Capturing the Essence of the Change Process in Educational Policy

Bethany Mickahail
University of Phoenix

Kate Andrews
University of Phoenix

This research highlights the role of parent activism, as realized through the volunteer organization Families for Effective Autism Treatment (FEAT) and their subsequent contributions to shaping autism services through foundational legislation, research, communities, and school programs. During the first phase of this research, themes related to effective educational change were captured in interviews and developed into an adapted systems change model. The focus of the second phase centered on continuing with second and third waves of activist parents, who were current members of FEAT, completing quantitative surveys based on the themes found in the first phase to substantiate the themes continuing importance. Additionally, the respondents were asked qualitative questions on aspects of the continuing change process. The results of this research provide a comparison and analysis of the themes related to past, present and ongoing change processes. In addition, the final research recommendations provide an action plan for all groups seeking to address the growing needs of children with autism and their families. Information gathered from the research points the way for those desiring to become part of a ground swell of groups and individuals dedicated to seeing lasting change in educational policy and programs in the autism community and beyond. The Praxis Documentation & Aesthetic Interpretation (PDAI) research model used for this study emerged from fascination with societal transformation and the endless energy of change pioneers. The PDAI research model continues to hold significance for those who seek to conduct research in new and inventive ways.

INTRODUCTION

As educational policy continues to evolve because of growing socio-cultural needs of students, parents, school personnel, and communities, effective, and practical methods of actionable change must be used. In the first phase of this study, researchers assessed the experiential knowledge of a dynamic parent community in the autism arena, Families for Effective Autism Treatment (FEAT). Solutions to remedy concerns regarding equity, diversity, and access were developed (Mickahail, 2010; Mickahail & Andrews, 2013). These solutions are used nationwide to extend the knowledge of teachers and administrators on how to create school communities of support for children through policy changes. However, the importance of the solutions proposed had not been quantified. Thus, during the second phase of the research study, the importance of the initial themes and resulting solutions were quantified.

PROBLEM

Stakeholders, parents and communities, are well aware of the challenge to provide equitable educational services to meet the needs of students with autism. The Centers for Disease Control reported, in 2009, autism occurring in one in every 110 school children in the United States. However, the 2013 statistic is one in 50 children (Blumberg et al., 2013). Communities addressing this reality and producing policies that provide practical solutions to promote equity for all is paramount. Knowing how changes in polices can be promoted and implemented successfully is a measurable necessity in today's environment.

As some disability statistics have remained relatively constant in numbers, autism numbers have more than doubled (Blumberg et al., 2013). Parents of children with autism are a force of advocates, establishing their own grassroots support groups as springboards for significant activism in educational programming, health care, and political arenas. The uniqueness of these groups present opportunities for understanding the factors that enable successful systems change to unfold. FEAT emerged early within the autism community to be not only a parent support organization but within two decades they became a vehicle for advocating significant, nation-wide changes in school communities and state public policies. Of the research available on parent involvement (Ballen & Moles, 1994; Jeynes, 2012; Souto-Manning & Swick, 2006), little has been written in the scholarly realm about the role of parents as change agents. Just as details about parental role has been neglected, the process by which parental involvement was successful in developing their significant contributions to shape the public policy that drives the educational and service-delivery models for children with disabilities has been unnoticed in prevailing literature (Zablotsky, Boswell, & Smith, 2012). The question remains: how to capture the essence of the process used by FEAT to accomplish such great change within a short amount of time in order for other concerned parental and community groups to capture a starting point? This starting point, based upon FEAT's past experiences, can be used as a ladder from which to start at a higher level thus possibly seeing lasting positive change even faster than FEAT and with even more effectiveness.

LITERATURE REVIEW

The review of the literature is rooted in the research in parent engagement, community leadership, disability legislation, and the health crisis of autism (Blumberg et al., 2013). These issues have ignited a wave of extraordinary parent advocacy efforts to change public policy, schools, and communities. New perceptions of parents evolved as education professionals were a paradigm shift toward family-centeredness, partnerships, and collaborative support in the education of children with disabilities. Parents, once viewed as passive observers, are encouraged actively to participate (Jeynes, 2012; Souto-Manning & Swick, 2006).

Parents of children with autism 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 Lanterman Act of 1974 (State of California DDD. 2013) happened only through concerted and organized parental engagement in the political process. These parents and their allied networks lobbied U.S. government representatives to the legislation for needed appropriation to make their vision of support a reality for their children (i.e., IDEA). This parental involvement brought about significant and effective legislation for children with disabilities. Pioneering parent advocates fought the injustice of exclusion, which embodied keeping those with autism separate from "normal" children. Parents affected 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 changed to address these needs. With government funds and organizational training, they progressed over the last century from passive onlookers to active and vocal advocates. In sum, parents continued to pass on training methods and skills to the next generation of parents as change agents, continuing the wave of political involvement and organization continually to meet the needs of children with Autism and other disabilities in the 21st century.

RESEARCH QUESTIONS/HYPOTHESES

The following research questions for the first phase of the study were

1. How did a 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 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? 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 importance of the experience of FEAT parents? 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?

The following research questions for the second phase of analysis of the interpretive information previously gathered in qualitative research:

> *R1. How important to the current membership are the themes developed during the first phase having to do with initiating change?*
> *R2: What additional factors are perceived to be important to the current membership to perpetuate the momentum for change?*

The first research question was investigated by collecting quantitative data to test the following:

> *$H1_0$: FEAT second and third wave members will rate advocacy, building for change, and impact of legacy themes no more than somewhat important in initiating change processes.*
> *H1: FEAT second and third wave members will rate advocacy, building for change, and impact of legacy themes more than somewhat important in initiating change processes.*

The second research question was investigated by collecting and analyzing qualitative data as answers to open-ended questions and then subsequent statistical analysis of the level of importance was performed.

METHODOLOGY

Using a mixed-method model of research as a guiding methodology, three theories provided the foundation for the qualitative portion of research previously conducted. The PDAI model (Figure 1) is a continual 4- step process: developing a praxis framework, documenting and collecting oral history data, creating an aesthetic representation, and interpreting results through data analysis. Within this study, PDAI was used to combine Kotter's (1996) Model of Change as the praxis framework for Eisner's (1998), *enlightened eye* in evaluating educational resources and the data collected using oral history tools.

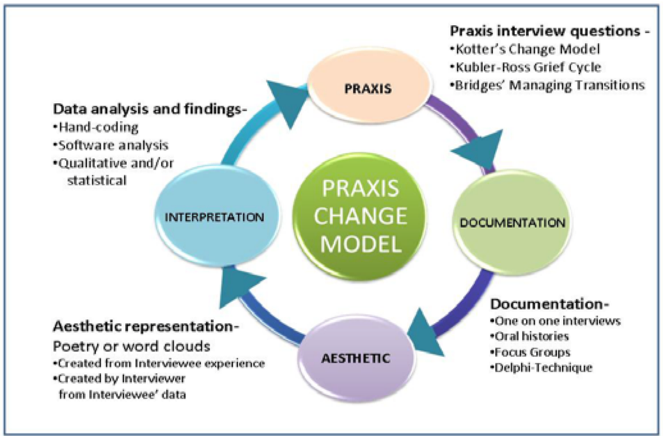
Participants

All current founding members of FEAT were participants in the first phase, the qualitative portion of the research. Seven founding members were interviewed and their information became the foundation upon which the second phase's questionnaire was built.

During the second phase of the study, with the permission of the FEAT organization, all current members of FEAT were given the opportunity to participate through newsletter information and email. Those who volunteered and met the criteria for participation were accepted as participants. There were 3,000 current members of FEAT and 96 responded. No segmentation of the sample was made in gathering male or female participants, age, or ethnicity as all members who participated were important to the data gathering. A sample size of 93 was calculated as required for a population of 3,000 members with a confidence level of 95% and a confidence interval of 10.

The risks to subjects were minimized using procedures that allow voluntary participation, anonymity, and choice in self-disclosure consistent with sound survey design. The selection of subjects was equitable in that all FEAT membership were given the opportunity to participate and those who choose to do so were informed of the scope and purpose of the research. The parents were informed of the voluntary nature of their participation and that no repercussions with FEAT membership would occur based upon answers or non-participation.

FIGURE 1
DEPICTED WITHIN THIS FIGURE ARE EXAMPLES OF POSSIBILITIES THAT MAY BE THE OUTCOME OF EACH STAGE OF THE PDAI MODEL



Instruments

All interview questions for the first phase of the study were based on Kotter's Model of Change (Kotter, 1996). The thematic coding of the answers to the interview questions were used as the basis for development of the quantitative survey. Subject matter experts became the validation team for the quantitative survey, ensuring that each theme was adequately covered within the survey and that the survey was understandable and met the criteria for sound survey development. Within the survey, open-ended questions were included to gather data for responses to the last research question.

Process

In following the PDAI methodology, a qualitative study was first undertaken. During the Praxis stage, the Kotter Model of Change was determined to be the cornerstone upon which to gather initial information from the founding members. After open-ended focus questions were developed, three interviews each lasting up to 1 ½ hours with each founding member were conducted.

In PDAI's aesthetic representation step, Eisner's interpretation, evaluation, and thematic analysis were applied through poetic representation to find resultant themes and significant findings. In the aesthetic stage, the public form for the data (or transcribed pages of participants' stories from each of the five interviews) was translated into poetic display. All data were displayed aesthetically through a poetic representation format distinctively named the *enlightened pen,* (Mickahail, 2010; Mickahail & Andrews, 2013). At the beginning of the 3rd stage of the PDAI methodology, interpretation, the aesthetic representation with the raw interview data was created. The poetic display was approved by interviewee validation and subsequent statistical analysis to portray consistently the perceptions of the founding members of FEAT. Within this multi-method research project, the quantitative portion was completed as a continuation of the interpretation step of PDAI with statistical analysis of the importance of the identified qualitative themes. The purpose of the second phase of this multi-method research was to quantify the viability of those themes captured from the first qualitative study's phase as well as capture through qualitative methods the perceptions of additional themes that may have contributed to the perpetuation of change. The themes were assessed in this second phase as potential contributors to successful system change in communities. The focus of this second phase was on continuing the research with all activist FEAT member parents completing surveys to substantiate the importance of those themes. Additionally, respondent opinions were gathered to collect potential themes for continuing systems' changes.

Quantitative analysis was used to affirm the validation of coded data. A continued mixed-method approach was undertaken through the following methodological steps. From the resulting themes gathered from FEAT's change efforts in the first phase, the researchers developed a preliminary map for effective change.

The second phase of the research project, in continuing with PDAI's interpretive analysis, began with the finalization of a survey based upon the thematic analysis from the aesthetic representation. Questions considering the importance of the themes generated during the first phase were answered in closed-ended, Likert-type scale format with each theme explored through a sub-scale of averaged Likert-type values. Open-ended questions were used to capture potential further themes perpetuating a momentum of change.

Through an e-mail and newsletter information from the FEAT of Sacramento organization, all current members were contacted asking for their participation in a survey. An explanation of the purpose of the survey and the fact of voluntary participation were included in the informed consent. An Internet company was used to host the survey providing a link that was included in the email to potential participants. The internet company provided the data in SPSS spreadsheet (for quantitative analysis) and Excel (for qualitative analysis transferred in text format for NVivo).

Averaged Likert-type subscales were used to generate the data for the themes from the first phase. Statistical significance at was set at $p < .05$. NVivo software was used for coding of the open-ended questions. Raw data will be stored in a locked facility for a period of five years.

More than adequate procedures are in place to ensure privacy and confidentiality of participants in the data collection. The online survey company did not transmit or save any names or IP addresses (i.e., any identifying information) to the researchers. All participants were provided an informed consent to which they gave their electronic acknowledgement to participate in the study. The acknowledgement was required in the survey setup before any questions were answered.

Raw data was reviewed by the research team for data analysis purposes. The survey company provided email addresses and names of those participants who elected to be entered into a drawing for a donation of $100 in their name to FEAT. No raw data was transferred to FEAT but only final analysis and results.

RESULTS

Through the use of the PDAI continual 4-step process (Figure 1), the qualitative interviewees' insights and perspectives of life experiences related to issues of urgency, advocacy, effective treatment, public awareness, research, and policy planning which were translated into recommendations for change through poetic representation. The participant's *descriptions*, or heart stories, emerged from the semi-structured research interviews.

Qualitative

The results for the first phase of the research project consisted of both aesthetic representation of data and coded themes. An example of the aesthetic representation is shown in Figure 2. The entire compilation of poetic representation covers 106 pages. The poetic representation of the interview data was triangulated with approval by the interviewees. After review of the data analysis into the six parent interviews, their stories were distilled into the poetic essence of 106 pages. The results of hand-coding were also double-checked with coding using NVivo coding software. The thematic coding found three primary themes from the interviews, advocacy, building for change, and impact of legacy.

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.

FIGURE 2
AESTHETIC REPRESENTATION OF INTERVIEW DATA

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
those with autism.

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.

Quantitative

The survey was developed to measure the agreement with the themes from the coded data in the qualitative, first phase, of the research project, advocacy, building for change, and impact of legacy. Each theme had a minimum of 11 Likert-type scaled questions included within the survey. Answers ranged from 1-5, with 5 being the highest indicator of agreement or satisfaction or importance. The themes became subscales of the survey. The score for each subscale was tabulated and a single sample *t*-test was run for each theme. Results for advocacy showed that FEAT current members rated the theme of advocacy (M = 4.06, SD = .65) as being more important than they reported advocacy as being unimportant, t (96) = 10.86, p≤ .001). Therefore, the null hypothesis was rej ected for advocacy. Results for building for change showed that FEAT current members rated the theme of building for change (M = 3.69, SD = .89) as being more important than they reported building for change as being unimportant, t (96) = 34.44, p≤ .001). Therefore, the null hypothesis was rejected for building for change. Results for advocacy showed that FEAT current members rated the theme of impact of legacy (M = 3.84, SD = .55) as being more important than they reported impact of legacy as being unimportant, t (96) = 10.86, p≤ .001). Therefore, the null hypothesis is rejected for impact of legacy.

CONCLUSION

This study provided valuable insights to inspire educators, in training or on the job, to stay the course of proactive, effective, and practical educational change. The related community resources, reciprocal relationships, conflict resolution and decision-making tools, and ethical issues involved were examined in the change process through the eyes of founding members of FEAT. These members forged ground-breaking efforts that provided needed early services to those with autism throughout the nation. 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 Rising and Alarm over Growing Statistics

A 2013 report of the CDC cited autism is occurring in one in 50 children school children. 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.

Advice 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

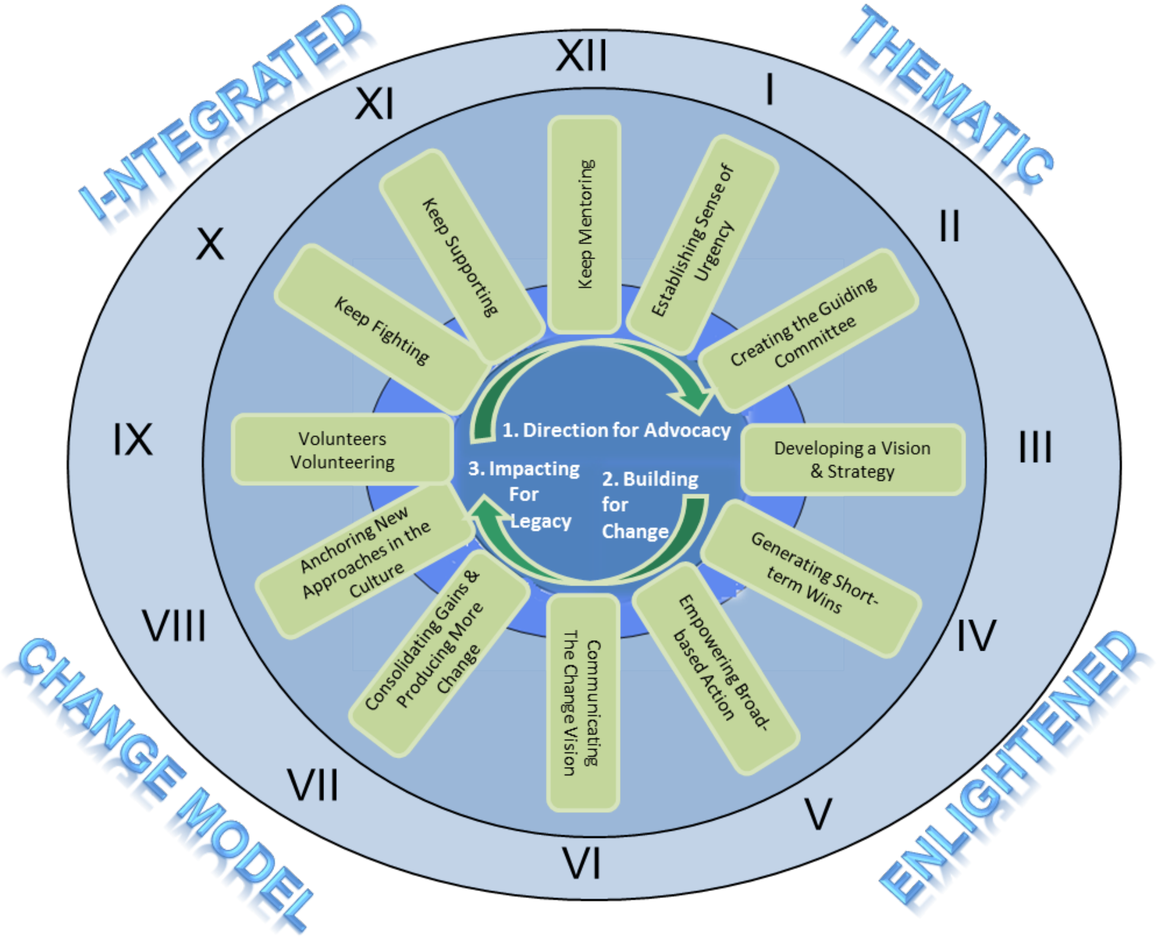
- *Be informed.* Get facts in order and find people who have more influence.
- *Keep a calm demeanor.* Be patient, but be persistent at the same time.
- *Get a group consensus* on what can be done improve the situation
- *Work openly with administrators, and the school district people*, with legislators 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.

FIGURE 4
PORTRAYAL OF THE I-NTEGRATED THEMATIC ENLIGHTENED (ITE) CHANGE MODEL AND THE FACTORS RESULTING FROM THE QUALITATIVE PORTION OF THIS RESEARCH WITH QUESTIONS FOR ASPECTS TO BE FOUND IN FURTHER RESEARCH (UTILIZING THE KOTTER (1996) CHANGE MODEL WITH 8 STAGES



The stories of those involved in founding FEAT continue to provide insights useful to all those eager to instill effective and lasting change (Mickahail, 2010; Mickahail & Andrews, 2013). Their story serves to improve communities' responses to the inevitable social, economic, educational, political, medical, and environmental repercussions of the modern crisis of autism. New themes emerging from the second study further validated FEAT parents' need for supportive caring communities (see Figure 4). The greatest challenges for the FEAT organization are recruiting more volunteers, avoiding burn-out of leadership and the continued development of mentors. Oftentimes, the organization has depended upon the energies of key parent leaders. FEAT's healthy future requires that the overworked leaders replicate their knowledge and energy to willing mentees, to push forward in its advocacy activity in California and beyond. A poetic representation of these challenges is in Figure 5 along with a word cloud depiction in Figure 6.

FIGURE 5
POETIC REPRESENTATION OF QUALITATIVE DATA ANALYSIS IS DEPICTED

Greatest challenges
Children
autism
Volunteer!
Volunteers volunteering-
Finding funding-
support organization!
Organization
Information
time and services.
Autism needs.
Families fundraising!
Financial resources-
autism awareness
agency system
adults.
People
Events
Government
Community ideas!
Continue the fight-
spectrum community.

FIGURE 6
WORD CLOUD REPRESENTATION OF QUALITATIVE DATA ANALYSIS IS DEPICTED

Numerous political, philosophical, practical, and societal reasons exist for schools to continue changing to enhance the future of our nation's children and their communities. Even as the need for change is recognized, the question arises. How are strategic decisions made to have equitable systems and resources for all? Educational policy makers, administrators, and teachers encounter this question pursuing systems change in bringing superior educational opportunities to students. The facets of the change process associated with a ground-swell organization of collaboration between parents and community were critically examined in this mixed-method research project.

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