people 
that held the federal money 
and the school districts to inform-- 
I lost a year. 
I was furious 
because then I found out how important that year was, 
and so that’s what motivated me to say, 
“We can’t let this happen anymore.”
So, anger harnessed 
and turned into a drive 
is a powerful thing!
As more people came in, 
we were able to build on our ideas. 
With IEPs, at first I didn’t know how to do an IEP 
and I didn’t know our rights.
As people came, 
then we were able to build an IEP team. 
When Jeannie came into our group, 
she was a lawyer for the school district, 
and she started teaching us about our rights 
and ways to work with the school district.
We also had help from the area board. 
They were very involved with us, helping us. 
As people came into the organization, 
we were able to build on our ideas 
of what needed to be done, 
and then the same with the Lending Library.
As we got started doing programming, 
then we saw all the materials 
that we would need to do programming 
with our children---
We were all going through 
different phases 
at different times, 
so we would just share our materials.
Then we thought, 
“Okay, now we need to make a 
central place that the materials go to 
so people can have access to it. 
It was just ideas that came from need 
and then built a better system ……..as it was needed.
It took everybody. Everybody did what they could in their part. We’re all gifted in different things, that we could make a difference and help out it’s a total team effort.

During our dinners, we would have different awards, but it was for Dr. Lovaas, Dr. Rimland, and professionals. As far as parents, the reward was what we were doing. the rewards came from each other, acknowledging how often it was and, I don’t remember giving out specific awards within the parent organization because everybody was equally due credit.

Impact of legacy

Legislative Day
   Rick Rollens, when he became involved, he was involved with the legislation in Sacramento. So it was more of an Autism Awareness Day, the people on the Board went to the State Capitol and were recognized for Autism Awareness. I saw it as recognition for the organization as a whole of what we were doing. It was a way to just become known in the capitol so there could be future talks of funding and things for autism. I have a plaque hanging in my office, a declaration of Autism Awareness Week. It’s more of in recognition of FEAT and what we were doing. Oh, I was very excited. Very happy that we were being recognized that high of a level and so soon after our start up. It was great that we were being recognized by the governor’s office. Rick Rollens was just awesome in that area.
God was bringing pieces of the puzzle
to us all the time
to fill us up and make us whole.

Rick was that part.
He knew the legislation
and he worked on it
and created a lot of interest.

Now there’s a lot of money given
to the Regional Center
for Autism, and for the MIND Institute.

There’s been more money made
available for autism
out there because of the work that Rick has done.

Rick was a part of FEAT,
He took that ball and ran with it.
I couldn’t have done what he did.
That wasn’t my piece of the puzzle.

That was his piece and for FEAT as a whole.
When you include all the pieces of the puzzle,
it was a great thing for FEAT.

There’s been a lot of change
in the school districts.

Some have tried to implement
the behavior programming their own way in the schools.
Some have gone ahead and started providing
the funds for
in-home programming.

Every school,
in their own way,
is trying to do some part--
They know now, because of FEAT,
the information and the parents.

In-home programming works
there’s a lot still fighting against it
because they don’t want to pay for it,
but there are some that jumped on board
and continued to support that type
of programming for the children.
That’s a great thing.

And then the Regional Center has stepped up somewhat,
but I hear that they’re still fighting
on some of the cases.

So there’s just going to be
a continuing battle.
Everybody’s trying to hold on to the money
that they do get from the government,
and they don’t want to give it up that easily.

But within the organization,
the support will continue to grow
and continue to help the families fight
for what is right.

We set a lot of precedents
in the school districts
and with the Regional Center
they can build on.

I didn’t have to fight that much.
thank God, I was in a school district
that was open to learning,
and because I also didn’t push for them to pay
for my home programming.

What I was trying to do
is have my daughter go to regular school,
learn in the environment,
grow from being around the other children,
But also teach them about autism.

Teach the children,
teach the teachers,
and, the principals
and the supervisors of the district,
that there was hope for these children.

At one point, I did have to….
take her out of special education.
We had been working at home
with home programming.
I had an IEP that I called,
and I took a videotape of my daughter
at home doing her programming.

At that time she was doing her ABCs
and learning to count
and say simple word sentences.
But she was very, very interested in learning.

She wanted to learn.
I took that tape of her
and showed it at her IEP,
and the speech therapist
her teacher and, one of the counselors
from the school started crying.
The speech therapist who always meant well,
she looked at me and said, “I didn’t know
that she could talk like that.” And I told her,
“Nobody ever asked her to talk.”
That was what was going on in the schools
they were asking her for information.
They weren’t expecting her to talk
or to know what she knew….
So they didn’t see what was going on.
At that point, we did get her transferred
into a regular school that I had chosen.
I had chosen her teacher.
they worked with me very well
in that they let me go
into the different schools
and classrooms
and look for the right teacher.
They trusted me once
they saw what we were doing at home.
They allowed me to choose her aide
who would go with her to school,
and so I felt like I had great support.
I didn’t ask them for much financially.
We took care of it through the Regional Center
and through the FEAT organization
for her home training.
So I kept a nice relationship
because they, in turn, were willing
to step up when they needed to
and do what it took for us to work together.
And so that was very nice.
I haven’t really asked them,
what are your goals?
They are the most awesome people
Who I’ve ever seen for an organization
and that they’re going to do what needs
to be done and just keep rolling
and passing that ball
along to the next parent that comes along.
I’m hoping for some answers with the MIND Institute
on what’s causing this
and if we find out what’s causing it,
we can find a cure.
There’s going to be information that comes out
that there are different causes
and different types of autism.

It’s not all the same.
So in the research, in ten years, I hope to see a cure.

As far as FEAT goes,
I want them to continue growing,
opening new chapters around the country
and around the world.

Helping people who contact them,
to lead them in doing---
so everybody can create what we have in Sacramento
instead of having to move your family
to a strange town so you can help that one child.

The conferences---
keep growing and are getting better,
and the Night of Caring dinners
the more people who are involved make it work.

Follow your heart and don’t take “No” for an answer
if you don’t think what is going on is right.

Keep focused on your goal.
Don’t get taken off your track by pettiness
or disagreements,
but always stay focused on the goal.

Don’t let other things get in the way.

One of the problems
when people are doing things together,
some people might get into the, “Me”
and there’s no “Me” when you’re trying
to work as a team.

Stay focused on the goals ----work together.

It’s not about “you,”
it’s about your goal.

Listen to other people.
Get lots of different opinions.

Stick with your heart, your gut
you’ll be guided to what is right
and what needs to be done.

I was part of the change
that helped the children and,
continued a legacy
that continued to go on.

My piece of the puzzle,
What did I do?
I just don’t feel like I did anything special,  
        so it’s hard to say.  
        I was just part of the team.

I allowed God  
        to use me in the way that  
        He wanted me to work

What did I do?  
        I opened my home to people.  
        I talked on the phone to people,  
        but isn’t that what we’re supposed to do?

Just be there for each other  
        Everybody together, doing,  
        working together for it.

It took everybody and everybody  
        to make it happen.

It’s not a one-person thing.  
        I was just at the conference  
        some people came up and introduced themselves  
        and said they always wanted to meet me,  
        and my husband said later,  
        “How does that make you feel?”  
        And I said, “It makes me feel uncomfortable because  
        ‘Who am I?’  
        Why would they want to meet me?  
        I’m no different from anybody.  
        I’m just me!”

FEAT-- It’s alive.  
        It’s a heart.  
        One of the things I keep going back  
        to with the dinner committee,  
        I keep telling them,  
        “Don’t take the heart out of the night.”

The organization is a heart - it’s the feeling,  
        it’s the loving, it’s the caring.  

You make it about raising more money  
        and using your time to get the money  
        out of people’s pockets and you lose.

Nancy and I were speaking about this,  
        and I said, “You have to talk to the committee  
        And tell them to keep the heart in the work.  
        Keep it focused on the kids,  
        keep your speeches about the children  
        and what’s been happening for years,
And remember the heart
because that’s what made FEAT
and that’s the most important part of FEAT.”

They talk about organizations being run
like a finely tuned machine,
but that’s not FEAT.

FEAT is a heart.
FEAT is people who really,
Really care and that’s why they’re there.
It’s my definition of a heart----
people who care.

Joni Price

Joni and Scott Price were the first founding couple of FEAT with whom I made contact. They very graciously extended an invitation to my family and I to visit their spacious country home in Placerville, California. They were eager to share their experience with their son Ben who has autism, and how they perceived their participation in the founding of FEAT as an organization.

Both Scott and Joni have been active members of the Placerville community for over twenty years where they established themselves as teachers in the public school system. Scott participated in a wonderful pilot interview for this research. Joni agreed to be a part the focus of my oral history research of FEAT. Speaking with them and meeting their son Ben at this woodsy and remote local reminded me of their “pioneer” status in the autism community in Northern California. As we shared, my family and I could appreciate the strength it takes to challenge existing systems in the way the Prices had done. Joni’s interview and the poetic representation that emerged indicate she is a mother who knows what she has to do to obtain services for her son’s development and future.
This was followed by two other phone interviews and emails. Her openness and candor come through her story ……

I was motivated……
  motivated to be involved with FEAT
  I felt helpless as a parent.
  I could not make my son understand me.
  He didn’t understand any kind of language.
As a teacher, my main goal
  with FEAT throughout, was to teach
  and to get resources for him… to help him.

As in my classroom … there’s politics in teaching.
  …….. politics in FEAT.
I didn’t want any of the politics.
  I was teacher… his teacher.

I had my credential, and had gone through college,
  I wasn’t afraid to dive-
  to learn a lot about what
  I could to do to help my son.
  It played a role.

I came from a family where every child went to college.
  It was expected!
I am sure it was my family background that sent me
  to college and made me a teacher,
  It helped me with Ben.

I was overwhelmed with the whole thing.
  I was very helpless.
  I didn’t know what to do……… how to help Ben.
  I tried certain things, with him; on my own,
    some behavioral stuff.
  I didn’t know the right techniques,

Scott, my husband, is the one who went to hear Dr. Lovaas speak.
  He met together with parents afterwards.
  He said, “Joni, we need to do this.”
  He’s the one who I followed at first,
    It was with his support that I was able to stay at home.
    While he worked, I worked with Ben.
  He supported us.
He was very involved with Ben too.
All the workshops
and doing what he could do to follow through.
It was definitely a team effort.
It would have been very hard to do this by myself.
At the time when we were doing Applied Behavior Analysis
there were no paid tutors.
I had to recruit a lot of students.

Autism-
My child’s impact--
It’s been huge,
I was a young mom when I had him…… 22 and in college.
It was an unplanned pregnancy.
I wasn’t ready to have a child, at that point in my life
When he was born and a difficult infant-
I couldn’t console him.
It was hard when he was little……
I felt inadequate as a parent.
I thought I couldn’t meet his needs
…… especially when he was an infant.
As he got older… we realized eventually.
When he was about two and a half, he was diagnosed…
it was devastating.
It was like somebody died.

When he was diagnosed.
I went through all the stages of mourning…
……the Kubler-Ross’ anger, denial, bargaining, reasoning,
All those stages.
It was devastating; when he was little.
He was my first child and I was young
So I was able to cope with it.
When he was two my mom said,
“I know this is hard, Joni.”
But, it wasn’t hard… I just needed to get through…
This became my getting through.
After getting through the grieving part--
Getting through became, this is my life-
this is what I do
and I love this kid to death!

When he was little, he was hyper……
The love I had for him made it easier to cope with a lot!

He’s had an enormous impact on my life. Enormous!
He has a sixth sense.
If I’m upset, even if I don’t say anything…. he knows.

When I’m happy, he picks up. He’s like an extension of me.

It’s strange. I was trying to explain
this to somebody the other day.
He’s part of me.
He’s added quality to my life.

He’s twenty-one now.
I was gone for two weeks.
I got home and Scott brought him to the airport to meet me.
I just cried. I missed him!
When I was gone, it was nice to have a break.
But I just miss him so much when I’m gone.

How I feel about Ben……
Can’t be put into words!
A lot of people look at my life and say,
“Oh, you are going to have to have this kid.
He’s just gonna just be this burden.
You’re gonna to retire……
……and you’re still gonna have him living with you
…… or you’ll have to be helping him a lot.”
I don’t see it that way.
He adds a lot to my life.
He doesn’t take away.
He’s an asset!

**Direction for advocacy**

When he was in school.
We relied on special ed teachers to help him progress.
He was just going nowhere.
…… and standing still in school.

When we started with the Lovaas training,
I started seeing him change, immediately.
He started to learn how to imitate. …
started to learn words.

Before ABA he had random echolalia.
With ABA, he was learning receptive…… expressive,
to imitate receptive words, expressive words
--at a high rate.
When we taught him before ABA --
We’d place an apple and a car
in front of him and say “pick up the apple.”
He wouldn’t even know!
   It was my major motivating factor.
We finally found something that worked to teach him.
   He was going to school part of the time.
I finally just said, “I am taking him out of school.”
   *It was wasting his time!*
I kept him at home full time.
   and went to the colleges and recruited students [to be tutors].
I talked to the psychology classes up
   in our area in the junior college,
I recruited students to come in and help
That’s how I got my help.
   I paid them. We had no money. I wasn’t working.
   I found ways to pay them…. I went to 20/30 club rotary club.
   I got people to make donations.
My parents were helping us.
   In my mind he was older when he started the program,
I had no time to waste.
   I took a leave of absence from my job
   and filled every minute with him.
I had waited too long, knowing nothing
   was available beforehand.
That was my motivation
   for getting services.
We were seeing him change—fast!
   He went off of medication for being hyper.
   We got him potty trained.
He went from having absolutely no expressive or receptive words
   to having hundreds!
Within a two-year period,
   he learned his alphabet.
   He was learning at such a rapid rate.
   It was an incredible time for us.
   We felt we were actually effective for once.
He liked learning.
   UCLA (experts) came up.
As soon as they left,
   we spent two days making resources for him.
Making more flash cards on the computer…
   cutting pictures out of magazines –
   as fast as we could!
Getting the materials -
I didn’t waste any time.
The major motivation was seeing him change so fast –
after so many years of nothing, and being helpless.

I was timid because I am a teacher for the county.
I work in this county and had asked the teachers
to participate in our UCLA trainings.
It was cutting-edge therapy but they resisted.
They just wouldn’t do it.
“What you’re doing in your own home
is your own business.”
“Look at what he’s doing!”
I videotaped everything, before and after…
every single thing we taught him.
We didn’t approach the district at first.
I just relied on private donations and my family’s support.
Scott’s parents and my parents gave us money
I made a slide show of Ben and his progress.
It was a traveling slide show.
I would do presentations.
I brought them to the colleges, too.
So, I did it myself…. being an educator helped me.
I’m afraid to talk in front of adults.
I can teach kids.
It was going out on a limb for me
because I had not been in that field.

He started the program when he was about six,
The first year we did not rely
on funding from the school district at all.
After the first year, I realized I had to take
another year off work.
Then we did approach the school district.
We hired a noted attorney
from Berkeley, Kathryn Dobel
She came up and we presented
our case and went to mediation.
Hands down, they gave us
everything we wanted.
They gave me a classroom to teach Ben.
They hired students for me, two on one, including me,
…it was actually three on one for a full year!
Yes, they paid me, but they didn’t pay a teacher’s salary.

I was happy just to be getting paid.
This was something we settled on in mediation and we were told not to share with other people.

It was been years ago……
They now have classes for autistic kids.
They gave me money for materials.
They gave me a big classroom to teach Ben alone.
Aides. There were three of us.
Full time eight hours a day.

Training, was paid though FEAT.
The grant through Sierra Health.
It paid for Lovaas.

After the first year of Lovaas,
I started realizing it wasn’t totally appropriate for Ben because of his age.

I started consulting with John McCaken,
a therapist, who worked at the Lovaas Clinic.

I had John McKaken put on a workshop for FEAT.
There were two or three hundred people…
We used funds to sponsor Ben’s program.

I arranged all… everything.
We had it at Red Lion Hotel,
They had a conference room.
It was incredibly crowded.
That’s how we funded a couple of his workshops.

The funds made went to people who wanted to consult with him {McCaken}.
It wasn’t just me.
There were a couple of other families also involved.
I was desperate.
Ben’s time was limited.
I had taken a leave of absence from my district--
But after that, I would need to quit.

I tried to raise funds.
It was very expensive to fly him (McKaken) up.
His rate was eight hundred a day,
plus air and then the hotel, and all.

The successes--
Seeing Ben change so rapidly over such a short period of time.
Then the challenges………

   Ben has limits.
   I was trying to teach him
   how to read sight words.
   I tried maybe ten different ways to do it.

I would make materials and he was angry
   because I was pushing, pushing, pushing…

   Using motivational words, things that he loved……
   … with bubbles or a train and then he would
   run over to the word wall and touch it.

I’d immediately give him a favored item.
   He was starting to learn to read sight words.
   So I had five words… and to me that was major,
I tried so many different ways
   to teach him how to read.
I was able to finally able to break through and do it,
I starting trying to add word “the” and “and” and “a”
   He started shutting down and getting angry.
   That was a major limitation, too……
   … being his mom
   and his teacher.

Building for change

FEAT….
   it was growing incredibly fast during that period of time.
More and more people were coming out of the woodwork –
   applying to get in line for therapy.
I don’t know how this happened, but I was the intake person.
   Not only was I working with Ben, seven, eight hours a day.
I was also training parents,
   how to do this program and how it works.
And then there was a signup sheet.
   It was first come, first serve.
   And it was horrible………… Horrible!

I remember there were times
   where people would be on this list
   and they would be desperate… Desperate!

They wanted therapy now.
   One guy went to a workshop.
   He was crying, saying, “I need to get therapy now for my son.”
He was tenth on the list.
   “How did I get myself in this position?”
   FEAT had the grant money to provide
   and it wasn’t just the grant money,
   It was the resources.

   UCLA just didn’t have unlimited amounts of therapists.
   They had people booked way in advance…

FEAT was on a hot line……
   they were very excited about what we were doing.

Lovaas.
   There were growing pains in this organization.
   Scott was more politically involved with it...
   My role involved scheduling the therapists……
   Ben needed therapy, too.

It had growing pains because it was growing fast.
   Early on Scott was a visionary
   He was saying, “We need to be doing this nationwide.”

At the time the board members of FEAT said, “No, no.”
   Scott had ideas that were ahead, maybe a year……

People had a different vision for the group.
   Should we be just local
   or should we be going nationwide?

Starting FEAT.
   I think about Ron Huff.
   We heard Ivan Lovaas speak.
   It was inspiring!

In ’93, we didn’t start over night
   We wrote a grant.
And it failed… Our first one!
   It was disappointing.

We were meeting on a regular basis.
   It took awhile to get the grant.
   Ben was five when we started.

He was able to access
   some of the training from that grant.
He was a little too old to be doing this,
   but, I didn’t care.
   We helped write the grants.

We’d been going to meetings twice a month or more.
   We sold cookies out in front of Mervyns.

We’re one of the original parents.
   It made a huge difference in his life.
   Teaching him language through this program,
   he was able to relate to us and calm down.
It was remarkable.
Scott and I were so happy.

Every day we’d see him change.
The vision of FEAT--
was support for parents
who had autistic children.
That was lacking, especially in our area.
There was no support!
Autism was rare back then.
It was 1 in 10,000 births and our county…
Ben was the only toddler in the whole county
who had autism.
It wasn’t very widespread
It was hard to get in touch,
to talk to other parents
that was a huge thing.

Our major focus—
raise money to get these grants
so we could do these
intensive
in-home programs.
It’s expanded into a lot more—
if you read the FEAT Handbook…
There’s a lending library…
Help with IEPs…
It’s a great network!

We were working on these grants,
we’d start talking about our kids, and
we would have our kids there
the support came naturally.

People who had a newly diagnosed kid would call
in desperation……
we started support group meetings.
Initially it was just this small group of parents
six to eight people
doing the grant writing,
and then after a couple years-
the meetings started getting bigger.
We were, at first, a goal oriented group……
trying to get stuff done,
trying to raise money,
trying to have this barbeque.
We all went to Linda Mayhew’s house -
twelve people there.

We had corn…
all were husking corn.
by the bucket load.

It was totally supportive!

The snowball effect……
It started with a few parents,
Once we got the grant—
it started growing.

“Where are all these people coming from?”
My son’s progress kept me going.
I could see how well he was doing
I wanted other people know
there’s help.

Our son was living proof --
(ABA) was a highly effective program!
To be honest, after a while, it got to be overwhelming…
parents would call me with newly diagnosed kids.
It is such a horrible emotional thing
to take all that on--
be comforting to somebody….trying to maintain my own wellbeing.

It got to be hard
and so I eventually started referring people
to other people.

As the organization grew, we thought,
“Okay, we’ve been doing this long enough.
Now it’s somebody else’s turn……to pass the ball.”

We were doing the program with Ben
he was making progress
I was going out to colleges.
To community clubs-
doing presentations to earn money.
It was wonderful time in our lives.
It was stressful,
but it was just so wonderful!
We were moving forward
seeing this little organization grow
into something huge.

My main focus was those two goals,
mainly, especially working with him.
Yes, the program, it had growing pains
it was growing so fast
and so many people wanted services.

Soon we had an intake procedure-
a waiting list and
training for parents.

I would tell them all that was involved.
Their whole life was going to change.
It was very consuming
I did the whole program with Ben.
I was always in the room.

Politics
with Applied Behavioral consultants—
our therapists
and we realized,
this shouldn’t be the only ballgame in town!

We sent some of our own students
down to UCLA directly,
They came back-
were able to work and
get vendorized by the Regional Center.

The growing pains……
the other organization that was affiliated
with providing students got mad.

Competition.
It got bitter!
I backed away from it -
“I do not need this.
I’ve got enough going on here.
I don’t need to be involved -
It doesn’t affect Ben.”

It got very nasty.
Couldn’t handle all that stress.

It was hard on us.
At that point I just withdrew
into my family……
I’ve got to take care of my own kids.
We’re not super people.

I felt weight of the world was on my shoulders…
to make my son better.
I would have nightmares at night.

I took him out of school.
I am the person, who needs to teach him.
With Ben, we started realizing that the Lovaas program wasn’t the end all. He was getting frustrated. I started looking outside of the Lovaas program—Sundberg and Partington two men in the Bay area who had a school called the Stars School. I started consulting with them. John McCacken, in LA who dealt with older kids, started consulting with him, started looking into a more natural approach to teaching Ben, started kind of branching out.

Other parents started looking into alternative therapy. A lot of people started looking into food…The low gluten diet.

FEAT evolved—initially starting the behavioral approach. When more and more people joined, they started bringing more and more information with them……and new ideas. FEAT became a resource for people. There could be more than one way to treat our kids than just the behavioral approach. So once you found something you’d share with others. So you just didn’t stay in one place. My son is more than a one dimension—he needed to learn how to play Our kids don’t know how to play!

Impact of legacy

We started getting more formal, the lending library. Support group meetings - we started meeting once a month and eventually that evolved into the MIND Institute.
Several years down the road……
    the founders were recognized at the Capitol.
        we all had plaques signed by the governor
    for Autism Awareness Day
        in front of the State Senate.
It was so exciting! I felt so important.
    What has this grown to?
        It’s… a snowball effect.
This little tiny grassroots thing that just exploded.
    We got a lot of the media attention!
FEAT made a tape for pediatricians –
    how to diagnose autism at earliest ages.
        We got a copy of it and gave it to our pediatrician.

Parents have kids that are diagnosed with autism,
    they need services immediately……
        support and services while they are young.

Everywhere, we see autistic kids now.
    In Hawaii--
        on this cruise ship—
            autistic kids.
Lake Tahoe,
    at the beach-
        we met an autistic kid at the beach.
            Every parent says,
                “Yeah, there’s just so many
                    everywhere we go.”
It’s amazing ---
    there never used to be autistic kids,
        around… anywhere…
            It’s scary…

It’s going to have a huge impact on our society--
    so many more kids with this severe disability
        that need life-long care.
    I mean that’s one area
        where parents need help and support.
A lot of our kids are getting older--
    Families for Early Autism Treatment,
        “they do grow up.”

That’s been a frustration of mine.
What is out there for our son?
   Do we have to be on the frontier again-
      developing new programs?
We were going to try to turn our house
      into day program
      I can’t do it anymore………
      looking at programs for our kids.

When we first started FEAT-
Ron Huff,
his main goal was to get them early
   when they needed treatment
      that would help the most!

Our experience,
   was surreal
   working with Ben
      and with the right kind of help—
      we were able to make a lot of changes.

I learned from FEAT-
to never underestimate what a few people can do!
      if your heart is into it.

There’s no way
   we could bring Ben to where he is today……
      or create an organization just out of a few parents.

   I mean, having a first fundraiser
      that was big!

FEAT……
   It started with this--
      “Let’s help our kids.”
   We felt empowered.
   We had tools.
      People helping us,
      supporting us.
      It helped us make
         a change with our kids.

Carl Haynie

Carl and his wife invited me to the first interview in person at their home in an isolated forest in the Sierra foothills. This was followed by two other phone interviews and emails. The Haynies have lived in the rural outpost for over fifteen years after
moving from Sacramento and their involvement with FEAT. They are a highly educated couple - Mrs. Haynie a graduate of MIT is a piano teacher and Carl, a trained Electrical engineer founded an Electronic business in the region. They raised both of their sons in the rural school system, one a typical student the other a young man with autism. Carl is a soft spoken and thoughtful man. He was very careful as he answered my questions in the interview poetic representation revealed below.

A child with special needs
   was something we never
      expected when he was born.
Neither my wife, nor my family,
   has ever encountered special needs.
      It was really a new thing for us when we discovered
         our son was autistic.
We were totally blown away.
     We didn’t know what to do.
      We didn’t know what was proper.

The Alta Regional Center got involved
   with us and a number of other people.
         Joe Morrow was another person
            who helped us.

**Direction for advocacy**

Through that community,
   we discovered there were
      a number of people facing the same situation—
         a number of people who had never dreamed
            that they would have a special needs child.
We met Linda Mayhew.
     My wife and Linda became acquainted with each other.
        Linda got us started in thinking about FEAT
            and the notion that we should involve
               ourselves and maybe create
                  a parent advocacy program.
                     to deal with that very thing.
Parents were coming into a new situation
and never dreamed they’d be involved.
    We tried to help them see through the
    stages of “What do I do now?”
I sometimes feel a little guilty
    that I wasn’t emotionally overwhelmed by it.
    I think a lot of folks that we’ve met
    are overwhelmed emotionally.

I sometimes feel a little guilty
    that I wasn’t emotionally overwhelmed by it.
Some ashamed.
    We’ve met a woman who didn’t want to be named-
          and I’ll respect her privacy.
She had a daughter who was mildly affected,
    and she was so strange about it,
She didn’t want anyone to know
    and tried to keep it secret.
Linda, frankly, was the opposite.
    Linda was happy to share her daughter’s problem
    with everybody.
    We adopted the latter.
We were not afraid to say,
    “Well, our son has some problems
          and needs and we’re going to try to address them.”
I think that has been a key issue
    throughout the entire advocacy with Nathaniel, our son.

We’re not at all ashamed
    and not at all afraid to share, and as a result,
    I think my wife’s involvement in the schools
    became something of a leadership.
People look up to how she did it
    and want to do what she did.
I don’t think we ever had any desire
    to put him away.
I think a lot of people
    who have the means, might find a way to have their child
    taken care of by someone else.
    We never dreamed of that!
Nathanial is 18 years old now.
    He was born fairly normal.
    We had two older children before him
          and those two children gave us
some sense of what is normal child development.
My recollection is that he was following
the exact same path as the others—
learning how to speak.

And then about a year and a half,
we began to recognize that
he wasn’t making progress anymore.

It was as if he had stopped…
in fact, he had regressed
I noticed that he wasn’t saying words
that he was saying before any longer.

I took him to a family portrait
and pointed to the people in the portrait
and he wasn’t able to identify them as he did before.

There was a definite regression--
from being normally developed,
to suddenly regressing.

We at first thought maybe
he had a hearing loss
and so we had him tested.

Doctors suggested physiological causes,
we had all those investigated.

It turned out none of them were accurate
and the truth was---- he had autism.

We learned that he was affected
at about 18 months to two years—
in that time frame.

That’s when the ABC program came in,
and I think they were under contract
with Alta Regional Center.

Before we knew it, we had people coming
to our house and instructing us
on what lay ahead for us---
intervention techniques and opportunities
and availability of different services and all.

Our son’s impact was very dramatic.
We consider it a positive impact.

He graduated from high school at 18.

His high school experience
was significantly adapted to his needs.

He didn’t go into the mainstream.

He didn’t ever pass the Exit exam.
He’s now at MORE, which is an El Dorado County program
that’s designed for kids with disabilities.

He loves MORE.
He’s happy there,
and taking a few college classes right now.
He’s doing pretty well to adapt, given his situation.
A lot of people like him.
He’s able to work a little bit.

**Building for change**

I wasn’t anxious to find
the so-called “free services”
that we could access, and maybe that’s because
I was still coming into the full realization
My wife, on the other hand,
had slowly recognized that this
was way more than she could handle.
She was rather equipped
to take advantage of Alta Regional Center,
Ron Huff was at the Alta Regional Center
at the time, and she met him.
For what services can we be eligible.
Nothing really drove me
to seek after advocacy groups
or after government-sponsored entitlement programs.
I think I was a little slow
to understand what the full magnitude
of his situation.
Then we also began to realize,
“Wow, if he’s not able to speak
or if he’s not able to respond to us.
We may be way over our heads.”
I think it finally started to dawn
on me when he became kind of a wild kid.
For example, he would go over to the
refrigerator and just pilfer food any time he wanted.
As a little toddler, he’d wander up to the fridge
and pry it open and go through
and eat whatever he wanted
and leave the fridge open and walk away.
And we immediately began to address it –
tied a rope around the fridge to keep it shut
For three or four years we had a rope
around our fridge just because
we wanted to make sure
that he interacted with us.
He began to then grab our hand
and walk us to the fridge…

It was then, in the refrigerator-tying phase of life,
that I realized that we’ve got a real big deal here.

We’ve got to figure out
how to teach this kid to operate
in the real world
and not operate in a world of his own
where he’s in a vacuum.

Or where he’s considering everyone
around him to be some sort of a machine.

So I gradually was opening up.
I was recognizing we were kind of over our heads.
My wife was well ahead of me
as far as understanding
we’ve got to learn how to teach this kid.

It was soon after that period of time
that she made the acquaintance of Linda Mayhew.
Perhaps Ron Huff put her in touch with Linda.
She was, at that time, living nearby.

She wasn’t too far away.
Linda was the real catalyst for forming FEAT,
and she talked to my wife about forming an organization.
So Diana and I went
to one of the earliest organizational meetings
and met with Linda and Ron.

I think Scott and Joni were there at the time
and this other woman who had a daughter
she doesn’t want identified.

There was also Linda Copeland.
She was a doctor.
A practicing medical doctor.

She was one of the early people,
They were trying to put information
on the computer and they were struggling.
They pulled me into the organization
because I could help get their computer running.
that’s how I got into FEAT.
They needed some technical help.
Then I began going to the meetings
and I began listening to
what was needed.

They talked about forming a public charity.
Legally speaking, that’s what we decided—
we wanted to form a public charity.

That has special meaning to the IRS.
I’m not a tax expert.
I’m not a business expert,

We clearly needed some expertise
in the realm of—in the mechanics of this organization.

Was it going to be a public charity or a private charity?
Was it going to be a 501C3…?
Or were we going to be something else?
I think that just snowed everybody.
Nobody really knew.

I volunteered to take on that task

to figuring out the legal entity of our organization.
I’m an engineer.
But I went to the Sacramento Library,
the public library downtown.

It was a new facility.
And I went in and started pouring
through books on starting your own charity
a public corporation.

And a very helpful librarian pointed
me to a NOLO book.

Apparently, NOLO Press is fairly well renowned
I checked that book out and read it,
and the book said, “Don’t use this book
if it is more than a year old.
Go buy a new copy.”

So I ended up buying it and through
the process of pouring through the book,
I realized what it took to
form a legal organization that the IRS
and California’s Franchise Tax Board would recognize.

We would be able
to receive donations from people
and they could be tax-free donations
because we’re a public charity.
I went through the whole list of things
that were required to be done.
I wrote the Articles of Incorporation for FEAT
and I wrote the by-laws for the FEAT committee—
the Board of Directors.

During that time everyone
was more into other aspects
of forming the organization.

So we’d go to the board meeting
and I’d present what I had done and they’d say,
“Okay, fine.” And I’d say, “Don’t you care?”

“Well, we’re fine with that.” So I thought,
“Well, oh, okay.”

They trusted me and we formed a 501C3 corporation
which is a public charity and had the benefits
of being able to receive donations
tax-free donations.

It wasn’t nearly as hard as I thought it would be-
because NOLO Press provided boiler-plate directions.

We followed the directions,
adding our little customizations here and there.

We established it in a way
that has been preserved to this day.

I don’t know if they’ve rewritten the Articles
People came in who had children.
I don’t know how they heard about us.
Early on we were meeting in someone’s living room
and it was crowded.

It didn’t take long for a number of people...
to get wind of us.

Building for change

I’ve got to give Linda Mayhew
a whole lot of credit because she is quite a go-getter,
and she went out and made friends
with a local radio personality.

She contacted Channel 3
and she contacted KFBK radio -
She was a very good catalyst behind our fundraisers.
We began having annual auctions -
   dinner auctions at nice hotels downtown.

One anecdotal story.
   I remember I was sitting behind the desk
       counting out tickets at the will-call line
       for one of our fundraisers.
I wasn’t looking up, and
   I said, “Name, please,"
       And this local radio personality walked up.
   “Oh, hi.”
       Oh, here’s our ticket.”
       And I put my head back down
       and the next person came up
       and it was another personality from the local radio.
   “Oh, I know you, too! Here’s your ticket!”

It was kind of exciting…
   I was in the action with all these people
       in Sacramento society.
It was kind of fun.
   It was probably well under two years
       from the start of my involvement.
   To decide what kind of group we wanted to form,
       and then I did all the incorporation.
Then we were really going to town
   with fundraisers and more in that second year.
Yeah, there were speeches
   The real point of those dinner/fundraisers
       was a silent auction raising money.
And Linda managed to go out--
   I keep giving her all the credit.
   There were probably others involved.
But we went out and got
   lots of donations from local companies
       all these groups that are always involved in societal change
       were very happy to donate their various products.
Lots of bottles of wine were auctioned off --
   and paintings!
       The usual stuff.
They never had any trouble getting people to donate.
Our cause was enough of a heart-softening cause that a lot of people were happy to be involved.

Our experience was,

“Our son has autism. Now what do you do?”

We were the dark for a little while until ABA.

Alta Regional was good because they took us and said, “Oh, you’ve got something significant lying ahead of you, so you need to start thinking about how you are going to deal with it.”

Early on intervention that we received was ABA, through a vendor funded by Alta Regional Center, so as a result the Regional Center was able to authorize a therapist, to come over to our house and introduce us to the Lovaas method of intervention. ABA was new on the scene at that time, in the early ‘90s.

This young lady had just finished graduating from Sacramento State, and she was very effective in terms of introducing us to this technique and teaching us how to reach him.

This was well before school started. This was before pre-school.

He was only about two or three, so for the first couple years of his life, we were intervening well in advance of becoming involved with the school.

Now school’s a completely different story.

We were in the San Juan School District down in Carmichael. We were living in Carmichael.

My wife was able to get him into a pre-school funded by the district because of his special needs…

He went to a preschool up there and, we were considering moving up here in Pilot Hill.

Now, we had no idea of San Juan’s opinion of autism. We’ve learned since, from others, that apparently San Juan is a pretty awful school district.

They’re pretty non-supportive, and so we just lucked out by moving out to Pilot Hill.

We avoided the conflicts with the San Juan District, but I do remember visiting what they called a “CH” class.
When Nathanial became eligible for kindergarten, he was old enough for regular kindergarten.

The people at San Juan were counseling us to put him in this “CH” class—
a communicatively handicapped class—
which was an inappropriate placement.

Because the kids had a variety of disabilities, none of them had autism.
The kids that were in various states of disobedience.
Kids that would act out and cause problems.
I remember there was an incident where they had a chair that would restrain a child.
My wife walked in and one kid was being restrained in this chair and it just terrified her.

We don’t want them to do this to our kid!
We chose not to put him in that program, and simultaneously we moved up here unaware that if had we did not come up here, we might have had a significant fight on our hands…
… to get him into more of a mainstream-
the least confining, least restrictive educational environment that he could handle.
San Juan, was getting into a fighting stance offering to let parents sue them instead of dealing with them.

I have a lot of admiration for the administration of this district up in Pilot Hill. This is the Black Oak Mine Unified School District, El Dorado County, They hadn’t seen too many cases of autism and frankly, didn’t know what to do either.
My wife and her ability to work with the district and their willingness to work with her resulted in a fairly good experience here.

We’re happy with what happened here. We put him in a preschool for a year until he was mainstreamed through kindergarten to the third grade at Northside Elementary School. The district provided him a full-time aide all four years.
A full-time aide.
You don’t get that too often!
They were trying to figure out,
“How do we handle autism?”
Some of the administrators were beginning
to see that we had a number
of cases coming their way.

There were children who were becoming eligible for school
with various disabilities.

During period we looked into the county programs,
a woman there pulled us aside and said,
“Your advocate for your kid and don’t give up on him.
They might try to put him in the county program
because it’s cheaper and easier,
but don’t let them do that.”

That helped us to realize,
“You know what?
We’re going to work with this district.
And we’re not going to let them
just put him in a county program.”

We felt that he could do mainstreaming.
A county program meant he wouldn’t
make any progress,
or in the county program, he might have to model
after kids with all kinds of disabilities.
That wouldn’t be appropriate for him.
He needed to be in a class where kids were talking!

When he reached about 4th grade,
the district had an IEP with us, and said,

“Look, we don’t think that he can
continue at Northside School.
We’ve established a special needs class
at Georgetown School, about 17 miles away.

We think it is appropriate for you
to move him to Georgetown School.”

And it was a bit of a hard sell
it was a pretty good year there –
He had a teacher there who was talented and
worked with a bunch of kids with a variety of disorders.
Nathaniel still got his full-time aide,
and made good progress that year.
So he remained at Georgetown School
fifth and sixth grade.
It was a special day class—
   Where all the same subjects were covered
       as in the normal classes.
Nathaniel was able to join the band.
   He played a keyboard---not a traditional band instrument,
       but he’s pretty good on the piano.
So he was able to participate in the band
   and the culture of being in a regular school.
Then he was in regular high school.
   He was in Golden Sierra High School all this time
       with a full-time aide dedicated to him.
The aide in high school was there primarily for his protection.
   The aide would help him stay focused
       and pull him out when he was restless.
He got somewhat of a high school education.
   He couldn’t pass the Exit Exam,
       but he had a social experience with high school peers.
He was at near grade level in many subjects,
   but not in all subjects.
As did a number of the founders.
   After a while with FEAT we said, “You know what-
       we’ve got to put our attention on him.
       We’ve got to let FEAT survive.
       It will sink or swim on its own.”
And it swam.
   So we’re happy.
You burn out.
   After two or three years –
       you just burn out and you just want to move on.
       We reached that point.
There was an event that frustrated me
   to the point that helped me burn out…
       “Ah, the heck with this. I don’t want to have
           anything to do with this thing.”
I finished my involvement with the Articles
   and the bylaws and it looked like there were
       a number of people coming in to take over.
Our tasks were being divided into
   smaller wedges and that was fine.
Committees were being established
   to do different things.
       I didn’t need to be there!
So as more people got involved,
   it was a natural progression of people broke off into committees.
It was fun to see it happening.
   But later both of us kind of said,
      “You know, we’ve got to pay more attention to our son.”
Overall the group was good.
   They wanted to do the right thing so that prevailed.
Thankfully!
   We just haven’t been involved
      because we didn’t really need the services.
   I perceived FEAT to be a place where parents go after
      just discovering their child has autism.

They would go to FEAT
   and learn how to handle it.
We were getting to be accustomed to our situation
   and didn’t really need to be hand-held at that point.

I remember having a number of meetings
   at which that was one of our principal agenda items.
What were we trying to do?
   Are we trying to be a service provider?
      Or are we trying to be an access point for people
         to find out what services were available?
FEAT offered an advocacy for kids with autism,
   if a parent would come to us.
We weren’t going to offer treatment,
   but we would have a way to point
people towards Dr. Lovaas,
   or towards some other doctor who
      had some other treatment that seemed to be effective.
Linda was the president.
   Ron Huff was also very high up but
      Ron, since he was involved with Alta Regional,
         he was restricted.
He couldn’t operate as a title-holder,
   although he was pretty influential
      as far as telling us what Alta’s view on what was needed.
We went to Ron’s house a time or two,
   and hammered out some details.
Scott and Joni both were involved at that time,
   as was Tina, as was Linda Copeland.
She was the doctor - Physician.
I wasn’t a leader.
    I was responding to a need.
A leader?
    I give Linda Mayhew a lot of credit.
    I give Ron Huff a lot of credit.
These were people that
    pushed on the rest of us, by saying,
    “We’ve really got to get things going.”
They were the ones
    that generated a sense of urgency.

They were the ones that
    got the community of us together,
    organized us into a committee,
and it was because of their insight
    that FEAT was founded.
Because of that leadership
    all of us, Scott and Joni
    Diana and I –
    Tina, and Dr. Linda Copeland –
    took our marching orders from them.
There were the leaders
    and the community responded
    to their leadership and founded FEAT.
I tried to lead in the sense of keeping the group
    out of trouble with not accepting bad money…
And when the word spread in the radio community,
    we began to get radio spots advertising our fundraisers
    and they were big affairs.
    We had lots of people there
    and all our stuff got bid on and sold
    and we raked in many thousands of
    dollars in a single evening.
    So that fundraising thing went real well.
I regret having left in a huff the way I did.
    I should have been a little bit more professional about it,
    but I said, “Ah, this is it.
    I’m getting out,” and stormed out. And I don’t know.
There really wasn’t more to be done
    as far as forming the bylaws and the Articles
    and submitting the paperwork to the IRS
    and the Board of Equalization.
That had all been done.
Whoever took over for me
would simply handle maintaining
and adapting the bylaws.

Honestly, I think I regret just walking out ---
I should have probably been a little bit more organized
and said, “Look, I’m going to go on out now,
So let’s get someone to take my place.”
But, I didn’t and they managed to survive.

Everyone who was involved in FEAT
because they either had a child that was affected
or they were specialists in the field of psychology,
specifically intervention with children who had difficulties.

And I’d say the majority of those people
were people with affected children.

So people were brought into FEAT when they discovered
or learned about an effort underway to organize FEAT.
Everyone brought in their own kind of perspective
primarily mapping it to their own needs.

In our own case, we had fairly recently come to the realization
that we had a child with a special need.

My wife, primarily, was the one getting involved
as far as being in contact with Alta Regional
and being in contact with ABC, and
ultimately becoming acquainted with
the principal people on the other side,
meaning the therapist-type people
who were Ron Huff and others.

We saw this as a possible way
we could develop an organization,
be a part of developing an organization
that would fill the needs that we saw,
the community needed.

Namely instructing new parents how to deal
with their situation, providing them some
resource connection to people nationally who
had various treatment programs
that might be effective.

In other words, contact FEAT
and FEAT could put you in touch with a successful program.
So we were thinking that we would get
something out of it in the long run…
as far as it being a clearinghouse of therapies
that might be available and valid for our son.
We were going to be able to create a resource
and then utilize that resource in his behalf.
FEAT was providing to us,
a society of people in the same situation
and therefore we were able to talk issues out
with other parents, but as far as being the remedy with all,
the clearinghouse with potential remedies,
it never got that far for us.
It didn’t meet our expectations.
But, on the other hand, we consciously bowed out.
We realized we had to concentrate on his treatment
and not the greater good, which was…
… establishing for the society or the community.
So it is meeting the promises.
We were not taking a whole lot of advantage of it because…
we’re remote and we have lots of things to do.
It’s not because of any bitterness
we might hold towards FEAT,
it’s more just because we’re out in the woods.
We gave a lot of focus to the Lovaas work
because that was something with which a number of us
were already familiar and we felt like it was effective
and wanted to share it with the newcomers.
We didn’t plan to offer any critique
of these things or any judgment
other than to make available treatments
that others had found to be effective…
Like a clearinghouse.
Not a testing lab.
In terms of clinical success,
I can’t point to any examples.
As far as the organization goes,
we were successful because we were able
to get a lot of attention from the community.
We were able to fund it with fundraisers
and we were able to do all the other hoop jumps
that needed to be done to establish the organization.
So, in terms of getting it going,
    we were successful.
FEAT is meeting its promise
    in terms of being an organization
    that parents with autistic kids would find useful.

FEAT is a very good resource
    especially if a parent was just coming to the knowledge
    that their child had autism or if they were frustrated
    with not being able to find resources.
    FEAT is a very good organization –
    I’d also make sure they were in touch
    with Alta Regional and…
    make sure they were in touch
    with their school district
    and all the other groups.

It was critical and something I didn’t understand at the time
    that the use of media is extremely important
    in forming a company or forming a group
    that succeeds in the sense that FEAT expanded
    interest in the organization rapidly.

A lot of people found out about us early,
    and that led to a lot of interest from a lot of people.
    Both people who could raise money
    and people interested in becoming in part of FEAT.
By the time I was leaving,
    there was a lot of people coming forward saying, “I can help.”
The reason they were coming forward
    was because of the media influence that we had.
We each were acknowledged
    for the things that we had done.
In terms of acknowledgement,
    I felt duly appreciated.
We certainly celebrated our success in those moments.
    We didn’t have specific, special celebrations.
    We never really celebrated……...
    We were always working.
During the time and we were involved,
    FEAT hadn’t gotten to the point
    of being able to offer any therapy.
It had plans to do so.
So, we never got anything back
in terms of the availability of a therapy.
In fact, that was one of the reasons
why we dropped out.
We decided that we had to become
a little more selfish with our own child…
about what we could do to affect him directly
and FEAT wasn’t going to get us there fast enough.
We wanted to be there for our child
and we realized that this wasn’t going to get us anything
in the near term when he needed attention right away.

He was becoming a preschooler
and a kindergartner and my wife had to get involved
in advocating for his case with the district.
My wife succeeded in getting services for him
and certainly there were moments when we celebrated.
We were able to keep him mainstreamed.
That was a moment of celebration.
We got him to graduate high school.
That was a moment of celebration,
but none of them had to do with FEAT.

Impact of legacy

The population of young people with autism has
dramatically increased.
It seems to me that FEAT is more important now than ever.
Many more families have discovered their kid has autism
As a kind of a first stop advocacy group --
It’s identification with others that have similar conditions….
that’s important.
FEAT’s role is continuing and growing dramatically.
It is regularly contacted by new people
who just get their child’s diagnosis
and don’t know where else to turn.

Could FEAT help
to address families with autism at all ages,
not just the early ages?

The early intent of FEAT
was to get kids early, when the
Lovass type of program could be effective.
FEAT’s success…
   It’s a prideful thing.
   I’m excited that FEAT has done well.
I haven’t kept up with FEAT over the last few years but…
   it’s a very successful group.
It’s cool being a part of an origination team of
   something that’s been so positive.
Hopefully it will be there for somebody in need.
   Even if we didn’t get a thing from our hard work,
   it’s nice to know we made our community
   a little better by being involved.

Tina Hendrix

The first appointment to meet Tina Hendrix took place on the campus of
UC Medical Center in Davis. This was followed by two other phone interviews and
emails. She lives in the mountains outside of Lake Tahoe with her husband and daughter
Mary, age 14, who has autism. However, she was in Davis for a special medical
treatment for her daughter. Tina was excited to greet me in the large meeting room of the
Medical Center’s Ronald McDonald House. She shared she was there to have her
fourteen year old daughter receive an experimental treatment.

   As her daughter slept quietly in the room nearby we were able to relax and get
acquainted. Tina, a former policewoman, welcomed the opportunity to share her insights
into the beginnings of FEAT.

FEAT—gave me the motivation to become
   involved with a group of parents,
   and that motivation to help your kid.
I did not join FEAT just to help kids with autism,
   the underlying motivation was my daughter
   and I needed to get help for her.
There was really nothing out there.
You know as a parent this gut-wrenching thing that just drives you.

It drove me
and just for the love of her
and wanting to make the best future for her.
My mom is a survivalist advocate person.

When we were young,

I remember if our dog bit us, I told my mom,

“Mom, you know our dog bit us.”

She’d say,

“Go bite him back! Don’t let him get away with it.”

When a boy down the street took our cat by the tail
and tried to throw it up over the telephone lines,
we came home running to my mom.

My little sister and I said, “Mom,” and told her what happened

and she said, “Don’t tell me. Go take care of it.”

We were five and six and he was in high school.
And she said, “I don’t care.

Go deal with it.” And so we did.

I think that’s what instilled the advocacy
My mom always had this survivalist sense of fairness,

an attitude.

She made us stand up for ourselves,

and it carried on to adulthood.

If I needed help I said,

“Oh mom, I have this child with autism,

and I don’t really have any funds
to pay for anything and I need help.”

My mom said, “Go out and raise them.”

It was that, and then also my faith in God.

There’s this Bible verse. It’s Proverbs 31:8
it says, “Speak up for those who cannot speak
for themselves for the rights of all who are destitute.”

I live by that verse.

Not just for my own daughter.

When I was a teenager, in school,
I’ve always had a heart
for animals, elderly people, little kids, disabled people.
I always had a heart for them.
I used to pray when I was younger
that if God would give me a child
a disabled child who needed a mom.
    Give that child to me.
    And, He did.

Then I became a police officer.
    for fairness, to fight for the underdog.
That was before I had Mary.
    I saw a lot of abuse,
a lot of underdog situations,
    a lot of unfairness within the criminal justice system.
It gave me more of a sense of how unfair the world is----
    there is work to be done.
    There’s no room to just sit down.

My child, Mary
    That’s what really shaped me.
    Having Mary!
Mary was a miracle for me.
    She was my first natural child.
    I had stepchildren.
I had been told in my prior marriage
    that I would never be able to conceive.
I had gone through some fertility work,
    I didn’t think I would ever have a child.
    I was mature.
    And just the love of her…
    Her dad, he didn’t want me to have Mary.
He wanted me to have an abortion.
    It just made me want to fight for her.
    We split up, not just because of her disability.
    He just couldn’t handle it.
But from the time she was in my tummy,
    I felt like I was fighting for her,
    and when she was born.
That’s when you fall in love with your baby
    and I fell head-over-heels in love with her.
To me she was a miracle
    and the child that I never thought I could have
    and I wanted a girl.
Then, I started seeing differences in her
    from about six months on.
    She was one of those babies who
had all those ear infections.
She was born in 1991,  
and that was when they were putting  
the thimerosal in all those vaccines.  
She had a reaction to the MMR.  
No one knew about that back then.  
I didn’t know about it.  
It wasn’t really prevalent out there.  
The internet wasn’t really popular in everybody’s homes.  
I just felt like I loved her so much.  
I actually had a friend who had five kids  
who babysat her, she said,  
“Okay, she was about nine months.  
You need to take her in.”  
The doctor just kept saying,  
“Oh, she’ll grow out of it.”  
About one year of age, she actually got a diagnosis  
it was called, developmental delay.  
Global developmental delay.  
That was her first diagnosis.  
I was referred by her primary physician,  
who gave her that diagnosis, to UC Davis  
to Dr. Robin Hansen,  
who is now at the MIND Institute.  
In the mean time,  
I was getting a little bit of services started.  
I had a comprehensive primary care physician,  
and he was with the UC Davis Medical Group.  
He was Dr. Peter Dietrich—  
he helped me get hooked up with the Regional Center---  
Alta Regional Center, with the special education system.  
So we started getting services right away.  
The special education system services were terrible.  
She went to this baby group  
the teachers were wonderful,  
I was really green  
about what was available.  
I was in, the “shock and awe” mode.  
Just like the “deer in the headlights” mode.  
I was a classic grieving process person ---- classic.  
First I was in denial, and I went through all the stages of grief……  
then I was, just heartbroken, and then I felt guilty.
Did I take too many hot baths?
   We were living on a farm
      that was being sprayed all the time with pesticides
   and I thought, “I wonder if that had anything to do with it? “
      I was going through the guilt and sadness phase
   and I took Mary to see Dr. Robin Hansen.
      She gave her the diagnosis of PDD.

So that was Mary’s second diagnosis.
   Mary was just a little over a year old,
      and I said to her, “Oh, thank God she doesn’t have autism.”
I knew nothing.
   Autism to me was *Rain Man*.
      And she said, “Well, PDD is like autism.”
It suddenly hit me like a brick.
   I remember sitting in that office at UC Davis
      and it was like somebody threw a brick on my chest
   and I balled. I just cried.

She said, “Well, I know of this parent, Linda Mayhew,
   who is starting a support group in Sacramento-
      and she gave me her phone number.

So I took that with me and I went home.
   When she got the global developmental delay diagnosis
      her dad and I split up.
   He didn’t really want anything
      to do with the disability.

So I was a single mom,
   and I was living at poverty level…..
   I had gotten very, very ill and landed in the hospital.
I could not work anymore.
   That was before I got pregnant with Mary.
I had Social Security Disability income,
   which was very meager.
   Her dad was not giving me child support.
   “I’ve got to just fight for this little girl.”
So I took him to court for child support.
   and then I met Linda Mayhew.

**Direction for advocacy**

I was not one of the first founders of FEAT.
   I came in a couple of months
      after they started getting it together.
Linda said, “Well, we’re not having
a support group meeting yet.
   We’re not kind of there yet,
but we’re meeting at Ron Huff’s house,
   and we’re writing a grant to the Sierra Health Foundation
to bring in the Lovaas Clinic.”

“Oh my gosh, what are you talking about?”
   I had a little grant writing experience.
   I did a SIDS program
   for the Sheriff’s Department
when I worked there
   and I didn’t quite write a full grant,
but I was involved in raising funds.
So I said, “Yeah, I might be able to help a little bit.”
   That’s when I met everybody ---
   I met Carl and I met Scott.
Ron was there, and Dr. Linda Copeland.
I just went to those meetings
and worked on those grants.
   I was starting to talk to other parents
and realized what Mary was gaining
   from the education system
   and the Regional Center
   was not working for her.
   It wasn’t working for anybody else.

My main motivation to help
   everybody else, was my kid.

The secondary idea was-
   why just get it for Mary when there are all these kids suffering?
If we are going to do this---
   let’s do it in a way where it will help other people, as well.
So, we worked on this grant.

I started learning about the Lovaas program.
   all the parents who were calling.
   FEAT was an entity that would be
   an administrative organization
   that would grow and,
and morph into whatever it needed to be
   to get services for these kids.

That the main focus would be—
   not let’s make an organization
   that looks like an organization.
Let’s see what the need is
and make the organization fit.
Forget all the rest—
this support issue is critical.
Get the parents in here
and let them talk to each other,
Then that becomes a bigger base for advocacy.
a bigger voice and more—
The other thing is we all had kids with autism,
except for the professionals.
We were exhausted
and overwhelmed!
Here we’re doing the work.
We needed to get more people
each to have little pieces.
That was what was in my brain.
and I know there were other people.
When we were doing these grant-writing meetings
and formulating this *entity*.

**Building for change**

The successes were
that we found out that we all had this commonality—
this urgency to do something for our children
in the formative years because there is that window.
How to move from having that urgency--
spinning wheels
and not knowing what to do-
to having that sense of urgency and thinking,
“We can do this.
We can do that--
A plan, something that really works.”
Right about this time,
what worked out best for me –
I entered the anger stage of my grieving.
That was huge.
What we wanted was to get the parents
and bring them past denial,
and love them through the sadness,
and once they got to the anger stage,
we wanted to give them some work.
When they went through the anger stage, they took on a little piece.
And so, that was the success part…
Everybody was supportive.
People had their fortes—
Carl was good with computer
Ron was good at the liaison work
    with the Regional Center.

Everybody had a common vision
    and goal –
    in the sense that
    these kids needed help.

These parents needed help
    and we need to get everybody
    to work together to
    make some changes.

There was that commonality.
It was obvious to the parents
    what these people
    were going through
    because we were going through it
    just like when someone came in, you knew,
“Okay, this person is going through denial.
We’ve got to educate them
    and help them go through this
    so that their kid doesn’t go without services
    because they are in denial.”

Some people would come in
    and they were just distraught.
The only thing we could do
    A that point was to support them
    and love them
    and listen to them.

You can’t really tell anybody,
    “Here, you got to do this, you’ve got to do that.”
You’ve got to get them through
    the grief stages.
I don’t know if we actually sat down
    and talked about that,
    but what we did talk about was,
    when someone was angry.

We spontaneously knew ….
I don’t know if we sat down  
and strategy-planned.

We all knew when someone was ready,  
talking to other parents that were going through it.  
talking to a couple of professionals.

You’ve got to let people know what your goal is  
and that you’re here to help them out  
and they have a place to come together.

Recognize the need.  
What is the need in the parents and children?  
What’s out there?  
What’s the need out there?

Then, supporting those needs  
because in doing that, you become successful.

I’ve seen people trying to get groups started  
over the years.

Look…… there’s a model.  
Let’s model our group after it!  
If it’s not tailored to really to the needs of the clientele,  
and it’s not a morphing type of changing…

FEAT went through major changing.  
it just went with what was needed, on both sides.

That’s why it was so successful  
so fast -- coupled with the drive----  
this sense of urgency in these parents.

Some of the early successes were that,  
we did reach a lot of people.  
We had both professionals and parents  
involved in our board of directors.

Ron could refer people from the Regional Center,  
and we had some special education people that were involved.

That was one of the successes.  
Then, we got the grant approved,  
and that shocked all of us----  
the Sierra Health Foundation!

We got $ 75, 000 grant!  
We were just really shocked,  
one of us were professional grant writers.

It was amazing that it was a big,  
huge success!  
We wrote the grant to replicate the study of  
Dr. Ivar Lovaas at UCLA.
We wanted to replicate that model in Sacramento, with the focus on providing ABA services for the children with autism. The only place we knew existed was down in UCLA. Maybe there was a replication site in New York, but, there wasn’t anything of that caliber. There were some ABA services through ABC, in Sacramento with Dr. Joe Morrow. They were decent, and there was STARS School with James Partington in Walnut Creek or Danville area. But there wasn’t anything really of caliber, of the real success rate caliber---that was documented, with real empirical evidence like Ivar Lovaas. The other programs were good, but there wasn’t the availability and the Regional Center, was not paying for ABA at this time. There was this big fight - “Well, that should be the education system that pays for it.” And the education system said “No, that should be Regional Center.” There was this black hole that services would go into because neither one of them would pay for it. We had already been in contact with Ivar Lovaas and his clinic at UCLA, and they were well aware of the grant, what we were doing, I had money backdated from Social Security and paid for it myself for Mary. I had Nina Lovaas come up and Mary was like fifteen, sixteen months. So, I was already doing it, and some of the people in the group weren’t happy. They asked, “Why don’t you wait for the grant?” Maybe they were a little jealous, and you know what? The grant can pay for someone who can’t pay. And I had this back pay money that I got and I was using it for my daughter. Because I already had it going, we had a PR parent, a parent who did PR for a living, public relations for some company.
She had all these contacts to TV and radio stations. She got a hold of KTLA-5 at UC Davis, called “Pulse.”

They showed a different segment about current health issues on TV-
We were the only ones,
who were doing ABA at the time.
There were a couple of families--
I know one other woman.
Who had done ABA,
and her child’s with their diagnosis was removed.
That’s what spurred us on,
seeing the success.
That got a lot of interest flowing.
Then all of a sudden there were radio programs,
and newspaper articles,
there was a lot of public media.

I was the treasurer
and I was the person that did the arrangements
What it paid for was consultations and for flights.

We were all board members
and we just moved around
and did whatever was needed.

It was like there were a few parents who did a whole bunch
and there were a lot of parents doing nothing
and there were a few parents doing a little bit.

We were all ad hoc committee members of *something*.
When we got the grant, and started programs,
we also had Channel 10 do a report.

FEAT paid to fly the clinicians up from the Lovaas Clinic
their consultations, and their lodging.

We would coordinate families together.
Whatever families were ready on the waiting list.
We would say, “Okay, five families can come to the consultation.”

We’d pay for the consultation,
and we would help the families.
This was huge.
We started a huge recruiting effort.

We’d help the families recruit the tutors
or aids to work the program with the kids.
We told them they needed
to come with their aides to get trained.
    So, we had a lot of prep before.
We couldn’t just say,
    “Okay, here, we’re coming to that meeting.”
And this kind of all evolved on us
before they came to the consultation,
they had to have their tutors to be trained.

So Mary and I partnered with Joe Morrow.
He wanted ABC to be a part of this,
We did what he called
    the “dog and pony show.”
We actually did a demonstration the very first time
    for one of his behavioral science classes.

We came in.
    We had Mary’s aides with us.
We were already doing our programs.
We did a demonstration in front of his class of 500.
    We called them Lovaas presentations.

    I would be waiting outside with Mary and her tutors-
    Michelle would go in and would talk about Lovaas.
She would show a film on Lovass----
    then the show the “Pulse” TV spot of Mary working
    and these students would get interested.
Wow---- then all of a sudden
    we’d open the doors and we would walk in
    and start doing a Lovaas demonstration
It just blew people’s minds.
    It just blew their socks off.
    They could see this child working
    right there and then.
We would do hundreds of these demonstrations,
    and people raised their hands.

    At the same time we were
    working on getting them field units
    so they could go out and work with these kids.
At the end of the presentation,
    we would recruit them to be tutors,
    then we would match them with kids who needed one.
You could see all the work that was going on,
There was tons of work.
   It was like a double full-time job for all of us.
We would match them by zip codes.
   We’d match them with the parent in that area.
So we helped these parents recruit.
   We went everywhere.
   We went to nanny colleges,
      pre-school teacher’s associations…
      business colleges.
We did several at UC Davis……
   presentations.
   Tons of presentations all over the place.
And then it got to the point where
   we didn’t even bring the behavior specialists.
   I just went in and did the initial presentation
      and then because they couldn’t come all the time.
      They were working!
Then I would bring in the whole crew in,
   and it was very successful.
We had professors and teachers calling us all the time
   to come back for the next quarter.

We were going to high schools.
   We were going to high schools.
   The problem kids were volunteering
      and it was turning these kids around.
It was amazing.
   We went with the need.
   We morphed with the need.
   FEAT… it evolved with the need.
   It grew to be overwhelming,
      but we taught parents how to do their
      own presentations.
There were other families doing the presentations—
   Mary and I weren’t the only ones.
There were some others.
   If the new tutors went to the clinic consultations with UCLA,
      they would be trained right there by those people.
They would be continually trained
   by ABC and by the parents.
Joe Morrow’s group,
   and there were other groups popping up.

130
At the same time

that all this was going on,

we were all embroiled in a huge battle with three agencies.

Number one was Alta Regional Center
to get more services.

I was fighting my own personal battle with them,

and I had huge success. A huge success!

I got them to pay for Mary’s pre-school,

for all of her tutors,

the wages for all of her tutors,

for the UCLA consultations.

Tons of stuff!

Then I was embroiled in a huge battle

with my school district for special ed.

I won and got them to pay for

all the supplies unavailable from the Regional Center.

So we were covered.

But, prior to that, I had run out of money.

I didn’t know what to do.

FEAT and the grant had not yet come through.

So, I prayed about it.

But I didn’t have a plan.

I just thought, “Well, I’m gonna have to raise money.

I’m going to have to go and do something concrete.”

I recruited kids from the high school

where I lived in my town of Winters

and those kids came

and got class credit,

and worked with my daughter.

They were excellent--

these high school kids!

A couple of them were delinquent kids and they just rocked.

They were ADD and they understood Mary.

So I went to the local newspaper

and said, “You know, these kids,
you’ve got to do a story on them.

They are just amazing!”

And so the newspaper reporter came

and did a story and she said, “I see so much more.”

We live in the little town of Winters. It’s awesome.

It’s a little small town

and she went to the town

and she told the people in the town.
She went to the Soroporists meeting, plus there were newspaper articles.

I kept a record of this ---
   I have the articles about what we were doing
   and how we were running out of money
   and how the schools wouldn’t pay.

We were embroiled
   in this battle with the school
   and the Regional Center
   and how this town needed to rally together.

They put together these huge fundraisers.
   Huge, big spaghetti feeds!
   They raised $11,000
   and set up a bank account for me
   and so I had a trust fund.

I started paying for everything out of that fund!

We were not only going out recruiting tutors,
   we were going all over Sacramento,
   all over the place
   and doing fund presentations.

We were going to the Lions Club,
   and anybody who would donate.
   So we were doing presentations,
   the same presentation.

We got people who volunteered
   to be tutors from those things, too.

Then we started raising money for FEAT and
   we had enough for us.

The third agency that we were embroiled with,
   embattled with,
   was the insurance company.

I think we had Health Net at the time.
   I was going through three due processes
   at the same time.

But, we fought the school district.
   It was the Yolo County Office of Education.
The first IEP I had them come to my home.
   I was like a sponge.
   I was absorbing everything
   I could read about autism.

I read the entire Lanterman Act.
I wanted to know.
   I read everything there was to know about
   special education. So I knew the law.

Plus I had my law background
   as a law enforcement officer.

So I knew.
   Well, I had everybody
   from the community
   in my home supporting me.

I had Mary’s tutors.
   I had two people from my church
I learned that I could have
   these people in my corner.

The director of Special Ed,
   he sat there
   and fell asleep
   and snored through
   the entire IEP.

It took several meetings,
   it was a due process.
   We were already in due process.
   I filed all the paperwork.

I got an attorney, Kathryn Dobel.
   She was the famous attorney who
   was doing the another noted case--
   Rachel Holland!

I got Kathryn Dobel.
   That kicked them in the butt!
   We got everything we wanted and
   more from the Regional Center and
   from the school district,
   and the really exciting thing--
   we had parents calling!

My house was a hotline.
   I had parents calling me
   from all over.

I was battling against them all the time.
   They gave me everything I wanted.
   Then I used to be able to get supplies,
   whatever supplies I needed.
What they did was
   set up a program—
       a Lovaas ABA program.
Our school district was one
   of the first districts with services.
       It was Winters Unified.
These were my personal battles
   but they were FEAT battles, too.
It was simultaneous.
   There were all parents who
       had to do our own battles because –
FEAT covers a nine region area and
   the only thing that we could do
       collectively was the Regional Center.
But, it had to be bricks out of the Berlin Wall.
   Each case had to file.
The successes that we had
   as a big group were that we did fundraisers,
       the dinner dance and which
           included Linda, myself, and Scott and Carl.
We did it pretty much all by ourselves
   the first couple years.
   And the third year is when everybody
       came and helped out a lot.
Those helped with the advocacy and
   raising money.
       Those were huge successes.
We called and got all kinds of donations.
   Linda Mayhew was friends
       with Linda Clayton, the local DJ-
           and that helped a lot.
We had the Regional Center involved.
   Involving them in a positive aspect helped
when we came to say,
       “Okay, here’s what we want.”
   So we tried to involve these agencies.
Whoever we were embroiled in battle with,
   we kept it impersonal.
       Emotions were high.
There was this competition
   with Lovaas and the other agencies
       and then with the Regional Center.
Everybody was in competition.
There was lots of antagonism going on
so what we tried hard to do was,
If we win,
    we’re going to be working with
these people on a daily basis.
    So we want to build a relationship.
We don’t want to alienate them because
    There are a lot of parents that alienate them
    and, no, we can’t do that—
    Not with an agency,
    and not as a parent.”
FEAT worked hard to be
    professional.
When I was with FEAT,
    working as a board member,
    I tried to separate,
    tried to be professional.
I thought, “I’m not going to take any of this personally
    because I do not want to alienate these people.
I want these people to work with us!”
    We tried to involve parents in
    a lot of the positive efforts--- we had a barbeque.
    We’d invite them or
    We did a barbeque fundraiser
    we had a lot of stuff that failed,
    but one of the successes that I can say is
    that we weren’t afraid to try.
We did as much research as we could
    to make sure that what we were doing was legal
    and everything else - but we took risks.

We took big risks, and we weren’t afraid to
    try and we weren’t afraid to fail.
    The only thing we were afraid of was not taking action.

The urgency is there in each parent already,
    and the only time that it’s not,
    is when they are in denial.
So, we helped them through the denial process to get to the point where, “Uh oh, wake up!
Now you have a need . . . . There’s something you got to do.”

It’s in the parents.

It’s already there.

We just help them get to the point where they need to act on it.

In the community, how do we create that?

We took the numbers.

We took the great numbers.

The number ten years ago, was 1:10,000, now it’s 1:110.

We took the numbers.

We started going out and telling people, “This is an epidemic. Crunch the numbers.
This isn’t genetic-

What is it going to look like in another ten years?”

We looked straight at the numbers,

When I would go out--

When I went out to my first presentations, I would say, “Okay, how many of you know someone who’s autistic?”

And most people didn’t even know.

Well, within a couple years, I had, five, ten hands. “Oh yeah, my neighbor has a kid with autism.”

And then after about five years, it was mostly the whole class that raised their hands and they would say, “Yeah, I know someone.”

So, even anecdotally we knew it was growing.

The numbers were coming out of the Regional Center.

I’ve been involved with FEAT from the very beginning and I still am a member, but not an active member for five to seven years.
Later, I got married and
moved to Santa Rosa and
I started a chapter, another chapter of FEAT
--the North Bay FEAT chapter.

So I was involved on a different level,
For about seven years, I was pretty active.
The first chapter that we ever started.
Our goal was national and international.
But that couldn’t be.
We knew that everybody needed
to be their own entity.

**Impact of legacy**

The first one was down in Stockton
and that was the first chapter that we started
collectively as a group.
And then, chapters were popping up everywhere!

The waves of the
*big* people came in,
like Sarah Gardner and Rick Rollens,
They had kids with autism.
There’s a first wave,
a second wave, and
a third wave of FEAT in Sacramento.
Rick Rollins was in the second wave.
And Sarah Gardner, a local anchorwoman
on channel three was the third wave.
Bruce Kaminski,
and all those people were attorneys and
doctors and people who really had some clout.
Then the MIND Institute.
Another story is the MIND Institute!
Those people put FEAT on a bigger page.
A year or two into FEAT, Rick Rollens joined.
He was early, and he was in the second wave.
The first wave to me was just the original people and
some of the parents that came in.
The second wave was Rick Rollens
and these people that started
to make more changes.
And the third wave was when the people like Sarah Gardner
and Bruce Kaminski, and all the other people
who made bigger changes.

137
That’s the three waves of FEAT.
I don’t think FEAT’s done anything more huge
since those second and third wave people.
In the very beginning, the vision was
to provide support and Lovaas replication assistance.

Later, it became support, Lovaas, ABA, branching out, advocacy,
with the Regional Center and school districts,
Then getting the health insurance companies to change and
reaching into the community and
educating the community.

The third thing that came in was
branching out past ABA.
That was my vision in the beginning,
to branch out past ABA.
ABA is one piece of it,
but there are a bunch of other pieces.
The biomedical --the health end,
the research end,
the numbers,
the genetic.

That was our vision.
Another piece of our vision was
replicating FEAT.
Getting FEAT to go national and international,
so that other parents could get
the same benefits and
so we could become a much larger voice.
We had so many people calling us from
all over and that’s when we all got on-line.
People emailed us from
the Philippines and Norway –
the need was there.

It was completely a need driven.
We were bombarded with need
from our own personal issues
to our local group
to the nation and world-wide.

Carl offered to help us incorporate.
Our vision was to become incorporated,
a full-fledged corporation and that was
bringing in funds all different ways and
assisting people in more ways than Lovaas.
We had a huge vision
  The MIND Institute was one of our huge visions.
When we started realizing that it was
  more than ABA.
  That people needed support.
They needed advocacy.
  They needed OT services.
  They needed health intervention services.
There was just a huge need—
  We have to go here and there and
everywhere and fight for it and so many--
  We were the case managers and
  we had all these doctors and no one would coordinate.
These kids need a one-stop shop place.
  They need one place where they can go and say,
    “Hey, I think I have autism.
    Give me a diagnosis.”
    Okay, you’ve got a diagnosis.
    “Now I need dietary intervention.
    I need ABA. My parents need support.”
A one-stop shop.
  That was our vision and
  we all had the same idea.
In our board meetings.—
  We need a one-stop shop.
  So, I don’t know who came up with this idea,
  but it came up at one of our board
  meetings or two or three of them.
And we decided that Ron Huff and I
  would go to UC Davis and talk about starting an autism clinic.
    A one-stop shop!
So, Ron and I did.
  This was in the second wave of FEAT
    like when Rick Rollins and people were there.

And we went over and we talked with
  him and we told him about our success
    with the Sierra Health Foundation.
And we told him that we
  wanted this one stop shop.
It could include a replication site for Lovaas,
    but that wasn’t going to be the only thing –
We explained to him.
Dr. Tom Anders—
what we thought would really work for these kids.

He told Ron Huff and I, “Oh my gosh, what a brilliant idea.
It will never happen.” He said,
“It will take millions of dollars,
and I just can’t see that happening.”

Everybody in the group heard,
“Oh, that will never happen.”
We heard that so many times,
we thought, “Okay, whatever.
He thinks that it’s a brilliant idea!”

He thinks it’s a brilliant idea!
Well, he gave us a challenge.
“It will never happen”.
Okay, it’s gonna happen!

We took that back to FEAT,
and we took that as a challenge.
And we thought, “How is that going to work?
And how are we going to make that work?”

Well, we need to get out and
get people in here that can make that happen.
We need to raise money.
We need to raise awareness.
It’s not going to happen overnight, and
we probably are not going to make it happen,
but we’re going to put the foundation down.

Then the third wave came in,
the Sarah Gardners, the Bruce Kaminskis,
the Greek family, a huge Greek family--
a rich family from this area joined!

Those people came in with kids with autism.
Those are the people that made it happen.
They’re the ones that took the ball and
ran with it and did the work
and made it happen.

We laid the groundwork.
We had the vision,
but they came in and made it happen.

Although I’m very disappointed
in the MIND Institute because
it was not what we envisioned.
It’s more of a research-based university, teaching-based.
    It’s not all the one stop shop clinic
that we had envisioned at all.
We were some of the visionaries, and
    they won’t even see my daughter now.
So, I have to go out and
    buy insurance for her and
    I can’t afford it.

My husband’s chronically ill and
    he’s out of work and
    I’m disabled and retired.
We don’t have the money to go out and
    buy a personal insurance policy for Mary.
So, Mary can’t even be seen there.
    That’s one of the disappointments.
I’ve talked to many parents, many, many, many—
    are very unhappy with the MIND policies.

The organization was continued
    by the parents that were brought in.
All these movers and shakers
    had kids with autism.
Our group was attractive to them
    because we were hitting
    the notes that they needed.
    So that’s what helped to grow.
We had a lot of parents that were support parents.
    We had a hotline……
    Listening to what they had to say.
We were trying to bring them through
    that grieving process
    and when they hit the anger,
    “Okay, here’s what you can do.”
Some hit what we call the Piranha phase
    where they want to gather up every
    little bit of knowledge.
“Here’s the web site.
    Here’s the information.
    Here’s the Autism Research Institute.”
We had all that compiled.
    We were an organization that was ready--
    that knew what these parents needed.
When other parents came in,  
    they, in turn, did the same thing.  
    And most of them give back in the same way.

There was a few that were leaders  
    and we recognized those leaders  
    and those were the people that we drew in  
    and said, “Here, you're a leader.  
    You can step up and really do more.”  
    “To whom much is given, much is expected.”

That’s how we perpetuated FEAT  
    to grow and to become  
    what it was and our idea was not just to  
    keep going what we had going.  
    We didn’t settle for,  
    “Okay, now we got a grant  
    from Sierra Health Foundation  
    and we’re replicating Lovaas.”

No, we thought,  
    “What would be better than this?  
    What’s improving on this?  
    Let’s send some of the therapists  
    that we recruited  
    and get them trained.  
    Okay, that’s great.  
    Now they’re back up here working.  
    Okay, now let’s set up a Lovaas program up here.”  
    And we never settled.

It was always  
    “Okay there’s always something better.  
    Let’s move on to this thing.”

That’s what we kept building on  
    Our foundation and also needs change  
    and information changes.

Now there’s not only ABA,  
    there are bio-medical needs.  
    We found out about the gut issues and the GF-CF diet.

Every time there was a need  
    we started building on that need.  
    so it made FEAT grow  
    and last and still be what everybody needed.

One of the things that lasted  
    is the yearly dinner-dance silent auction.
We learned that we had to plan right away.
As soon as the thing was over, we had to start for next year.
We learned that it took more than two people.

We learned that we had to have a better system of seating people and registering them and we kept that information, used it and built on it.
That’s what made it lasting.

The MIND Institute was the brainchild of people related to FEAT.
It wasn’t FEAT-created.
We had to partner with the community, partner with the services out there, partner with the organizations and agencies and that’s what FEAT did very well.

FEAT is a moving, breathing organism because we were moving, living people and everybody had different ideas, emotions.
We all had the same goal or the same outcome, but we all had different ideas on how to get there.
One person’s idea would catch on-- “Oh, that’s great. Let’s look at that!” Then we’d find glitches.
“Okay, let’s move to this other person’s idea.” The different systems were working with each other to make it work together.
What fed into our long-term goals - what did our kids need to be successful? Or how to reverse their diagnosis or be as healthy…?
What was lacking?
There was no funding for anything and there were no services.
So our long-term goals were we need to create these services or find them.
And then we needed to advocate for funding to raise funds to fill in the gap. Then we wanted to be a gap-filler. We wanted to use whatever was out there first and encourage people.

Dr. Ron Huff

Dr. Ron Huff is an accomplished clinical child psychologist he serves as the Director of Clinical and Intake Services for Disability at the Alta Regional Center in Sacramento since 1988. His resume includes a PhD from Ohio State University, early childhood psychology research done under Todd Risley, a well known experimental psychologist at Florida State University, a professor post at California State University in Los Angeles, the development parent training programs with UCLA’s Bruce Baker for South Los Angeles’ Regional Center for thirteen years, along with frequent contact with Ivar Lovass, founder of the LOVASS Autism intervention. Dr. Ron although not one of the “founding parents” of FEAT, was fundamental driving force behind the founding of FEAT in the early years. He served as an evaluator, practitioner, resource and motivator for the organization. His caring involvement went beyond the boundaries of a “professional” and he became fellow advocate and strategic planner for early FEAT. Ron’s voice is one of a unique psychology professional who allowed himself to be involved so significant changes could happen through this unique parent group. My first interview with him was in his book-lined office at the Alta Regional Center in
Sacramento. He was open and articulate during that hour which was followed by two phone interviews.

**Direction for advocacy**

I grew up in a small town in Kentucky where literally through my whole elementary and high school years, I never laid eyes on a person with a developmental disability. They didn’t exist. And one day I was back there visiting my mother… after I had graduated from Ohio State University with my PhD. We were driving along the road, and I asked my mom, “What was that building? That big school-like place over there?” She said, “Well, that’s the Mary Kendall Home.” She said, “That’s where people who have developmental disabilities live.” And so I grew up in a segregated community where individuals with disabilities were not even viewed in public. So while I was at Florida State, I had the good fortune of going into an experimental laboratory, with Todd Risley, who is a very well known psychologist and tremendous contributor to the research field of psychology. There was a child with autism. By this time, I was twenty years old. And I broke into tears.

It was something that I’d never experienced before and I think I was profoundly affected by that experience. So that affected me deeply I think it still continues to motivate me to this day. I went on to Ohio State and was trained in behavioral psychology. While at Ohio State, I was further influenced by my experience at Columbus State School.
In the late ‘60s, there were these large institutions
of which California still continues to operate five.

We actually went out there
and did research on individuals, on human beings…
to study the effects of reinforcement
how to teach discrimination training,

That was kind of a mixed experience for me
because the children who lived in this institution
didn’t receive a fraction of the kinds of services and supports
that we think of today.

Then, after graduating,
   I went to Los Angeles where I was employed
   by California State University at Los Angeles.
   I was a professor there for about five years.

After about five years,
   I realized that academia was
   not something that was personally that motivating for me.

I wanted to get into something
   that was more applied --
   where I could work with real families.

So, I took a job
   at the Regional Center in Los Angeles,
   in South Central Los Angeles.
   I worked for thirteen years
   and developed parent training programs.

At that time I was working with Bruce Baker
   at UCLA and parent training was unheard of in those days.
The idea that you could
   actually prepare families to teach
   with ten or fifteen basic skills.

If they mastered those skills, every day,
   day in and day out, with teaching their children
   as the children grew up.

That was a tremendously positive thing.
   We developed other programs.
Also, that experience
   in that neighborhood, was very key
   to bring me to this point.

I was in Los Angeles until 1988
   at which time I moved to Sacramento.
A big part of the time I was in Los Angeles
I had regular contact
with Dr. Ivar Lovaas at UCLA
who is the godfather of all
autism treatment.

He has done more than any human being
on the planet to develop autism treatment programs.

I realized that there were behavioral programs
at that time that were very effective
Not every child was able to respond
as much as others, but there were
a lot of positive results going on there.
It took a lot of energy
and time and expense.
It was a huge impact on everybody
to treat a child with autism.

I moved to Sacramento,
I was working at this very Regional Center.
I was a clinical psychologist.
I was diagnosing kids here.

I’d been here for almost a year,
and I noticed that I had developed
a little routine, a debriefing routine,
that I was sharing with families
if I diagnosed their child with autism.

I would find myself saying
to them at the end of the interview,
and sometimes the evaluation
would last three or four hours.

I would have to end up saying,
“Well, your child has autism.
Your child has these strengths.
Unfortunately, there are no programs here
in Sacramento that I can refer you to for treatment.
If you lived in Los Angeles,
I could help you, but not here.”

After the tenth or fifteenth family
that I was giving this little spiel to,
I realized this is not right.
Something’s wrong here.
We’ve got to look at developing
   something for these families.
   We can’t continue to just ignore this problem.
It was the late ‘80s, early ‘90s.

I was seeing nearly two kids a month,
   and that was an increase from my experience
   in Los Angeles where I would maybe see
   one child every two months.

So I was seeing a slight increase
   in the number of kids with autism…

By 1990, the local Autism Society of America
   chapter president heard that I was here,
   and had an interest in autism
   and invited me to a meeting.

There were about thirty families--
   I did a presentation on
   some of the research findings
   from Dr. Lovaas’s research in Los Angeles
   and his treatment program.
   I even had a little film footage--
   ten minutes, of a child,
   participating in an actual discrete trial program
   receiving treatment!

Unfortunately, I didn’t realize
   that the parents in this meeting were
   parents of adult children with autism.
   And so I presented this whole research approach,
   this whole treatment approach to working with
   young children with autism.

They sat there and stared at me,
   almost as if in disbelief,
   “Is this man making this up
   or where did this come from?”

I spoke for about 45 minutes,
   I entertained a few questions,
   and I later realized that not a person in that room
   believed that it was possible to treat a child with autism.

I found myself trying to convince them
   that it was possible to work with children,
   and even adolescents and adults who continue to see progress.
That was the end of the meeting.
    They thanked me. They really appreciated
    all the information.

About three weeks later,
    one dad who was in that meeting,
    who had a farm out in Dixon, called me
    and said, “Is what you were saying
    at that meeting really true?”

And I said, “Yes.” And he said,
    “Well, my son……” I think his son was about six years old.
    He said, “I’d like to try that out,”
    I said, “Fine.”

So, I went to talk to the
    Director of this Regional Center
    at that time, Ralph Levy.

We asked him if it would be okay
    to think about beginning
    to start some kind of autism treatment program
    here in Sacramento.

He said, “Yeah. I’ve been hearing that there’s some kids
    who have been starting to populate us.”

At that time, there were three or four thousand kids
    in the whole state with autism.
    Now we’re up to 37,000.

Autism was a very low incidence disorder
    so no one minded if we went ahead and started a program.

I actually called the UCLA Clinic
    and talked to Dr. Lovaas
    and he was willing to come up here.

At the same time, Dr. Joe Morrow,
    who was a professor of behavioral
    psychology over at Sacramento State,
    he wanted to invite Dr. Lovaas up for a lecture.

When Dr. Lovaas came up,
    we chatted, and I said, “Well, I’d like to experiment
    with getting something started in Sacramento
    and we have one family that would like to try that out.”

In fact, Linda Mayhew
    and a few of the initial FEAT parents actually were present…
    at that first lecture to see Dr. Lovaas,
    and to hear what I’d been saying here in Sacramento,
    but I think people were very skeptical.

Sure enough, Dr. Lovaas, he was very persuasive
    and convincing.
He had an extremely high standard for scientific research.
So after he returned, he sent up Annette Gruen, one of his well trained clinicians out of the UCLA Young Autism Project Clinic.
Annette worked with this family and literally, within a few weeks, this child began to respond.

**Direction for advocacy**

So, other parents heard-
This dad started talking to other parents,
and the next thing, a couple other parents are asking me, “Could they do that?” So, I said, “Well, yeah, why not?”

So, I went back to our Regional Center Director, Ralph Levy, and he gave us $2000.
I didn’t want to have the UCLA Clinic come up and teach only one family.
We needed to recruit people who could be trained as tutors—
... hands on therapists.

I wanted to begin to set up something so as we did this training, it would involve several tutors—
that’s what we called them.
They were people who did the *hands-on* in those days.

They are still called that today…
in some places.
I wanted to begin to recruit and begin to create a pool of resources in those young tutors.

So the $2000 was used to pay Joe Morrow who had just founded Applied Behavior Consultants, which is his behavioral program today.

He was willing to have his higher trained, masters level therapists actually sit in on the Annette Gruen workshop…

Then we had three families involved!
As a result, we were able to make significant progress with this one child.

This workshop lasted for an entire week—five days a week, 8 hours a day.
During that time, we had six or seven therapists present who were receiving training and were taking turns working with the kid under Annette’s supervision. Annette left them with a complete curriculum and she would come back and consult. There was tremendous progress.

The child that we worked with, was about four years old--a young boy!

He had his parents kicked out of their most recent residence because he loved to play with water, as most kids with autism. He would go upstairs, turn on the bathtub, put the plug in the bottom of the tub, and then go outside and play.

In an apartment building, this had led to a huge catastrophe with flooding the upper floors so the parents were asked to leave. They tried everything in their power to get control over this child’s behavior and couldn’t do it.

Within about four hours, we had this child sitting quietly, at a table, working for reinforcers, following instructions, and showing clear signs that he could acquire a large number of discriminations. That child was one of those excellent response kids who has since gone on and has a fairly typical life now.

The word got out. Parents began to hear about the treatment of that child and the success we had within one week and then the follow-up in the month to come. Joe Morrow’s ABC staff was working with that family to continue to treat the child.

The family committed to all of the things that were required for those kinds of programs—a huge commitment. They had to get reinforcers ready. They had to have teaching materials.
They had to set aside a special place in their homes. They had to do all those things, plus a whole lot more… … to make it all possible.

I was getting criticism from some of my colleagues here at the Regional Center for the fact.

“I was going to completely stress these families out and cause marital divorce. This was the wrong thing to do. I shouldn’t be doing this!”

But we went ahead anyway.

After that first workshop experience, then Linda Mayhew approached me, and said, “We want to do this in a more organized way.”

And I said, “Fine.”

She said, “There are a lot of families out there who want this service. How do we get this?”

I said, “Well, the Regional Center can’t afford to pay for all this. We’ll have to find a way to raise the money.”

My idea was to demonstrate to the community and to the Regional Center and to the school districts was that this intensive approach of treating kids early on.

It is now accepted and recognized as fundamental principal and “best practice” today, and will work in getting these kids prepared for school.

Dr. Lovaas had already published his 1987 classic article that showed that approximately half the kids could be brought to the point where they could be almost typical as they entered the school district at age five or six.

So when Linda approached me and said we’ve got to expand this whole opportunity for getting more families into treatment for young children.

“That’s a big task. I’m going to challenge you and all the other parents.” I said, “I challenge you to open up your living room, and invite ten or fifteen families.
If you think these families are really serious about this, have a meeting, and I’ll come, and I’ll speak to them. We’ll discuss whether this will be possible or not.”

I found myself on a hot, Sacramento afternoon, about 4 o’clock in the afternoon, in her living room. About 25 families had shown up in her tiny, little house.

There was such an enthusiasm for this idea and I said, “Here’s what we’re facing. We don’t have the resources now.

We’ll have to build those resources. We don’t have the funding. We’ll have to find ways of getting funding, and plus there’s a lot of skeptical people who don’t agree with this approach—

a lot of people put off by a behavioral approach to treating kids with autism and we’re gonna face some political resistance to get this to go.”

And they said, “Fine. What do we have to do?” I said, “Well, really, if you’re going to have to do fundraising, you’re going to have to organize yourselves into a non-profit.”

I think that’s when Carl Hainey stepped up and said, “Well, I’ll fill out the application.”

His wife, Diane, had a master’s degree from MIT and she was a good writer. I said, “Well, we’ll have to write and see if we can get some, write a grant and get some funding.”

Some of the parents wanted to have bake sales. I said, “Fine, you can do a bake sale.”

They raised three or four hundred dollars in a parking lot in a mall shopping center on a weekend. I said, “You’re going to very quickly figure out that that’s going to wear you out and you’re not going to get much money.”

But they were so enthusiastic, they did it anyway.
But, sure enough, after about three or four go arounds
they said, “You know, there’s got to be a better way.”
So, we developed these packets for these moms
to go out to large corporations like Hewlet-Packard
and other places and solicit donations.

And amazingly we got donations from
several huge, large corporations
that gave us thousands of dollars.

Southwest Airlines gave us airline tickets
to have the UCLA staff fly up here for free.

Marriot Hotels gave us free hotel space
for the consultants as they were coming up to consult,
to train all the therapists we needed.

We had rental cars companies
give us free rental cars to cover that expense.

That went on for about a year.
We were now writing this grant
to the Sierra Health Foundation,
which at that time was the non-profit.

They would have to offer money
to support community development,
in terms of resources for families.
They were just beginning to hear
about the increase in autism
and we had to convince them that treating kids
with autism was possible.

We also had to convince the parents.
But they said, “Well, write up a grant.”
And so we wrote up a grant.
They gave us $75,000…
to treat 21 families!

We thought that given the limits
to what we could do, we could treat 7 families,
each year, for three years in a row for a total of 21 families.
And so once we were awarded that money
through the Sierra Health Foundation,
I managed that grant, and Dr. Linda Copeland
helped me write that grant.

We made two or three trips down to Sierra Health.
Each trip we made down there, we kept meeting
with higher and higher officials in the foundation
because they were a little skeptical.
Dr. Linda Copeland was very instrumental, very enthusiastic, and has been a tremendous resource to this community ever since.

Actually, Linda has been so influenced by the whole behavioral approach treating kids, even though she’s a physician she’s now in training to get her BCBA. She’s one of the few pediatricians I’ve ever known was interested in doing Autism therapy.

So, that was back in 1993. We had funding for 21 families, seven families for three years in a row. I was managing the whole project. We developed a way of recruiting students off of the college campuses and Linda Mayhew and a couple of other parents actually went with me, volunteered their child with their tutors. We would go to all of these university classrooms. We would say, “This child has autism.” The child would be in the classroom to demonstrate a treatment. The students in special education and psychology would see the child.

“We’re going to treat this child. We’re going to show you how it’s done.” We put on a ten-minute demonstration of some discrimination tasks, some receptive language training—The typical things that were in that child’s program and we would ask the students to applaud. The kids loved to hear them applaud them when they succeeded.

They loved it! We would sometimes show a videotape of what the child was like before the treatment started.

Some of the students would be in tears. Others would be excited.

Out of a class of 50 or 60 students, we’d get 5 to 10 kids who were truly eager to come out and volunteer to be trained as tutors to work with the families…

In that effort, we created, at one point well over a hundred college students who had the qualifications to do the first three, six months maybe nine months of treatment of young kids with autism.
Beyond that, it takes much more clinical training
and the experience.

So that was the start of FEAT
By this time, we had a 501C3 in place…
… so we could do our fundraising.
   We were devoted to advocacy, education,
   and other types of supports.
And back in that day, one of the fundraisers,
   … was to have a dinner dance.

We would go to rock and roll bands
   that would volunteer their time.

We rented a large ballroom downtown Sacramento,
   and we would charge a certain amount of money
   and we would invite wealthier people.
When we started off, we were raising in the 10’s of thousands,
   and now it’s just become just a silent auction dinner.
FEAT raised over a hundred thousand every year this way.
I asked the families to do a lot in the beginning,
   which I think is important.

The parents kept saying,
   “Well, Ron, what are we going to call this thing?”
   And I said, “Well, let me think of some acronyms.
      It’s got to have an acronym!”

So I worked out about six or seven different combinations
   of acronyms and we were over at Carl and Diane Hainey’s house
   one evening for our usual meeting
when we were first getting started and I said,
   “What about this one?
      Families for Early Autism Treatment.”
      They said, “Ron, whatever you want.
         We don’t care what you call it.
            Let’s just go with that one.
               Call it FEAT.
              Yeah, yeah. Let’s just call it FEAT.”

   “Oh, well, I thought you guys would have
      a really big say in what we called this.”
They said, “We don’t care what you call it.
       Just call it that. If you like that, go ahead.”
       And so, we called it FEAT.
Once we wrote our bylaws
   we sat in the Hainey’s living room--
   and in Linda Mayhew’s living rooms, then other places.
We drafted our bylaws.
   We agreed that for any other group that wanted to start
   a chapter anywhere in the nation
   and also could provide the supports for
   their kids in the community,
   we would simply give them the bylaws
   and the right to call themselves FEAT.

The urgency was built in
   if a child got an early diagnosis.
   Early in those days, early was between four and six.
Early now is between 18 months and 36 months.
   But by the time parents got a formal diagnosis,
   there’s a mom and dad whose lives
   were completely turned upside down.

There was absolute chaos and turmoil,
   emotional confusion!
After the diagnosis was rendered,
   that created the immediacy
   and the urgency of any parent’s mind.
   and any professional who was a party.
   They had to be motivated to want to do something
   as soon as possible!

At that time,
   there was beginning to be a little research to show
   that the earlier you intervene with kids with autism,
   the better the outcome.

There were challenges.
   Some families couldn’t handle the stress
   or had to get outside support for managing the stress on them.
Other families remarkably,
   took right to the task.
   It actually brought the families together!
   But there were some families that were
   pushed to the breaking point.

**Building for change**

There were problems with direction.
   Now FEAT was formed.
There was a president and a secretary
and a treasurer and the beginning of this formal structure.
Then there was this political energy starting to percolate.
Some parents wanted to go in one direction and do other things.
The struggle was to keep the organization
focused on its original purpose,
which was one of the commitments.
As they did the fundraising,
could we stick to the principal of applying
every penny to the child’s treatment?
I insisted that they do that.
And they’d kind of look at me and why?
Why is that so important?
And I wanted it to be strictly a volunteer effort.
I didn’t want people being paid for doing things.
We wanted it to be wall-less—an institution without walls.
We didn’t want to pay for rental space.
It had to be operated out of family’s homes.
And fortunately, to this day, it still that way.
So, there was stress.
What we figured out very quickly,
to handle that stress, we rotated the responsibilities.
So that meant that some of the parents
tended to sit back and enjoy the fruits of this labor
Of these other parents, were those who were killing themselves,
literally, 12, 14 hour, 16 hour days, day in and day out.
We put a little fire
under the other less active parents, and
said, “You’ve got to step up.”
And that began to occur.
We would recruit new families
and we would explain to them right up front,
“You’re not just signing up to get resources here,
you’re signing up with a responsibility.
You’re going to have to write a newsletter.”
We created all these little committees.
We had parent mentors—
parents that would go out
and work with new families,
these newcomer families…
… and say, “I’ve been in this program for a year now.”
We had counseling for families.
We had all these committees.
We had fundraising committees.
We had all these different things,
so it took a lot of energy
and so there were problems getting that organized.
Someone had to step up
and, thank God, Linda Mayhew and a few other families
were really excellent leaders.
They’re all bright families.

There was one incident where one of the people
who stepped up to be the president,
all of a sudden started to monopolize the resources
and became very negative
to some of the supporting agencies like the Regional Center.

And the other parents, to their credit,
had to speak to that person
and eventually they ousted him as the president
after about six to nine months.

You’ve heard the expression,
“The cream always rises to the top.”
That’s what I’ve witnessed over the years.
That the people who really have leadership ability
are attracted to want to kind of step into that kind of role.

And there are also silent leaders.
There are moms and dads who have made this chapter,
this local chapter, this founding chapter,
here in Sacramento, successful.

We may never know about them
because they don’t feel the need to be in the spotlight,
and yet the key decisions that they made,
the key efforts that they put in, and their stick-to-itiveness,
their persistence to get something to occur
made possible what seemed impossible at the beginning.
Each time there would somehow be some parent
who would step up to the plate
to keep us going forward.
That is tremendous. That’s the kind of
leadership that you want!

We developed our brochure
and we developed a handbook—
and I’m sure you’ve seen their handbook.
It’s in its 7th or 8th edition now,
but the original handbook.
We wrote in the handbook our mission was education, advocacy, and development of resources.

The vision came out of the practical, day-to-day lives of families.

The vision was to have enough resources so that every family, if they so chose, could offer something to their child---Autism treatment.

That was the vision.

Choices.
Options.

I kept emphasizing over and over, “If you don’t do this, no one else is going to do this for you.

If you want this to occur, you’ve got to make it happen yourself.”

They got the message.

Parents who were absolutely, 115% committed to developing the resources that we now take for granted were not only willing to get something for their families and their child, but they were willing to share.

There was a strong need to fold other families into this success. And so those moms would go out and do public speaking and would challenge other parents, and would sit and develop educational materials, and would provide a lot of energy towards stimulating other families to get involved.

Sometimes our parent mentors had to be very direct with these families. In some cases, mom would understand and know immediately that something had to be done, but dad would be in denial, and it would take six months, nine months, maybe a year before dad would even talk to the parent mentor.

We would try all sorts of things.

The attraction for most new FEAT members when the first group first got going there was the hope.
They could get some direction and information about how to proceed with deciding options for different services and treatments for their own children.

So that was a huge attraction at a time when there were no other options!

There was no active and meaningful local Autism Society of America chapter in this area.

I pointed the parents in the direction of things that constituted best practices; the kinds of approaches that had the greatest empirical support and were likely to be the most effective in creating change in their kids.

They shared with other families.

The families were welcome to hear because they couldn’t get that information anywhere else.

The average social worker was not enough in touch with the field in those days, to be effective in guiding families.

The attraction was the simple fact that they could hear about the experiences of other parents who had been through the whole planning, design, and implementation of treatment plans.

They could have the benefit of the Lending Library for toys and teaching materials.

They could have the support of the tutors that FEAT had recruited and tried to maintain them in the field as a resource to new families that joined.

They did have to take risks.

The most of the early participants, risked the alienation of their own families because in some cases extended family been willing to support them.

Yet the parents sensed that if anything was going to be possible, they were going to have to do it themselves.
So they, in a sense, were risking the disapproval, the lack of acceptance by people who had never experienced anything like this before as they moved forth. After all, this was the first time that anyone had demonstrated that you could run intensive programs. That’s where they started.

We started with 20 to 40 hours a week programs in-home.

After the demonstration grant was completed, the ABA program showed that kids with Autism could be treated effectively in the home environment.

Then the parents had to go to the Regional Center and other public agencies to ask for money. And so there were risks. They were rejected sometimes. The school districts were another front that had to be confronted.

It was both the Regional Centers and the school districts because the Regional Center system was set up for persons who are the classically involved persons with mental retardation. That’s why Lanterman wrote the original act. Remember autism, as a category of eligibility, wasn’t even added until a couple of years after the Lanterman Act was completely finished. It was a second thought.

It was so rare in those days that they were willing to add autism onto the Act. Yes, the families had to go and then convince the schools that a behavioral approach to treatment was about the best-known way to get change to occur in kids with autism. They had to convince the Regional Centers to fund ABA. A lot of people were very uncomfortable with the behavioral approach, and so they opposed it, and in some cases, they put up barriers, administrative barriers, and all sorts of other barriers.
It’s been a constant struggle from day one
    and it continues to be even to this day
    to get the needed services for this population.

First of all, most people were skeptical that children
    could make a lot of progress.
One couldn’t tell by looking at a child’s behavior
    or their psychological test results
    whether or not they would respond to treatment.
But at that time, it was beginning to be clear that,
    or especially within the first three years
after we were working here,
    that the younger the children, the more
likely were some positive outcomes.

It is easier to teach children how to learn
    if it’s earlier, than later.
The other idea was that the intensity of the training
    to implement behavioral programs is a huge burden.
It takes many, many people associated with one single family
    in order to get all the input you need
    to have an effective behavioral program.
    That was kind of a barrier that had to be overcome.
Plus, the idea that one could simply, get results
    by repeating an experience with child,
    over and over again,
    and then reinforcing it in a variety of ways.
The kids could actually begin to learn
    and then generalize to brand new situations.
    That was a novel idea!
And parents routinely now use all of those concepts
    in their day-to-day language.
The one big thing that contributed the most
    to getting collaboration with schools,
    was the fact that they began to see
    after the first, and certainly by the second year,
    that some of those kids that they had almost written off
    in their own minds, that were completely
    out of control - within a year or so,
    were now starting to look like typical kids.
They could learn.
    They could follow instructions.
    They were far less a behavioral problem
    and they were showing more of an interest
    in having contact with people.
That really amazed a lot of special educators
who had been in the field for a long time,
especially if they had seen the child,
and then did not see the child
for six months or a year later.

Then all of a sudden......
we had a few instances where the person denied
it was the same child!

They didn’t even recognize the child.

This was twenty to thirty percent of the kids,
not all of the kids could respond that way.

Some of the kids had a very poor response
to treatment.

Unfortunately, the brain is so disturbed in the way it grew,
that it cannot integrate information efficiently,
and the child is functionally mentally impaired.

Their primary diagnosis is autism,
but their capacity for learning is so significantly impacted
that they can only learn a certain amount.

If you go back and think
about what Dr. Lovaas was doing at UCLA,
his whole goal was to take a child,
and if that child was four years old,
but was functioning like a two year old,
he wanted to, in a twelve-month period,
accelerate that child’s development
beyond twelve months.

He wanted to achieve 18 months of development
in a 12-month period.

Over a two-year treatment period,
that child would have gained a whole complete year.

The idea is “catching up.”

We are accelerating this child so that eventually
the level of development equals their chronological age.

If after we have demonstrated the use of quality, therapeutic techniques,
and we have well-trained therapists,
doing the appropriate interventions,
and we’d tried all these different things
and the child was still not responding.

Then we changed the program to something
that was less demanding and less stressful on the
family and the child.
And that’s what he did, and that’s what
should be the practice today.
We have to follow
the principals that have evolved.

Lovass’ great contribution was that he took
all that was known
in the theory of learning at the time,
and packed it into programs
for kids with autism.

That included teaching them expressive language--
very sophisticated language programs.
It involved teaching them how to
make very subtle discriminations
and how to play and do other things.

A parent can come to FEAT
and meet another parent who’s
already been down the road
that they are about to embark on,
and, at the same time,
get a lot of information.

For the most part, the information is valuable
that parents can share with one another.
That kind of welcome, so to speak,
and the fact that it gives hope to a new family
is what has maintained FEAT
throughout these years at a time.
When, maybe when a lot of public agencies
just haven’t the kind of sensitivity
and professional knowledge
that they would really need
to deal with this complex childhood disability.

The problem persists.
We just got the numbers at the end of September,
and we just brought in about 1060 kids.

So, in three months, throughout the state,
we identified a thousand sixty new people
who will be added to the roll {in 2007}.
That’s in California.

If that may kids have a medical disorder,
parents should be coming together
and talking about it!
Impact of legacy

The level of advocacy has been intense
   because this disorder has such an impact
      on a family’s life.

   It compels any typical person
      to want to do anything
         they can to get resources
            and supports for it.
   The fact that these families
      are willing to talk to legislators.

The Blue Ribbon Commission-
   it wouldn’t even be in existence if it weren’t for parents.
It’s the parents that make all these things happen.
   Parents motivated me to get it organized
      and give it a little bit of direction
          in the beginning.

The parents have run it entirely since
   I’ve left the Regional Center twelve years ago.
   They’ve certainly done a good job.
It’s just that parents somehow or another
   are always the driving force in these things.

The 501c3 status requires,
   that members don’t directly get engage
      in a lobbying kind of effort in local politics
         or work to achieve legislative reforms.

But I think what has worked very well for the FEAT parents
   is that they have kept the autism issue
      enough in the news
          and in the minds of the people
              responsible for serving children.
Legislators have been made intimately aware
   of the tremendous need for change
      in the way services are delivered.

Through the Blue Ribbon Commission,
   the legislature has been kept aware of the issues.
   There are some wonderful programs that exist
      through the Regional Centers
         and the school districts throughout California.
   There were still huge gaps in services.
The legislature continued to receive input from different communities from all around this state.

As some legislators actually have families who now are on the spectrum, that set up the awareness it was necessary for the legislature to pass the resolution that authorized the Blue Ribbon Commission’s existence.

The Blue Ribbon Commission in the few past years has gone around the state to speak to all kinds of family members.

There have been some FEAT members who have shown up and have given us input, in addition to other parent support groups around the state.

FEAT is not the only parent support group now. We have heard from many different groups and to that end, it’s been very helpful. Parent group members tend to focus on the really core issues and that’s what the Commission members wanted to hear.

The legislature recognized Autism Awareness Month and gave us plaques for creating FEAT. Senator Thompson gave me that plaque on the floor of the Senate.

I got to make a little speech.

Joni and her husband, Scott…

Tina Hendrix and Linda Mayhew were there.

Rick Rollens was there.

I felt wonderful because when I initially challenged the parents to have that first meeting over in Linda Mayhew’s living room and we had to open up her patio door because so many people showed up, there wasn’t even room in her living room!
I was talking to them
for about an hour about my vision
of what we could do,
and they were like all eyes.
I had no idea that they would possibly follow through.
  I thought, “I’ll walk out of here
  and that will be the end of it.”
But amazingly, they did most of everything I asked them—
so that day on the floor of the Senate was “Wow!”
If you put in the effort, it will happen!
  If one goes back to the 1960s,
when autism was so rare,
  and many were being put in state institutions…..
it was a small group of families
  over in the Bay Area that
created the Regional Center system.
They talked with Frank Lanterman
  and got the whole Lanterman Act started.
  So here we are now, at the turn of the century.
This whole system has now evolved.
  We have the new system like autism
  in a spectrum of services.

Now, FEAT members have to collaborate.
  FEAT has had a stake in trying
  to change the system.
They have questioned the eligibility criteria
  that all the Regional Centers use statewide
  which has been the standard for the past 40 years.
They have challenged some of the limits
  that some of the Regional Centers have put on services.
  Work more carefully with all the agencies.
My advice?
  Participate more. Be out there in a constructive way…
Some of the directors are doing their very best
  to maintain a balance between the public’s perception
  of what goes on with kids with autism
  and the funding and to meet
  everybody’s needs to create.
Some of the people who are in leadership now
  just have stronger personalities.
Maybe they are able to articulate
  and kind of drive that whole process.

168
More collaboration, using evidence-based practices 
    has to be the future, especially as budgets 
    and everything else tightens up.
We have to squeeze more effective outcomes. 
    We have to squeeze more effectiveness out of 
    the procedures that we use for better outcomes… 
    … than we have in the past.

What I’m seeing in the future—
    is that we have to do a better job 
    of providing more information to families 
    so they can make better informed choices.
Chapter Five

Understanding the Founding of FEAT

This research has focused throughout on the overarching question posed in Chapter One, What has been the experience of parents of children with Autism who are also founders of the parent organization, FEAT (Families of Early Autism Treatment)? This primary research question has been explored through the following four sub questions based on Kotter’s Change Model (1996):

1. How did they establish the dynamic advocacy organization, Families for Early Autism Treatment (FEAT)?

2. How do they create change? When successful, what factors contributed to success?

3. What’s the import of their experience? What were their challenges? Their triumphs?

4. Of what benefit would the FEAT experience be to other parent advocacy groups? What advice do they give other parents of children with disabilities?

The development of FEAT as a change organization follows Kotter’s Eight-Stage Change Model (1996); beginning with Stage 1- How did FEAT create a sense of urgency
to help children with Autism? Stage 2- How did you attract leaders and promote teamwork? Stage 3 -How was the vision for FEAT created? How was it planned? Stage 4 questions: How did others become involved? What attracted you? Stage 5 questions: What changes were FEAT priorities? What risks were taken? What new ideas were implemented? Stage 7 questions: What was learned? Who or what was celebrated?

Stage 8 questions conclude with: How were FEAT’s goals perpetuated and its successes anchored? (See Figure 2)

The answers to all the Kotter Change Model Questions are imbedded in the interview data obtained from the founders’ oral history interviews. The data have been analyzed and structured to address the above four research questions. As noted earlier, there is scant research on the role of parents and volunteers affecting change in their schools and communities. So the founders’ accounts and life experience stand for some of the “literature” in this chapter.

In chapter Four we were introduced to the founding members of FEAT and their personal stories. Their efforts to create inroads into areas unknown as parents, professionals, and advocates not only supported their children with Autism but other families as well. The French Writer and Author of ‘The Little Prince’, de Saint-Exupery (1900-1944) wrote, “How could drops of water know themselves to be a river? Yet the river flows on.” As one drop in a body of water sends forth waves of change throughout the pool it touches; these individuals, worked tirelessly and ultimately founded FEAT in Sacramento and established effective local LOVASS /ABA programs to support young
children with Autism. This snowballed into the establishment of other FEAT chapters and subsequently more effective therapies for children with Autism.

This chapter will focus on the Who, What and How of Autism and the answers revealed through analysis of the founders’ interviews. How did these parents cope? How did they keep the goals of FEAT moving forward? And so many other answers to questions, have surfaced as shining pearls in the ocean of information emanating from the founders’ interviews. It is these pearls of wisdom that this research highlights. The excellent pearls, each selected for quality and significance—ideas, thoughts and actions are distilled into an essence for this research analysis and later as a poetic representational waterfall in Chapter Seven.

Question 1: How did they establish the dynamic advocacy organization, Families for Early Autism Treatment (FEAT)?

Most of the parents interviewed saw FEAT as a vehicle to achieve a higher goal; the obtaining of LOVASS/ ABA services for their children with Autism. They were propelled by the urgency of what they felt was a “developmental window” of opportunity for their child to obtain the optimum benefit from the services through a well conceived “home tutoring” program. Recent studies have validated the importance of reaching children with Autism as early as 18 months. In 1999 the U.S. Surgeon General stated in a Mental Health report that thirty years of research on the ABA therapy approach when used as an early intervention tool for Autism, have shown very positive results (USDHHS, 1999). The support for early ABA therapy for young children with Autism is further supported by the originator of ABA therapy, Dr. Ivar Lovass, (1987) and other

Some of them started the ABA program services before they could get them funded by FEAT’s efforts Joni, Carl and Tina all started without any FEAT generated funding out of desperation. They felt their children may already be “too old” to benefit from ABA therapy. FEAT emerged from the informal home support group meetings at the founders’ homes. Dr. Ron Huff noted how many parents would crowd into the Mayhew home each week, eager to find a way to help their newly diagnosed child. Linda Mayhew remembered some of them first met after hearing the renowned Dr. Ivar Lovass speak about his method one evening in Sacramento, “We decided we needed to start a support group. We wanted to keep talking to each other. We knew that there were other families who would enjoy sharing stories. She further noted, “By the end of the first year, my living room was full.”

They organized, strategized, brainstormed, held bake sales, obtained corporate and government grant funding and Dinner Dance fundraisers to raise the money to expertly recruit and train tutors for ABA/LOVASS home tutoring. Joni recalled, “FEAT had the grant money to provide and it wasn’t just the grant money. It was the resources. UCLA just didn’t have unlimited amounts of therapists. They had people booked way in advance. FEAT was on a hot line ……they were very excited about what we were doing.” Many of the parents sensed the need or urgency to obtain ABA therapies within a certain window of time. Joni said,” There were no other therapies that were effective, (like ABA/LOVASS). This was the most effective therapy. You could see real changes in
your kid. They always were saying, “There’s an open window.” When your kid is between the ages of, two and four. That’s when you need to get him into therapy. That created a lot of urgency with people….the Open Window.” Carl further reflected on the urgent need his child’s Autism brought forth, “Parents need to understand if they are going to make a change; they’d better make it now. So that was also in our minds. We had to convey that message effectively--“we can help you by putting you in touch with these various therapies….” FEAT was providing to us, a society of people in the same situation.”

Several recent research reports base their studies on the Lovass UCLA model of ABA. The United Kingdom Young Autism Project (UK YAP) has found that a “successful early intensive behavioral therapy program includes parent involvement, different settings, and flexibility to meet the needs of individual children with Autism.” (Hayward, Gale and Eikeseth, 2009). Another study found that the participation of trained parents resulted in more effective ABA therapy for the children involved (Solish, & Perry, 2008).

Dr. Ron offers a valuable professional perspective in recounting the rise of Autism cases from the nineties to the present,

The urgency was built in, if a child got an early diagnosis. Early in those days, was between four and six. Early now is between 18 months and 36 months. But by the time parents got a formal diagnosis, we had a mom and a dad whose lives were completely turned upside down. There was absolute chaos and turmoil, emotional confusion! After the diagnosis was rendered, that created the immediacy and the urgency in any parent’s mind and any professional who was a party, they had to be motivated to want to do something as soon as possible!
Once the founders discovered they could work effectively together, their cause met no bounds. They were able to have a powerful media presence which pushed their stories and the need for ABA therapy along with its funding into the mainstream. Linda reflected on the media’s impact from FEAT’s beginnings,

So the urgency came from people seeing the children. We did a lot with getting the news involved. We went to the news stations and had TV crews come into our homes and do interviews ----to create an awareness of Autism in the community. We went to the newspapers and had them write stories so people could read about Autism. And we were able to create a sense of urgency in that way. We were also able to contact other families with children with Autism through that (approach). I remember one day we had done a TV interview with Kristina, and after the interview, we had put my phone number on the TV, My phone was ringing off the hook, non-stop, it was just crazy! The phone company called and they couldn’t handle it. It was incredible we were able to use (the media) to find other parents and to find people who cared.

Carl remembered how the media exposure made a success of their fundraisers and in bringing more parents who had children with Autism, “I’ve got to give Linda Mayhew a whole lot of credit because she is quite a go-getter and she went out and made friends with a local radio personality. She contacted Channel 3 and she contacted KFBK radio, she was a very good catalyst behind our fundraisers. We began having annual dinner auctions at nice hotels downtown. Parents came to us in this panic. ‘Oh, now what do we do?’ ”

**Question 2:** How do they create change? When successful, what factors contributed to success?

The group was quick to harness the energies of new parent members. FEAT developed their own “training agenda” for parents of newly diagnosed children with Autism. Novice members were provided with meaningful activities that benefitted their
families and the organization. This exemplified the principle of family centeredness, a strengths perspective (Allen & Petr, 1996). The strengths perspective acknowledges the expertise of parents and other family members and their contribution in working with professionals. In FEAT’s case, they worked closely with concerned medical and psychological professionals who were instrumental in helping the parents navigate the foreboding waters of disparate disability services, needed therapies and their children’s Autism.

The skills the founders learned in working closely together and with participating professionals, made them successful and confident in working with education professionals as they advocated and obtained appropriate special education services for their children. As the education professionals learned to value the founding parents as resources and community members, many built a system supporting the parents to take on this additional educational role as a partner in the education of their children. This preceded parent involvement studies of Siegel, 2003, Santelli, Turnbull, Marquis, and Lerner, 1997, and Sanders, 2000.

Tina perceived there was a certain type of parent that invariably came to FEAT and thrived,

Kids with Autism usually have parents that are Type A, motivated, driven, intelligent people. They usually do. So these parents were leadership people. Most of them were Type A leadership and motivated. So it wasn’t like we had to attract them. As far as professionals, well there were a lot of professionals out there who were raising these kids who didn’t know what to do. They were leadership type personalities anyway. We said, “We need somebody in here who can help us with our organizational skills...” We recruited people that way, but we just did that individually. Usually it went like this: “Wow, we need someone who’s good at PR or has a connection to the school.” Usually we’d have a parent call us that had
a kid newly diagnosed who said, “Yeah, I work in Special Education.” That’s how it usually went.

It is no surprise the families fed off of one another’s enthusiasm and various areas of expertise. A unique recent study by Twoy, Connolly & Novak (2007) noted the coping strategies parents (of newly diagnosed children with ASD) developed to survive. Most participants were experiencing extreme pain from the stress of caring for a child with ASD. The study on parent support networks showed the positive ways affected parents coped in the areas of informal and formal social support networks.

FEAT became a compelling support network to harness the resilient power of new parents as they adapted to their children’s Autism diagnoses. For FEAT to create change and be successful it needed leaders. Joni noted how the group attracted, nurtured and developed leaders,

It took a lot of teamwork, to write the grant... Ron {Huff} wrote a lot. Each one of us had a little job to do. We’d each to go and research, this, that, or the other… and then give information to Ron for the grant, or whatever was needed. That was teamwork. As far as leaders …... many people stepped up to the plate with FEAT, and took over different jobs-- the fundraising……the dinner dance and a barbeque in the summer. The first one was the dinner dance and that was small. We were getting the word out. The next year, it was double in size.

Once the group was established and developed a stronger membership base it offered volunteer services on various levels. Dr Ron remembered,

We had parent mentors—parents that would go out and work with new families, these newcomer families…and say, “I’ve been in this program for a year now.” We had counseling for families and all these committees… fundraising committees. We had all these different things, so it took a lot of energy and there were problems getting that organized. Someone had to step up and, thank God, Linda Mayhew and a few other families were excellent leaders. They were all bright families. You’ve heard the expression; the cream always rises to the top?
That’s what I’ve witnessed over the years. The people who really have leadership ability are attracted to want to kind of step into that kind of role. And there are also silent leaders. There are moms and dads who have made this chapter, this local chapter, this founding chapter, here in Sacramento, successful.

FEAT’s success and growth was due to the community it also provided while parents met the needs of their children with Autism. Carl says parents found each other in a community of What to do now,

Through that community, we discovered that there were a number of people facing the same situation. A number of people who had never dreamed that they would have a special needs child. Parents were coming into a new situation and never dreamed they’d be involved. We tried to help them see through the initial stages of “What do I do now?” Then I began going to the meetings and I began listening to what was needed. They talked about forming a public charity. Legally speaking, that’s what we decided. We wanted to form a public charity.

The incoming FEAT parents were encouraged to contact other parents with similar concerns about Autism therapies and education. The home meetings were vehicles through which many of the members discussed educational, developmental and health problems of their children. The parents developed strategies to best address these issues. FEAT’s growth as a volunteer organization affirmed the parent support studies of Toseland & Rivas (1995).

As FEAT set priorities for action, a strategy for approaching school staff, petitioning the school board, and speaking out at school board meetings, it further supported what scholars have written about effective parent involvement (IEF, 1998). FEAT parents became engaged and expanded the role of parental involvement with their creative collaboration with medical professionals and later with some schools. The
founders of FEAT became the change agents who McCalman and Paton (1992) describe as a person who “facilitates change in the particular area in which it is needed.”

**Question 3: What’s the import of their experience? What were their challenges? Their triumphs?**

The group did not go forward without risks and rewards. The founders have many insights. Risks had to be taken and many of the founders placed their lives on display to gain attention from the media and other supporters. Linda notes,

> A lot of the parents would not want their child labeled in public as autistic. People were afraid of labels. As part of FEAT, you were out in the community saying, “My child has Autism.” That might have been the biggest risk perceived at that time. I wanted other people to learn from my daughter that kids with Autism could still learn. They could still be a part of the community. part of the classroom, a regular classroom. But for other parents, that was a big concern. By becoming involved with FEAT you were known as a parent of an autistic child, so then your child was labeled.

As we look for support of parent involvement in schools, one study about parents of children with Autism found mothers who had social support were more likely to be active at their child’s school (Benson, Karlof and Siperstein, 2008). FEAT provided a solid base of support to mothers and fathers of children with Autism who were seeking to impact their schools and communities.

**Early Accomplishments (FEAT, 2009)**

- Growth of FEAT

According to the founders, the organization’s growth was gradual at first. They grew with each small project and step taken. As FEAT had people who organized, advocated and networked for ABA services, it quite suddenly, grew
exponentially. With the influences of the Internet and the media FEAT reached out across the country, and the world, having long-term effects.

The original Sacramento chapter grew to serve over 600 children with ASD. It is now serving the entire population of children with Autism from infant to children through high school. According to its current website, FEAT upholds its motto of “effective treatment for all children and young adults with Autism.”

• Lending Library and parent support

In 1995, FEAT established a Lending Library to provide information and materials to families involved in early intervention programs. Beginning in 1993, FEAT sponsored monthly resource meetings, which are designed to provide continuing information, education, and support for families of children with Autism. FEAT has also published a quarterly newsletter and annually updates a Handbook for Parents.

• Media outreach communicated the urgency of the need.

Early on, in 1992-3, FEAT reached out into the public with the media, newspapers and TV. Support for FEAT’s cause, and their message continued to flow into the media. The founders wanted to get the word out and let people know that there was hope and help to families of children with Autism the Sacramento area. The Internet along with the media all reached out across the country having significant, long-term effects. In 1997 FEAT produced video, “Doctor, My Child Doesn’t Talk” – The Importance of Early Autism Diagnosis. It won the 1997 Autism Society of America’s award for excellence in video. Since this distinction,
copies of this video have been widely distributed nationally and internationally to physicians, parents, and others involved in the early diagnosis of Autism.

- **Fundraisers/Dinner Dance**

FEAT became a well organized cohesive group and has sponsored very large, well organized fundraisers. Every year since 1993, FEAT has held its annual “Night of Caring” fund-raising Dinner & Auction. The first year, they started small, raising a modest sum. In 1994, FEAT sponsored State Autism Awareness Week and held its second Dinner Dance. The guest of honor was Dr. O. Ivar Lovaas Ph.D., Director of the UCLA Clinic for the Behavioral Treatment of Children. The fundraisers are highly organized events, and volunteers spend nine months in preparation. As a successful fundraiser for FEAT, the annual “Night of Caring” continues to be FEAT’s main public outreach event.

- **Early grants to fund ABA Therapy**

Over 100 children in Northern California have participated in Workshop and Clinic programs sponsored by FEAT and several providers of Applied Behavior Analysis (ABA) services since 1993. Workshops were provided through a grant of $75,000 from the Sierra Health Foundation the same year. This grant and continued fund-raising efforts provide funding for FEAT services. The FEAT funded ABA programs, have given young children with Autism the opportunity to maximize their potential. Many of these children are now attending regular public school programs, with the assistance of an aide.

- **Tutor Training**
FEAT sponsored six student tutors to attend a summer training session at the UCLA clinic in 1994 and 1995, the trained tutors returned to Sacramento as Early Intervention Consultants to help direct home programs under the guidance of professional consultants. FEAT sponsored in 1996, 13 local children to receive ABA therapy from the UCLA Clinic established by Dr. Lovass.

- Capital Conference and Newsletter

FEAT has sponsored the Capitol Autism Conference in Sacramento since 1997. It features national and international experts in the diagnosis, treatment, and services for children with Autism. Also in 1997, the FEAT Daily Online Newsletter was established. It provided access to information on current Autism topics. It was distributed throughout the United States to over 8,000 subscribers. This online newsletter became the Schaffer Newsletter, edited by FEAT member Lenny Schafer.

- The M.I.N.D.Institute

In 1997, several FEAT members (the Third Wave), worked alongside the California Secretary of State, Rick Rollens, (also a FEAT parent), to have funding for a research center to study, identify and treat Autism. Rollens lobbied to have an Autism Awareness Day proclaimed in the state legislature, bringing more state attention to FEAT and the need for Autism research. These FEAT parents working together applied for and received a $220,000 grant from the Department of Developmental Services for Project HOPE programs at UC Davis Medical Center to identify, treat, and ultimately cure Autism. It was later renamed The
M.I.N.D. Institute for the Medical Investigation of Neurodevelopmental Disorders.

- Advocacy assistance services

FEAT continues to expand its volunteer assistance to parents in obtaining early diagnosis and treatment for their children. FEAT helps families to obtain intervention programs, speech programs, occupational therapy, and evaluations when treatment has been delayed, either by local school districts or the regional center. Additional FEAT services are available through an Advocacy Committee and Parent Mentor Program that assist families during the IEP/Planning Team Meetings, Fair Hearings, and Due Process Hearings.

The FEAT founders were effective leaders because they nurtured leadership skills and opportunities in their membership. They were transformed into change agents, accessing expertise about their children’s Autism and the therapies needed to move them forward into school and life. Many possessed the fifteen competencies articulated by Buchanan and Boddy (1992); sensitivity, clarity, flexibility, team building, networking, tolerance of ambiguity, communication, interpersonal skills, personal enthusiasm, stimulating motivation, negotiation, selling, managing, political awareness, and ultimately influence. These exemplary leadership qualities are further affirmed in the studies of Cripe 1993, Werner and Lynch, 1994, Butcher and Atkinson, 1999.

Each FEAT member had a niche to fill and task to follow through to contribute to the vision of FEAT. Dr. Ron stated, “The vision came out of the practical, day-to-day lives of families. The vision was to have enough resources so that every family, if they
so chose, could offer something to their child in the way of treatment.” Tina extolled FEAT’s advocacy efforts,

We picked one thing at a time to go after. And after we won the first battle, it was just easier and easier to win the other battles. It was the same thing with the school district-- we would look at one school district, and here would be one person in that district who was battling for services and we would help. It was like pulling bricks out of the Berlin wall!

Educational researchers have found that parent involvement in the education of their children, regardless of the disabilities is essential for their success in school (Green & Nathan, 2005, Henderson & Berla, 1994, Seligman & Darling, 1997). Many of the FEAT founders and the group’s members were able to partner with their schools (often after a legal fight), for the benefit of their children’s education in special education. Tina and Joni were pushed into legal battles but were able move forward to collaborate with complying school administrators. Linda remembered how the founders supported one another’s advocacy efforts in the public schools for special education and related services,

In the beginning, we had support with each other. I remember an IEP with Tina for her daughter Mary; it was probably a seven day IEP! We just kept reconvening. It was Dr. Huff, and Dr. Copeland and I, and, some other parents with Tina at her IEP. Now, that’s not how normal IEPs go, but through the organization, we would go as a group and support each other, and we did the same with the Regional Center and all the school districts. We didn’t have to fight alone anymore. I saw that as a blessing.

Joni along with several other founders had to struggle with the school districts to obtain appropriate services for their children. She noted the FEAT advocacy experience as an action group,
We were doing something. …. as an action group. It wasn’t just to sit around and cry about our kids. We were getting stuff done! That was huge and brought us together as parents who were winning during this time.

There were battles with the school districts. Many immediately started opening all the Autism classes to our children. First, it started in pre-school, and then in the primary grades, and now we have them all through high school. They saw, “Wow, this family, they got an attorney.” ….Many districts didn’t have a program that was appropriate. Since they saw parents winning, they said, “Okay, we’d better start training our teachers.”

FEAT provides support at IEP meetings. We did it all on our own and it was stressful for us because we’re both teachers up here in Placerville. We had Area Board III helping us. There was the principal of special education up here. She was just nasty and mean to us.

We were all fighting our own individual battles. They were all very, very different. I would talk to someone who lived in another district. The district would be hiring their attorneys, and, and in some cases they were able to get services, a one-on-one aide or whatever was needed. And so everybody had their own individual battles going on. We were all doing individual programs in our home. And we were all successful! No matter what level, it was working. We were a definite threat.

Carl and his wife practiced the bridge building approach in advocating for their son, and his special education in public school. He noted,

I have a lot of admiration for the administration of this district up in Pilot Hill. This was the Black Oak Mine Unified School District, Eldorado County. They hadn’t seen too many cases of Autism and frankly, didn’t know what to do either. My wife and her ability to work with the district and their willingness to work with her resulted in a fairly good experience here. We’re happy with what happened here. The district provided him a full-time aide ……A full-time aide. You don’t get that too often! They were trying to figure out, “How do we handle Autism?” Some of the administrators were beginning to see that we had a number of cases coming their way—children who were becoming eligible for school with various disabilities.
Linda, struggled to convince school authorities at first, but after the family did home based ABA therapy, they were able to partner in their daughter’s education. She affirmed,

It was ABA. But it was not, a strict Lovaas program. We didn’t have that training yet, but it was working. It was helping her. She was learning. We were excited. She was getting her first words. And with her words, her behaviors started decreasing. She was a very violent child. We found out later it was all because she didn’t know how to communicate. She was very angry. She didn’t understand anything we said and she couldn’t talk. As we started being able to communicate with her, her behaviors started decreasing back at school. She was learning to talk, along with her ABCs and her numbers at home. And they did not even know at school. They never asked her and never tried to get her to talk because they didn’t think she could talk.

And so what we did was start videotaping her at home. When I thought she was ready to go into the regular kindergarten classroom where she would have role models, I took the videotape to an IEP meeting and showed them that Kristina was doing at home. They were silent and crying and when we were done-- they said they could not believe that she was able to talk like that and to learn. They said that we could put her into a kindergarten class. I started searching for classes because I wasn’t going to put her in with anyone. I found an amazing school with an amazing teacher who I observed letting the children help each other while she was teaching. The teaching style was called brain-based teaching where they use multiple ways of teaching. It wasn’t just a strict learning on paper. This was what Kristina needed. She did kindergarten, first and second grade with the same class of students who became her friends in Ms. Giffin’s classroom. She did have an aide; the school started allowing her tutors to be hired by the school to be her aides in the school. They saw that with training, it was much better for her. Ms Giffin found that Kristina was wonderful to have in the classroom.

Tina noted that although FEAT was effective in the battle for high quality special education services for children with Autism the struggle continues to the present,

Every school, in their own way, is trying to do some part …..because of FEAT, because of the information and the parents. In-home programming works but there are many still fighting against it because they don’t want to pay for it. But there are some that jumped on board and continued to support that type of programming for the children. That’s a great thing.
And then the Regional Center has stepped up somewhat, but I hear that they’re still fighting some of the cases. So there’s just going to be a continuing battle because everybody’s trying to hold on to the money that they get from the government, and they don’t want to give it up that easily. Within the FEAT organization, the support will continue to grow and to help the families fight for what is right. We set a lot of precedents with the school districts and with the regional center on which others can build.

The advocacy approach demonstrated by the FEAT founders reflected a model developed by the Intercultural Development Research Association (IDRA). The IDRA studied the creation of a parent-centered model and the process for developing parent leadership in their children’s education. It outlined four types of parent involvement with schools: parents as teachers, parents as resources, parents as decision-makers, and parents as leaders and trainers (Montemayor & Romero, 2000). The FEAT founders were teachers, resources, decision makers, leaders and trainers to other parents in their schools and community.

**Question 4: Of what benefit would the FEAT experience be to other parent advocacy groups? What advice do they give other parents of children with disabilities?**

Autism is rising and many are alarmed by the growing statistics. A recent report of the CDC cited Autism is occurring in 1 in every 110 school children (CDC, 2009). Who is more impacted by this crisis more than the parents of children with Autism? More and more families of children who have Autism are seeking quality services and supports in their schools and communities. As the numbers climb and state and school budgets decline, the need for effective parent advocacy groups like FEAT is paramount. The founders were asked during their interviews the advice would they offer to other groups wanting to advocate for their children, and impact their schools and
communities. The founders each had opportunities and time to reflect upon what worked and did not work for their group and its impact. They were precise and thoughtful in articulating their recommendations to parents and others wishing to forge a pioneer change-maker trail, and those who specifically need ABA and related services. Therefore, no in-depth discussion is required. All of these recommendation lists have implications for anyone who works with children and adults who have Autism. This not only includes parents but leaders and laypeople in the education and medical fields and community workers at large.

**To parents and advocates who seek meaningful change**

- *Don’t be afraid* to get involved or afraid of our institutions.
  
  Do not be afraid to challenge where there’s a definite problem.
  
  Be an advocate. Nobody else is going to be an advocate for your child. Nobody cares about your child like you do.
  
  Do not be afraid to challenge or question what everybody’s supporting.
  
  Do not be afraid of people. You will still need to work with the people you confront. It doesn’t pay to burn bridges. When you are challenging people, realize these are people…..with whom you may have to end up working, whether you like it or not!

- *Follow your heart* and don’t take “No” for an answer if you don’t think what is going on is right. *Keep focused on your goal.* Don’t get taken off your track by pettiness or disagreements, but always stay focused on the goal. Don’t let other things get in the way. One of the problems when people are doing things together,
some people might get into the, “Me.” There’s no “Me” when you’re trying to work as a team. Stay focused on the goals ----work together.

- **Listen to other people.** Get lots of different opinions. Stick with your heart, and your gut. You’ll be guided to what is right and what needs to be done.
- **Look and try to solve problems** in an unemotional way.
- **Don’t lose sight of the need.** the actual need. And always be looking out so you can steer parents away from the bad or at least make them aware of your experiences. You can’t serve a population with a need if you’re not addressing their specific needs
- **Bring people in to participate and use their gifts** to help the organization sustain itself and grow.
- **Be open to change and differences.** There is success in differences. Be open to ideas. One of the things that made FEAT successful was key people. The board members were people that were very different from each other and disagreed on a lot of things. A lot of people might say, “How can you get moving?” But that helped them have some excellent checks and balances and it helped to create a more objective and balanced organization. Look for people to be on the board that come from a different place and from a different opinion. Embrace that and know that what will help in the long run.
- **An enthusiastic core is needed in the organization.** Have an enthusiastic core. Rapidly grow your organization with people who can provide the services and develop skills that you need. FEAT had a good fundraising core. They had people
who knew about the interplay between FEAT and the governmental agencies like Alta Regional Center. FEAT had medical people. Doctors provided some medical guidance about the therapies advocated. Get someone who knows how to do organization in the right form—a 501C3. Then write official By-laws and Articles of Incorporation and make sure they are done well. Have a lawyer in your group, who can look over documents and contracts and be rapidly able to approve of those efforts. Have someone representing legal rights in your core. Surround yourself, with an enthusiastic core of people with the right kind of skills.

- **Fundraising, publicity, and organizational skills** are essential. Knowledge of the types of organizations with which your group will be interfacing. In this case, Alta Regional, the IRS…the legislature.

- **Publicity.** Make sure that someone knows how to get a hold of the media that was a big boost for us. Use publicity and get the word out quickly to a lot of people.

**Advice to parents and groups specifically seeking special services**

- **Be informed.** Get facts in order and find people who have more influence.

- **Keep a calm demeanor.** Be patient, but be persistent at the same time.

- **Get a group consensus** on what can be done improve the situation

- **Work openly with administrators, and the school district people,** with legislators and institutions, such as local hospitals and professionals.

- **Seek to create more training programs.** This may involve obtaining grant money for more training, or whatever is needed to obtain funding.
• Support state sponsored commissions that study your issues, such as your state Autism Commission, which can actually be in a position to influence the passage of Autism related legislation.

• Work with agencies, with state departments, and legislators related to your cause. Take time to write, call and meet with them as a group.

Advice to educators, medical and community professionals

• Be informed about Autism and its symptoms. Get facts in order and find stay current of the latest best practices in Autism treatment, and the needs of people with Autism in education, skills and life.

• Be open to including people with Autism in all aspects of the school and community life.

• Partner with parents and recognize they are experts about their children and the disability. Work openly with parents and families of people with Autism. Seek solutions together.

• Be proactive! Open doors and windows. Be open to change and seek out those who will help in supporting the necessary changes, innovations and adaptations to help people with Autism live life to their fullest potential.

• Seek to create more training programs for staff to understand and effectively work with people who have Autism. This may involve writing for grant money for more training, or whatever is needed to for more resources.

• Work with other groups in your community who support people with Autism. Take time to write, call and meet with them as a group.
**Chapter Summary**

The analysis of the founders’ lived experiences is presented to answer this researcher’s main research questions. We are given the puzzle pieces to each person’s perspective to create a dynamic mural outlining the risks, rewards, community and wisdom of the FEAT founders. Metaphors for the change making group have emerged from the interviews. Several see FEAT as a living breathing heart that needs all its members for proper functioning. Others see it evolving organism, extending arms to meet the greater needs of the Autism community. Examples of FEAT’s outgrowth are the efforts of several *Third Wave* FEAT members (those who came after the founders in the early 1990s), who with the help of Rick Rollens founded the MIND Institute in 1998 and the California Blue Ribbon Commission on Autism in 2005.
Chapter Six

Significance and implications

The lived experiences of four parents and a professional have been examined and analyzed. What can be learned from their efforts and the formation of FEAT? Of what importance are the founders’ efforts and recommendations?

The purpose of this study was to explore the primary research question: What has been the experience of the founders of the parent organization, FEAT? The information revealed through the founders’ accounts indicate the impact of their volunteer efforts were profound and enduring. In many aspects, their work as change agents in their schools and communities follows the systems change model set for by Kotter’s Eight stages. The founders have shared their insights for establishing, nurturing and anchoring a volunteer parent organization. In addition they have provided specific strategies for advocates seeking specific services for their children with disabilities. Of what significance are the founders’ efforts and recommendations? Does this study provide information for broader applications?

The FEAT founders’ experiences may be applied to many volunteer groups that want to impact their schools and communities. In studying this research’s broader
applications, schools and communities may seek a means to respond constructively and proactively to a health crisis like Autism as the numbers increase.

The themes that emerge from this study have applications that have foundational concepts transferable to similar societal challenges in schools and communities and beyond. The overall themes emerging from the interviews with the FEAT founders’ lived experience as change agent are *direction for advocacy, building for change, and impact of legacy*.

**Direction for advocacy**

Initially, all the founders were thrust into an advocacy role for their children with Autism and the urgency the diagnosis carried. Rather than retreating into denial, depression, and inaction they convened into a small planning group and set about the business of creating an effective organization of volunteer parents and professionals. They created direction or a map for others to follow by reaching out to the media and invited other parents of children with Autism with both hands. The founders’ experience as effective advocates highlights the unique partnership FEAT parents had with highly qualified and dedicated professionals in medicine and psychology. They were fortunate to all connect and find a focus for their advocacy that was based on scientific study and “best practices.” At a time when services for children with Autism were lacking, the group was able to bring ABA therapy to a region of California that had no quality programs specifically for children with Autism. As word about the effectiveness of ABA therapy spread, almost simultaneously with the rise in Autism cases, so did the FEAT membership base. According to Linda the positive results from ABA therapy upon the
founders’ children had a great impact, “That’s what spurred us on, seeing the success. And so they came and found us doing it, {ABA}). That got a lot of interest flowing. Then all of a sudden, there were radio programs and newspaper articles ----- there was a lot of public media.”

Parents of newly diagnosed children urgently needed a program that would help treat Autism. Dr. Ron affirmed,

One of the goals was to share everything that we accomplished with any other community in the United States that wanted to do it. I was literally going around. I spoke in Boston. I spoke in Wisconsin. I spoke in several different states about--I was invited out there to talk about the fact that there was this grassroots, parent-driven, community-based organization that was essential to the creation of services for kids with Autism. I would go and speak and the following months we’d get emails and phone calls. We mailed out our by-laws and talked to people. I would sit on the phone with parents and tell them who to get in their community down in Texas or somewhere in Illinois or anywhere it might be and give them hints on how to get going based on what we had learned here.

The FEAT founders found through the encouragement of involved professionals, direction for their energies and abilities that benefited the organization and their goals to establish therapy programs for children with Autism. The founders, in their modest accounts, mention how they harnessed abilities they never imagined they possessed and became a group that exceeded any of their expectations. Joni remembers, “It started with, ‘Let’s help our kids!’ We felt empowered. We had tools and people helping us, supporting us. It helped us make a change with our kids.”

The founders contend that the urgency to help their children with Autism was the driving force behind their advocacy. Motivation was built in and innate due the crisis the disability presented to each member, and every family that joined FEAT membership.
According to Dr. Ron, “We would recruit new families and we would explain to them right up front, ‘You’re not just signing up to get resources here, you’re signing up with a responsibility.’ The attraction was the simple fact that they could hear about the experiences of other parents who had been through the whole planning, design, and implementation of treatment plans.”

It is important to note that any of the FEAT founders or its later members could have been paralyzed by the “crisis” of their child’s initial diagnosis. The path of raising a child with a disability is challenging.

It a very compassionate person who would seek to work directly with children affected by Autism. That individual is often a professional with expertise in psychology and/or medicine.

The early FEAT group was privileged to have the perspective of concerned professionals working alongside them. The knowledge and direction the parents received gave them the confidence to step forward and become leaders for FEAT’s cause and their children. They were ushered from the darkness of a sudden disability diagnosis to the light of knowledge about a therapy program that would help their children. They became beacons for their cause to fund and establish ABA therapy programs to treat their children and ignite their full potential. The passion of parent engagement in fueling their children’s progress and development is not to be underestimated. Coupled with the caring and compassionate collaboration of professionals, this unique human energy is an untapped, “virgin” resource that demands more attention and study. It is a vital resource the Autism research community has begun to embrace. Schools and communities would
be wise to follow their example, as they seek solutions for the growing population of persons with Autism.

The importance of parent and professional collaboration permeates every aspect of FEAT’s success and any impact this study highlights. This collaborative experience gave the founders the direction for their advocacy, so they could be not only successful in attracting members but also anchor change in their communities through the spread of ABA programs for Autism treatment in their region and beyond. The same spirit of collaboration gave way to the establishment of the MIND institute and the California Blue Ribbon Commission for Autism.

Building for change

In their sincere efforts to obtain services for their own and other children with Autism, the founder also raised awareness and partnered with many gifted and influential leaders. The founders are hesitant to comment on their specific contribution to FEAT’s success, Linda noted, “Our leaders were the parents and Dr. Huff and Dr. Copeland. We attracted them by their wanting to help their children and the doctors caring so much about the children that they’d been serving…. and not being able to serve enough. So, again, it was the children that attracted all.”

The founders were also transformed into leaders for their cause.

A mother became a media spokesperson, a teacher became an advisor and fundraiser, a former policewoman became a counselor and master planner, an engineer became a legal incorporation expert, and a psychologist became a trainer and organizational strategist.
They all were pushed beyond their comfort zones and challenged to fill a need to further FEAT’s cause. Carl affirmed this fact,

A lot of folks were out of their comfort zone. I certainly was. I was going to the library and looking up books on how to organize a group I was definitely out of my league. But in the end, I what I provided was a successful contribution. Linda had never done a fundraiser before and she did an outstanding job of getting people together making the fundraising activities happen. In fact, just about everybody had never done anything like this before…..We had no idea if we were doing it right and we had no idea whether it would succeed or not, but we did it right enough! We did it right enough and the need was large enough that it caught on and did well.

Linda and others contended that the media was a valuable tool for growing the organization and furthering its cause,

We did a lot with getting the news involved. We went to the news stations and had TV crews come into our homes and do interviews ----to create an awareness of Autism in the community. We went to the newspapers and had them write stories so people could read about Autism. And we were able to create a sense of urgency in that way. It was incredible we were able to use {the media} to find other parents and people who cared.

Carl remembers how quickly the organization drew members,

The use of media, is extremely important in forming a company or a group that succeeds ……. We expanded interest in our organization rapidly. A lot of people found out about us early, and that led to more interest from others. Both groups of people could raise money and more people were interested and became a part of FEAT. By the time I was leaving, there were many people coming forward saying, ‘I can help.’ They came forward because of the media influence.

Impact of legacy

When FEAT was founded in 1993, a group of Sacramento area parents and professionals saw a need to improve the early intervention services for children with Autism. In their sincere efforts to obtain services for their own and other children with Autism, they also raised awareness and partnered with many gifted and influential
leaders. Since FEAT’s inception, over 100 children in Northern California have participated in FEAT sponsored workshop/clinical programs and the services of several ABA providers. FEAT continues to raise funds through grants and ongoing fund-raisers. These efforts, along with advocacy activities, have provided many of the ABA services for children with Autism in the region.

The M.I.N.D. Institute (a government funded medical facility dedicated to researching, treating and discovering the causes of Autism), was started at UC, Davis by a few FEAT members who sought out government grants to establish the institution. Presently, several FEAT members serve on the California state Legislative Blue Ribbon Commission for Autism, to work out public policy to best serve the growing Autism population. The result has been Autism related legislation based on the recommendations of the Blue Ribbon Commission for Autism in California.

Nancy Fellmeth the current FEAT president, remarked on how the group continues the founders’ legacy,

We are sustainable because we always have another generation of people willing to help. I tell parents when I meet them. “You know, you’re going to learn that right now your job is to first get your child the services and get his program going, off and running. But there will come a time when you’re going to turn around and hopefully help another family. In fact, you’re going to be helping a family whose kid hasn’t even been born yet. And you’ll be helping that family deal with the same things that you did.” ….That’s how we keep going. And that’s your roll as part of FEAT.

The group continues to attract members and leaders, primarily because the members care about children with Autism. The surging number in children with ASD further fuels their work in the schools and community. Nancy affirmed, in contemplating the current and future role for FEAT,
It’s all about people having great passion for what they do and I always say that’s why we will prevail in the end. We usually do get what we want for our families because we’re willing to be up at 2:00 in the morning ……and we never stop! We don’t have hours ………it’s our lives, and we understand ………we have the compassion to understand how some of us as the parents, feel. …. We care. Very deep passions motivate us!

In the last two decades, FEAT parents and professionals have made remarkable gains as a group of volunteers dedicated to helping children with Autism. This partnership has built inroads to the state legislature and medical communities in Sacramento, the nation and beyond.

Chapter summary

The overall themes emerging from the interviews with the FEAT founders are direction for advocacy, building for change, and impact of legacy. As the Autism numbers rise, this study provides important findings that apply to policy makers, medical and psychology professionals, school administrators, concerned community members and teachers who work together with parents, to seek “best practices” to meet the growing needs of children with Autism. As parents of children with ASD seek out programs and solutions to help their children learn and reach their full potential, the FEAT experience is a realistic organizational model to empower their efforts. FEAT and its legacy of positive social action is an inspiration for other parent organizations seeking to be effective and successful change agents in their schools and communities.

Initially, the founders were thrust into an advocacy role for their children with Autism and the urgency the diagnosis carried. Rather than retreating into denial, depression, and inaction they convened into a small planning group and set about the
business of creating an effective organization of volunteer parents and professionals. They created, through collaboration with medical and psychology professionals, a direction or a map for others to follow by reaching out to the media and invited other parents of children with Autism with both hands. In their sincere efforts to obtain services for their own and other children with Autism, they also raised awareness and money, partnering with many gifted and influential leaders. This partnership has built inroads to the state legislature and medical communities in Sacramento, resulting in the establishment of the MIND Institute and Autism related legislation based on the recommendations of the Blue Ribbon Commission for Autism in California. The story of FEAT, its founders and legacy of positive social action, are inspirational for other parent organizations seeking to be effective and successful change agents in their schools and communities.
Chapter Seven

Implications

The lived experiences and analysis of the five founders of FEAT presented in this research examine the formation of five resourceful, energetic, and positive change agents. All were participants in three 90 minute interviews. The thoughts and perceptions of three mothers, one father and a professional were analyzed and displayed as poetic representations. With the direction from Eisner’s educational connoisseurship and criticism qualitative research approach, the data was carefully examined and the findings gleaned.

Conclusion

The educational policy and practical implications of this research are manifold. However, it must be noted that this study cannot fully capture the total spectrum of all parent organizations and/or parents of children with Autism experiences. Rather, it focuses on the lived experiences on five founders of an effective volunteer parent organization. To over generalize and attempt to make the FEAT experience the experience of all parents groups is not possible, nor is it desired. The insights brought forth through an in depth study of the FEAT founders’ stories are but a “piece of the puzzle,” as described by Linda about her contribution to FEAT. In these days of depleting
resources and withering budgets, more studies need to be done that emphasize the Who, What, Why and How of volunteer groups, like FEAT, who force remarkable and effective change to improve their schools and communities. The role of “the community of support that affects change,” created by a crisis, such as Autism, deserves more attention. More studies are needed into how communities of support transform into social action groups that shape and force necessary change in health, educational and related fields.

As the numbers of school children diagnosed with ASD (Autism Spectrum Disorder) continue to rise, policy makers, school administrators, concerned community members and teachers together with parents, will continue to seek “best practices” to meet the growing needs of children with Autism. Schools and communities are challenged to respond proactively. And as parents of children with Autism seek out programs and solutions to help their children learn and grow, they need workable organizational models, such as FEAT, to empower their efforts. A valuable conclusion to be drawn from this research is that schools and communities need to positively and constructively respond to the growing Autism health crisis. The collaboration of parents with professionals from all aspects of the educational, medical and related communities is essential to meet the needs of children with Autism. Ultimately, all are touched by Autism and are invited be part of the community of support to find the best practices for the children, adults and families impacted by this startling wave of disability.

The model FEAT provides in this study is a feasible action plan for other parent organizations seeking to be change agents in their schools and community.
A final poem distills the essence of the FEAT founders’ efforts. Each member’s contribution can be viewed as a small stream, yet they combine into a grand waterfall. The flowing cascade has impacted schools and communities, and ultimately supports children with Autism to reach their full potential. Through its legacy, FEAT has become a surging force, plunging and furrowing into a rapid river of change that flows throughout the land and beyond.

The Waterfall that is FEAT---

Direction for advocacy

In the beginning
    it was more of a support group,
        a network for families,
Soon after we decided
    we needed to get programs going.
When we met in our support groups,
    we all, knew now
        there was something that we could be doing.

We all started using ABA
    in our children’s lives,
        but it wasn’t a full program.
We knew that we needed that full program.
    We needed the UCLA training
        and their people to work with our children
            to get the best results.
So when we started putting together
    a mission statement and a plan,
        and we did incorporation—
We had a parent,
    Carl Hainey, who knew how to put together
        a corporation.
        He did it all.
We were all pieces to the puzzle
    that were put together
        to do what we needed to do.
My biggest role was getting ideas out in the community, making money, doing interviews……. because I was the one that wanted to contact the media.

We needed to be out there. We needed people to know.
It was the only way we were going to find the other families.

It was like being shipwrecked and knowing there were a lot more people on the island. We needed to find them somehow.

The vision came out of the practical, day-to-day lives of families. The vision was to have enough resources so that every family, if they so chose, could offer something to their child—Autism treatment. That was the vision.

The urgency was built in If you have a child who gets an early diagnosis we’ve got a mom and a dad whose lives are completely turned upside down. You have absolute chaos and turmoil, emotional confusion after the diagnosis. There was at the time (early 1990s), some research to show that the earlier you intervene with kids with Autism, the better the results.

That created the immediacy and the urgency in any parent’s mind and any professional who was a party. They had to be motivated to want to do something as soon as possible!

The children created that sense of urgency - They were nothing but love and how do you look at a child -- people say it doesn’t have a future… and just let it be?

So the urgency came from people seeing the children.
We did a lot
with getting the news involved.

We went to the news stations
and had TV crews came into our homes
and did interviews ----
to create an awareness of Autism in the community.

We went to the newspapers
and had them write stories
so people could read about Autism.
And we were able to create a
sense of urgency in that way.

We were also able to contact
other families with children with Autism.

We decided we needed to start a support group.
We wanted to keep talking to each other.
We knew that there were other families who
would enjoy sharing stories.

By the end of the first year, my living room was full.

Linda Mayhew approached me, and said,
“We want to do this in a more organized way.”

And I said, “Fine.”

She said, “There are a lot of families out there
who want this service.
How do we get this?”

I said, “Well, you know, the Regional Center can’t afford
to pay for all this. We’ll have to find a way
to raise money.”

I found myself on a hot, Sacramento afternoon,
about 4 o’clock in the afternoon, in her living room.

About 25 families had shown up in her tiny, little house.

There was such an enthusiasm for this idea
and I said, “Here’s what we’re facing.
We don’t have the resources now….but..”

Building for change

FEAT had the grant money to provide
and it wasn’t just the grant money.

It was the resources.

UCLA just didn’t have unlimited amounts of therapists.

They had people booked way in advance.
FEAT was on a hot line ……
    Many were very excited about what we were doing.
There were no other therapies
    that were effective, {ABA/LOVASS}.
It was the most effective therapy.
    You could see real changes in your kid.
    They always were saying, “There’s an open window.”
When your kid is between the ages of, two and four.
    That’s when you need to get him into therapy.
    That created a lot of urgency with people.…
    the Open Window.

Parents need to understand
    if they are going to make a change;
    they’d better make it now.

So that was also in our minds.
    We had to convey “we can help you by putting you
    in touch with these various therapies….”

FEAT was providing to us,
    a society of people in the same situation.

Yes, they’re parents or,
    grandparents.
    They’re being affected by the Autism.
    In FEAT, there’s
    no real paid position.
It’s all volunteers. Some are burned out parents
    with autistic children that continue to do it –
    they love the children and they care
    about everyone’s child
    not just their own.

We took the numbers.
    We took the epidemic numbers.
The number ten years ago,
    was 1:10,000, now it’s 1:110.
    We took the numbers.
We started going out and telling people,
    “This is an epidemic. Crunch the numbers.
What is it going to look like
    in another ten years?”
We looked straight at the numbers.
When I would go out--
to my first presentations,
I would say, “Okay, how many of you
know someone who has Autism? “

I remember one day we had done a TV interview,
and after the interview,
we had put my phone number on the TV.
My phone was ringing off the hook, non-stop.
it was just crazy!

The phone company called
and they couldn’t handle it.
It was incredible we were able to use
the media to find other parents
and to find people who cared.

“I’ve got to give Linda Mayhew a whole lot of credit
because she is quite a go-getter
and she went out and made friends
with a local radio personality.

She contacted Channel 3
and she contacted KFBK radio,
she was a very good catalyst behind our fundraisers.
We began having annual dinner auctions
at nice hotels downtown.
Parents came to us in this panic.
“Oh, now what do we do?”

Kids with Autism usually have parents
who are Type A, motivated, driven, intelligent people.
They usually do. So these parents were leadership people.
It wasn’t like we had to attract them.
As far as professionals….there were a lot of professionals
out there who were raising these kids
who didn’t know what to do.

We said, “We need somebody in here
who can help us with our organizational skills…”
We recruited people that way,
but we just did that individually.
Usually it went like this:
“Wow, we need someone who’s good at PR
or has a connection to the school.”
Usually we’d have a parent call us
who had a kid newly diagnosed who said,
“Yeah, I work in Special Education.”
That’s how it usually went.

It took a lot of teamwork, to write the grant...

Ron wrote a lot.

Each one of us had a little job to do.

We’d each to go and research,

this, that, or the other… and then give information
to Ron for the grant, or whatever was needed.

That was teamwork.

As far as leaders …… many people stepped up
to the plate with FEAT, and took over different jobs—
the fundraising……the dinner dance,
and a barbeque in the summer.

The first one was the dinner dance and that was small.
We were getting the word out.
The next year, it was double in size.

We had parent mentors—
parents that would go out and work with new families…
and say, “I’ve been in this program for a year now.”

We had counseling for families
and all these committees… fundraising committees

It took a lot of energy
and there were problems getting that organized.

Someone had to step up and, thank God,
Linda Mayhew and a few other families were excellent leaders.

They were all bright families.
You’ve heard the expression;

the cream always rises to the top?

That’s what I’ve witnessed over the years.
The people who really have leadership ability
are attracted to that kind of role.

And there are also silent leaders.
There are moms and dads who have
made this chapter, this local chapter, this
founding chapter,
in Sacramento, successful.

Through the FEAT community…
we discovered that there were a number of people
facing the same situation.
A number of people who had never
dreamed that they would have a special needs child.
….and never dreamed they’d be involved.

We tried to help them see through
the initial stages of “What do I do now?”

Then I began going to the meetings
and I began listening to what was needed.
They talked about forming a public charity.
   Legally speaking, that’s what we decided.
   We wanted to form a public charity.

A lot of the parents would not want
their child labeled in public as *autistic*.
People were afraid of labels.
As part of FEAT, you were out in the community saying,
“My child has Autism.”
That might have been the biggest risk perceived at that time.
   I wanted other people to learn from
   my daughter that kids with Autism
   could still learn.
They could still be a part of the community.
   part of the classroom,
   a regular classroom.
But for other parents, that was a big concern.
   By becoming involved with FEAT
   you were known as a parent of an
   autistic child,
   so then your child was labeled.

We picked one thing at a time to go after.
   And after we won the first battle,
   it was just easier and easier to
   win the other battles.

It was the same thing with the school district—
   we would look at one school district,
   and here would be one person in that district
   who was battling for services
   and we would help.
   It was like pulling bricks out of the Berlin wall!

We were doing something. …. as an action group.
It wasn’t just to sit around
and cry about our kids.
We were getting stuff done!
That was huge and brought us together as parents who
were winning during this time.
There were battles with the school districts.
Many immediately
started opening
all the Autism classes to our children.

First, it started in pre-school,
and then in the primary grades,
and now we have them all through high school.
They saw and said,
“Wow, this family, they got an attorney!”
…Many districts didn’t have a program
that was appropriate.

Since they saw parents winning,
The schools said, “Okay, we’d better start
training our teachers.”
FEAT provides support at IEP meetings.
We did it all on our own and it was stressful for us because
we’re both teachers
up in Placerville.

We had Area Board III helping us.
There was the principal of special education--
She was just nasty
and mean to us!
We were all fighting our own individual battles.
They were all very, very different.
I would talk to someone who lived in another district.
The district would be hiring their attorneys, and in some
cases they were able to get services,
a one-on-one aide or whatever was needed.

And so everybody had their own
individual battles going on.
We were all doing individual programs
in our homes.
And we were all successful!
No matter what level, it was working.
We were a definite threat.

211
I have a lot of admiration for the administration of this district up in Pilot Hill. They hadn’t seen too many cases of Autism and frankly, didn’t know what to do either. My wife and her ability to work with the district and their willingness to work with her resulted in a fairly good experience here. We’re happy with what happened here.

The district provided him a full-time aide ……A full-time aide. You don’t get that too often! They were trying to figure out, “How do we handle Autism?” Some of the administrators were beginning to see that we had a number of cases coming their way -- children who were becoming eligible for school with various disabilities.

There will always be the controversial because to keep original, and to stay on the cutting edge, you have to be controversial. There’s just going to be a continuing battle because everybody’s trying to hold on to the money that they get from the government, and they don’t want to give it up that easily. Within the FEAT organization, the support will continue to grow and to help the families fight for what is right. We set a lot of precedents with the school districts and with the regional center others can build on.

Follow your heart and don’t take “No” for an answer if you don’t think what is going on is right. Keep focused on your goal. Don’t get taken off your track by pettiness or disagreements, but always stay focused on the goal. Don’t let other things get in the way. Listen to other people. Get lots of different opinions.
Stick with your heart, your gut
    you’ll be guided to what is right
    and what needs to be done.

When you see problems in the community
    like we did not have the services
    and supports for our children-
    You need to get involved
    and continue to move forward.

If it’s not there,
    create it!

Answer the questions
    and find out why there are “no’s”
    and turn them into “yes’s.”

Find out why, why people are saying,
    “No, we can’t do this and we can’t do that.”
    Find out why –and then figure out
    how you can turn it into……
    “Yes, we do have that -
    and we can do this.”

Have had a disabled child?
    Don’t be afraid to get involved.
    Or afraid of our institutions.
    Do not be afraid to challenge
    where there’s a definite problem.

Be an advocate for them.
    Nobody else is going to be an advocate for them.
    Only you can………
    Only you!

Nobody cares about your kid …
    Do not be afraid to challenge.
    Question things
    everybody’s supporting.

It doesn’t pay to burn bridges….  
    when you are challenging people,
    realize these are people…..
    you may have to end up
    working with,
    whether you like it or not!

Look and try to solve problems the best you can.
    in an unemotional way.
Do not afraid of people -
you still need to work with them.
Collaboration. Do it, do it, do it, do it.

Do it immediately because your adversary --

Remember that saying?
"Keep your friends close, but keep your enemies closer."

Your adversary has the information
that you need.
And your adversary is another person, like you.

When you come to a point where you’re going
to be working with that adversary,
you need a good working relationship.

I always kept my adversaries very close.
to know them every which way I could—
the adversarial agencies.
I knew the people in those agencies
who were rooting for us---
and the people who were
willing to take risks.

Know that their goal is
the same as ours,
they are just lost and are not doing things the right way.
Money and politics are there!
Those adversaries are people
we are going to need help.
So we have to help them change.

They do not have the motivation
to stay up on the current need or
what’s currently out there.

What’s really working?
The current effectiveness.
They think, “Okay, what does the research say?”

They don’t have that drive
like the parents do to be on the cutting edge.
They’re caught up in red tape
and don’t have the pathway that we have been given.

So it’s really important that the parents
to make their voices heard.

More collaboration and use of evidence-based practices
have to be the future, especially as budgets and everything
else tighten up.
We have to squeeze more effective outcomes.
   We have to squeeze more effectiveness
      out of the procedures that we use
   for better outcomes…
   …than we have in the past.
Create more training programs.
   Get grant money for more training.
Support these state commissions that study these things
   and can actually be in a position to pass legislation.
   That’s the sort of thing we ought to be doing.
Work with agencies, with state departments, with legislators.
   Get your ideas in order. Keep a calm demeanor.
   Be patient, but be persistent at the same time.
   Be informed.
   Find people who have more influence
      to represent your cause.
Surround yourself,
   with an enthusiastic core of people
      with the right kind of skills.
Fundraising skill.
   Publicity skill.
   Organizational skill.
   Knowledge of the types of organizations
      with which your group will be interfacing.
   In our case, it’s been Alta Regional, the IRS…the legislature.
Then all the publicity--
   Make sure that someone knows
      how to get a hold of the media
      that was a big boost.
An enthusiastic core.
   Surround yourself with the right kind of people.
   Use publicity and get the word out quickly to a lot of people.
Yet we all kind of burned out.
   either burn out because you are disgusted
      with something that’s happening or you have a
   personality conflict
      or you have to move on because
      you’ve other commitments.
So people are going to have to move out.
   People are going to leave the organization.
   New people are going to come in.
You have to deal with personnel changes in some organized way.

As a leader, don’t do it all yourself.
Find the people out there that need an avenue.
Let them to come to you.

Find out what their need is,
Everybody’s need is a little different,
but collectively, be on the same kind of page.

You have to thoroughly assess their need.

Find out what their needs are
and find that point where they are ready to learn
how to help themselves and educate them.

To educate you have to motivate---
and to stand really firm.

We had parents coming to us wanting us to do it all.
“Oh, you know how to do it.
You’re so good at it.”

But wait a minute, we have kids like you and we’re fighting our own battles.

We can’t fight your battles
So you’ve got to let them understand--
“I’m not going to fight your battles.
You’ve got to fight your own battles.”

I think one of the huge things was organizing the resources.
Here’s a list of the resources – So, it’s like a load with special needs.

Here are these people who have this need.
You’ve got to step in and give them just enough help to get them to the point that they’re self-sufficient---
but not give them too much help that they’re not going to do it themselves.

And hand them a list of resources and say, “Look, here’s the list. Start calling.”
We all had a hotline or
a warm line in our homes, and
we would say, “If you run into trouble,
call us and we’ll help guide you through it,
but we’re not going to do it for you.”

A lot of us became advocates.
We would go with them to IEP meetings or,
they would call and consult with us,
They had to make the effort on their own.
They had to make a certain amount of effort before
we would come in and advocate.

**Impact of legacy**

There’s been a lot of change
in the school districts.

Some have tried to implement
the behavior programming their own way in the schools.
Some have gone ahead and started providing
the funds for in-home programming.

Every school,
in their own way,
is trying to do some part--.
They know now, because of FEAT,
because of the information
and the parents.

In-home programming works.
There’re a lot still fighting against it
because they don’t want to pay for it,
but there are some that jumped on board
and continued to support
that type of programming for the children.
That’s a great thing.

I learned from FEAT-
to never underestimate what a few people can do!
if your heart is into it.

*There’s no way*
we could help our child or
create an organization just out of a few parents.
I mean, having a first fundraiser
was big!
FEAT….

It started with this--
“Let’s help our kids.”
We felt empowered.
We had tools.
people helping us,
supporting us.
It helped us make
a change with our kids.

I’m excited that FEAT has done as well
as it’s done.

It’s a very successful group
and it’s cool being a part of an origination team of
something that’s been so positive.

Even if we did not get a thing from it,
it’s nice to know we made our community
a little better by being involved.

FEAT in the future, will be broadening its resource base,
more on the advocacy end of helping parents,
working hard on the legislative
issues with both state and national.

It will be set up for a larger influx of parents.
FEAT has done well on finding a person’s gift
or finding a volunteer within the organization
and having them stay,
such as Gordon Hall, and Nancy Fellmeth
There’s longevity now.

When we first started, we had a president.
We switched around whoever needed to be treasurer.
The parents have been able
parents stay in their position,
do a great job, and have longevity.
That’s key to FEAT’s success.

Everybody in their own niche
FEAT’s direction is just to become stronger
and to be a part of raising public awareness
and partnering with other parent organizations
and a stronger voice.

They were able to leave and grow.
It reminds me of a singing group.
There are singers who go out.
They leave and they grow  
and yet they’re still a part of the original music family.
And they can get together  
when needed.
The very agencies and organizations  
that have been set up supposedly to help us  
like the school districts and special education…  
and the Regional Centers  
and the health insurance---
are more often working against us.
And the very laws that are set up  
for us,
we have to fight for what we are already entitled --

So that’s why  
these parents need  
to be listened to --
that’s why entities like FEAT work  
because we are not getting what they need from what’s  
already set up for us and our children.
Many are not being provided for  
under the laws that are already set up
So FEAT and other groups are  
providing the support and helping  
to get the services  
that they already should have from the agencies.
Everything that we create, when it becomes  
It’s not our property any more.  
Take the MIND Institute, for instance.
We need to be the watchdogs  
to make sure that it is  
what it’s supposed to be  
and make the changes when it isn’t,  
and advocate when it isn’t what we planned.
We can’t just let it go.
Once it becomes an agency  
and they have the people  
who are not directly involved  
in parenting, so much is lost!
The level of advocacy has been intense  
because Autism has such an impact on a family’s life  
that it just compels any typical person  
to want to do anything they can---  
to get resources and supports!
The fact that these families are willing to talk to legislators.

The Blue Ribbon Commission—
it wouldn’t even be in existence if it weren’t for parents.

It’s the parents that make
all these things happen.

Parents motivated me to get it organized
and give it a little bit of direction in the beginning.

The parents have run it entirely since
I’ve left the Regional Center twelve years ago.

They’ve certainly done a good job.

It’s just that parents somehow or another
are always the driving force in these things.

The budget deficit crisis right now, especially
with the declining housing market,
is reducing the tax revenues.

The Blue Ribbon Commission has released its final report.

It’s got recommendations
for all three areas where the problems exist.

So, policy and legislation is being drafted,
that will be considered for different
projects and pilot projects
that could be used to try to experiment
with how to streamline services.

Federal money from the 2006 Combating Autism Act…
that money is already going out to some states,
to the so-called “Centers of Excellence.”

That Act was really for research, pure research.

It’s more about the practice
and the actual services for people with Autism.

The money won’t go to any states.

It will only go to universities.

And it will go to private research groups.

California is spending four billion dollars
…each year here………in this state!

“Do we need shift our policies?”

When we’ve got the money there.

It’s really more about how.

What’s the most effective way to
use it at this point?
The Blue Ribbon Commission has a focus on a few areas where there can be greater consistency and greater streamlining of the way services are actually delivered.

It’s not the time for a complete overhauling of Lanterman… …because we just don’t have the money.

But the question is—
how can we improve services without spending a whole lot of more money?
Simply by changing the process, the procedures and the way we go about it?

An organization like FEAT could be very instrumental… …in affecting things.

The population of young people with Autism has dramatically increased.

FEAT is more important now than ever with the intake of families that discover their child has Autism

As a kind of a first stop advocacy group -- identification with others that have similar conditions, is important. That role is continuing and growing dramatically. FEAT is regularly contacted by new people who just get their child’s diagnosis and don’t know where else to turn.

FEAT needs to help to address families with Autism at all ages, not just the early ages.

The early intent of FEAT was to get kids early, when the Lovass type of program could be effective.

In the future—we have to do a better job of providing more information to families so they can make better informed choices about their treatment options, as opposed to just reading on the Internet or talking to their families and guessing.
What really founded the FEAT organization? 

The demonstration grant.

I was there at the right time
   and with the right background
      and the right familiarity because I’d been working
         with the Regional Center in southern California for many years.
   I’d worked with Dr. Lovaas in LA
      and I knew what could be done.
         I happened to be at the right time
            and the right place.
There was a huge, behaviorally based,
   empirically researched teaching technology available—
      LOVASS.

We never went in the wrong direction.
   We always stayed with the empirically based,
      research evidence-based practices,
         We got results.

And it was the kids’ response to treatment
   that really sold the whole thing.
There will always be the controversial
   because to keep original, and to stay
      on the cutting edge,
         you have to be controversial.

People were coming into FEAT
   as they were needed.
I kept saying,
   “Someone is putting together this puzzle
      and it’s amazing that everyone
         keeps coming in
            and coming together.”

Now looking back,
   It’s not me,
      it’s not another parent,
         it’s not the doctor,
            but it’s letting God use us
               to put this puzzle together
                  so we can help these children.
References


Nathan, J., & Radcliffe, B. (1994). *It’s apparent: We can and should have more parent/educator partnerships*. Minneapolis, MN: University of Minnesota Humphrey Institute of Public Affairs, Center for School Change.


Shank, G. D. (2002). *Qualitative research: A personal skills approach*. Columbus, OH: Merrill/Prentice Hall.


231


Appendix A: Conceptual Framework

Change in Schools & communities

The HOW of Change: Kotter’s Model & FEAT

The WHY of Change: Autism in Crisis

The WHO-WHAT of Change: Parents as Change Agents
Appendix B: Interview Protocol

Appendix A: Interview Protocol – Kotter’s Eight Step Change Model

Explanation of research concerns- the experience of parents who formed FEAT

- the impact of daily dealing with a child with autism,
- the challenges faced as individuals and in forming FEAT
- the main purpose for FEAT, how they increased membership and its effectiveness. The accomplishments and legacy.
- their advice to other who want to be change agents in their schools and communities.

Introduction of oral history methods and protocols

- Role of oral history in recording life histories and meaning of individual’s experience for posterity.
- Protocols based on Kotter’s Eight Step Change Model.
- Their experience as a possible model for future change agents.

Discussion of Informed consent

Identifiable information was removed from the data displayed and provided in dissertation. Member checking of information was requested, by asking founders to read their transcribed interview stories and correct as needed. They also have the right to detail any information or withdraw from the study at any time. They were encouraged to share about their interview participation in this study with those close to them.
First Interview

Parents were asked to provide some background about their personal experience as a parent of a child with autism and how this experience led them to participate in the formation of FEAT. They discussed their perspectives as leaders and mobilizing others as related in the quote:

"Leaders mobilize people to face problems, and communities make progress on problems because leaders challenge and help them to do so."

- Ronald Heifetz (1994)

What does this mean to you?

Step 1 Questions

How did FEAT create a sense of urgency to help children with autism?

Step 2 Questions

How did you attract leaders and promote teamwork?

Step 4 questions

How did others become involved? What attracted you?

Step 5 questions

What changes were a priority to FEAT? What risks were taken?
What new ideas were implemented?

**Step 6 questions**

Generating short-term wins

What plans were made?

What changes were created?

Who led the changes?

**The Third Interview**

**Steps 7 questions**

What were the plans for improvements?

How was Implementation of improvement plan done? How were the movers & shakers recognized?

What was learned?

Who or what was celebrated?

Anyone specifically recognized?

**Steps 8 questions** conclude the interviews with:

How were FEAT’s goals perpetuated?

How were its successes anchored? Any examples of continued programs in place?

Institutions that represent and continue your efforts?

Legislative success?

What is the plan for FEAT’s future?

Where do you see the group in another decade? Why?
What advice do you have for others who seek to be change agents in their schools and communities?

How should historians write about your experience? If you could help them what do you think they should say or include?
Appendix C: Informed Consent

Project Title: Parents as Change Agents

Researcher: Bethany Mickahail

Faculty Sponsor: Dr. Ellie Katz, College of Education, Denver University

You are being asked to take part in an oral history research study being conducted by Bethany Mickahail for a dissertation thesis under the supervision of Dr. Ellie Katz in the College of Education, Denver University.

According to the Oral History Association, “oral history is a method of gathering and preserving historical information through recorded interviews with participants in past events and ways of life.” You have been approached for an interview because you are a founding member of FEAT and/or the Mind Institute.

Purpose:

The goal of this oral history project is to examine and record the experience of parents of children with autism who are also founders of the parent organization, FEAT (Families of Early Autism Treatment). This interview will supplement written records about parents as change agents in their schools and communities.

Procedures:

There are three interviews approximately 60 minutes each.

The interviews will take place at a location agreeable to both parties. In the interviews you will be asked questions about your specific role and experience as a founding member of FEAT.
The interviews will be audio-taped and transcribed.

Upon the completion of your interviews’ results, you will be asked to review the written version of your recorded interview transcripts to make corrections as needed. Upon the completion of the three interviews I will make an appointment to meet you and provide you with the themes I have gleaned from the process. Your constructive feedback on them will be welcomed at that time. It is hoped that your tapes will also find a place in UC, Berkley, and Bancroft Library’s Oral History of the Disability Rights Library (we are presently in negotiations about this matter).

**Risks/Benefits:**

The risks associated with participation in this interview are minimal. The benefits for participating in this study include your opportunity to contribute to your own knowledge and understanding of life as a parent of a child with autism and your experience as an advocate. Through this interview process, the sharing of your story and its meaning, you will contribute to the awareness of life as a parent of a child with autism and what formed your advocacy efforts. You will be assisting others who must also advocate for children and promote change in their schools and communities.

**Confidentiality:**

Unless you check below to request anonymity, your name will be referenced in the transcript and audiotape and in any material generated as a result of this research. If you request anonymity, the tape of your interview will be closed to public use, and your name will not appear in the transcript or referenced in any material obtained from the interview.
In addition, at the conclusion of the interview you will be asked to sign a “Deed of Gift” form to donate the transcript and audiotape of the interview to Bancroft Library, UC, Berkeley. If you choose to sign the “Deed of Gift” form, the materials from your interview will remain the property of the Bancroft Library) and will be available for use by others.

**Voluntary Participation:**
Your participation in this interview is voluntary. Even if you decide to participate, you may withdraw from the interview without penalty, or request confidentiality, at any point during the interview. You may also choose not to answer specific questions or discuss certain subjects during the interview or to ask that portions of our discussion or your responses not be recorded on tape.

**Contacts and Questions:**
If you have any questions about this research project or interview, feel free to contact me at xxx-xxx-xxxx, Dr. Ellie Katz, dissertation chairperson at 303-xxx-xxxx. If you have questions concerns or complaints about this research study or your rights as a research participant, please phone Dr. Maria Riva, Chair, Institutional Review Board for the Protection of Human Subjects at 303- xxx- xxxx or Dawn Nowak, Office of Sponsored Programs, 303-xxx- xxxx. You may also write to them at the Office of Sponsored Programs, 2199 S. University Blvd., Denver, CO 8020
Statement of Consent:

I agree to participate in this oral history interview, and to the use of this interview as described above. My preference regarding the use of my name is as follows:

___ I agree to be identified by name in any transcript or reference to the information contained in this interview.

___ I wish to remain anonymous in any transcript or reference to the information contained in this interview.

________________________________                                _____________
Participant’s Signature                                                                         Date

Print below:

Name: _____________________________________________ ___________________

Address: __________________________________________ ______________________

Phone: ________________________Email:______________________________

______________________________                               _____________
Researcher’s Signature                                                                    Date
Appendix D: Letter of N. Fellmeth, FEAT President

FAMILY FOR EARLY AUTISM TREATMENT

September 23, 2005

To whom it may concern:

Families for Early Autism Treatment (FEAT) of Sacramento, is honored to support the research of Bethany Mickahail as it relates to our efforts to effect positive change in the educational and life opportunities for persons with autism. To this end, I have contacted or placed Ms. Mickahail in contact with the founders of FEAT who are all excited to contribute toward this project. The current members of our Board of Directors are also willing to participate in interviews if needed and we will arrange for interviews with our members as needed. We look forward to the documenting of our efforts in such a thorough and creative manner. In addition, we have been informed of the rights of participants in research and the standards to which doctoral candidates must conduct research.

Sincerely,

Nancy Fellmeth

Nancy Fellmeth, President
Families for Early Autism Treatment
Appendix E

Fraenkel and Wallen’s Interview Guidelines (1993)

1. Respect the individual being interviewed
2. Be natural
3. Ask the same questions in different ways during the interview
4. Ask the interviewee to repeat an answer or statement when there is some doubt about the completeness of a remark.
5. Vary who controls the flow of communication
6. Learn how to wait.