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A CASE STUDY OF THE ANN SULLIVAN CENTER IN LIMA, PERU

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A qualitative study was conducted to describe and explain the educational program at the Ann Sullivan Center, a nationally and internationally recognized program for individuals with disabilities in Peru. The program provides educational programming to individuals with autism, severe disabilities and challenging behaviors across the lifespan. A case study approach was implemented through focused interviews and direct observation. The participants of the interview segment were educational administrators, teachers and parents. The study found four key factors contributing to the success of the program: the school community; program philosophy; continual training of teachers and families; and teacher attributes.

The education of students with autism and severe disabilities has gone through many metamorphoses over the past several decades. Historically, students with autism and severe disabilities received instruction in segregated classrooms and programs based on a belief that segregation was necessary in order to provide specialized instruction and that these students learned differently than their typical peers (Putnam, 1993; Putnam, 1998). As this perspective began to change, the primary educational goals for students with autism and severe disabilities began to focus on instruction within the mainstream so that the student could learn to function in a productive manner in integrated community environments (Koegel, Rincover, & Egel, 1982; Koegel & Koegel, 1995).

There is strong evidence that students with autism and severe disabilities can learn age-appropriate behaviors when instructed in an environment with same age non-disabled peers (Koegel & Koegel, 1995; Koegel, Koegel, & Dunlap, 1996). Inclusive classes provide students with autism the opportunity to relate to typically developing peer models who demonstrate appropriate communication, social, functional and academic skills.

Inclusion into the community is equally as important as inclusion into the regular education classroom. Community inclusion allows students the opportunity to practice a variety of functional skills (e.g., grocery shopping, ordering from a menu), which complement instruction that occurs in the classroom (Falvey, 1989; Baker & Brightman, 2004). Additionally, community inclusion is an important component in successful vocational preparation. Students are provided with opportunities to bridge their classroom learning with skills critical for employment (Berkell, 1992; Wehman, 2001).

Inclusion into family life is important for the successful development of students with autism and severe disabilities (LeBlanc, Schroeder, & Mayo, 1997). It is equally as important that the child be included into the family and be included into an educational program, vocational setting, and the community. Families often alter their daily activities and routines to accommodate the needs of their child with disabilities. These changes may lead to stress within the family and create a *family with disabilities* (Koegel, Schriebman, Loss, Dirlich-Wilhem, Dunlap, Robbins, & Plenis, 1991; Turnbull & Morningstar, 1993; Turnbull & Turnbull, 2000).

This paper explores the integrated educational program at The Ann Sullivan Center in Lima, Perú. The Center is recognized internationally for providing quality educational programming to individuals with significant disabilities (Mayo, 1991). The Center supports approximately 181 students in a variety of programs ranging from early intervention to adult programming

The philosophy of the Center stresses respecting all students regardless of their disability. The goal of the Center's educational program is to increase student independence both within the Center and in other educational programs outside of the Center, as well as in the community and home environments. The curriculum emphasizes independence, communication, socialization, self-care, and functional skills for use in the student's community and home.

From the outset, *la Escuela de Familias* [a School of Parents and Families] was an integral part of the program. Parental participation was mandatory and the school trained parents to be successful teachers of their children. They learned to teach their children in natural situations and to teach with procedures that ensure generalization and maintenance of the learned skills.

The teachers attended inservice training one to three times per week for two hours. The workshops included behavior change programs, research strategies, behavior analysis procedures, instructional methodology, and communication programming. All teachers and educational administrative staff were involved in research projects conducted within the classrooms as part of the daily activities.

The Study

The study employed the techniques of case study methodology (Yin, 1989) to describe and explain the educational program. Information was obtained through prolonged engagement in the setting by the researcher, as well as through observations, and interviews. Forty eight interviews were conducted with parents, educational administrators, and teachers. Parent participants were selected on the basis of their child's age and their family income level in order to represent a range within the Center. Sixteen mothers, three fathers and one grandmother were interviewed. The data collected from the interviews were divided into 24 major categories and 31 subcategories.

Reliability was performed for 35% of the data sorting and for the accuracy of the five randomly chosen transcriptions and translations. The reliability for the sorting of the data chunks was 66% before consensus was reached between the researcher and the external evaluator. Reliability for the transcriptions and translations of the interviews found that the transcriptions and translations were accurate. There were a small number of literal translations, which did not alter the meaning of the responses.

An analysis of the collected data indicated that there were four main characteristics unique to the Center's programs. The first of these was a sense of community. The Center is referred to by both parents and staff as *La Familia Ann Sullivan*, [The Ann Sullivan Family] and it provided support and encouragement to all of its members.

The program's *family* philosophy was the underpinning of all of its educational goals through a variety of teaching activities which encouraged the students to be *integrated into life* (J. LeBlanc, personal communication, 1989).

The curriculum represented the second characteristic. It was a functional and natural curriculum, focusing on the development of skills which would increase participation in the community, school, family life, work environments, etc.. The goal of the curriculum was to prepare them for all that life had to offer.

Continuing education was a third characteristic that contributed to the Center's success. Ongoing educational programs were provided to both staff and families. There was a constant striving for improving the program, as evidenced by the continual inservice training.

The final characteristic was teacher attributes. The teachers and educational administrators impacted the education of the students beyond teaching methodology. Their personal

characteristics and spirit influenced the attitudes of the parents and others who interacted with the students and created an enjoyable environment that was conducive to learning.

Families and the teachers worked together to assist the students in attaining their goals. Formal collaborative teams did not exist; however, the respect for all members and their contributions was evident in the relationships that developed between families and staff members. Respect for the students as individuals was a key component of this *family* community. Respect for all members of the community extended itself to ensure that the students are seen as individuals with thoughts and feelings of their own. The slogan *treat me as a person* (J. LeBlanc, personal communication, 1988) represented the Center's efforts to provide education, as well as the personal relationships needed to thrive as human beings. The philosophy of the Center created an environment in which all community members gained status as viable, productive contributors.

This inter-related community support is evidenced in the interview statements made by one mother.

They help us as parents, when we come here sometimes, with low morale, with the problems at home and they are always ready to help us and talk to us and get us through it...Because like I told you, sometimes one comes here and they always listen to us and they never tell us that they are busy, they always have a moment for us. And they talk to us, and all of a sudden, you see your problems differently, as if by magic, and realize that it isn't as hopeless as you might think and that it can be resolved so that you can press forward and this allows us to work better with our children.

The teachers provided a variety of supports to the families; educational and emotional supports were given freely. Parents felt comfortable discussing a variety of issues with the teachers - issues related to their child's education, including larger family issues which may have impacted the child. Thusly, the Center became an extension of the nuclear family and was seen as an important extended *family*.

The goal of a team approach has been incorporated into the program since 1991 (L. Mayo, personal communication, 1991). Parents were considered partners in their child's education and were expected to participate in the education of their children. Parents signed a contract when their child entered the Center. Initial participation was mandatory, however, parents developed into willing partners as they interacted with the staff, teachers and the curriculum.

The working relationship that developed between parents and teachers was seen by one mother, whose son had attended the Center for less than a year, as key to understanding her child's behaviors.

It seems to me that it is a program in which teacher and parents work together and this allows us to have a better understanding of children's behaviors and allows us to modify the behaviors so that the child can be integrated into society.

Relationships that developed between teachers and students, teachers and parents, and parents and children were all contributing factors in the development of the school community.

An educational administrator described the confidence that teachers have in their students.

...I think one of the benefits of the program too is the change that we have made basically is having faith in the kids. It is very definite, we send our kids alone sometimes to their house but we never think that they are not going to do it. I think that believing in them has made a big difference.

Another educational administrator pointed out a positive characteristic of the parent/teacher relationship.

We share a lot of good times with the parents, it is not only the formal relationship that you are the professionals and they are the parents. We work as partners, it is not our responsibility, the professional responsibility only, it is the parent/professional relationship that is important.

Since parents are seen as partners, equal participants in their child's education (L. Mayo, personal communication, 1986), their input and participation is valued and necessary for the success of the program. Students were seen as individuals with whom one would want to have a relationship. The importance of building a positive relationship with the student was seen as a foundation necessary before successful instruction would occur. A mother whose daughter was new to the Center found that the respect she learned to have for her daughter transferred easily to other situations and individuals.

Also we as parents have learned to treat them as people...their independence has been achieved little by little. We as parents with all these teachings that we have received, we have benefited much, because it helps use quite a bit, not only to educate our children, but also to extent our experiences to other children who we see around us, we are now not going to commit previous errors so we can treat others like we have with Ana.

The development of friendships between the teachers and students ensured that the students are respected and that their feelings are seen as valuable.

Integration into life is a phrase used at the Center to describe opportunities for interaction and activities with non-disabled individuals and involvement in typical activities appropriate to the age group of the student. These activities can be broken into three subcategories based on the interview responses of the participants and the program at the Center: functional and natural curriculum, community integration and integration into family. Two educational administrators describe *integration into life*.

To integrate into life. Not only to the community, not only in one place, I mean into life. I know that it is a big word but it means that it is not only to be integrated in something special.

Integrated into life, our kids use public transportation, they are in their homes with their own family. They are not in institutions or in group homes. The parents make them participate in all the activities that they do, if they go to parties, if they go to church, if they go to mass on Sundays. Before they didn't used to do that but now they are doing that. Even they are sending them alone. I find that the parents are happy, not only because I tell you but you should see the evaluations that the parents give us.

Initially, the majority of the education programs offered by the Center were segregated. Recently, however, a strong move has occurred toward integrating students with non-disabled peers either in the community or in schools. For those students who were in a segregated environment, teaching activities occurred in the community with both teachers and parents who were instructed in ways to include their children in all aspects of family life. A functional and natural curriculum was used to attain the goal of integration into life. The curriculum adopted by the Center directed the focus to activities and skills that the students would need to make independent and meaningful contributions throughout their life span. Instruction was provided in natural situations and in a natural sequence of activities. Skill building programs strove to teach students to perform activities that would have to be completed by someone else if they did not do it themselves. Teachers and educational administrators believed that the functional and natural curriculum was one of the greatest benefits of the Center. Accompanying the shift to the functional and natural curriculum was an encouragement to continually analyze the teaching procedures and to test the documented research. A teacher explains how this continual evaluation occurs.

Sure, all of those activities without a doubt, all those activities that are programming at the Center, what we try to do with these are achieve an independence of the children and all of the objectives that are taught to them here are functional. It depends on us if we want a child to learn a practical objective, we teach him functional and practical things and if the child doesn't learn it is because of the procedure we are using to teach, so our work consists of looking for the procedures that will enable the students to learn and achieve an objective. So that they become independent, right? Because the objective is always functional, so it may be of benefit to the student.

Integration into the community consisted of activities, which made use of community services and places, as well as the establishment of relationships with neighbors and other community members. One teacher explains how perceptions regarding community integration have changed at the Center.

The most important is that the kid could be part of his environment and we observe this in the activities that we do outside the Center. Students were involved regularly in community activities, which provided them many opportunities for learning new skills. Well, also the activities that are related very much to the community, and are done outside, the opportunity is given to them to go out to shop and all other activities outside. These opportunities encouraged the skill development required for independence. It was also important for the students to be in the community since it helps the community see it as more natural.

Integration into *the family* is seen when the individual is a contributing member of the family with household responsibilities and opportunities to participate in all the typical activities of the family. It also includes acceptance of the individual by the family, without this acceptance true membership is not possible.

For parents, important components of integration were increased independence with daily activities and participation in the activities in the home. The ability of the individual to do things for himself/herself was valued by the family not only because someone else did not have to perform the task but because it also allowed the child to contribute to the household.

I think that she has progressed a lot, she can change her clothes, she washes herself with some help, and bathes herself, she loves water. She is more calm, she doesn't blow up at us like before, and she eats like a normal person would.

At the Center, parents and families were recognized as the most effective teachers of their children. Parents received 70 hours of classroom instruction in twice monthly large group instruction and bi-monthly small group instruction. Parents and teachers then role played in small groups the material they learned in the large group sessions. Each parent/family received an additional 20 hours of individual, in-class or community training. Parents were taught to be partners in their child's education. Teachers used modeling to demonstrate the teaching methodologies. The participation of the parents in the educational program maximized the student's *integration into life*. One mother believes that the education she received made her a better parent.

Because I feel I am a better mother, a very good mother for my daughter because what a mother wants the most is to be able to help her child and as my daughter is not a normal one, she needs a mother with training in many things. With some studies or knowledge to be able to help her, so they've told me the secret and I am trying to reach my goals.

The education that parents received further motivated them to assist their child reach his/her maximum potential. Parents were able to provide the student with opportunities to practice skills-building exercises and further generalize these skills into the child's everyday life. Parents learned how to recognize and respect their child as an individual. A teacher described the acceptance and integration that occurred based on the education and support provided through the *Escuela de Familias* [School of Parents].

And one of the greatest things that the School of Parents has achieved is changing, not changing their mentality but changing the opinion that they have with respect to their children and that helps the parents to initiate things that previously they didn't dare do. The children benefit a lot because they are more integrated into their homes and are considered more as, as people and they also on the other hand would be showing their parents that they know how to do and are able to do many things and are useful.

The education provided to the parents and families improved the child's integration into his/her family. Parents were able to use materials typically found in the home. Activities that did not require special materials were very important since many of the families had limited financial resources.

The parents and the families were the most constant sources of education and support for the student and their ability to perform these roles was a critical. While the involvement of the parents was the key for success, some teachers were surprised by the parents' level of commitment to participation.

Well, the thing that has really surprised me about the work that is carried out here is the work with the parents. I've never seen in any other institution so much participation from the parents and really the tremendous results that it gives when the parents become so involved in the work that we do here.

The teacher and educational administrators continually evaluated the methods used to teach the parents in the same way they analyzed and evaluated the procedures used to teach the student.

The other thing is doing adequate training for the parents and have them not only work with the tasks that we give them but also that they feel that it is their responsibility to educate their children throughout their lives.

The teachers and educational administrators also received continual inservice training aimed at increasing their professional skills. Training was provided by unpaid outside consultants (often professors of Special Education or related fields from universities in the United States) and from the Center's staff. The training was based on principals of behavioral analysis. Teachers and educational administrators were taught to analyze and evaluate their teaching procedures, as well as challenging behavior exhibited by the students. The teachers received inservice training from one to three times per week. The Center stressed the importance of current best practice procedures among its teachers and staff members. The continual training of the staff was viewed as a way to attract, retain and reinforce the teachers, since salary increases were often difficult to secure.

Another other thing that is important for the success is that we have continuous training of the staff. We have a minimal of three to four consultants coming [this year], our principle consultant and teacher has been the Research Director who is doing this all these years. I think that if we cannot pay the staff all that they deserve, giving them healthy salaries not a luxury salary, we want to pay them with training and that is something that we do for free.

The education provided to the staff was seen by several teachers as key to the program success. *The activities which are effective are the continuous training and the classes that the specialists receive to be able to affect the work with the children.* The continuous training provided the teachers with effective methods to instruct the students and provided them with opportunities to improve the quality of their work. The training provided to the educational staff impacted the quality of the educational program and the development of relationships, which were important to the Center as a community. *The other thing that is good is the constant preparation of the personnel, which is what I believe to be a central point, that we are continuously educating ourselves, thinking and trying to better....*

The attributes of the teachers impacted the educational success of the students and the satisfaction of the parents and the staff. The attributes of the teachers at the Ann Sullivan Center created a school climate that was warm and inviting, and conducive to student and parent learning. The teachers were encouraged by the educational administrators to maintain a positive attitude. The educational administrators modeled a positive attitude through their interactions with the students, parents, and teachers. Teacher attributes were an elusive quality to measure. One quality, a loving caring attitude, consistently impacted the educational program provided at the Center. Two parents found the teachers love for the children to be a quality they appreciated and respected.

What the teachers have done to help them progress and through this someone can see how to do it better with the children. I AM VERY HAPPY...and am grateful to...and to all of the family at Ann Sullivan because they have a lot of love for the children.

I am very happy because the Center does so much, in other words, they give everything that they have; their trust, lives...above all their love that the Center gives to the children.

The caring attitude shown by the staff at the Center significantly contributed to the Center's characteristic of being *a family*. It has also been demonstrated that *caring* attitudes can significantly increase student learning (Noddings, 1984; Noddings, 1992). Teachers were encouraged to constantly question and analyze the program, the curriculum and the school environments. Such questioning contributed to the success of the educational program since the teachers were constantly renewing their skills. Their minds were open to new ideas and they were accustomed to challenging and changing their procedures when they are not successful.

Center staff members were extraordinarily enthusiastic and appeared to have boundless energy. Job satisfaction was high and worked in conjunction with staff enthusiasm. One teacher describes this enthusiasm and teamwork.

The preparation that we have here in the Center is a very important activity; the other one is sharing, sharing knowledge between ourselves. We are not selfish in what each of us knows...in certain moments we work as a team where each one has something that, knows that, the enthusiasm that we put into teaching and really be convinced that any kind of person can develop himself, it doesn't matter what the problem is but they can reach a level of development.

The desire to consistently perform at one's top level of ability was critical to the success of the program. One teacher described this, *well, I think I am trying to do my best when I am working with parents and their children. I always do my best.*

Conclusion

The purpose of the study was to describe and explain the educational program at the Ann Sullivan Center of Lima, Peru'. The research was guided by questions regarding (a) parent involvement in a school program, (b) best practice methods for dealing with challenging behaviors, (c) the impact of staff development on educational programming, (d) quality program indicators, and (e) the impact of teacher qualities.

The major question asked in this study was: what are the contributing factors at the Center that are responsible for their quality educational program for individuals with significant disabilities? The key factors contributing to the success of the program were the integration of parents, staff and educators within the school community, program philosophy, continual training of teachers and families and teacher attributes.

Decision-making was shared regarding the development of instructional programs to be taught at the Center and in the home. Literature in the United States stresses that collaborative teams are considered stronger if they formally meet on a regular basis, construct methods for ensuring group and individual accountability, and formalize a system for sharing expertise across group members (Cook & Friend, 1991; Johnson & Johnson, 1994; Rainforth & York-Barr, 1997; Thousand & Villa, 1992; Thousand, Villa, & Nevin, 2002). Perhaps, the initiation of a formal system of collaborative teams would improve the educational services received by the students within the Center. It might, however, change the natural, less formal system of collaboration.

Parent participation in their child's education also improved the child's integration into the family. This home training was instrumental in increasing the inclusion of the child into the activities and routines of the family.

The active role that parents took as members of the school team was important to their satisfaction with the educational program. They were contributing members of the team with their ideas and opinions being considered first with selecting objectives for their child.

The parents had a good working relationship with the teachers and educational administrators at the Center. They were able to discuss with them their child's educational program and more

global family issues that impacted the child at home. The Center was the place where parents got encouragement and support from the staff, as well as other parents, significantly contributing to their level of satisfaction.

Improved parent/child relationships were, however, the most significant marker for parental satisfaction. Parents learned to value their child as a person and to recognize his/her unique contribution to the family. Several parents expressed that their relationship with their child improved dramatically after they and their child began receiving Center services.

The positive behavioral support model frequently followed in the United States as an effective process for the reduction or elimination of challenging behaviors (Horner et al., 1990; Horner, O'Neill & Flannery, 1993; Koegel, Koegel, & Dunlap, 1996) provided a framework for the behavioral interventions at the Center. This comprehensive methodology is made up of the following components: an emphasis on antecedent manipulations; building environments with effective consequences; minimizing the use of punishers; distinguishing emergency procedures from proactive programming; and social validation and the role of dignity in behavioral support (Horner et al., 1990; Koegel, Koegel, & Dunlap, 1996).

The program at the Center incorporated several of these components. Lifestyle enhancement was found in the principle of *integration into life*. The Center emphasized developing relationships within the family and the community. Students were provided opportunities and instruction in choice-making. Their quality of life improved as they were accepted as contributing and valued members of their families and community.

A formal process of functional assessment was only implemented in situations when the other supports provided by the Center did not succeed in reducing the occurrences of challenging behavior. The *friend approach* by the Center stressed the communicative intent of challenging behavior. Recognition that challenging behavior was an attempt at communication reduced the need for the students to exhibit it.

The procedures used at the Center represented a multi-component support package. Challenging behaviors were addressed through a variety of instructional programs, parent education, communication skills instruction, nonaversive programming, respecting dignity and not using emergency management procedures as methods for effecting behavior change. An assumption at the Center was that a good, well-implemented curriculum would eliminate all or most challenging behaviors.

The educational staff at the Center received between one and three, two-hour inservices per week with sessions provided by in-house and outside consultants. Each staff member expressed the view that they possessed a particular skill set that was exceptional and unique (e.g., early childhood education, teaching daily living skills, and vocational instruction).

The educational staff at the Ann Sullivan Center was always eager to learn new things and quickly applied the new knowledge. They often sought out expert opinion and integrated suggestions into their procedures. For example, a class was going to the bakery to buy bread for a morning snack. At first, the teachers were providing too many cues to the students and ordered the bread for the individual students. It was suggested that the teacher expand the students' communication boards to include the items they wanted from the bakery. A few days later, the teacher had implemented all of the suggestions for increasing their independence.

The teachers genuinely cared for the students, which was clearly apparent in their interactions. They were concerned when a student exhibited challenging behaviors. They spent time analyzing the behavior in order to find a better way for the students to express their feelings. They recognized the students as valuable and contributing individuals and treated them with respect and dignity. This caring attitude provided a warm and welcoming atmosphere at the Center, a place where students, parents and other professionals were happy to come.

The Center is dedicated to integrating the students into life. Parents received enough training and support and provided their child with all the opportunities afforded a typical family member. The

children were part of the activities of the family and became active and contributing members of their families. Through the instructional programs at the Center and the activities of the parents, the students were provided with opportunities to participate in a variety of activities within the community. Students at the Center had Individualized Education Plans (IEP) that were updated annually and reported quarterly. While there were no formal IEP meetings, the goals and objectives were reviewed weekly by the educational administrators and modified by the staff if needed. A variety of supports were provided to parents to assist them in meeting the needs of their child with disabilities within the home setting. The functional and natural curriculum adopted by the Center emphasized autonomy and individual responsibility in conjunction with opportunities for choices.

The students were provided with opportunities to demonstrate their skills and independence. Students were encouraged to travel on public buses or in taxis by themselves to get to the Center. There was a level of independence encouraged that would not be possible in the United States due to issues of liability. Student progress reports were collected and reviewed weekly. Teachers reviewed students' IEPs and planned for the upcoming week. The teachers were skilled in data collection and used data to make decisions regarding student programs. A weekly review of student data allowed the teachers to continuously update and evaluate their procedures. The parents received report cards four times per year with grades on their progress, as well as the progress of their child.

The Ann Sullivan Center continues to provide quality educational programming to individuals with severe disabilities, autism and challenging behaviors. The Center has embedded the main components of quality services, as defined in the United States, into its philosophy and program. The one area the Center has not totally accomplished was integration into school educational programs. In the United States, this indicator of quality is accepted by most researchers and professionals in the field of special education. Nonetheless, the United States school system must make much more progress before it can be said with confidence that all education provided to students with disabilities occurs in inclusive settings. The Ann Sullivan Center, therefore, is close to, or equal to, many typical school integration programs in the United States. In areas of community and family integration, or *integration into life* however, the Center frequently surpassed what is offered in U. S. schools. Educational programs in the United States are primarily concerned with persons with disabilities while they remain in school. They do not provide the continuum of services from birth through adulthood that was offered at the Center. The approach used at the Center to create an extended family of support is not currently in line with the nuclear family values in the United States. Perhaps as increasing numbers of new immigrants children become part of the school system an approach such as *La Familia Ann Sullivan* can be used to support children and families in the American system. Currently observed struggles to support children with disabilities from immigrant families may be lessened when the American educational system looks beyond the borders of the United States to successful educational programs for children with disabilities that are found abroad.

The quality of the Ann Sullivan Center may be attributed to two factors: the visions held by the director and its affiliation with a major research University. There was a strong commitment to providing the students and their families with the best educational services possible, as well as providing the educational staff with continual state-of-the art pedagogy.

While the Center was a private educational program in a country with no educational laws to ensure the provision of education to children with disabilities, in reality this lack of central governmental structure may have assisted the Center in providing quality programming. Lack of external controls and monitoring allowed a great deal of flexibility in programming, curriculum, staffing and day-to-day operations. For the students at the Ann Sullivan Center, whose administration was dedicated to quality, this appeared to be a positive factor.

Recommendations for Future Research

The spirit of the Ann Sullivan Center remains strong. Researchers and consultants frequently return to the Center for further study. It would be interesting to continue to explore how the

philosophy of *La Familia Ann Sullivan* is fused with best practice pedagogy to produce an enthusiastic commitment to excellence. An additional area of study is the potential of parental support and training and how this could be incorporated into the American educational system.

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