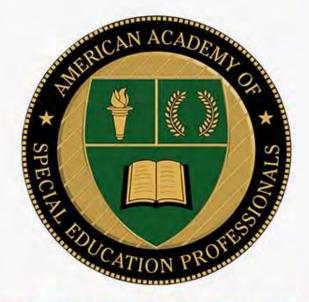
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## The Implications of a System-Wide Positive Behavioral Intervention Initiative: From Design to Successful Implementation

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#### Abstract

Residential schools for students with emotional and behavioral disorders have been steadily evolving since the beginning of the 20<sup>th</sup> Century. Traditional behavioral approaches involving physical restraint and confinement have been replaced with more humanistic interventions involving positive reinforcement. This article traces this transformative journey from the punitive techniques employed in the 1950s and 1960s through to the present and the use of prosocial interventions recommended in current best practices such as PBIS. The authors share the success story of one such residential school as it embraced a sea change in behavior management philosophy, moving from a more traditional behaviorist model to a positive behavior intervention and support system (PBIS) dubbed: "WISE."

## The Implications of a System-Wide Positive Behavioral Intervention Initiative: From Design to Successful Implementation

#### A Brief History of Residential Treatment Systems circa 1925-Present

Residential educational placements for at-risk youth have a long history, initially advocated in the 1920s by Aichhorn, Freud, and other psychoanalysts, as a way of reaching and rehabilitating court-involved youth (Aichhorn, 1925). In the early 20<sup>th</sup> century, the task of the psychoanalyst and other therapeutic caregivers was to identify the potential for delinquent behavior in children and youth and, through reeducation, to "weaken the latent tendency to delinquency" (p. 41). Early in the twentieth century, "training schools" were placements to which court-involved youth were uniformly assigned. Today, many of these youth would likely be classified as having emotional/behavioral disorders" under IDEA (2004), and some might be most effectively educated in a "residential treatment facility." which stands as the modern equivalent of the "training schools" of the 1920s and 1930s.

Unfortunately, children housed in early residential treatment facilities received little or no behavioral therapy, as they were seen as a burden to society and/or individuals that would likely become chronic lawbreakers. So these children would be lifelong wards of the state for which therapeutic interventions were thought to be fruitless and futile (Aichhorn, 1925). Very little

literature of the early 1900s supported the use of positive behavioral supports or interventions to treat the needs of youth housed in residential facilities.

By the late 1900s, researchers and practitioners began to provide information to caretakers regarding alternative treatments for youth housed in residential facilities (Ainsworth & Fulcher, 1981; Whittaker, 1981). It was during this time that "milieu or group therapy" for children and youth, was introduced to the literature as an effective approach for the treatment of youth delinquency for those in residential facilities. Ainsworth and Fulcher's historical overview provided evidence that the notion of "group care" in residential treatment was regarded as an important sub-system, as an "occupational focus" and worthy "field of study" (p. 2-3) for future research.

#### The Efficacy of Residential Treatment Facilities

Residential treatment facilities of the latter half of the twentieth century have been criticized for being the most costly care alternative for at-risk youth. However, there is evidence that these facilities present a more viable and appropriate alternative for many students as compared with the educational status quo: the inclusive classroom (Sunseri, 2005).

Current educational accountability requirements, according to Owens (as cited in Kott, 2010), will likely compel residential treatment facilities to measure and report program effectiveness (p. 34). At a time when school budgets are being cut and school districts look for the most effective yet least expensive alternative, placement decisions may be made with greater attention to the school budget than to the needs of the child. Therefore, in this climate of fiscal responsibility, it is incumbent on the residential facility to provide compelling evidence about when residential placements are the best choice for students, based on the results of their own data collection systems. Unfortunately, residential treatment programs historically have been immune from data collection and therefore are lacking in evidence-based research. Many residential treatment programs simply suffer from a lack of a consistent definition of the population served as well as well-defined treatment plans with data collection protocols. The reluctance of residential programs to define their population in part stems from the stigma associated with training schools' procedures, the prevailing predilection for community-based placements, and their association with 19th century reform movements, which unilaterally removed identified delinquent children from their homes in the name of social progress. Notwithstanding misguided social reforms and residential treatment procedures, the literature clearly shows that residential treatment school placements are an important option that can, in the long term, prevent costly repetitive lower-level placements (Sunseri, 2005).

Indeed, in an effort to remedy the lack of empirical evidence supporting the placement of students in residential treatment schools, researchers have begun to cull together the research that does exist and call for more investigators to examine current practices (Jolivette & Nelson, 2010; Lehr, 2004; Simonsen & Sugai, 2013; Van Acker, 2007). Kott (2010) observes that residential treatment facilities, in addition to empirical research, can and should conduct case studies at the facility level that may contribute substantively to our knowledge of residential treatment efficacy. Finally, Kott (2010) purports that promoting a research perspective at the facility level would create the opportunity to collect data that could be used to consistently assess the effectiveness of the program and make timely evidence-based decisions for continual

improvement (p.21). The use of positive behavior interventions and supports has been shown to be a viable solution to address these issues.

A literature review, conducted by Safran and Oswald, (2003) examined the use of school-based positive behavior supports (PBS), in planning intervention priorities. The efficacy research focused on the three types of PBS; namely, school wide (universal), specific setting, and individual student levels. Overall, the findings validated the efficacy of implementing PBS in all three settings. Safran and Oswald (2003) also noted that some consistently reported characteristics of PBS include: (a) person centered planning, (b) collaborative teaming, (c) the use of functional behavior assessment, (d) hypothesis development, (e) multi-component planning, (f) evaluation of program efficacy, and (g) ultimate systems change.

By way of contrast, a survey of practitioners, conducted by Miramontes, Marchant, Allen Heath, and Fischer (2011) revealed that whereas most respondents agreed that PBIS initiatives fostered positive improvement in school climate, many did not find the application of PBIS methods to be practical. Nevertheless the authors conceded that statistically significant correlations were found between the fidelity of program implementation and increased social validity, suggesting that the more consistently a program was implemented, relative to its theoretical framework, the more viable it was perceived by its stakeholders. This finding underscores the need for research that examines the social validity of PBIS and its consequential impact on program implementation (Miramontes, Marchant, Allen Heath, & Fischer, 2011).

#### The Emergence of PBIS in Self-Contained Settings

Positive Behavior Interventions and Supports have been described as a "systems approach for establishing the social culture and individualized behavior supports needed for a school to be a safe and effective learning environment for all students" (Sugai & Horner, 2009). This specialized approach to behavior management has been studied in a wide variety of settings with little empirical evidence of its efficacy in self-contained and/or alternative educational settings (Kalke, Glanton, & Cristalli, 2007; Nelson, Sprague, Jolivette, Smith, & Tobin, 2009; Scott, Liaupsin, Nelson, Jolivette, Christie, & Riney 2002; Nelson, Sprague, Jolivette, Smith, & Tobin, 2009; Swain-Bradway, Swoszowski, Boden, & Sprague, 2013). Benner, Beaudoin, Chen, Davis, and Ralston (2010) examined the effects of PBIS on the behavior of students identified with emotional/behavioral disorders in self-contained settings. One focus of the investigation was to measure the degree to which teacher fidelity of PBIS implementation influenced pro-social behavioral development over the course of a school year. The results of the study and several others (e.g., Medley et al., 2008; Muscott et al., 2008; Warren et al., 2006) showed significant reductions in both externalizing and internalizing problem behaviors for students. Furthermore, teacher fidelity to PBIS was identified as a critical factor in the development of pro-social behaviors in these students.

Likewise, research conducted by Simonson, Jeffery-Pearsall, Sugai, and McCurdy (2011) suggests that implementing an Alternative Setting School-Wide Positive Behavior Support program (A-SWPBS) is both viable and effective for self-contained settings. Once again the issue of program fidelity emerged and the researchers asserted that practitioners in these settings, all staff and personnel, must receive and participate in systematic training from qualified, vetted district, regional, or state-level trainers. Only in this way can programs ensure the establishment

of meaningful behavioral expectations, make evidence-based decisions about programs, implement viable practices to support students, and invest in systems to support long-term A-SWPBS program application with fidelity (Nelson, et al., 2009; Simonsen, Jeffrey-Pearsall, Sugai, & McCurdy, 2011).

Additionally, Kalke et al. (2010) noted it is essential that a top down approach be utilized; with the administration of the residential treatment facility modeling the tenets of the PBIS program tailored to the specific behavioral needs of the institution, and providing substantive and ongoing support to staff and students to ensure fidelity of implementation. Furthermore, conclusions suggest that the positive relationship between the residential treatment facility and the home is critical to ensure the application of consistent behavioral expectations between the two settings (Lewis, 2009). This bi-directional communication between home and school helps to reinforce the positive behavioral development that is vital for student success.

More recently, Johnson et al. (2013) found school-wide PBIS to be effective in the reduction of security referrals and school behavior incidents in a secure juvenile facility after one year of implementation. The researchers also noted that school attendance rose and the number of students who received career and technical certification was higher with SW-PBIS than without.

Finally, to support the efficacy of PBIS initiatives as applied to alternate settings, such as residential treatment facilities, Sugai and Horner (2006) posit the need for further investigation. The more studies conducted that describe successful PBIS interventions with a broad range of children and adolescents, the greater the evidence over time that PBIS may be implemented as a successful approach to use in these special settings.

#### **PBIS Implementation in a Residential Treatment School**

The Apex School, a residential and day treatment school located in a suburban hamlet in the northeast region of the U.S., was operationalized in the early 1970s. The school followed the popular treatment approach of the decade, which was a form of "milieu therapy" providing the student residents with a complete array of services: psychiatry and clinical therapy, pediatric care, nutritional guidance, speech-language and occupational therapies, child care support and supervision, as well as academic instruction in a traditional school setting.

Historically, the school and on-site residences employed a quasi-Skinnerian approach to behavior management that included a point system with contingent secondary reinforcers such as extended on and off-grounds privileges, later curfews, greater canteen and "deli" access, and more frequent home visits. In contrast to these positive reinforcers, the staff employed an escalating scale of punishments for misconduct and rule violations that ranged from minor infractions, such as being late to class or missing curfew, to physical aggression, willful destruction of property, and fighting. The less serious rule violations incurred nothing more than a loss of points, typically 1-3 out of a possible total of 9 for the school day. These points were tallied daily and the total point value obtained by the student was used to determine cottage levels; associated with the awarding of lesser or greater privileges to the student. In a similar way, major infractions such as physical aggression towards self or others might involve a brief "time out" in a designated safe space or, in the case of a more serious physical altercation, removal to and confinement in the "quiet room." The transfer process from the site of the altercation to the quiet

room might involve as many as four to six staff members. Two individuals were hired as crisis intervention staff whose sole job it was to escort students in crisis to and from the quiet room and provide on-site supervision of students detained therein.

To be sure, every infraction committed during the school day or afterwards in the residences incurred the requisite loss of points, proportionate to the severity of the (misbehavior) rule violation. A major repercussion, and deterrent, for rule violations was the loss of after-school privileges, which might include, as deemed appropriate and proportionate to the offense, reduction in cottage level resulting in a loss of off-ground privileges and an earlier curfew, or, if more serious or chronic, cottage restriction, which essentially confined the student to the cottage from the end of the school day to an early curfew, with only a break or two to smoke or go to the dining hall for supper. Historically, the points system worked best with residential students as the staff could assign, monitor and administer privileges for the student's precious after-school time.

During the subsequent three decades, the school honed and promoted a "family oriented" childcentered approach and strategically altered the admission profile to focus on students whose primary diagnosis was within the mood or anxiety categories, thus still falling within the Individuals with Disability in Education Act (IDEA) federal category of emotional disturbance (ED), but screening out the preponderance of aggressive students. However, the sea change in the institution's behavioral management system really began to take shape when a New York State Education (NYSED) Board of Cooperative Education Schools (BOCES) Positive Behavioral Intervention and Supports (PBIS) "coach" approached the administration of the school with an offer to help institute and provide long-term training and support for a PBIS school-wide system. The coach was careful to explain that the program required a commitment from all the institutions' stakeholders, not only to assent to its adoption, but also to participate in the longitudinal planning and training essential to the fidelity of implementation. After a series of surveys and focus groups, a PBIS Committee was formed with constituents representing every aspect of the facility, to include, child-care workers, teachers, related service providers, members of the administration, as well as secretarial, kitchen, and ancillary staff members. This newly formed "steering committee," conducted more surveys, organized several all-day PBIS professional development workshops, in collaboration with the BOCES PBIS coach, and eventually initiated a pilot study to determine the efficacy of a PBIS system in the school and residence facility.

Next, with the guidance of the BOCES PBIS coach, the PBIS steering committee identified, through a survey of its caregiver constituents, key pro-social behavioral criteria that could be used to assess the students and provide appropriate incentives, as warranted. The four behaviors identified as most characteristic of pro-social individuals were: (a) accountability, (b) engagement, (c) safety, and (d) respect. At the urging of the BOCES PBIS coach, the staff was invited to create an acronym that would include these four behavioral criteria that would make them easily remembered. After several meetings and much iteration of related terms, the faculty and staff settled on: "W.I.S.E." (Where you should be; Involved; Safe; Ever Respectful), which captured all four of the agreed upon behavioral criteria. Staff were encouraged to adapt the criteria for their specific environmental contexts; for example, classroom teachers were invited to individualize the WISE criteria to be relevant to their subjects (e.g., one of the science teachers interpreted the W as "in your seat," the I as "engaged in lab work and in-class assignments," the

**S** as "wearing safety glasses and gloves and following lab safety procedures as directed," and **E** as "respectful towards peers, teachers, and self by always being courteous and polite").

#### The Process of Program Review

The PBIS steering committee, now known as the "WISE Committee," conducted an initial pilot study involving four randomly selected teachers and 24 students. The duration of this pilot study was one school quarter, or ten weeks. A point system was developed for the school day as an addition to the nine-point residence point program already in place as previously noted. The participants involved in the pilot investigation were provided with point sheets consisting of four points per period encompassing the 12 periods in the school day, which included four homeroom periods, lunch, mentoring, and six subject periods for a possible 48 points per academic day. A point conversion was created for resident students only, to enable the residence staff to continue to use the traditional nine-point system in the residences, for the duration of the pilot investigation. As incentive, any student who was able to accrue the maximum academic points, 48, for four weeks was treated to an extended lunch period in a separate, desirable location. For this lunch reward, the student's favorite pizza or Chinese food was ordered from a local restaurant. In addition, the names of those students attaining the 48 points for the month was posted conspicuously in each classroom and an announcement was made extolling the accomplishment.

After the successful completion of the pilot program, the school decided to implement the PBIS WISE program throughout the entire school. Apex's self-contained setting consists of students in grades nine through 12 who are entitled to special education services under the federal classification of ED, although most students also arrive at the school with multiple mental health diagnoses including Attention Deficit Hyperactivity Disorder (ADHD), Bipolar Disorder, Depressive Disorder and Anxiety Disorder to name a few. The school population is comprised of 85% residential students who participate in a 24-hour program that provides therapy, education, and social supports. The remainder of the student population, approximately 15%, consists of day students that attend academic classes and receive therapeutic services at the school. Upon roll out of the PBIS WISE program, data was collected for 72 consecutive school days during the spring of the 2013-2014 academic year. For the roll out of the WISE program there were 160 students enrolled, but due to incomplete data and student attrition, only 99 students, 59 males and 40 females are reported on for the purposes of this review. Of those 99 students, 71 of the students were enrolled in the residential program and 28 of the students were day students. As noted in the PBIS literature, teacher fidelity plays a large and statistically significant role in improving the behavior of students with ED, and as such, all individuals who were part of the day school program and residential facility were trained on the implementation and data recording procedure of the PBIS WISE program.

Once again, at the start of the program's roll out, the participants were provided with point sheets consisting of four points per period encompassing the 12 periods in the school day; including four homeroom periods, lunch, mentoring, and six academic subject periods for a possible 48 points per day. The point conversion remained intact for resident students, to enable the residence staff to continue to use the traditional point system in the cottages, for the initial school-wide implementation process.

Results from the first 72 days of the program found that student success followed a similar pattern to that of PBIS programs in general education settings; the majority of the students accept the program from the onset, a smaller group needs additional encouragement to participate fully, and the smallest group need intensive support to buy in. In this particular review, 63% (62 students) of the students earned enough points to provide them with access to full privileges (extended curfew, off grounds privileges), 36% (36 students) of the students earned limited privileges (time off of curfew, on grounds privileges) and were given additional supportive encouragement to work toward full, and 1% (1 student) of the students was on limited privileges (9 pm in Cottage Curfew) and individual intensive support was provided (see Table 1 below).

Table 1. Total Number of Privileges Earned.

Point Range	Privilege Earned	Males	Females	Percentage
43-48	Full Privileges Extended curfew, permission to go off grounds	34	28	62.6%
33-42	Full privileges, curfew = ½ hour early, on grounds	19	8	27.3%
23-32	Limited privileges, curfew = 1 hour early, on grounds	5	4	9.1%
22 – below	Curfew = on time, in cottage access only	1	0	1%
	Total	59	40	100%

Therefore the results of this examination proved to be analogous to the hierarchy structure of PBIS as it is implemented in a general education setting; the bulk of students respond appropriately to the universal structure of the program, a smaller subset of students receive less privileges due to their lack of compliance with the general program and a minimal amount of students receive intensive individualized support and structured privileges due to noncompliance with the program.

Consistent with the literature (Sunseri, 2005), this program review provides support for the tenet that PBIS programs instituted in self-contained settings are an effective option as a component of a continuum of care and may prevent costly repetitive lower-level placements for students. Given a structured program with desired incentives and consistent application, the majority of the students were successful as determined by this program review. Similar to the findings of Kalke, Glanton, and Cristalli's (2010) investigation, as a direct result of the implementation of the PBIS WISE program at the Apex School, students have obtained consistent evidence of their own success. Furthermore, the direct instruction provided to students about the PBIS WISE program enabled students to seek support more often from teachers, related service providers, and child-

care staff prior to a behavioral crisis. Consistent with the observations of Kalke et al. (2007), Muijs et al. (2004), and Sterbinsky et al. (2006), perhaps the greatest contribution of the PBIS program implemented at the Apex School is the affirming, pro-social climate created by the school and residence staff as well as the administration and related service providers, recursively reflected in the positive behavioral responses of the students.

#### Implementing Improvement in the Apex PBIS "WISE" Program

The benefit of program review and reflection is that program enhancement is a natural consequence. Through the course of the analysis of the first 72 days of data, challenges to the fidelity of the program was noted, as well as ways that the program could be improved. Some of the specific challenges noted included (1) the paper and pencil administration of the point system proved unwieldy and contributed to lost data, (2) the recognition that there is a small range of variation between the total points obtained, teachers want to be generous to students in order to positively shape behavior, (3) inter-rater reliability of point assignment by faculty and staff was problematic, some faculty and staff were more lenient than others (4) continual movement of students in and out of the program due to reassignment to home districts, further contributing to lost data, and (5) the lack of meaningful incentives that provided both short-term and long-term goals. The incentives that were in place benefitted the residential students more than the day students; there was a lack of ability to incentivize the day students as most of the incentives related to after school or cottage privileges.

With these challenges in mind, changes to the "WISE" program have been implemented. First, the program is now fully computerized so that faculty and staff can input points for each of the designated periods into a computer tracking system. Full transition to the SSIS Online System was instituted in fall 2014. Furthermore, there was an overhaul of the 48-point system to integrate the cottage residence points into the program. Residence points have become an extension of school points and students now earn a total of 100 points per day. Also, as many researchers had noted, fidelity of application of the program was important (Benner, Beaudoin, Chen, Davis, & Ralston, 2010), so ongoing professional development has been scheduled to monitor, and re-train faculty and staff on the administration of points. As part of the fidelity training, more rigorous criteria were developed for the assignment of points and how students earn points. Lastly, the inconsistent benefits to day and residential students were noted and the development of increased incentives for day students is being addressed.

Future improvements being considered are the incorporation of students and student' input. Specifically discussed was the implementation of a "Student Ambassador" program to facilitate student understanding and incorporation into the program; this would benefit high levels of student movement and transition. Also, there is interest in a Menu of Incentives. Using preference surveys with students would provide students with the ability to choose their own incentives from a list of possibilities; students with internalizing and externalizing types of behaviors may prefer different incentives thereby increasing reinforcement level.

Accountability reforms that permeate all educational settings and practices have the same potential to improve services in self-contained settings as in general education settings. PBIS is a system wide program designed to address teaching and supporting positive behaviors with a scaffolded level of support to students. The PBIS system provides a toolbox of positive,

proactive, and preventative strategies to utilize with students. With data-analysis and program effectiveness documentation, student achievement outcomes are documented and the validity and appropriateness of serving at-risk students in residential treatment schools can be substantiated. However, it does require a philosophical shift from a punishment mentally that historically has permeated residential treatment schools to a direct instruction and reinforcement model.

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#### Creating an Environment for Pre-Service Teachers to Work with Learners with Special Needs

#### Jeanne Hager Burth, Ed.D. University of Pittsburgh at Greensburg

#### Abstract

In this study, pre-service teachers were afforded the opportunity to participate in two on-campus activities for students with low-incidence disabilities. The project explores the attitudes and perceptions of a group of pre-service teachers before and after participating in two educational experiences with students with low-incidence special needs. An informal educational environment was created on campus to give the pre-service teachers a familiar and casual experience when interacting with learners with cognitive deficits, autism spectrum disorder, physical exceptionalities, and emotional and behavioral disabilities. This study seeks to answer the following questions: (1) Can pre-service teachers' attitudes towards teaching students with disabilities change by providing them with non-academic experiences with persons who have disabilities? (2) Does a familiar setting impact the pre-service teacher's knowledge of teaching persons with exceptionalities when participating in a field experience with persons with low-incidence disabilities?

#### Creating an Environment for Pre-service Teachers to Work with Learners with Special Needs

#### Introduction

In addition to coursework and theory, learning to teach consists of spending time in schools observing and interrelating to teachers and students (Darling-Hammond et al. 2009). Wilson, Floden and Ferrini-Mundy (2002) summarized research on teacher preparation and found that "study after study shows that experienced and newly certified teachers see clinical experiences as a powerful component of teacher preparation. Whether the power of field experiences enhances the quality of teacher preparation, however, may depend on the particular experience" (p. 195). Teacher confidence levels in interaction with students with exceptionalities have been shown to increase with training, exposure to specific situations, knowledge, and utilization of interventions. However, there is little evidence that questions whether it is an easier transition for pre-service teachers to interact with the populations of students with special needs in a non-academic, informal experience rather than a formal classroom.

#### **Literature Review**

Including all students has new importance given the accountability mandates under No Child Left Behind (NCLB). This progression toward inclusive schools has been an impetus for change, not only in curriculum and instruction, but in the roles of programs preparing future teachers. Teacher training institutions have an obligation to ensure that all teacher educators, including pre-service teachers are well-prepared to meet the needs of all students under the guidelines of NCLB and Individuals with Disabilities Education Act (IDEA) requirements (Harvey, Yssel, Bauuserman, & Merbler, 2010).

Researchers Blanton, Pugach, and Lani (2011) state that policy-makers are promoting specific roles for higher education institutions in better preparing general education teachers for working with students with disabilities. According to Leko, Brownell, Sindelar, & Murphy (2012), elements of teacher preparation programs that are evolving as effective, and therefore should be considered, include the following: coursework that blends content knowledge with practical or pedagogical knowledge, pedagogies that promote active engagement, coursework aligned with high-quality field experiences, opportunities for special education and general education preservice teachers to collaborate, and extended opportunities to learn to teach.

The use of field experiences is considered to be an important mechanism for providing preservice teachers with opportunities to apply knowledge in real-world teaching situations. Field experiences that were carefully designed to facilitate pre-service teachers' implementation of strategies acquired during their coursework seemed to have the most promise for increasing sense of efficacy, perceptions of competence, planning abilities, knowledge, and classroom performance (Leko, et al., 2012).

Several researchers have examined the effect of providing pre-service teachers with different forms of contact with people with special needs in an educational context. For example, Brownlee and Carrington (2000) sought to answer the following question: Can pre-service teachers' attitudes towards disability change by providing them with sustained contact with a person who has a disability? In this study, students interacted with one teaching assistant with a physical disability over the period of one semester. The students reported that the interaction with the teaching assistant was generally a positive experience for them, provided them with first-hand knowledge of disabilities, and helped them to develop more knowledge about people with disabilities. Furthermore, they believed that more practical experiences with people with disabilities would have helped them in their future career as teachers.

Davis and Layton (2011) also found that pre-service teachers' insights tended to fall into one of two categories: beliefs that students with disabilities would be unable to meaningfully partake in grade level activities and beliefs that students would be unable to conform to behavioral expectations. Participating teachers were equally concerned with the possibility of encountering challenging student behaviors.

Other researchers sought to create a simulated inclusive environment to provide training for preservice teachers. Bishop and Jones (2002) led a small-scale research project using structured workshop activities with children with profound learning disabilities. The project searched the attitudes and perceptions of a group of pre-service teachers before and after participating in a series of eight workshops. Pre-service teachers planned short activities related to their specialization, and they were encouraged to do this in small groups. Children chose which activities they would like to do using symbols and pictures. The atmosphere in the workshop was very relaxed and supportive with plenty of pre-prepared "backup" activities so students could move the children on if they felt they needed. Pre-service teachers were interviewed before and after these workshops with the analysis indicating that pre-service teachers' attitudes were positively changed toward these children.

It is important to note, however, that mere interaction with students with disabilities may not be the sole factor associated with more promising attitudes. Furthermore, the way the contact is structured seems to have an impact on the change of attitudes. For example, pre-service teachers who participated in structured exchanges with people with disabilities in teacher education programs reported more encouraging attitudes (Brownlee & Carrington, 2000).

#### **Description of Study**

This study affords the pre-service teachers the opportunity to participate in two on-campus activities for students with low-incidence disabilities. This research seeks to explore the attitudes and perceptions of a group of pre-service teachers before and after participating in an informal, non-academic educational experience with students with low-incidence special needs. For both activities, a simulated educational environment is created on campus to give the pre-service teachers more familiar and casual experiences when interacting with learners with cognitive deficits, autism spectrum disorder, physical exceptionalities, and emotional and behavioral disabilities.

The projects provide community experiences for students with exceptionalities and afford the pre-service teachers the opportunity to interact with student populations with special needs. The two experiences bring learners from schools for students with exceptionalities to the university campus to participate in activities planned by the pre-service teachers. One activity, called College Day, offers a day on a college campus for students who may never gain the experience of a college education. The second is a dance for students with disabilities, where the college students interact with the students from the schools for autism and emotional and behavioral disorders. Research tells us that all children learn best in natural environments with typically developing peers (Allen & Cowdery, 2011; Brown, Hemmeter, & Pretti-Frontczak, 2005). This interaction with peers of the students with exceptionalities, not only benefits the child with special needs, but also helps individuals who are in teacher preparation programs learn about tolerance and acceptance of others.

Each of the two programs has unique distinctions. College Day provides a day in which the students from Clelian Heights School are invited to spend the day engaged in activities on the university campus. These students are cognitively challenged or have autism spectrum disorder, and therefore they may never fully experience college. College Day is a chance to provide a limited experience for these students with disabilities. The students in the Education Major plan and lead all activities for the day (five hours) under a specific theme, for example Wizard of Oz theme or Pittsburgh sports theme. Activities include hands-on experiences, such as making dioramas of a scene or using maps to identify locations in Pittsburgh. Clelian Heights' students also enjoy lunch in the campus dining facility, so that they may continue the experience of "going to college" for a day. Five informal learning episodes are planned in addition to the lunch experience. The day concludes with a completion ceremony which awards students with a certificate of completion or participation. This concluding activity includes a light snack. See Appendix A for a sample schedule for College Day.

In one particular semester, the theme for College Day was Disney. All learning activities were designed around the theme. For example, in the Computer Lab station, students used particular websites to find information about a Disney movie. One example was the use of the movie *Mulan* raising questions about the character's country of China. The Globe learning station included finding countries or settings, where several Disney movies took place. *Lion King* and *Mulan* were both set in the country of China, where *Aladdin* took place in Arabia and *The Jungle Book* in India. Music was shared from some of the Disney films, and students were able to participate in a sing-a-long. Other stations were used for creating dioramas and tie dying t-shirts with Mickey Mouse ears on the front. Each year the theme changes, and the pre-service teachers plan learning activities around the themes.

Book bags filled with school supplies, trinkets, and small toys are given to all the visiting students with special needs. Items to fill the bags are donated by faculty and staff from the campus. Lunches, certificates, and snacks for the visiting students are paid for by the campus chapter of the Student Pennsylvania State Education Association.

The second program, which meets the goals of providing real-life experiences for exceptional learners, while also providing experiences for pre-service teachers to interact with exceptional learners, is the Autism Dance. The Autism Dance, planned and provided by the students from the Teacher Education Department, is the second activity which offers students with exceptionalities an opportunity to participate in a real-life experience in a secure setting. Although the NHS Autism Schools enroll mostly learners with autism spectrum disorder, there are also students with cognitive deficits, physical disabilities, and emotional and behavioral disorders. The NHS Schools strive to continue to teach the students skills that can assist them to succeed in the community. "The students work on transition and social skills throughout the day, including socially interacting with each other either at the school or in the community," according to Cindy Coulson Head Teacher at the NHS School/Latrobe. The chance to go to a college campus for a social gives students an experience that is outside of their own school, affording the students the opportunity to use the social skills learned at the school.

The Teacher Education Department also provides the students the occasion to attend a fall dance. By interacting with college students who are close to their chronological ages, the students with exceptionalities are given the opportunity to participate in a social activity which mirrors that of their peers, but includes supports needed for the experience to be positive. The dance is held on the university campus, and, in addition to music and dancing, includes sensory activities (for calming or stimulating learners with autism spectrum disorder), Wii interactive games or other electronic games, table games, and snacks. The pre-service teachers plan and conduct the activities for the two-hour dance and interact with the students from the NHS Schools.

When planning and hosting the event, several considerations are always valued. The NHS School contacts the parents of the students with information regarding the details of the dance, such as times for drop off and pick up, as well as location. The NHS Schools also collect emergency contact information and releases for photos. A nurse from the school usually attends, as well as school staff members, who handle any misbehaviors or melt downs. Ideas for activities include dance music, karaoke, line dancing, table games, crafts, corn hole, video games, a photo booth, sensory activities, and snacks. The sensory activities are located in a smaller, adjacent

room to allow students a place to retreat from the music and flurry of activities in the larger room, if needed. Snacks include finger food with healthy choices and salty (sometimes preferred) choices, with few sweet selections. A theme is incorporated, as well. For example, suggested themes have included Decades of the 1900's, Around the World, Wizard of Oz, and the like. Some students dress according to the theme. One theme was Country Western and many attended wearing jeans, flannel shirts, and even some cowboy hats.

#### Methods

#### Instrumentation

Mixed methods were used to evaluate the success of the implementation of these two programs. The instrumentation used for the study included pre- and post-surveys, which were completed by the university students. The surveys questioned the participants regarding perceptions and basic knowledge of the exceptionalities and whether the pre-service teachers gained knowledge about working with students with special needs by participating in the programs. Results of the pre- and post- surveys were compared, however, the size of the study did not give enough information for significance, and further studies are needed. The researcher collected demographic information, including gender, age, race, educational program (Early Childhood or Secondary), and prior experiences of interacting with or teaching students with low-incidence disabilities. Further, the surveys questioned the perceptions of the pre-service teachers concerning teaching students with disabilities and their basic knowledge regarding disabilities. The survey was anonymous, so the results of the pre and post surveys were compared aggregately.

The researcher also collected information through the surveys by asking open-ended questions to allow university students to express their thoughts regarding anxieties and concerns about the experiences. The university students described fears and anxieties prior to the experiences of College Day and NHS Autism Dance, such as uncertainties of being able to connect with the students with disabilities, doubts regarding appropriate communication, and reservations about whether the planned activities would meet the needs of the lessons and the students. There were hesitations about how to interact appropriately in a social setting (NHS Dance), with one noting, "I would be more comfortable in a classroom setting where rewards and consequences are part of the routine." Others noted no uncertainties at all.

Qualitative information was also gathered by conducting interviews of small focus groups. This allowed the students to express thoughts and reactions from the programs in a more open-ended manner.

#### **Participants**

Eighteen college students, or 100% of the students enrolled in the Exceptional Learners in the Classroom II course, participated in the surveys. Fifteen were female, and twelve of the eighteen students studied Early Childhood Education while six were Secondary Education students. Fifteen of the pre-service teachers were traditional students ranging in age from 17 through 22. Two pre-service teachers were 23 – 25 years old, and one was 26 years old or older at the time of the survey. One sophomore, 14 juniors, and one senior university student participated in the survey. All were Caucasian.

Students reported varying previous experiences in working with students with low-incidence disabilities. Eight students reported that their experiences were drawn from babysitting or volunteer work, while three had family members with disabilities. Three others had familiarity with persons with disabilities from camp or church, and one worked with an individual in a daycare. One noted that he or she had a friend with a disability.

Ten of the pre-service teachers had no formal training in working with individuals with disabilities. Ten of the college students had eleven or more hours of experience observing or working with individuals with disabilities; six claimed six to ten hours; one noted only two hours of experience.

#### Results

The survey measured the pre-service teachers' confidence levels in teaching students with disabilities. Table 1 shows how the experiences from College Day and the NHS Autism Dance effected the pre-service teachers' perceptions of their preparedness to teach individuals with disabilities.

The table demonstrates that the pre-service teachers' perceptions changed after participation in the two events. For example, there was a positive change in confidence in the ability to teach students with special needs and the ability to recognize the characteristics of ASD (autism spectrum disorder). The table also exhibits that the pre-service teachers felt more confident in applying various instructional techniques, like using strategies to address the needs of pupils with Autism and using differentiated instruction. The survey showed an increase in confidence in handling misbehaviors. There was still uncertainty to meeting the needs of students with cognitive and physical disabilities.

Table 1

Pro-service Teachers' Percentions of Their Preparedness to Teach—Comparison of Refore and After Events

re-service Teachers' Perceptions of Their Preparedness to Teach		Strongly		Neither Str	
Questions	Agree	Agree		Disagree Di	
I am confident in my ability to teach students with special				8	8
needs.	0	3	12	3	0
Post Activities	1	11	4	2	0
2. I believe that all children can progress academically.	9	9	0	0	0
Post Activities	7	11	0	0	0
3. I become anxious when I learn that I will be teaching a pupil					
with Autism.	0	6	12	0	0
Post Activities	1	3	6	8	0
I have the ability recognize the characteristics of ASD.	0	9	9	0	0
Post Activities	2	12	4	0	0
5. I am aware of strategies to address the needs of pupils with ASD	. 3	9	3	3	0
Post Activities	3	12	2	1	0
6. I am able to put into practice strategies to develop social skills					
of pupils with Autism.	3	6	9	0	0
Post Activities	1	14	2	1	0
7. I have the ability to put into practice visual strategies to meet					
the needs of pupils with Autism.	5	0	15	0	0
Post Activities	2	12	2	2	0
3. I would become easily frustrated when teaching a pupil with AS	D. 0	0	12	6	0
Post Activities	1	2	5	8	2
9. I am able to differentiate the curriculum to meet the needs of					
pupils with cognitive deficits.	0	12	6	0	0
Post Activities	3	12	2	1	0
0. I have problems teaching a student with cognitive deficits.	0	0	15	3	0
Post Activities	0	4	7	7	0
11. I know how to adapt and apply curricula (e.g., content					
standards, social skills, study skills) to meet the needs of students.	0	15	3	0	0
Post Activities	1	11	5	1	0
2. I know how to address misbehaviors of students.	3	12	0	3	0
Post Activities	2	14	2	0	0
3. I know how to differentiate instruction to meet the needs of					
students with physical disabilities, including sensory deficits.	0	15	3	0	0
Post Activities	3	11	4	0	0

The following table (Table 2) represents the perceptions of the students after their experiences. Table 3 gives evidence of confidence in interacting with students with special needs in a formal classroom setting, as well as in an informal setting, and also in recognizing when a student with special needs is becoming frustrated. The table also demonstrates that students are assured in adapting an activity when a student with special needs is not grasping the information or concept.

Table 2					
Student Perceptions–After Events					
Mean Ranks:					
Questions	Generally Prepared	Somewhat Prepared	Not Sure	Somewhat Unprepared	<u>Greatly</u> Unprepared
Relating to students with special needs	11	7	0	0	0
2. Teaching academic skills to special needs Students	3	14	1	0	0
3. Interacting with students with special needs \in a formal classroom setting	9	8	0	1	0
4. Communicating with students with special Needs	16	2	0	0	0
5. Managing behavioral problems with students with special needs	2	13	2	0	0
6. Recognizing when a student with special needs is becoming frustrated	8	10	0	0	0
7. Adapting an activity when a student with special needs is not grasping the information or concept	8	8	1	1	1
8. Recognizing when to ask for help	12	3	3	0	0
9. Interacting with students with special needs in an informal non-academic setting	12	6	0	0	0

Open-ended responses on the survey assisted the researcher in understanding the experiences for the pre-service teachers. The findings are explained here. The setting on the college campus impacted the experience for the university students. Students commented that the comfort level was increased due to being in a familiar setting. Being in a place, in which they were accustomed, made the students more relaxed, one noting, "The setting impacted my experience because it was at a place where I was comfortable, and I was around my friends which helped as well."

There were differences in the two experiences, in that College Day was more academic and required that the pre-service teachers prepare and deliver a lesson, while the NHS Autism Dance

was more of a relaxed social activity. Students found that College Day gave them more opportunity to explain content and practice teaching. In contrast, the Autism Dance added to their experiences with interacting more informally. Students noted that both experiences contributed to their confidence in teaching and in their preparedness and security levels for interacting with persons with disabilities in future experiences. University students also noted that being able to talk to the students with disabilities and interact with them in small groups was helpful in adding to their comfort levels.

After participating in both events, pre-service teachers were invited to participate in one of two focus groups. Findings from the focus groups reinforced the discoveries of the surveys and allowed the researcher to collect additional qualitative data. In the focus groups, pre-service teachers discussed some of the anxieties that they had prior to the activities, such as interacting with the special needs students and adjusting the instructional levels for the academic activities. One student expressed concern about dealing with misbehavior, saying, "I was nervous thinking about students coming with behavioral issues and maybe throwing a chair out the window or something. If one of them gets frustrated with what is happening, we would need to make sure that we had a sensory room for him." Others questioned, "What are we supposed to do if there is an outburst?" and "What can we do as teachers if they are having trouble or are frustrated?" Another student asked, "What about those who are not vocal or able to tell you what they need? How are we to know or understand that something is happening before it goes too far?"

The following information was also learned from the focus groups. The small groups for College Day gave the university students time to interact on a more individual basis. Since the college students planned an academic activity that was repeated to small groups throughout the day, the range of the levels of abilities was evident. The lessons had to be adapted as some students with disabilities participated with ease, while others struggled. Also noted were the frustrations in dealing with students who were more introverted and did not readily participate in the lessons. One pre-service teacher stated, "We had to increase or decrease the performance levels of the activities without changing the activity." Another student said, "There are going to be varying degrees of ability in my future classroom, and I need to be able to adapt appropriately. This was good practice for teaching me how to reach all of my students. It's just going to require more effort on my part."

Focus group participants noted that the NHS Dance was more informal and interactions were non-academic. One student phrased it beautifully by saying, "It wasn't like a teacher-student relationship. It was like a student-student relationship."

Students gained a better understanding of the spectrum of autism spectrum disorder from both experiences. Some of the students from both visiting schools were identified as having ASD, however some students were more severe. For example, one student rocked back and forth; one repeated everything that was said to him; one listened to music with earphones in the corner of the room; one yelled and tried to leave the building. Other students participated fully in activities with little difficulty. Yet another student surprised all participants by performing songs from Disney movies. He had all the words and motions memorized. One student noted, "I learned that just because a student has autism, it doesn't mean that it is a severe case. I was able to talk to a

few of the students as if they were my friends. Others were not able to pick up on what I was saying. There are different levels and understanding those levels is definitely a key aspect."

Pre-service teachers confirmed that the setting of the college campus for the two activities helped to alleviate some of their concerns. "It definitely felt better. I felt more comfortable. I'm not territorial, but I am familiar with the setting and knowing where everything is, was a lot easier." Another stated, "It took a little of the pressure off." A third student said, "It was more comfortable than going to them and not knowing where things are. We were able to set up our things early and be prepared." Still another reiterated in saying, "It would be harder to adapt to their school especially not knowing what it looks like ahead of time. It was a lot easier for them to come here."

Lastly, several students talked about how their thinking changed after participating in the two activities. One understood, "I think the biggest thing that I gained from working with these kids is that I realized that they are people, too. They are not much different than us." Another specified, "I definitely feel that if I had a student with autism or another disability in my classroom, I could work with him and be comfortable with having him in my classroom someday."

#### Conclusion

Through these two ongoing programs (College Day and The NHS Autism Dance), pre-service teachers are given quality professional development opportunities on the college campus, and real-life experiences are provided to the students with exceptionalities. Through both the survey and the focus groups, pre-service teachers confirmed that the familiar setting of the college campus impacted their levels of confidence when participating in a field experience with persons with low-incidence disabilities.

Since the population which was studied was small, further studies are needed to glean more information to support the findings. However, this study has evidence to support that pre-service teachers' attitudes towards teaching students with disabilities can change by providing them with non-academic experiences with persons who have disabilities. By participating in both activities held on the college campus, pre-service teachers noted that they felt more confident in their abilities to teach students with special needs and in their abilities to recognize the characteristics of ASD. Further, pre-service teachers felt more confident in applying various instructional techniques, planning and using strategies to address the needs of pupils with autism, using visual strategies, handling misbehaviors, and applying differentiated levels of instruction. Students continued to lack confidence in meeting the needs of individuals with cognitive and physical disabilities.

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#### About the Author

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#### **Appendix A: Sample Schedule for College Day**

College Day Schedule

Theme: Disney

9:00 – 9:15 PLAN FOR EARLY ARRIVAL JUST IN CASE

SCENE IT

UPSTAIRS OPEN AREA

9:15 – 9:25 Arrival; Get tote bags and schedule; Get into groups with leaders – Upstairs Open Area

	Computer Lab	Library Tour (SCENE IT) (pick up group in Computer Lab)	T-Shirts (Patio or Kitchen/ Conference Room)	Globes (Downstairs Study Room)	Music (Room 238)	Dioramas (Upstairs Group Study Room)	
9:25 – 10:00	GROUP 1	GROUP 6	GROUP 5	GROUP 4	GROUP 3	GROUP 2	
10:00 – 10:35	GROUP 2	GROUP 1	GROUP 6	GROUP 5	GROUP 4	GROUP 3	
10:35 – 11:10	GROUP 3	GROUP 2	GROUP 1	GROUP 6	GROUP 5	GROUP 4	
11:10 - 12:10	:10 Lunch in the Hempfield Room						
12:10 - 12:45	GROUP 4	GROUP 3	GROUP 2	GROUP 1	GROUP 6	GROUP 5	
12:45 - 1:20	GROUP 5	GROUP 4	GROUP 3	GROUP 2	GROUP 1	GROUP 6	
1:20 -1:55	GROUP 6	GROUP 5	GROUP 4	GROUP 3	GROUP 2	GROUP 1	
1:55 – 2:15 Closing ceremony; cake (Upstairs Open Area)							

#### **Appendix B: Survey**

#### **Survey Introduction**

The beginning of the survey included the following introduction:

**Greetings Pre-service Teachers!!** 

You are invited to participate in a research study, which is being conducted to assess the impact of non-academic field experiences with special needs populations. In order to participate, you will be sent two surveys (pre and post) which will gather your perceptions regarding the field experiences with special needs population on our campus. You will also be invited to participate in a focus group in which you will be interviewed as part of a small group after your field experience in order to gather more open-ended responses.

Your responses will be kept anonymous or confidential; at no time will your name be revealed during reporting. Your participation is entirely voluntary. You can stop the survey at any time, and you do not have to respond to every item or question. Your academic status will not be affected by your refusal to participate or to withdraw from the study.

Your responses will be combined with the replies from students of several other participating courses. You will not be identified in any way. Your responses will be used to assist me as the researcher in gathering and categorizing pre-service teachers' perspectives relative to non-academic field experiences with special needs populations. Thank you for your participation in this research study.

#### **Survey Questions**

Gender of pre-service teacher

Age range of student

Program

Early Childhood Secondary

Race African American Asian Caucasian Hispanic Native Indian Other, please specify

Experience of interacting with a child with Low-incidence Disability

Previous experience of working with a child with a low-incidence disability

Day-care worker

Family/friend/neighbor with Autism

Babysitting or voluntary work

Camp Church

Peer Tutoring

Other, please specify

#### None

I have had previous interactions with a person with a disability.

None

Little (1 - 5 hours)

Some (6 - 10 hours)

Much (16 or more hours)

I have had formal training in working with and/or educating students with disabilities.

No

Yes

My level of experience teaching a student with a disability is

None

Little (1 - 5 hours)

Some (6 - 10 hours)

Much (11 or more hours)

My level of confidence in teaching students with disabilities is

Very Low

Low

Average

High

Very High

College Level Freshman Sophomore Junior Senior Graduate

Perception Questions on Efficacy: (Likert Scale)

I am confident in my ability to teach students with special needs.

I believe that all children can progress academically.

I become anxious when I learn that I will be teaching a pupil with Autism.

I have the ability recognize the characteristics of ASD (autism spectrum disorder).

I am aware of strategies to address the needs of pupils with Autism.

I am able to put into practice strategies to develop social skills of pupils with Autism.

I have the ability to put into practice visual strategies to meet the needs of pupils with Autism.

I would become easily frustrated when teaching a pupil with Autism.

I am able to differentiate the curriculum to meet the needs of pupils with cognitive deficits.

I have problems teaching a student with cognitive deficits.

I know how to adapt and apply curricula (e.g., content standards, social skills, study skills) to meet the needs of students.

I know how to address misbehaviors of students.

I know how to differentiate instruction to meet the needs of students with physical disabilities, including sensory deficits.

#### PRE SURVEY ONLY

Indicate your comfort level or preparedness to work with students with special needs according to the following descriptors. Drag and drop item responses into the appropriate category which describes your preparedness.

- Greatly prepared
   Somewhat Prepared
- 3 Not Sure
- 4 Somewhat Unprepared
- 5 Greatly Unprepared

Relating to students with special needs

Teaching academic skills to special needs students

Interacting with students with special needs in a formal classroom setting

Communicating with students with special needs

Managing behavioral problems with students with special needs

Recognizing when a student with special needs is becoming frustrated

Adapting an activity when a student with special needs is not grasping the information or concept

Recognizing when to ask for help

Interacting with students with special needs in an informal non-academic setting

#### Open Ended Responses:

Explain what fears, uncertainties, or frustrations you have regarding working with students with special needs at College Day?

At the NHS Dance?

What do you hope to learn at College Day and the NHS Dance about working with learners with special needs?

When interacting with learners with special needs would you be more comfortable in an informal, non-academic setting or in a formal, academic classroom? Explain your answer.

#### POST SURVEY ONLY

Choose how the experiences from College Day and the NHS Dance affected your preparedness to teach students with special needs according to the following descriptors.

- 1 Greatly prepared
- 2 Somewhat Prepared
- 3 Not Sure
- 4 Somewhat Unprepared
- 5 Greatly Unprepared

Relating to students with special needs

Teaching academic skills to special needs students

Interacting with students with special needs in a formal classroom setting

Communicating with students with special needs

Managing behavioral problems with students with special needs

Recognizing when a student with special needs is becoming frustrated

Adapting an activity when a student with special needs is not grasping the information or concept

Recognizing when to ask for help

Interacting with students with special needs in an informal non-academic setting

#### Open Ended Responses:

Explain one or more experiences during College Day that elevated the level of confidence and knowledge for your ability to teach students with special needs?

Explain one or more experiences during NHS Autism Dance that elevated the level of confidence and knowledge for your ability to teach students with special needs?

Explain how the setting impacted your experience at College Day or the NHS Dance.

#### Appendix C: Focus Group Prompts

#### **Prompts for Focus Groups**

Was College Day/NHS Autism Dance a positive or a negative experience for you? Why? Please provide specific examples, if possible.

Will you provide specific examples of any positive impacts College Day/NHS Autism Dance had on your ability to gain knowledge about working with students with special needs?

Will you provide specific examples of any negative impacts College Day/NHS Autism Dance had on your ability to gain knowledge about working with students with special needs?

Before working with students with special needs at College Day and the NHS Dance, what were your thoughts about your readiness to work with this population?

Prompt further if needed: Explain what fears, uncertainties, or frustrations you had before working with students with special needs at College Day and the NHS Dance.

What, if any, impact did College Day/NHS Autism Dance have for changing the way you felt about working with students with special needs?

What did you hope to learn about working with learners with special needs?

Academically

Socially

What did you actually learn through these two experiences?

What, if any, impact did the setting have on your experience? Did the setting help you or hold you back from learning to work with students with special needs? Give me one or more examples.

Would you have gained more from this field experience if it had been held in a more formal setting, like a school? Why?

What suggestions do you have to make College Day/NHS Autism Dance a more positive experience for your students?

## Are We Ready to Have Teachers with Learning Disabilities? A Study of School Principals' Observations

#### Heidi Flavian, Ph.D. Achva Academic College

#### Abstract

For decades, lawmakers, parents, and educators have advocated for including students with learning disabilities (LD) and addressing their needs within the education system. However, LD-related challenges do not vanish with age; consequently, for college and university graduates with LD, the issue of inclusion begins again when they reach the job market, including when they want to become teachers. The success of inclusion relies on the society's readiness to change and to accept people with a variety of difficulties in all areas of life. This study focuses on school principals' views regarding the hiring of teachers with LD. Apparently, although principals understand the variety of ways students with special needs should be included, they still struggle with the idea of including teachers with LD.

## Are We Ready to Have Teachers with Learning Disabilities? A Study of School Principals' Observations

The inclusion of people with special needs is an ongoing process that began early in the twentieth century and has spread around the world in a variety of ways. The process is not, and probably never will be, complete. Each time a new type of special need is recognized, society as a system faces a new challenge. This is because the inclusion of people with special needs is not a just a phrase or a slogan; rather, it is a practice that affects society at large. The inclusion approach is a principle that leads to the creation of an inclusive and caring society. Inclusion is practically expressed as the reciprocity between people with special needs and the rest of society. When people are willing to accept those with special needs as capable of contributing to their social environment and not as a mere burden on society, then inclusion is on the right path (Kozminsky, 2003).

Over the last thirty years, the inclusion of students with special needs in the education system has been encouraged by lawmakers, parents, and educators. Although schools are continuously improving the processes for inclusion, the process in society in general has not evolved accordingly (Flavian, 2011). Thus, special needs that are readily visible are more easily accepted and accommodated than are special needs which are not immediately detected, such as learning difficulties. Although for the most part, children with LD are included and are able to study with their peers throughout their school years, when they seek admission into higher education programs in order to become teachers, they are often frowned upon or discouraged, if not openly rejected. Nevertheless, over the last decade, some teachers with special needs have begun teaching in mainstream schools, but this path is not open to all (Green & Storm, 2010).

#### **Learning Disabilities**

The concept of "learning disabilities" indicates difficulties and/or disorders that interfere in the process of acquiring basic academic skills, such as reading, writing and math. These disorders are caused by dysfunctional neurological processes related to the development of language, visual perception, and attention. Their manifestations can range from minor disorders, which can be overcome through hard work targeting specific learning goals, to major disorders that are best addressed by studying in specially-devised programs (Chandler, 2010). According to the DSM-5 (Paul, 2013), LD can affect a variety of academic skills; assessments are initiated when a student's performance is significantly lower than expected of the pertinent age group. In addition, other difficulties that often accompany LD include low self-esteem, behavioral problems, and difficulties in adjusting to school or work settings.

In addition to the general goals of imparting knowledge and introducing students to unfamiliar domains, schools aim to provide students with the tools needed for cognitive, emotional, and social self-development. Teaching students with LD necessitates the use of teaching and learning strategies that can help them meet and overcome the constant challenges and barriers that the LD might pose. Given that learning disabilities do not diminish over one's lifespan, the acquisition of proper learning strategies increases the ability of people with LD to study, organize their time, and deal with everyday tasks and assignments. Moreover, these tools give them the opportunity to identify their strengths and to learn how to use them when facing specific learning difficulties.

#### **Adaptations for Learning and Professional Training**

Modified learning programs are developed in schools to provide students with LD the opportunity to graduate with their peers (Flavian, 2010). The same academic adjustments can be offered in the process of professional training, as long as the modifications do not detract from the level of professionalism. Teachers in training need to become experts in the domains they teach, while studying pedagogy and the didactic approach to teaching. In order to manage teaching others, teacher-trainees with LD need to master extra skills related to self-management, class management, teaching strategies and the use of certain technologies in the classroom. Not surprisingly, people with LD training in any domain or profession can develop and become very effective workers in their respective fields, provided they have received the necessary support and acquired helpful and complementary strategies with which to meet the related challenges (Gerber, 2012).

Few researchers (Stacey & Singleton, 2003; Leyser, 2011) have studied the challenges adults with LD face on a daily basis and have addressed the type of adjustments that they require in their workplace in order to be able to succeed like everyone else. Likewise, the process of including teachers with LD at schools requires the support and understanding of colleagues, supervisors and others, who are prepared to take into account the needs of these teachers. Affording these professionals the adjustments they require would ensure their inclusion in the schools and in the workforce, and thus would be beneficial not only for the student body at the schools, but also for the development of a more just and equitable society.

The current study attempted to investigate ways to make the process of inclusion teachers with LD as a viable goal for Israeli schools, by examining the attitudes of school principals. More

specifically, the purpose of the study was to explore ways to help conduct inclusion efficiently and not automatically, so that this practice might truly have a social-educational impact.

#### **Research Questions**

The main goal of this study was to better understand principals' views regarding the challenges and advantages schools face when opting to include teachers with LD as members of their school's educational staff. Gaining an understanding of the principals' views may be helpful both in preparing teacher-trainees with LD to enter the job market after graduation, and in preparing the school-community and the work environment in which they will be included.

Three main questions guided this study:

- What are the school principals' attitudes to inclusion in general, and to the inclusion of teachers with LD in particular?
- Do the school principals experience any difficulties or dilemmas about hiring candidates with LD to teach in their schools, and if so, what are they?
- What advice might the school principals have for teachers with LD?

#### Methodology

#### **Participants**

This study included 10 principals of public, state-funded schools. These schools operate under the aegis of the Ministry of Education and therefore they are obligated to follow to a core curriculum. Students are assigned to these schools according to their place of residence, precluding any option to choose a preferred school. Nine of the participants were principals of ordinary public schools, while one of them was the principal of a special-education school for children with complex learning disabilities.

School principals selected for participation in this study met the following criteria: had 10 years of experience teaching in state-funded schools; held a Master's degree in a field related to educational leadership; had worked in their current position for at least three years; and expressed their willingness to participate in this study on a voluntary basis. The 10 schools are located in five different cities, and the school principals were not informed of the identity of the other participants.

Given the fact that the school was already following the governmental mandate regarding the inclusion of people with disabilities in the workforce, there was no need to specifically inquire whether other members of the school staff approved of the inclusion of teachers with LD.

#### **Materials and Procedures**

This study used a qualitative methodology in all stages, from data collection through context analysis and culminating in the final conclusions. Each of the 10 principals participated in an indepth, individual interview, which was led by two interviewers working simultaneously and employing open ended questions. While one interviewer was engaged in conversation with the interviewee, the role of the second interviewer was to mind the direction and development of the conversation, making sure that all questions were addressed and all aspects of the issue were sufficiently explored (Shkedi, 2011).

The following opening question was used in all of the interviews: "From your perspective as principal, tell us what you envision for your school". Using the answer as a point of departure, the interviewers developed a discussion, during which interviewees revealed their key educational values and attitudes towards the inclusion of children and adults with special needs in school and in society in general. The interviewer then introduced the issue of teachers with LD.

As principals did not consent to have the interviews recorded, notes were taken during the interviews, transcribed in full at the conclusion of each interview, and then submitted to context analysis, which was conducted separately by three researchers. The analysis focused on identifying concepts and criteria that could help emphasize the essential views of the principals. Next, all three researchers discussed their findings, in preparation for the next interview. Therefore, although the basic interview questions had been formulated in advance, prior to each subsequent interview, a few unique questions were added.

Following the 10<sup>th</sup> interview, the three researchers jointly analyzed the aggregated context as a whole. In addition, at the end of the study, researchers offered to share results with the participants in order to integrate their insights as part of the study and to learn if they had other points of view to present. Only two principals agreed. The leading-researcher met with each of them for an hour, explaining the data-analysis process and the conclusions. Feedback from both participants strengthened the researchers' conclusions.

#### Results and Discussion

This study is based on information collected through in-depth, individual interviews held with 10 school principals, in order to add new information that could help more efficient inclusion of teachers with LD. Although some of the staff hiring decisions are made by regional supervisors, principals usually opt to interview prospective new teachers so they can better prepare for the school year. Therefore, understanding principals' overt and covert views could help reveal the potential advantages of (as well as potential obstacles to) the inclusion of teachers with LD. Nowadays, children with various special needs, including LD, are integrated into mainstream schools and are directed to specific academic, behavioral or emotional programs. Therefore, it was not surprising to find that all the principals in the study were familiar with the concept of "learning disabilities" and with the adaptations these students need in order to succeed in school. Moreover, they all agreed that when children's special needs are unrelated to either emotional or behavioral difficulties, the entire student body benefits from the inclusion. Only one principal, who was the head of a special-education school, presented a slightly different approach: "although it is very important to include students with special needs in schools, it is more important to find the right schools for them that have teachers with special training and who can teach them despite their difficulties".

Unexpectedly, although all participants were familiar with the notion of LD and with the successful outcomes related to the learning processes they experience and the special strategies they acquire, the principals found it hard at first to accept the fact that adults with LD might wish

to become teachers. The principals' attitudes towards inclusion were less enthusiastic when the issue of teachers with LD was introduced.

In answering the question regarding the inclusion of teachers with LD in schools, all the principals raised four main issues: advantages, challenges, teachers' responsibilities, and principals' responsibilities.

## Advantages of Including Teachers with LD

The advantage mentioned by all principals was that teachers with LD could serve as role models for their students. One of the principals explained the advantage thus:

Students who have difficulties at school easily give up on themselves. But if their teachers could speak frankly about their own experience with LD and emphasize that success is possible, as they themselves can attest, students might be motivated to keep trying.

All principals voiced the same idea, highlighting the fact that by sharing their own experiences, teachers could develop strong interpersonal relationships with their students, which could serve as a source of encouragement for these students.

Both researchers (Vogel, 2003 and Flavian, 2011), and the principals who were interviewed in this study mentioned that teachers with LD, who are constantly aware of the strategies they need to implement on a daily basis, are likely to integrate them automatically throughout the teaching process and by doing so, demonstrate the practical effects and the importance of using such strategies. In addition, teachers with LD may be more aware than their professional peers of the need to integrate a variety of learning strategies in their lessons, a practice which is undoubtedly helpful for all students, and not only for those with LD.

Another advantage mentioned is that teachers with LD may be particularly aware of and considerate towards students with LD. As one of the interviewees said: "I really think that teachers with LD have a kind of radar... it is like... if they reflect on their own learning difficulties, they can recognize their students' learning difficulties before students develop extreme feelings of frustration". Another principal said "sometimes they can detect LD better than professional diagnosticians can". This advantage has a positive effect on the teaching process overall, since a teacher who can understand the source of the difficulty can help accordingly.

## Challenges to the Inclusion of Teachers with LD

After expressing the important advantages teachers with LD may have, all participants pointed out that teaching is a very stressful and complex task that demands efficient organization and planning, two skills which people with LD often find challenging. Participants said that "it is not an acceptable situation to have a teachers who cannot plan lessons ahead of time and teach accordingly", and "how can teachers teach time management if they cannot manage it for their own needs?" In these and other similar comments, the principals indicated that, in their view, teachers who cope poorly with their own LD challenges are likely to have difficulty handling the demands of the job. Nevertheless, all principals agreed that referring to the above challenges as

the school-community's challenges rather than as pertaining solely to the individual teacher would be generally beneficial for the practice and goals of inclusion.

# **Teachers' Responsibilities**

There is no question that teachers' responsibilities encompass everything associated with students' learning processes and class management. Therefore, unsurprisingly, only a few of the principals said that it did not matter to them whether teachers had LD, as long as the teaching and learning processes were proceeding efficiently. One participant said "teachers are responsible for their students' learning....they should do whatever is needed in order to ensure learning among all", and another stated that "they [the teachers] knew well before they began their training that they had LD; it was their decision to choose a profession that would challenge them on a daily basis". While it is rational and understandable to demand that teachers be responsible for the entire learning process and the social dynamics in the classroom, the principals' reactions quoted here focus only on the degree to which the teachers handle the disability, ignoring the potential role of a supportive work environment.

In contrast, there were two principals who emphasized that "the major responsibility teachers have is to know what they do not know and to ask for whatever support they need". For teachers in general, not to mention for teachers with LD, such self-monitoring constitutes an integral part of their professional responsibility. Costello and Stone (2012) emphasize that people with LD often have a low sense of self-efficacy, which may prevent them from asking for help. Nonetheless, people with LD who choose to become teachers have a responsibility to overcome whatever obstacles or inhibitions they might face in order to fulfill their duties as mandated by the job and the situation. One participant expressed the sentiment underlying the perspective of the two principals quoted here in a more direct manner, saying that "teachers with LD cannot use their LD as an excuse for not doing their job".

## **Principals' Responsibilities**

The question of principals' perceptions regarding their own responsibilities vis-à-vis the inclusion of teachers with LD was not posed to them directly; instead, the views on this issue implicit in their replies were highlighted in the context analysis. All the principals referred to their responsibilities in response to a direct question asking whether they would hire a teacher with LD: "I cannot hire a teacher if I am not sure she would be suitable for the job. I have a responsibility towards the children and their parents", or, "I am not sure I would like to have teachers on the staff for whom I would need to do all the organizational work. I cannot be responsible for their duties".

Despite the negative approach that might be understood from the above quotes, it is reasonable that a principal would not like to hire any candidate who could not meet the demands of the job. A more practical, and perhaps positive, view was expressed by one of the participants, who said "if I hire a teacher with LD, I need to prepare myself and the rest of the staff, since in order to benefit from all the advantages this teacher can offer, we would need to extend support and help when needed. It is our responsibility to be receptive to all".

A prominent but confusing finding was that although principals overall agreed that society has a responsibility to include everyone in the work place without discrimination, and although they

expressed their conviction that people with LD should not feel shy to be open about it – as this approach could help the teachers cope with the challenges – some of the principals strongly recommended that teachers with LD avoid talking about their struggles.

Maybe, the fact that one openly talks about LD might deter principals [from including teachers with LD in their staff] ... maybe they [teachers with LD] should do their best without telling, and should reveal this only after they have proven themselves in the professional arena.

This view is confusing also because it is inconsistent with the previously-mentioned statements that emphasized that teachers with LD should ask for help and support from their colleagues when needed. Therefore, there is no consensus among school-principals in regard to how teachers with LD should act while confronting their difficulties.

## Summary, Conclusions and Recommendations

The inclusion of people with special needs in general and with LD in particular is a humanistic value that acknowledges society's responsibility to care for everyone, as well as the potential of every individual to make a positive contribution to society in a variety of ways. This value is most apparent when adaptations to the environment for the purpose of inclusion are integral to the cultural milieu, rather than a superficial response to an imposed rule.

With this caveat in mind, we turn to consider the findings of the current study. On the one hand, the principals interviewed in this study understood the benefits to be gained by including teachers with LD on the staff, yet on the other hand they also expressed hesitations about hiring them. These contradictory feelings suggest that the development of preparation programs for inclusion of teachers with LD may be a more timely strategy than drafting and enforcing new rules.

Recognizing the fact that each person has strengths and weaknesses leads students with LD to recognize their own strengths, and empowers them to deal with the LD-related difficulties by finding the appropriate strategies that suit them (Flavian, 2011). Throughout their school years, students with LD learn to adopt learning strategies that can help them succeed in all aspects of life. This experience translates into a particular advantage in assuming the role of educational leaders. More specifically, the reflective process of observing one's own functioning and selecting the most suitable strategies for a given situation is a worthy model for all students. Teachers need to make sure that every one of their students knows how to study, and can understand and implement the materials learnt. School principals who participated in this study also agreed that teachers with LD, who are aware of their own difficulties and have had to develop their own unique methods of learning, could apply this experience and, thus, may have a facility for devising practical solutions for students with LD. It is likely, as the principals in this study noted, that teachers with LD are well-equipped and uniquely qualified to guide students with LD to identify the source of their difficulties and find effective coping strategies. Moreover, these principals also agreed that offering proper support and guidance to teachers with LD would help these teachers maximize their abilities when planning lessons and implementing their knowledge and experience, for the benefit of all students.

The advantages presented herein regarding the inclusion of teachers with LD in the school's educational staff highlighted aspects of professional teaching that are not typically studied in teacher-training programs. Although becoming a role model for students is one of the values teacher-trainees are taught throughout their teacher-training programs, from the findings of this study we can learn that the subject of teachers' role-modeling and its effects should be studied further. The principals suggested that teachers with LD should share with their students their own personal experiences as students with LD, in order to become significant role models. These principals believe that if teachers share their personal stories of LD-related challenges and successes, students will look up to their teachers and feel encouraged, which in turn will strengthen their resolve to face their own (LD-related or other) personal challenges. Another aspect of professionalism that emerged from this study relates to teachers' ability to detect and understand students' academic difficulties. In addition to the common expectation of being an expert in the domain one teaches and to know how to teach, school principals believe that teachers with LD can offer an additional type of expertise, thanks to their daily struggle with their LD. Guided by their own experience, teachers with LD may be able to not only to detect the type of difficulties their students encounter, but also to help them manage their academic tasks by integrating learning strategies in their lessons, from which all students stand to benefit.

The main advantage of including teachers with LD is that it is expected to help inculcate an essential social value. Educators need to remember and to remind others that beyond the personal role model which teachers with LD can provide for their students, these teachers also have an opportunity to guide all their students to recognize and appreciate diversity among people. Students can thus learn to acknowledge their classmates on a personal level, beyond the measure of academic achievements. They learn that each one of them has unique abilities and that no one is perfect. Only by disseminating this tolerant point of view can true inclusion develop. Students may learn that everyone, including people with special needs such as their teachers and classmates, can and should contribute to others and to society.

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# Follow-Up Study to Family Members' Reactions to the Initial Special Education Meeting

Dr. Lawrence Ingalls Dr. Helen Hammond Mr. Carlos Paez Mr. Ivan Rodriguez

# University of Texas at El Paso

#### Abstract

Family involvement is a central component of Individuals with Disabilities Education Act (IDEA). Family members are to be integrated in all aspects of the special education process. At the onset, of family involvement, it is imperative for educators to be aware of possible reactions family members may experience in this initial stage. This follow-up study examined family members' reactions from their initial introduction into the special education system. Interviews with 281 family members over a five-year span provided supportive results of a previous study examining family members' reactions. In this study, the researchers also report on detailed suggestions from the family members on ways to improve their initial involvement were additionally compiled in this study.

# Follow-Up Study to Family Members' Reactions to the Initial Special Education Meeting

## **Legal and Legislative Imperatives**

The original special education law, titled the Education for All Handicapped Children Act (EAHCA), was enacted by Congress in 1975. This law was later amended in 1990 and the title was changed to Individuals with Disabilities Education Act (IDEA). This law mandated that individuals with disabilities would receive an Individual Education Program (IEP) conceptualized by a committee including the family members/parents of children with disabilities (U.S. Department of Education, 2001). The IEP document is a legal agreement between the school and the family detailing the educational services, goals, and objectives, instructional modifications, and timelines for services for students identified as having an educational disability. This law was groundbreaking because it laid a foundation for parents of students with disabilities to have an equal partnership with the education system in planning the most appropriate program for their children (Boyle & Provost, 2012; Drasgow, Yell, & Robinson, 2001; Friend, 2005; Heward, 2009; Lo, 2014; Martin, Marshall, & Sale, 2004; Mueller & Buckley, 2014; Smith, Gartin, Murdick, & Hilton, 2006; Vaughn, Bos, & Schumm, 2013; Yell & Drasgow, 2000). Although the law has provided for equal partnerships between schools and families for several decades as noted in the cited studies, parental participation in the IEP process has yet to be one of equality, and as such, relationships between parents and educators have been tenuous (Deslandes, Royer, Potvin, & Leclerc, 1999; Friend, 2005; Hammond, Ingalls, & Trussell, 2008; Rock, 2000). Research dating back to the 1970s (McAleer, 1978) and extending to current years has consistently reported similar disparities (Lo, 2012a, 2014; Vaughn et al., 2013).

In order to create true equal partnerships, parents must be involved at each level of their child's educational program. These levels include parental involvement in pre-referral, assessment, IEP development, IEP implementation and monitoring activities. Boyle and Provost (2012) outlined IDEA's increased emphasis on the importance of parental input in the IEP process. They stated school districts must take the necessary steps to include parents in the meetings for all discussions and decisions. In order to create educationally beneficial and legally valid IEPs, schools must be equal partners with families in identifying student needs and determining the array of educational options.

## **Parental Experiences in the IEP Process**

Regrettably, past research has demonstrated that many families have had negative experiences with educational professionals during the initial IEP meeting (Hammond et al., 2008; Vaughn et al., 2013). These researchers indicated that parents reported that IEP meetings focused exclusively on their child's weaknesses. As a result, parents have expressed an assortment of negative feelings experienced during IEP meetings, including guilt, embarrassment, intimidation, and alienation (Fox, Vaughn, Wyatte, & Dunlop, 2002; Hammond et al., 2008; Lo, 2012a). Some family members feel a great deal of pressure and discomfort having to accept responsibilities regarding the development of the IEP (Bateman & Linden, 1998; Lo, 2012b) found family members commenting that school personnel were not culturally sensitive to the families during the IEP process. In this study, family members stated that they thought the school did not want them to be equal partners. Smith (2001), Flynn (2006), Hammond et al. (2008), and Mueller, Milian, & Lopez (2009) found that family members felt intimidated by the IEP process. The parents commented they felt overwhelmed by the number of professionals at the meeting, experienced guilt regarding their child's disability, were confused by the jargon, and believed teachers lacked respect for them. Smith et al. (2006) reported parents may not only feel intimidated by the professionals at the meeting, they may also be distrustful of the school personnel and believe personnel may question why parents are even involved. Parents did not feel prepared for the meeting and did not enter the meeting with the confidence of an equal partner with the school personnel.

Research over a substantial period of time (Deslandes & Bertrand, 2004,2005; Hardy, 1979; Wright, Stegelin, & Hartle, 2007) have reported there are a vast number of reasons parents are nervous to involve themselves with school personnel. These researchers stated many challenges stem from parental beliefs and values. Some parents have had negative school experiences, feel incompetent to work with teachers, may not feel valued by educators, may believe teachers are the authority figure and consequently not open to parental ideas, and they may not be prepared for the professional jargon that frequently occurs at the meeting. Soodak and Erwin (2000) had similar findings stating family members felt the professionals at the IEP meeting were the primary decision makers and family feedback was not valued. Hammond et al. (2008) reported family members stated they did not feel comfortable sharing their ideas at the meeting. They believed the professionals at the meeting might negate any concerns, ideas, and/or opinions they had.

Turnbull, Turnbull, Erwin, and Soodak (2006) noted that a main problematic area in family involvement was when family's priorities for the IEP were neglected. They stated that many family members become disempowered during the IEP process. When family members feel

devalued and their knowledge is not appreciated, their participation diminishes (Bezdek, Summers, & Turnbull, 2010). Families may believe the IEP meeting is a meaningless event with predetermined goals. As a result, family members may view their role as a mere technicality whereby their role is limited to solely providing a signature on the IEP document (Rock, 2000).

Although considered equal partners under the law, many parents are not prepared to function equally because they are not familiar with the school's special education terminology and procedures (Deslandes & Bertrand, 2004, 2005; Lo, 2012a; Turnbull et al., 2010). This disadvantage makes family members hesitant to contribute to educational decision-making. Additionally, they may be vulnerable to making decisions about their child's education that is influenced solely by school personal (Rock, 2000). Parents have also reported feeling as though educational professionals intentionally discouraged their participation in IEP meetings. Furthermore, educators tend to dominate the meetings creating an impression that parental input is not encouraged (Dabkowski, 2004; Mueller & Buckley, 2014).

According to Fish (2006), family members reported that their initial IEP experiences had been negative. Parents indicated that educators were inconsistent with their acceptance of parental suggestions and input that parents believed to be best practice for their children. Additionally, parents expressed concerns about the school's application of both special education law and the IEP process (Hammond et al., 2008). Parents suggested that the IEP meetings should be reconceptualized to provide parents better opportunities for meaningful participation and preparation prior to the initial meeting.

These researchers also found a vast majority of parents were overwhelmed with the IEP meeting. They just simply did not feel prepared for the agenda, jargon, number of people, and their role on the team. Interestingly, of these parents involved in this study, half stated that they knew their child had a disability, but were still traumatized by the initial IEP meeting. Even with the awareness of their child's disability, these parents had negative experiences including difficulty communicating effectively, understanding terminology, voicing their concerns, or feeling equality with professionals at the meeting.

#### **Promising Practices**

From the review of previous studies on parental reactions to the IEP meeting and process, it appears a key to improving the collaboration between family members and professionals is to prepare the parents for the IEP meeting. IDEA states that notices sent to parents regarding an upcoming meeting should contain information on the purpose, time, location, and people who will attend the meeting (Boyle & Provost, 2012). Parents who have been involved in the IEP process have made some general recommendations. They suggested to other parents that if they want to become more actively involved in the IEP process, they must become more knowledgeable about special education law and options (Applequist, 2009; Kayama, 2010). Also, family members need to be unrelenting in demanding the appropriate services for their children (Fish, 2006). Singh (2003) found that parents valued honest and open communication with teachers. Research from this study also found parents considered the quality of communication as important as regularly scheduled opportunities to communicate. Further, parents reported that they appreciated teachers taking the time to explain information to them.

## **Purpose of the Study**

The purpose of this research was to complete a follow-up study to determine if the types of reactions family members experienced from their initial introduction to special education services were similar to the findings from the original study. Further, this study focused on obtaining parental suggestions to other parents and school personnel to improve the IEP process. In the original study, which occurred over a four-year time span with a total of 212 parents, the research focused on determining the types of reactions family members had from their initial introduction to the IEP process. Results from this study indicated a vast majority of parents (72%) were overwhelmed with their initial involvement. Generally, parents stated they were not prepared for the meeting as they were unfamiliar with the jargon being used, the purpose of the meeting, who would be at the meeting, and their role with the school personnel.

#### Method

## **Participants and Setting**

This study examined the reactions of family members of children who had been referred for special education services. Of particular interest were their perceptions of attending the initial IEP meeting. The family members consisted of individuals who resided in a southwestern community in the United States. This region borders the United States and Mexico. The population of this region consists of approximately 85% of individuals coming from a Hispanic background. The family members interviewed in this study mirrored the population of this region with approximately 85% of respondents identifying themselves as being Hispanic. The family members came from six rural school districts and one urban school district within this border community. Additionally, the family members interviewed came from a variety of educational backgrounds ranging from less than a grade twelve education to a master's degree. A majority (53%) of the family members' knowledge of special education services at the time of their child's referral ranged from no knowledge to minimal knowledge.

## **Procedure**

Data were collected over a 5 year time span through a semi-structured interview process (Gay, Mills, & Airasian, 2006). A criterion sampling technique was used to identify a sufficient number of participants (family members) for this study (Gay et al., 2006). The sample size included 281 family members who met the following criteria: (a) family members of children in early childhood and elementary schools, (b) family members with children who had recently been referred for initial special education evaluations, (c) family members who had recently participated in the initial IEP meetings for their children, and (d) family members who attended the initial IEP meetings in order to discuss qualification and services for their children. By selecting families following these criteria, this study assures a strong representative sample of parents' perceptions and experiences who are involved in the initial referral and assessment stages of the special education process. The interviews of the family members occurred at a time that followed the formal referral of the family member's child, but prior to the family member's attendance at the initial IEP meeting.

Family members verbally responded to a set of questions addressing: (a) reactions to their child's referral for an initial special education evaluation, (b) reactions to their experiences at the initial IEP meeting, (c) reactions regarding their level of participation at the meeting, (d) degree of

comfort during the meeting, and (e) other questions relating to their perceptions of the initial IEP experience. Please see Table 1 for a complete list of the interview questions.

## Table 1.

## Interview questions

- 1. What were your first reactions when you were notified that your child was being referred to be assessed for special education services?
- 2. How did you feel when you entered the room for the IEP meeting and saw the group of people who would be attending the meeting?
- 3. Did you feel that your child needed special education services?
- a) Yes
- b) No
- c) Unsure
- 4. How would you describe your understanding of the terms and issues discussed at the IEP meeting?
- a) I understood all of the information;
- b) I understood most of the information;
- c) I understood some of the information;
- d) I didn't understand any of the information;
- 5. Were you given the opportunity to voice your concerns or opinions?
- a) Yes
- b) No
- c) Somewhat
- 6. Did you feel comfortable to voice your opinion or did you feel you had to agree with what was decided by the team
- a) Felt comfortable
- b) Had to agree
- c) Not comfortable
- d) Both comfortable and had to agree
- 7. Do you feel your child is receiving the help from the special education program that is needed?
- a) Yes
- b) No
- c) Somewhat/Unsure

- 8. Please tell me two things that happened to you in the meeting that were positive.
- 9. Now please tell me two things that happened to you in the meeting that were negative.
- 10. What would you recommend to the members of the IEP committee or recommend to other parents who attend the meetings to improve the quality of the meetings?

The protocol for completing the semi-structured interviews was predetermined by the researchers. The individuals who facilitated the interviews were graduate students in a master's degree program within the Department of Educational Psychology and Special Services. These data collectors were seeking a Master's Degree in Special Education or Educational Diagnostician. Family members were selected based on the aforementioned sampling criteria. To minimize selection bias, data collectors identified family members with whom they had limited professional or personal interactions. Data collectors were trained in using a semi-structured interview process which utilized both structured and unstructured questions. This interviewing process enhances validity and reduces bias (Gay et al., 2006). In order to assure standardization across the interviews, data collectors received predetermined interview questions which consisted of a set of ten questions. Five questions were structured with closed-ended items and five questions entailed an unstructured item format with an open-ended design. Since this research was a follow-up study focused on making comparisons of a previous study, the exact same questions were asked and the same procedures were used. The data collectors were trained in the administration of the instrument to ask the questions in both a particular sequence and wording. Each of the comments and responses from the family members was written verbatim.

From the written responses, the researchers analyzed the collection of responses by organizing, categorizing, and interpreting the data. Organization of data included tallying the data from closed-ended questions and assigning percentages of like responses. The data from open-ended questions were compiled according to verbal responses. The data from open-ended questions were categorized according to common themes. Initially, the data were organized and categorized by the researchers independently. This was accomplished by three researchers analyzing the data and identifying themes and categories. Through the process of review and revision, themes and categories of participant responses were agreed upon. Data were then interpreted to determine parental perceptions of the initial IEP meeting (see Figures 1 through 7 and Tables 2 through 4 for results).

#### Results

Question one asked parents about their first reactions when notified that their child needed to be evaluated for the possibility of an educational disability. There were 323 responses to this question. Please note that although there were only 281 parents in the study, some parents provided more than one response to the question. Forty-seven percent (150/323) indicated they were prepared and relieved to hear the news that their child had a disability, 16% (52/323) indicated that they were shocked by the news and/or felt a sense of disbelief, 14% (44/323) indicated the news made them sad, 13% (42/323) indicated that they were frustrated and/or angry

by the news, and 11% (35/323) stated that the news caused them to be scared and/or worried (see Figure 1).

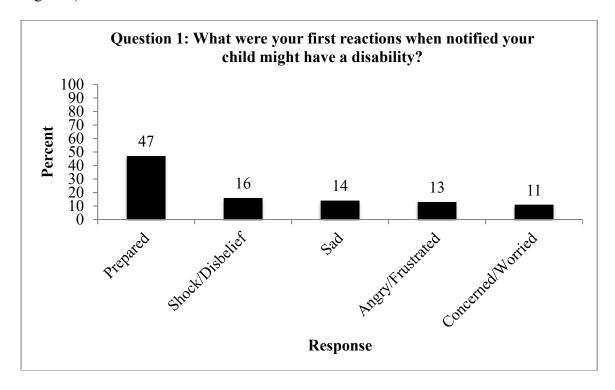


Figure 1. Responses to question 1

Question two asked parents about their initial feelings when entering the first IEP meeting for their child. There were 339 responses to this question. Again please note that some parents provided more than one response to the question. Responses from parents indicated that 69% (235/339) felt overwhelmed, anxious, and/or shocked; 19% (63/339) stated they felt comfortable, 11% (36/339) reported they felt uncomfortable and unwelcomed, and 1% of the parents (5/339) indicated that they felt guilty (see Figure 2).

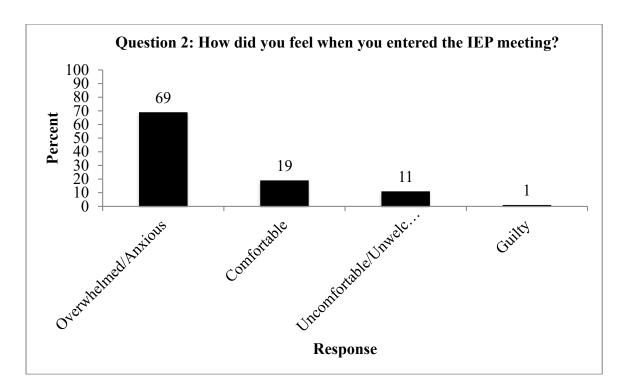


Figure 2. Responses to question 2

Question three asked parents if they felt that their child needed special education services. There were 281 responses to this question. Results indicated that 61% of the parents surveyed (172/281) stated they felt that their child needed special education services and 30% (83/281) indicated that their children did not need special education services. Nine percent of parents (26/281) were unsure (see Figure 3).

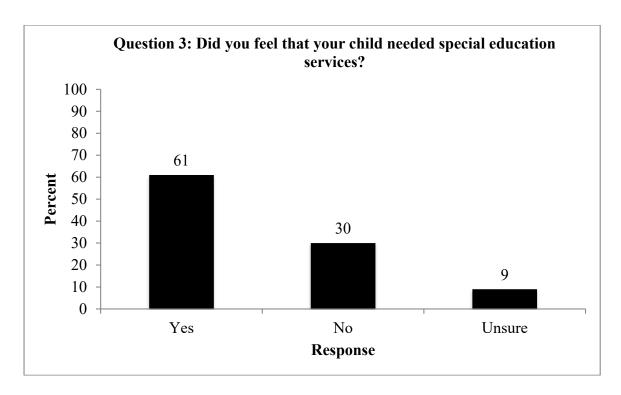


Figure 3. Responses to question 3

Question four asked parents how well they understood the terms and issues presented at the IEP meeting. There were 281 responses to this question. Seventeen percent (47/281) stated that they understood all of the terms and issues. Thirty-nine percent (109/281) stated they understood some and 30% (83/281) stated they understood most of the terms and issues. Fourteen percent (38/281) indicated that they understood none of the terms or issues at the IEP meeting (see Figure 4).

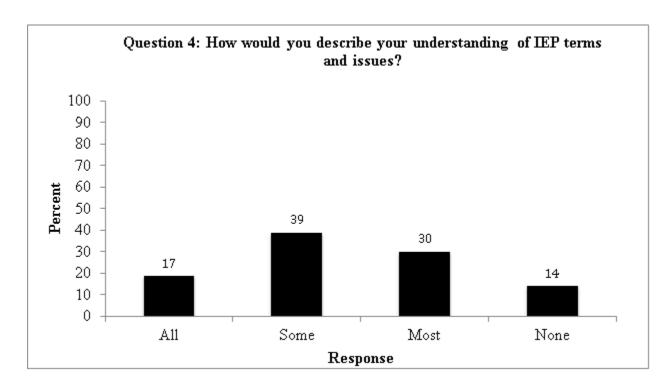


Figure 4. Responses to question 4

Question five asked parents if they were given the opportunity to voice their concerns at the initial IEP meeting. There were 281 responses to this question. Results revealed that 79% (223/281) of parents questioned stated that they were given the opportunity to voice their concerns. Results indicated that 10% of the parents (28/281) stated they were not given the opportunity to voice their concerns, while 11% (31/281) stated they were somewhat/sometimes given the opportunity to voice their concerns (see Figure 5).

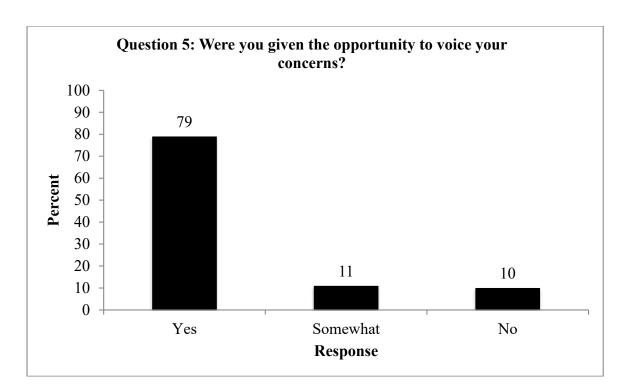
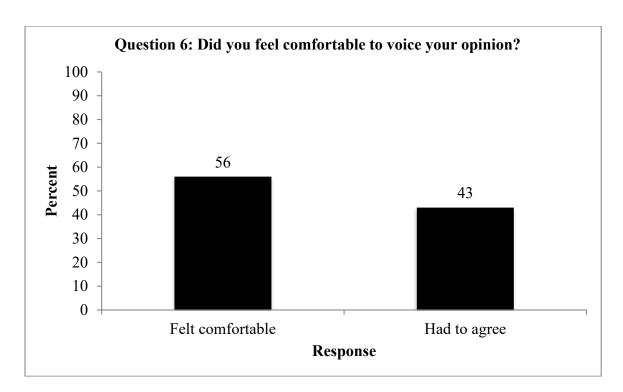


Figure 5. Responses to question 5

Question six asked parents if they felt comfortable voicing their opinions at the IEP meetings. There were a total of 281 responses to this question. Results showed that 56% of the parents (158/281) stated that they felt comfortable voicing their opinions. Results revealed that 43% of the parents (120/281) stated they felt they had to agree with the decisions being made at the IEP meeting (see Figure 6).



Question seven asked parents if they believed special education services determined at the IEP meeting were helpful for their child. There were 281 responses to this question. Of those, 62% of the parents (174/281) indicated their child was benefiting from the special education services. Results stated that 11% of the parents (30/281) believed their child was not benefiting from the special education services and 26% of the parents (74/281) indicated they were unsure if their child was benefiting or that there may be some benefits from the special education services (see Figure 7).

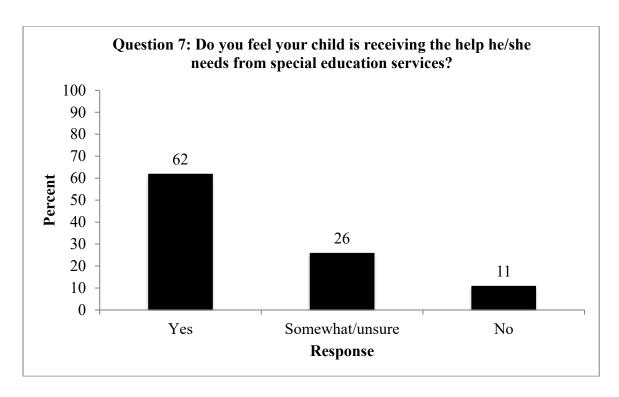


Figure 7. Responses to question 7

Question eight asked parents to tell two things that were positive about their initial IEP meeting experience. There were 410 responses to this question. Results showed that 55% of responses (227/410) indicated parents felt support during the meeting and that their child was going to get the help that he or she needed. An additional positive comment from 19% of responses (76/410) indicated the parents felt it was positive to learn about their child's special education program. Additionally, 17% of responses (69/410) stated parents were happy to meet the school personnel. Also, 6% of parental responses (24/410) stated it was good to get written information on special education so to make the information at the meeting clearer. Two percent of responses (10/410) stated "nothing" was positive and 1% of responses (3/410) described the most positive point of the meeting was "having the meeting end". Finally, less than 1% of responses (1/410) indicated "everything" was positive at the meeting. (see Table 2).

Table 2.

Responses to question 8	
Feeling supported and that their child was going to get	
the help he/she needed	55%
Positive to learn about their child special education	
program	19%

Happy to meet the school personnel	17%
Positive to receive written material on special education	6%
Nothing was positive	2%
Positive to have the meeting end	1%
Everything was positive	<1%

Question nine asked parents to tell two things that were negative about their initial IEP meeting experience. There were 388 responses to this question (see Table 3). Results revealed that 32% of responses (123/388) stated there were negative interactions among people at the meeting. An additional 25% of responses (97/388) identified a negative aspect as being the final outcomes of the meeting. Respondents, who were concerned about the outcomes, stated that school personnel had predetermined meeting outcomes that were brought to the meeting prior to any discussion with family members. Further, 18% of responses (70/388) indicated the meeting was poorly organized and structured. Also, 14% of responses (55/388) stated the meeting was overwhelming with unclear terminology being used and there was a lot of paperwork. Nine percent of responses (36/388) revealed satisfaction with the meeting as the responses stated there was "nothing negative about the meeting". Finally, 2% of responses (7/388) that indicated the parents did not feel involved or "heard" at the meeting. (see Table 3).

Table 3

Responses to question 9	
Negative interaction among people at the meeting	32%
School personnel came to the meeting with	
predetermined meeting outcomes	25%
Meeting was poorly organized and structured	18%
Overwhelmed with unclear terminology and paperwork	14%
There was nothing negative	9%
Parents did not feel needed or heard at the meeting	2%

Question 10 asked parents to make recommendations to school personnel and other parents based on their experiences at the initial IEP meeting. There were a total of 480 responses to this question. Responses to this question were as follows: (a) 28 % of responses (132/480) stated parents should acknowledge their own expertise, get involved, and ask questions during the meeting, (b) 26% of responses (125/480) indicated that school personnel should be more positive and supportive to the parents during the meeting, (c) 17% of responses (80/480) suggested that parents should be prepared for the IEP meeting before going to it, (d) 9% of responses (45/480) stated school personnel should be more knowledgeable about special education services and options, (e) 8% of responses (37/480) indicated school personnel should use simpler terms and have the language being used in the meeting be the family's native language, (f) 6% of responses (31/480) suggested that school personnel should not rush the meeting, (g) 4% of responses (19/480) stated that the meeting area should be more comfortable, and (h) 2% of responses (11/480) indicated they had no recommendations as everything that happened at the meeting was positive (see Table 4).

Table 4

Responses to question 10	
Parents should acknowledge their own expertise and be	
involved in the meeting	28%
School personnel should be more positive and	
supportive of parents	26%
Parents should be prepared for the meeting	17%
School personnel should be more knowledgeable about	
special education services and options	9%
School personnel should use less professional jargon	
and be sure parents are understanding the information	
when English is their second language	8%
School personnel should not rush the meeting	6%
Meeting atmosphere should be more comfortable	4%
No recommendations, everything was positive	2%

# Discussion and Implications

This research was a replication of a 2008 study. The same procedures were followed and the same questions were asked as in the previous study. Upon reviewing the results of these interviews, it is obvious that the families' level of comfort during the IEP meetings continues to be a concern. This follow up study from the Hammond et al. (2008) original study suggests that little has changed in educators' success in gaining parental comfort in the initial IEP meetings. Table five provides a side by side comparison between responses of parents' perceptions and reactions to the initial IEP meeting from the original study and in this follow-up study. With a great deal of emphasis in the literature on the importance of parents on the IEP team, one would think the data would be changing in a positive direction. Overall, Table five shows minimal differences between the data during the seven year time span between the two studies.

In the 2008 study, 49 % of the parents had some level of negativity regarding the referral of their child for special education assessment (question one) as opposed to 54% expressing negativity to the referral in the current follow up study. This trend continues throughout each of the questions. In 2008, 86% expressed negative feelings upon entering the IEP meeting (question two) as opposed to 81% today. The current study revealed that 83% of family members did not clearly understand terms used in the meeting (question four) as opposed to 73% in 2008. Little change was noted regarding parents' feelings regarding whether or not they were given the opportunity to fully voice their concerns in the meeting (question five). Another 21% felt hesitant to voice concerns in the current study compared to 17% in 2008. In response to question six regarding parents' comfort in expressing their opinion, 43% reported they felt uncomfortable or forced to agree with the educators opinions in the current study as opposed to 35% in 2008.

Some positive increases occurred in the parents' comfort level of feeling they could disagree with decisions made by the educators. Currently, 39% of the parents questioned whether the educators were correct regarding their child having a disability compared to 25% in 2008. Additionally, 37% of family members in this current study questioned that their child would receive the services they needed compared to 26% in 2008. Although these areas appear to be positive increases in the parents' attitudes, it is important to note that these comments were made to the data collectors and not to the school personnel during the meeting. Thus, it cannot be concluded that the parents actually voiced their disagreements during the meeting.

Table 5
Interview responses from two studies

	2008 Study	2015 Study
Comparison of Key Parental Responses	Affirmed	Affirmed
	response	response
Parents who had some level of negativity regarding the referral	49%	54%
of their child for special education assessment		

Parents who expressed negative feelings upon entering the IEP meeting	86%	81%
Family members who did not clearly understand terms used in the meeting	73%	83%
Parents who felt hesitant to voice concerns in IEP meeting	17%	21%
Parents who were comfortable in expressing their opinion	35%	43%
Parents who questioned whether the educators were correct regarding their child having a disability	25%	39%
Parents who questioned that their child would receive the services they needed	26%	37%

Upon examining this table, it is evident that there is an ongoing problem of parental involvement in the initial IEP process. Educators clearly need to recognize that we are not making progress in helping parents and/or significant family members to become equal contributors in these meetings. This is an important issue as Public Law IDEA undoubtedly intended to have parents be highly involved in the IEP meetings and that educators should be involved in helping parents achieve this goal.

Although this study focused on parents from primarily Hispanic backgrounds, the results are similar to those findings involving in other ethnic groups (see Deslandes et al., 1999; Friend, 2005; Lo, 2012; Rock, 2000; Simpson, 1996; Turnbull et al., 2006). Although not conclusive, it can be assumed that the results from this study are relevant to other ethnic groups and should be added to the body of research that suggests parents of children with disabilities are not fully participating in planning and implementing their child's education, particularly in the initial stages.

As was noted in the initial study in 2008, a limitation to this research involved the level of knowledge of the parents who responded to the interview. All of the parents who were interviewed had little or no knowledge about the IEP process and the legal guidelines regarding the development of the initial IEP. The legal guidelines that are in place in the United States through IDEA are very family focused and encourage to the maximum extent possible equal participation between professionals and families. Unfortunately, the application of these mandates are not always family focused and do not match the intent of IDEA regarding family involvement. This factor may have skewed the data since parents may not have adequate knowledge about their rights to be an equal participant. If a family member was more aware of his/her legal rights and the legal guidelines, his/her responses to the questions may have been different. Their perceptions of the initial IEP process may have become even more negative as they realized they were not adequately prepared or supported to be an equal partner with school personnel.

The historical fact that parent involvement in the special education process has been problematic for decades and that parent involvement continues to be a challenge today is notable. As reported earlier, research results on parental participation and comfort levels in participation, dating back to the 1970s (see McAleer, 1978) and continuing on to present day has been concerning. This would suggest that education agencies are having difficulty fulfilling the legal requirement of full parental participation in children's special education programs.

IDEA has, since its initial conception, strongly supported the concept that parents of children with disabilities are to be full participating partners in their child's education. However, legal monitoring of IDEA in regards to parental involvement has been limited to issues such as assuring parental signatures are in place for permission to test, to provide services and other tangible components of parental involvement. The structural system of tangible parental involvement has been monitored, but true parental satisfaction, participation, and involvement has not been monitored and consequently not improved upon. School districts may need assistance in developing methods to track the levels of satisfaction, participation, and involvement of parents in their meetings.

Throughout the years of IDEA's reauthorizations, IDEA has guided educational systems in improving their services for the various principles contained in the law. For example, initially, IDEA allowed special education personnel to work only with children who had been identified as having a disability. However, in an attempt to strengthen the principle of least restrictive environment (LRE), in one reauthorization, changes occurred to allow special education personnel to work in a general education setting with any of the children in the classroom as long as there was a child with a disability within the classroom. This provided the educational system with a means to allow special educators and general educators to collaborate and to keep children with disabilities in the general education setting. Additionally, effective practices such as Response to Intervention (RTI) (Vaughn et al., 2013), has changed the identification practices of children with mild disabilities. The RTI model, which focuses on the amount of intervention required to yield student success, is used as a qualifier as opposed to standardized tests and the use of a discrepancy model.

Therefore, in order to effectively stimulate increased parental participation, there needs to be legal mandates added to IDEA that allow for parental assessment and feedback of the IEP process. Successful renovations in future reauthorizations of IDEA targeting parental participation would hopefully result in improved measures of parental satisfaction. For example, if IDEA required that following every IEP meeting with parents, a confidential satisfaction survey would be completed by the parents and their feedback would be given to the school. If these surveys yielded negative feedback, the schools would presumably work harder to gain positive feedback in regards to parental satisfaction. If parental satisfaction surveys were to be a part of a monitoring system it could encourage education systems to develop practices to address satisfaction levels of parental participation and their involvement at meetings.

This follow up study strongly suggests that in order to assure we have adequate parental participation in the special education of children, more attention must be directed at specific strategies to assure this outcome. Currently, the intent of IDEA is to encourage and support parental involvement in all aspects of a child's special education program; however, it appears

there is no catalyst present to evoke this type of equitable involvement. Perhaps if measures of parental satisfaction regarding their participation in the IEP process were part of the equation, school practices might make some positive changes.

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# Perceptions of Parents of Children with Autism Spectrum Disorders Towards Their Partnerships with Teachers

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## Abstract

The purpose of this study was to investigate the parent perceptions of partnerships between parents of children with autism spectrum disorders (ASD) and teachers who provided services. The instrument used in this study was the *Beach Center Family-Professional Partnership Scale (Family Version)*. The results showed that parents of children with ASD were close to satisfied with their partnerships with teachers, but they were more satisfied with family-focused relationships rather than child-focused relationships. Two family demographic predictors that contributed significantly to family-professional partnership were the age of the first child with ASD and type of school services received.

# Perceptions of Parents of Children with Autism Spectrum Disorders Towards Their Partnerships with Teachers

It is important for educational professionals to establish positive partnerships with families of their students (Blue-Banning, Summers, Frankland, Nelson, & Beegle, 2004; Dunlap & Fox, 2007; Summers et al., 2005). These positive partnerships are mutual supportive relationships built among families and professionals with the goal of meeting the needs of both children and their families (Summers et al., 2005). The importance of these positive partnerships between families of children with disabilities and the educational system is reinforced by the Individuals with Disabilities Education Act (IDEA, 2004), and this concept has been incorporated in one of the six principles of the IDEA (2004) focused on developing and implementing special education programs (Blue-Banning et al., 2004; Summers et al., 2005). Parental involvement in educational decision-making is mandated in this legislation.

As the prevalence of autism spectrum disorders (ASD) increases, the demands for educational professionals to provide services for students with ASD and their families have risen (Stoner & Angell, 2006; Stoner et al., 2005; White, 2014). Partnerships between families and professionals are critical for the success of all students (Giovacco-Johnson, 2009; Hindman & Morrison, 2011; Stevenson & Baker, 1987), including students with ASD. Unfortunately, although parent-professional partnerships have been addressed in federal policy, parents of children with ASD continue to express that they are not satisfied with the school services provided to their children (Fish, 2006; Starr & Foy, 2012; Stoner & Angell, 2006). White (2014) examined a total of 97 complaint investigations filed by parents of children with ASD in a Midwestern state of the United States from January 2004 to January 2009 to identify the most frequently complaint issues. Common complaint issues included (a) problems with content and implementation of the individualized education program (IEP), (b) parental involvement, (c) procedures of evaluation and services determination, (d) qualifications of teachers, paraprofessionals, and other school

staff serving students with ASD, and (e) behavior management and disciplinary procedures (White, 2014). White (2014) noted the issues regarding parental participation and proposed the importance of fostering honest, trustful, and respectful relationships with parents of students with ASD.

Aligned with the above complaint investigations, parents of children with ASD also reported negative experiences they had in IEP meetings and felt that they were not viewed as equal partners in the IEP process (Fish, 2006; Starr & Foy, 2012). Additionally, many parents of children with ASD believe that they are not welcome and that the educational system often views them as hostile, demanding, and adversarial (Stoner & Angell, 2006). It can be seen that these parents still believe that they do not have equal power in their relationships with teachers (Hodge & Runswick-Cole, 2008). The development of the positive partnerships between parents and educational professionals is certainly not easy. Thus, to establish partnerships between families of children with ASD and educational professionals is a critical issue to address (Stoner et al., 2005).

In order to establish positive partnerships between families of children with ASD and educational professionals, the first step that needs to be taken is to understand parental perceptions of their relationships with educational professionals who serve them and their children with ASD. In addition, research is needed to understand the relationship between family demographic variables and family-professional partnerships to identify ways for improving the relationships and meet the needs of each individual family. Although many studies have explored these issues, most studies regarding family-professional partnerships between families of children with ASD and educational professionals conducted in the United States have a small sample size and/or are qualitative studies (e.g., Fish, 2006; Stoner & Angell, 2006; Stoner et al., 2005; Spann, Kohler, & Soenksen, 2003). For example, Fish's (2006) study used seven participants from one family support group chapter to investigate perceptions of parent of students with ASD towards the IEP meeting, and both studies of Stoner and Angell (2006) and Stoner et al. (2005) used eight parents of children with ASD to investigate parent perceptions and roles when they monitored their children's educational programs and interacted with school professionals. The results of these studies seem difficult to generalize to other populations. It is therefore timely to extend these studies to include a larger sample of parents of children with ASD. This will allow more generalization of results and will help schools develop systems and policies to support the improvement of parent-professional partnerships. The current study expanded the participant pool and used a quantitative method to investigate the current status of partnerships between families of children with ASD and teachers as perceived by parents of children with ASD. Specifically, this study evaluated the difference in parental satisfaction between child-focused relationships and family-focused relationships, and the relationships between family demographic variables (e.g., ethnicity, education, income, marital status, age of the child with ASD, and type and length of services received) and family-professional partnerships. The research questions that guided the current study were as follows:

- 1. How did parents perceive the quality of their relationships with teachers who work with them and their children with ASD?
- 2. Was parental satisfaction different between child-focused relationships and family-focused relationships?

3. Could the satisfaction of the family-professional relationships as perceived by parents be predicted from their ethnicity, education, income, marital status, age of the child with ASD, and type and length of services received?

#### Method

In order to answer the proposed research questions, a survey research design was used to collect information about the perceptions of parents of children with ASD in regards to their partnerships with teachers who provided services to them and their children with ASD.

## **Participants**

The participants of this study included parents with at least one child with ASD. Parents were recruited through the assistance of four sources, including an ASD center, two ASD organizations, and an ASD service provider in a southwestern U.S. state. There were 230 valid surveys finished by parents of children with ASD in this study. Of these participants, 85.7% were female (n = 197) and 14.3% were male (n = 33). Over half of the participants were White (n = 152, 66.1%). A majority of participants were married (67.4%), 21.8% were divorced or separated, and 9.8% were never married, widowed, or living with a partner. About 50% of participants had a bachelor's degree or higher. In terms of the total household income, 17% of participants had an income of less than \$29,999, 15.7% earned between \$30,000 and \$49,999, 23.9% earned between \$50,000 and 69,999, and the remaining 42.2% made more than \$70,000. Some parents had more than one child with ASD in their families; a total of 260 children with ASD were reported from these parents. Of the children with ASD, there were 215 boys (82.7%) and 45 girls (17.3%), aged younger than 5 (29, 11.2%), 5 to 12 (145, 55.8%), 13 to 18 (62, 23.8%), and older than 19 (23, 8.8%), and 1 (0.4%) was missing. More specific demographic information for participating parents and information on their children are shown in Table 1.

Table 1 Family Demographic Information

Characteristics	Number of Parents (%)
Gender	
Male Female Ethnicity	33 (14.3) 197 (85.7)
White (non-Hispanic)	152 (66.1)
African American	13 (5.7)
American Indian or Alaska Native	0 (0.0)
Asian Native Hawaiian/Pacific Islander	12 (5.2) 4 (1.7)
Hispanic or Latino	27 (11.7)

Two or more races Other	17 (7.4) 5 (2.2)
Relationship status of parent(s) in household	155 (67.4)
Married	155 (67.4)
Widowed Divorced	5 (2.2) 39 (17.0)
Separated	11 (4.8)
Never married	10 (4.3)
Living with a partner	10 (4.3)
Educational background	10 (1.5)
No high school diploma or GED	4 (1.7)
High school graduate (diploma or GED)	36 (15.7)
Postsecondary, but no degree	48 (20.9)
Associate's degree	25 (10.9)
Absociate 5 degree	25 (10.5)
Bachelor's degree	71 (30.9)
Graduate degree	46 (20.0)
Total household income	44 (4.0)
\$ 10,000- \$ 19,999	11 (4.8)
\$ 20,000- \$ 29,999	28 (12.2)
\$ 30,000- \$ 39,999	17 (7.4)
\$ 40,000- \$ 49,999 \$ 50,000- \$ 59,999	19 (8.3)
\$ 50,000- \$ 59,999 \$ 60,000- \$ 69,999	28 (12.2) 27 (11.7)
≥ \$ 70,000	97 (42.2)
Missing	3 (1.3)
Number of children with ASD	3 (1.3)
Male	215 (82.7)
Female	45 (17.3)
Age of children with ASD	<b>\</b>
< 5	29 (11.2)
5- 12	145 (55.8)
13-18	62 (23.8)
> 19	23 (8.8)
Missing	1 (0.4)
Type of therapy received in school	
ABA (Lovaas, DTT, etc.)	47 (20.4)
Floortime/RDI	9 (3.9)
Speech therapy	142 (61.7)
Denver early childhood	6 (2.6)
Other	73 (31.7)
None of the above	58 (25.2)

Length of therapy received in school weekly

0-5 hours	126 (54.8)
6-15 hours	22 (9.6)
16-25 hours	9 (3.9)
26-40 hours	14 (6.1)
> 40 hours	1 (0.4)
None	58 (25.2)

Note. Percentage for Number and Age of children with ASD was calculated using the number reported divided by the total number of children reported (n = 260). Some families have more than one child with ASD. Because parents checked all that apply for the item Type of therapy received in school, percentage for this demographic information was calculated using the number of parents reported divided by the total number of valid cases (n = 230).

#### Instrumentation

The Beach Center Family-Professional Partnership Scale (Family Version) (Summers et al., 2005) was the main instrument used in this study to examine the parental perceptions of satisfaction with partnerships between them and the teachers who served their family and child with ASD. This 18-item scale is comprised of two subscales: Child-Focused Relationships and Family-Focused Relationships. Each subscale has nine items. Parents were asked to rate their satisfaction concerning their partnerships with the main teacher who worked with their children with ASD over the past six months. They rated each item on a 5-point Likert scale from 1 to 5 (i.e., very dissatisfied, dissatisfied, neither satisfied nor dissatisfied, satisfied, and very satisfied).

In addition to the items on the *Beach Center Family-Professional Partnership Scale (Family Version)*, the survey also contained background information for the researcher to obtain family demographics from participating parents. This information included gender, ethnicity, educational background of the parent, relationship status of the parent(s) in household and total household income. These parents also self-reported information about their children with ASD, including number of children with ASD living in the home, gender and age of their children with ASD, type of therapy their children received in school, and weekly length of therapy received in school.

## **Data Collection and Analysis Procedures**

A web-based survey software, *Qualtrics* (Qualtrics Labs Inc., 2009), was used to distribute and collect data. Invitations to participate in the study were made with the support of the four aforementioned ASD organizations; these organizations distributed the e-mails that invited parents to participate in the survey.

The analysis was computed using the *Statistical Package of Social Science* (SPSS). The research questions guided the data analysis. The mean score and standard deviation were used to calculate the descriptive statistics of the scale. A dependent *t*-test was used to examine the difference between child-focused and family-focused relationships as determined by parental satisfaction related to family-professional partnerships with teachers. A stepwise multiple regression analysis was conducted to determine which variables contributed significantly to the family-professional relationships. Dummy coding was employed to recode categorical variables: ethnicity (White vs. non-White), educational level (postsecondary, but no degree and undergraduate vs. associate's

degree and above), and relationship status of parents (parents who were married or living with a partner vs. one-parent family). Age of the first child with ASD and the type of services received in school were treated as continuous variables. Income level was recoded. Total household income level from  $\leq$ \$19,000 to \$49,999 was recoded as one, from \$50,000 to \$69,999 was recoded as two, and  $\geq$  \$70,000 was recoded as three. Length of services received in school was recoded. When the family received no service, it was recoded as one, 0-15 hours was recoded as two, and 16 hours and above was recoded as three. Alpha level was set at .05.

#### Results

The mean scores and standard deviations for each individual item, subscales, and whole scale of the *Beach Center Family-Professional Partnership Scale* perceived by parents of children with ASD were shown in Table 2. Examination of the grand mean score across 18 items of the scale revealed that overall, parental satisfaction of their partnerships with teachers was relatively positive (M = 3.68, SD = 1.04), with a range from 3.17 (SD = 1.28) to 4.12 (SD = .95). In the subscale, the average mean scores for child-focused relationships (M = 3.54, SD = 1.13) and family-focused relationship (M = 3.82, SD = 1.00) were relatively positive as well. Two items rated the lowest mean scores among all items were in the subscale of child-focused relationships. These two items were the item, "your child's teacher helps you gain skills or information to get your child's needs" (M = 3.17, SD = 1.28), and the item, "your child's teacher provides services that meet the individual needs of your child" (M = 3.23, SD = 1.32).

Table 2
Descriptive Statistics of the Family-Professional Partnership Scale as Perceived by Parents

Scale	M	SD
Child-focused relationship	3.54	1.13
Your child's teacher		
Helps you gain skills or information to get your child's needs.	3.17	1.28
Has the skills to help your child succeed.	3.40	1.29
Provides services that meet the individual needs of your child.	3.23	1.32
Speaks up for your child's best interests when working with other staff.	3.44	1.25
Lets you know about the good things your child does.	3.64	1.32
Treats your child with dignity.	3.82	1.19
Builds on your child's strengths.	3.62	1.25
Values your opinion about your child's needs.	3.69	1.22

Keeps your child safe when your child is in his/her care.	3.87	1.14
Family-focused relationship	3.82	1.00
Your child's teacher		
Is available when you need him/her.	3.63	1.22
Is honest, even when there is bad news to give.	3.77	1.14
Uses words that you understand.	4.12	.95
Protects your family's privacy.	3.93	1.00
Shows respect for your family's values and beliefs.	3.90	1.08
Listens without judging your child or family.	3.74	1.16
Is a person you can depend on and trust.	3.60	1.26
Pays attention to what you have to say.	3.72	1.21
Is friendly.	3.99	1.06
Grand total	3.68	1.04

A dependent *t*-test was used to examine the difference in parental satisfactions between child-focused relationships and family-focused relationships. The result indicated that there was a significant difference in parental satisfaction between child-focused relationships and family-focused relationships (t = -9.34, p < .001). That is, parents reported higher satisfaction with family-focused relationships than child-focused relationships.

A multiple regression analysis was conducted to predict perceived family-professional partnerships based on (a) ethnicity, (b) education, (c) income, (d) marital status, (e) age of the first child with autism, (f) type of services received, and (g) length of services received. The results indicated that the two variables that contributed significantly to the family-professional relationships were age of the first child with autism ( $\beta$  = -.188, p < .01) and type of school services received ( $\beta$  = .154, p < .05). The overall percentage of variance explained by these two variables was 6.8%. That is, as the age of the child with ASD got older, the parental satisfaction of family-professional partnerships decreased, and as the family of the child with ASD received more types of services in school, the perceived parental satisfaction of the family-professional relationships increased.

#### Discussion

The primary purpose of this study was to investigate parents' perceptions of their relationships with teachers who worked with them and their children with ASD. The findings of the present study indicate that parents of children with ASD were close to satisfied with the professional partnerships they had with teachers who served them and their children. These relatively positive satisfaction ratings are consistent with a previous study focused on parents of young children with disabilities (Summers, Hoffman, Marquis, Turnbull, & Poston, 2005). However, due to the grand mean score in this study being only close to the scale of satisfaction (i.e., lower than 4), it can be concluded that parents still believe there is room for improvement in the familyprofessional partnerships developed. Specifically, parents rated the item, "your child's teacher helps you gain skills or information to get your child's needs" and the item, "your child's teacher provides services that meet the individual needs of your child" with the mean scores close to "neither satisfied nor dissatisfied" in the domain of child-focused relationships. This implies that teachers might need to make more efforts in helping parents gain skills or information to meet their child's needs, and may need to develop an understanding of individual student's needs so that they can provide appropriate services. In addition, teachers might need to understand what parents' needs are first so that their help can meet those needs and find ways to support parents in gaining information and skills relative to identified needs. It could happen that teachers thought that they had made efforts to help parents, but parents thought that what teachers helped were not what they wanted.

The second finding from this study was that parents of children with ASD were more satisfied with family-focused relationships than child-focused relationships. This result is consistent with the work of Spann et al. (2003) concerning parents' involvement in, and perceptions of, their children's special education services. Spann et al. (2003) found that the majority of parents reported high to moderate satisfaction with the communication that they had with their children's school. However, many parents also indicated that their children's school did not address, or minimally address, the most pressing needs of their child. To explain this more elaborately, it is important to focus on the results of the subscales. The subscale of family-focused relationships focused on respectful and supportive programs for the family as a unit, and communication as one of the most important elements (Summers et al., 2005). The subscale of child-focused relationships emphasized attitudes, activities, and services for the child with a disability, particularly children with ASD. More specifically, these items concern the professionals being reliable and competent to provide services that meet a child's specific needs (Summers et al., 2005). Thus, the results of this study may imply that parents believe that teachers make efforts to communicate with them but do not address what parents consider the most pressing needs or priorities of their children with ASD. This result implicates that in order to improve the childfocused relationships, as mentioned above, teachers may need to understand what parents' most pressing concerns/priorities are for their children and what skills or competencies parents think that their children need the most help with (Spann et al., 2003).

The final important finding of this study was related to any variables that were predictors of parental satisfaction with their family-professional partnerships. These results indicated that two family demographic variables were statistically significant predictors of family-professional partnerships. They were the age of the first child with ASD and the type of services children

received in school. The results indicated that as a child with ASD got older, parental satisfaction with their family-professional partnerships decreased, and as the child with ASD received more types of school services, the parents rated their family-professional partnerships at a higher level. The finding that the age of the first child with ASD was a predictor of family-professional partnerships supports previous research that parents of older children with disabilities report lower levels of satisfaction with their partnerships with professionals (Spann et al., 2003; Summers et al., 2005). There are two potential explanations for this outcome. One is that teachers of students with ASD at different ages may develop partnerships with parents in different ways in terms of their compassion and willingness to accommodate children's individual needs (Spann et al., 2003); the other is that parents of older children with ASD may have engaged in more conflicts with teachers and this could lead to unreasonable expectations or negative views of teachers in their ability to show care and concern for their children with ASD (Spann et al., 2003). However, these explanations need to be further examined in detail. The result of the type of services received in school as a predictor of family-professional partnership could be explained using the study by Summers et al. (2007) in which the data indicated that the adequacy of service provision in early childhood programs was a significant predictor for familyprofessional partnerships. These results implicate that teachers may need to understand the age of the children and the type of services they receive prior to recommending services to parents and their children with ASD. However, in the current study, these two variables (e.g., age of the child with ASD, school services received) accounted only for a small portion of variance. This indicates that there are other factors related to family-professional partnerships that may impact the relationships more. Further research is needed to identify these factors.

Several limitations in this study should be acknowledged. As the data in this study were only collected in a southwest state of the United States, the representativeness of the sample is confined. For example, the majority of the participating parents in the current study were White and about half of them have a total household income more than \$60,000. Findings should not be generalized across the entire population of parents of children with ASD. Further studies need to recruit more varieties of participants in terms of different family demographic variables. Also, only parents with access to the internet were able to complete the survey. These parents might not represent those who were unable to access to internet.

In conclusion, the present study contributes to the current literature as it offers an overview of parental perceptions of satisfaction with the relationships with teachers who served them and their children with ASD, and identifies potential predictors related to their partnerships. Understanding the current status of partnerships between parents of children with ASD and teachers helps teachers further identify the strengths and weaknesses of the development of partnerships and helps professionals work toward improvement of the partnerships.

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Brain Gym: Pseudoscientific Practice

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#### Abstract

There is an abundance of scams and pseudoscientific practices promising seemingly magical cures for whatever ails a person. A short viewing of late night television will readily reveal a whole host of scams that may be more effective at relieving the viewer of the cash in his or her pocket than alleviating any unwanted symptoms. Unfortunately, ineffective practices are not only advertised on late night television, sometimes, children who are compelled to attend school are forced to participate in practices that waste valuable instruction time. This paper will provide a brief review Brain Gym which is one commercial program used in schools in over 80 countries under the assumption that it will improve student learning and a whole host of other skills, without actually teaching the skills. There is no quality empirical evidence supporting this claim, yet schools continue to expend valuable time and fiscal resources on such programs.

## Brain Gym: Pseudoscientific Practice

In the United States and across the globe, teachers are being called upon to integrate best practice with scientific evidence to provide a quality educational experience for the children with whom they work. In the US, specifically, two federal laws, the No Child Left behind Act of 2001(NCLB) and the Individuals with Disabilities Education Act of 2004 (IDEA), require schools to provide students with academic instruction using scientific, research-based methods whenever possible. Unfortunately, teachers have difficulty following these laws when they lack the skills needed to determine whether a particular practice has a sound scientific basis. While there is debate in the field regarding the level of scientific rigor needed for a particular methodology to be judged as evidence-based or research-based, there are general guidelines that can be used by individuals who may not have a high level of training in research methodology to determine the likelihood that a particular educational intervention may have merit (Cooper, Heron, & Heward, 2007; Cozby, 2007; Kazdin, 2011; Moran & Malott, 2004). Some of these guidelines include: 1) the findings of controlled research studies should be published in high quality peer-referred journals, 2) the findings should be replicated in subsequent studies to help demonstrate that the changes in performance were related to the intervention and didn't happen by chance or due to some unknown environmental factor, and 3) the body of research is conducted by impartial researchers. Some indications that the program has not been supported by impartial research include the following: 1) the intervention program became popular due to its portrayal in the media before receiving research support, 2) the body of research associated with the program was primarily conducted in-house by individuals or organizations who had a

vested interest in the program, 3) the evidence provided was primarily anecdotal in nature (anecdotal stories may be interesting but cannot serve as a substitute for research), 4) the program purports nearly miraculous results with little or no effort on the part of the subject, and 5) the program is based upon previously discredited theoretical propositions. Finally, it is important to recognize that the responsibility of demonstrating the efficacy of the program rests with the developer not the consumer.

Brain Gym is one popular program that has failed to provide research support for its use (Hyatt, 2007; Spaulding, Mostert, & Beam, 2010). The developers claim that performing simple movements will improve intellectual and physical development, bringing swift improvements in areas such as reading and writing. They go further with their claims and state that Brain Gym activities will help a wide array of activities such as salesmanship, surfing, attention deficit (Official Brain Gym Website, 2005), discipline, fine motor control, and vision improvement for seniors (Brain Gym International Website, 2011). Perhaps due to these claims or due to simple ignorance and gullibility, Brain Gym has gained a large amount of support amongst educators in the United Kingdom, United States, and as well as other countries. This paper will provide a brief review of the Brain Gym program (for in-depth reviews, see Hyatt, 2007; and Spaulding, Mostert, & Beam, 2010) and present evidence why the program itself should not be considered a scientific, research-based method to be used in a classroom environment by educators. This paper will contain a brief review of the assumptions made by Brain Gym and its failed theoretical foundations (neurological repatterning, cerebral dominance and perceptual-motor training) (Hyatt, 2007; Spaulding, et al., 2010).

Brain Gym is based on a simplistic view of neurological functioning and promotes the view that learning problems arise due to the inability of different parts of the brain to work in a coordinated manner (Hyatt, 2007). This means in order to have different sections of the brain operate in a coordinated manner, an individual needs to activate his or her mind by using different movements that integrate the specific brain functions. As Stephenson (2009) noted, the Brain Gym program consists of 26 exercises claimed to bring about "rapid and often dramatic improvements in concentration, memory, reading, writing, organizing, listening, physical coordination and more" (p. 110). According to the Brain Gym website, these 26 exercises assist with three aspects of the brain's functioning, based on their over-simplified and questionable view of brain operation. One aspect is *laterality*, which refers to the coordination between the right and left hemispheres of the brain, particularly relevant to reading, writing, listening, speaking, and the ability to move and think at the same time. Another aspect is focusing, which refers to coordinating the front and back section of the brain in order to affect ones comprehension and attention-deficit/hyperactivity disorders. Finally, the last aspect, centering, refers to the coordination of the top and bottom of the brain that is necessary to balance rational thoughts with emotion (Hyatt, 2007). One of the main theoretical foundations of Brain Gym® is the suggestion of *neurological repatterning*. This refers to the belief that the development of the individual must encompass all the developmental stages of the species, from primitive to complex in order for efficient neurological and intellectual development (Spaulding, et al., 2010). If motor skills associated with a developmental stage were skipped by a child, then the neurological development could also be stalled and learning abilities limited (Doman, 1968). According to this theory, if a child learned how to walk before he or she learned how to crawl properly, his or her learning could be negatively impacted. Belief in this theory could encourage

educators to deem that if their students are having difficulty in reading, the skill may be improved by re-teaching the children how to crawl appropriately instead of requiring the teacher to re-evaluate his or her teaching practice and curriculum. Since the foundational belief is that the problem resides in the child's faulty neurology, the child would be provided with exercises that mimic the primitive motor development missed during infancy and/or toddler years in order to ensure that movements at all stages of development are mastered correctly. The proponents of repatterning, also called Doman-Delacato procedure, failed to provide evidence supporting their theory. In a review of the Doman-Delacato procedures, MacKay, Gollogly, and McDonald (1986) clearly described the different crawling treatments associated with the procedure and noted that the program was not effective in improving performance in children with disabilities. In 1968 and again in 1998, the American Academy of Pediatrics published strongly worded and unequivocal warnings regarding the use of the neurological repatterning intervention and noted that inclusion of ineffective, pseudoscientific practice should be incorporated in medical training programs to ensure that new physicians are aware of the failures of the past, thereby, decreasing the likelihood of those practices being used at a future point in time. So for educators, the message seems clear, rather than teaching students how to crawl and hoping that will improve academic skills, educators must implement interventions that have actually been supported by scientific, research-based studies and are related to the skill being taught. For example if one wants a child to crawl, teach him or her to crawl, but if one wants a child to read, teach him or her to read using evidence-based interventions to the extent they are available.

Cerebral dominance is a second theoretical foundation of Brain Gym that has failed to meet the rigors of scientific inquiry. Cerebral dominance refers to the idea that reading difficulties resulted from problems with cerebral dominance, particularly prevalent among individuals who were left-handed, left-footed, or had mixed cerebral dominance (Orton, 1937, Spaulding, et. al 2010). This belief, while not supported by the research (Mayringer & Wimmer, 2002; Mohan, Singh, & Mandal, 2001), forms a basis for many of the Brain Gym exercises. An example of an intervention focused on cerebral dominance would be teaching students the names or sounds of letters by having them trace or write the letters in the air as well, similar to the *Lazy Eights* activity in Brain Gym as described by Spaulding, et. al (2011).

Perceptual-motor training is the third major theoretical foundation of Brain Gym in which little to no empirical evidence has been shown to date (Kavale & Mattson, 1983). Perceptual-motor training is based on a belief that learning problems are related to the faulty integration of perceptual and motor skills (Hyatt, Stephenson, & Carter, 2009). The Doman-Delacato repatterning procedure previously discussed is technically a perceptual-motor program, but was presented separately due to its unique focus on crawling and absolute failure to remediate skill deficits. As with the other foundational concepts of Brain Gym, perceptual motor programs assume that the difficulty resides within the child, and the appropriate perceptual skills should be taught to the student to enable the child to overcome their learning problem(s). Some of the strategies used in order to improve perceptual-motor skills and improve learning have included activities such as crawling, walking on a balance beam, jumping, bouncing balls, and activities similar to carnival games, but none directly related teaching the target academic skill. Overall, increased ability in the above skills were assumed by Brain Gym to result in a more efficient reading ability. However, to date a considerable amount of research has failed to demonstrate that perceptual-motor training activities are effective academic interventions. Nevertheless,

"Despite little evidence validating the efficacy of perceptual motor training or substantiating perceptual-motor assessments for predicting later reading ability, it continues to have intuitive appeal for BGI (Brain Gym® International)" (Spaulding, et al., 2010, p. 21). Similarly, Salvia and Ysseldyke (2007) note the "appalling lack of empirical evidence" supporting the use of perceptual motor training programs as academic interventions (p. 377).

Ultimately, while a great deal has been written about the Brain Gym program and its applications in academics, it has generally been written in-house and published through Brain Gym's own magazine and/or not been subjected to careful and rigorous investigation. Most reports claiming the program's efficacy are testimonials, such as:

We cannot believe the improvement in our daughter after five sessions with you. Before we were referred to you, our daughter Abigail, age 8, could not tie her shoes without help, could not ride her bike without training wheels, and was having a difficultly reading at her grade level. Since working with you, Abigail is riding her bike without assistance and training wheels. She is tying her shoes by herself, but most important her reading rate and reading fluency have greatly increased, which has also increased her reading comprehension... we feel that Brain Gym® provided the missing link so that Abigail's body could integrate all the previous therapy. Because of your work, Abigail has made huge improvements academically and socially in a very short time period. (Brain Gym, 2011)

As noted by Spaulding, et al., (2010) when discussing testimonial evidence, "While these testimonials are persuasive, passionate, and compelling, they do *not* meet the established criteria for quality research in special education ... articles are descriptive explanations of what an individual experienced through participating in BGI activities or how an educator, caregiver, or trainer used BGI activities with individuals in their workplace" (p. 26).

In conclusion, given the limited time children are able to spend in the classroom environment, educators need to implement practices that have been validated by empirical research and not waste valuable time participating in the nuisance of Brain Gym or other pseudoscientific interventions that claim to provide a magical cure for all that ails humanity. As with the recommendation from the American Academy of Pediatrics regarding training of new physicians in the ineffective fads of the past, it seems that educators must also receive training in past fads lest they continue to commit the errors of the past. In addition, they must be informed of past failures since the practices are commonly re-packaged and marketed through slick advertising campaigns. Barring research that does support the efficacy of Brain Gym, its use as an academic intervention should be abandoned.

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# Additional Biography

<u>www.badscience.net/category/brain-gym/</u> This site provides access to a website called bad science. It is a nice place to check when investigating the efficacy claims of many practices that appear to be controversial or pseudoscientific.

<u>www.youtube.com/watch?v=M5rH7kDcFpc</u> This is a link to part 1 of an eye-opening investigation and review of Brain Gym practice in the United Kingdom. In 2008, Jeremy Paxton from Newsnight conducted this approximate 9 minute review.

<u>www.youtube.com/watch?v=YjRhYP5faTU</u> This is the link to Part 2 of the Newsnight review in which the founder of Brain Gym, Paul Dennison, is interviewed by Jeremy Paxton. This testy interview lasts about 5 minutes.

<u>www.thesekpticsguide.org</u> This site does not address Brain Gym, but is a great source of information for scientific inquiry and logical argument. They even have a free podcast. The leader of the group, Dr. Steven Novella, is neurologist at Yale University School of Medicine.

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# Housing and Independent Living for Individuals with Intellectual and Developmental Disabilities

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#### Abstract

This manuscript provides a review of housing and independent living options for individuals with intellectual and developmental disabilities (I/DD). While there has certainly been an increased emphasis on community integration and inclusion for people with I/DD, barriers to delivering housing supports and services in natural, integrated settings still exist. An overview of the various housing options that are currently available for individuals with I/DD is provided followed by a discussion of the main themes related to promoting full community integration and funding sources that are available to support these efforts. This essential information will help special education teachers involved in delivering transition services and supports better plan with students and families as they consider independent living options upon graduation from high school.

# Housing and Independent Living for Individuals with Intellectual and Developmental Disabilities

Historically, housing for individuals with intellectual and developmental disabilities (I/DD) mainly consisted of forced institutionalization without consideration for the individual's preferences, hopes, dreams, or quality of life (Prouty, Smith, & Lakin, 2006). Throughout the past several decades, national and international perspectives on housing for individuals with I/DD has continued to focus more and more on the use of person-centered planning approaches, the development of self-determination skills, quality of life considerations, and reducing inequalities (Bradley, Ashbaugh, & Blaney, 1994). However, there continue to be major barriers to providing safe, affordable, accessible, and integrated housing for individuals with I/DD. Public policy and programs often tend to promote more segregated living options due to funding issues and inflexibility with the use of Medicaid funds. This manuscript provides an overview of housing and independent living options for individuals with I/DD. This essential information will help special education teachers involved in delivering transition services and supports better plan with students and families as they consider independent living options upon graduation from high school.

#### AAIDD Position Statement

It is important to utilize the work of professional organizations that have a strong history of leadership and advocacy in the field of intellectual and developmental disabilities when developing plans and strategies to overcome housing barriers for individuals with I/DD. The American Association on Intellectual and Developmental Disabilities (AAIDD) is such a leading

organization. In 2012, AAIDD adopted a position statement related to housing for individuals I/DD. Excerpts from this position statement are provided in Table 1. Go to <a href="http://aaidd.org/news-policy/position-statements/housing#.UrIBQSivSJg">http://aaidd.org/news-policy/position-statements/housing#.UrIBQSivSJg</a> to view the complete position statement. Unfortunately, there is much work to be done for AAIDD's position statement to become a reality in communities across the nation and throughout the world. However, it is essential that advocates do not lose sight of what individuals with I/DD should have access to when it comes to housing and community living regardless of the ongoing challenges of existing options.

#### Table 1

### AAIIDD Position Statement

# Excerpts from AAIDD Position Statement on Housing for Individuals with I/DD

People with I/DD have the right to live in safe, accessible, affordable housing in the community.

People must have freedom, authority, and support to exercise control over their housing, including choice of where and with whom they live, privacy within their homes, access to flexible supports and services when and where they choose, choice in their daily routines and activities, freedom to come and go as they please, and housing that reflects their personal preferences and styles.

Housing should afford people with I/DD the opportunity to interact with people without disabilities to the fullest extent possible.

The health and safety of people with I/DD must be safeguarded wherever they live, but should always be balanced with the right to take risks and exercise choice and control.

To ensure that people with I/DD can make informed decisions about where and with whom they live, they and their families must be given understandable information about the benefits of living in the community, have the chance to visit or have other experiences in community settings, have opportunities to meet other people with disabilities who are living in the community, and have any questions or concerns addressed.

Adults with I/DD should receive the supports they need to transition out of the family home when they wish to do so.

Housing for people with I/DD must be coordinated with home and community-based support systems, including transportation services, and should ensure access to other typical public resources.

There must be adequate funding of services to support people to live in the community. Funding must be stable and not subject to arbitrary limits or cuts. People with I/DD must not be subjected to unnecessary institutionalization or removal from their homes and communities due to state budget cuts.

Public policy should promote small, typical living situations for people with I/DD. Information about innovative housing models that promote independence should be widely disseminated.

Housing for people with disabilities should be scattered within typical neighborhoods and communities, and should reflect the natural proportion of people with disabilities in the general population.

Public funds must be shifted from restrictive institutional settings to community supports, regardless of type or severity of disability.

Affordable housing options must be available to people with I/DD, including those with very low incomes.

Universal design should be adopted for all new housing..

People with I/DD have the right to be free from housing discrimination, and there must be robust education, outreach, and enforcement of that right.

## Housing Options

In the literature on housing for individuals with I/DD (e.g., Kim, Larson, & Lakin, 2001; Kozma, Mansell, & Beadle-Brown, 2009) there are a variety of terms used to describe the options available such as family housing, out-of-family housing, clustered housing (i.e. village communities, intentional communities, residential campuses), dispersed housing, group homes, and supported living, In the sections that follow, each of these terms will be described followed by a review of recommended practices and research findings for each of the options discussed. The main focus will be on examining the quality of life of individuals with I/DD living in various housing arrangements. Quality of life considers a variety of factors including emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, independence, self-determination, social inclusion, occupation, and rights (Felce 1997; Schalock et al., 2002).

## Family vs. Out-of-Family Housing

A large number of individuals with I/DD live in a family home supported by their parents or other relatives (Braddock, Emerson, Felce, & Stancliffe, 2001). This may be due to limited options for out-of-family housing, limited access to funding to support the needs of individuals with I/DD in out-of-family housing, and/or long waiting lists for options that are available for out-of-family housing. Most of the quality of life research for adults with I/DD has focused on those living in out-of-family supported accommodations (Seltzer & Krauss, 2001). There are mixed findings among the few studies focused on family vs. out-of family housing. A 2006 study (Stancliffe et al., 2006) analyzed self-reported satisfaction and well-being of individuals with I/DD living in six different states and reported higher ratings of well-being reported by those living with family members vs. those living outside of the family home. Specifically, adults with I/DD living in family homes were less likely to feel lonely, fearful, or sad and more likely to report liking where there were living than those who were not living with family members. Other studies (e.g., Krauss, Seltzer, & Goodman, 1992; Lunsky & Benson, 1999; McConkey, Naughton, & Nugent, 1983) comparing the quality of life of individuals with I/DD living in family homes vs. out-of-family homes indicate that those living in family homes often have limited contact with those living in their neighborhoods, and their leisure activities are often solitary in nature, passive, or are family dependent. A recent study in England (Felce, Perry, & Kerr, 2011) found that individuals with I/DD living independently had higher household participation than those living in family homes. Similarly, those living in staffed housing had higher household participation and did more community activities more frequently than those living in family homes.

Something that must be considered with family housing is that as older caregivers become unable to maintain their role in supporting the individual with I/DD, there is likely to be an increased demand for formal housing and support services for individuals with I/DD who are aging (Hogg, Lucchino, Wang, & Janicki, 2001). With the long waiting lists for such formal housing, this will not be a seamless transition. If individuals are supported in family housing vs. out-of-family housing, when it comes time that the family members are no longer able to provide the necessary care and support, the individual with I/DD must make a significant transition late in life as opposed to learning the skills required to live as independently as possible early on in supported living environments. A recent study (Shaw, Cartwright, & Craig, 2011) examined the housing and support needs of aging individuals with I/DD. Results indicated that many parents who provide family housing and support report that their adult child does not acquire the skills necessary for independent living when they can no longer support the individual in the family home.

#### **Clustered Housing**

Simply put, clustered housing means that individuals with I/DD are grouped together to live in close vicinity to one another forming a separate community from the surrounding population (Mansell & Beadle-Brown, 2009). There are three types of clustered housing: cluster housing, village communities, and residential campuses. Cluster housing entails a small number of houses on the same site within a wider community. For example, there may be three houses in which individuals with I/DD live that are very close to one another in a residential neighborhood. A village community is a self-contained community with services provided on site. Support

workers (who may be paid or unpaid) and their families live in the village communities with the individuals with I/DD. Residential campuses are similar to village communities but usually include individuals with more severe disabilities, and paid staff members provide support to residents.

Proponents of clustered housing (e.g., Cox & Pearson, 1995; Segal, 1990) suggest the following three advantages of this option: 1) those living in clustered housing have a better social life, 2) clustered housing provides safety to residents, and 3) the cost associated with clustered housing is lower than dispersed housing. However, a 2009 study conducted by Mansell and Beadle-Brown found that dispersed housing results in better outcomes than clustered housing for individuals with I/DD when examining the following quality of life domains: social inclusion, material well-being, physical well-being, self-determination, personal development, and rights. The only exception was that village communities resulted in better physical well-being outcomes than dispersed housing due to increased hours of recreational activity, contact with medical professionals, contact with family and friends, visitors to the home, and satisfaction with relationships. The only difference in the safety of the individuals with I/DD was that those living in village communities were less likely to have been victims of crime or verbal abuse by the general public than those living in dispersed housing.

# **Dispersed Housing**

The term "dispersed housing" refers to the model of providing housing and independent living supports to individuals with I/DD within the community. The apartments or houses in which the individuals live are scattered throughout residential neighborhoods (Mansell & Beadle-Brown, 2009). As far as cost is concerned, dispersed housing is likely to be just as expensive as clustered housing for individuals with high support needs. However, dispersed housing for individuals with low or moderate support needs is likely to be less expensive than clustered housing. Dispersed housing allows for a more individualized model of care in which residents only receive the supports they need rather than providing the same level of supports to all regardless of individual characteristics (Mansell & Beadle-Brown, 2009). This type of service delivery is referred to as targeted support and entails flexibility in staff allocation providing supports at the right level at the times when they are needed (Perry, Firth, Puppa, Wilson, & Felce, 2011). A study conducted in England (Emerson, 2004) compared cluster housing to dispersed housing and found that individuals with I/DD supported in cluster housing were more likely to be exposed to restrictive management practices such as seclusion, sedation, and physical restraint, and were also more likely to live sedentary lives with few leisure, social, and friendship activities than those living in dispersed housing. In general, the literature shows that dispersed housing offers a better quality of care and quality of life than clustered housing (Mansell, 2006).

**Group homes.** There are two main types of dispersed housing: group homes and supported living. Group homes are typically owned by a governmental or non-governmental organization. They house a small number of individuals with I/DD receiving support from full-time paid staff. With the de-institutionalization movement, more and more group homes have been established. Unfortunately, simply moving individuals out of large scale institutions into care facilities that are set up in single family homes, semi-attached homes, or apartment buildings doesn't

guarantee that residents living in group homes will be treated the same as other neighbors in the community (Mansell & Beadle-Brown, 2009).

Neighborhood opposition to the establishment of group homes still exists and is usually based on two beliefs or fears: 1) the group home will bring down the property value of the homes in the neighborhood, and 2) the invalidated perception that individuals with I/DD are "deviant" and may be a threat to their neighbors (Cook, 1997). Of course these beliefs and fears should not deter the development of group homes simply because of the uninformed public. There will continue to be neighbors who have those invalidated concerns, but there will also be neighbors who are supportive. In a study examining the views of people with I/DD about their neighbors, a group home resident indicated that there was a petition to prevent the development of a group home when neighbors learned of the plans. However, that was also a petition started to encourage neighbors to welcome the new residents (van Alphen, Dijker, van den Borne, & Curfs, 2009). In this same study results indicated the following:

- Residents who traveled in a group mini-van to work or community places had fewer interactions with neighbors than those who traveled by bicycle or public transport.
- Several residents indicated that staff would invoke rules that would inhibit the development of relationships with neighbors such as not being able to talk to strangers and not being able to go for walks.
- Many residents indicated that although they would like to interact with their neighbors, they do not feel comfortable making those initiations. They worry that they would not be understood and that they will feel different.

A follow-up study (van Alphen, Dijker, van den Borne, & Curfs, 2010) examined the relationships between individuals with I/DD living in group homes and their neighbors, identifying the following themes:

- The presence of staff often inhibited relationships between residents and their neighbors. Staff members who do not live in the home typically do not display the expected behaviors of neighbors. Unfortunately, the staff members are often more visible to neighbors than the residents themselves, so this disconnect can negatively impact neighbor relationships.
- The organization that manages the group home often has paid workers engaging in gardening and home maintenance activities instead of residents. This takes away possible opportunities for residents to interact with neighbors during such natural activities that typically result in casual interactions between neighbors.
- The high turnover of residents may deter neighbors from establishing relationships with residents since they may not stay in the home for very long.
- The presence of staff members may deter the development of relationships between individuals with I/DD and their neighbors because neighbors are likely to interact directly with staff members instead of the residents.

These findings suggest that staff members supporting individuals with I/DD in group homes need to reconsider the manner in which they are delivering services and interacting with the residents and neighbors. Involving residents in the day-to-day home maintenance activities,

teaching them ways to interact appropriately with their neighbors, and making themselves less visible to the neighbors whenever possible can help foster more meaningful relationships between residents with I/DD and their neighbors. Research shows that the more a group home resembles the neighbors' homes and the more functionally autonomous the residents, the greater the likelihood that there will be positive contact and recognition of similarities between individuals with I/DD and their neighbors (Makas, 1993).

**Supported living.** Supported living involves the individual with I/DD owning or renting his/her own home, sharing it with a roommate or roommates if desired, and receiving independent living supports from an agency if they choose to do so. Emerson and colleagues defined supported living as having no more than three people with I/DD living in the same residence (Emerson et al., 2001). The main difference between group homes and supported living is that with supported living, individuals with I/DD have the same housing rights as other citizens (Mansell & Beadle-Brown, 2009). Lakin and Stancliffe (2007) discuss several factors that define the differences between supported living and other housing options. These include:

- With supported living, the purpose is to shift the power to the individual with I/DD when
  it comes to making decisions about how they live, work, and participate in their
  communities.
- Living in one's own home changes how services are delivered because service delivery is not dependent on a relationship with a particular service provider. Instead the individual with I/DD controls who enters the home to provide support services.
- There is a focus on natural supports and efforts to limit formal support provided by paid staff. This shift to natural supports has led to some changes in funding provisions that allow payment to family members so that those that know the individual best are the ones providing supports to help the individual achieve their independent living goals.

Research shows that individuals with I/DD who live in smaller, individualized accommodations are more likely to engage in community activities and to have wider social networks than those living in congregated settings (Emerson et al. 2001; McConkey et al. 2007). Research also shows that supported living achieves better outcomes in some quality of life domains than group homes for individuals with low or moderate support needs (Stancliffe, 2004; Stancliffe & Keane, 2000). Individuals with I/DD who receive supported living supports in their own homes report a greater variety and frequency of community and social activities, more participation in preferred activities, better compatibility with living companions, and greater self-determination than those in more traditional group home settings (Howe, Horner, & Newton, 1998). However, social activities with typically developing peers or friends are not necessarily frequent simply because an individual with I/DD lives in the community (Cummins & Lau, 2003). Supports must be put in place to ensure the individual is not isolated. A great deal of collaboration and support among key stakeholders must be in place to achieve true integration within the community. A 2010 study (McConkey & Collins) indicated that paid staff hired to serve individuals in supported living arrangements place a greater emphasis on social inclusion than staff that work in group homes or in day programs. This study also found that part-time staff members are less likely to emphasize social inclusion than full-time staff members. Thus, training and support must be given to part-time staff members who provide supported living services to ensure they focus not only on care tasks but also on increasing the individuals' social integration in the community.

## Moving to a Focus on Community and Public Services

Historically, and presently, housing solutions for individuals with I/DD focuses on government funding to social service agencies. The reality is, however, that government funding alone is significantly insufficient, and this results in agencies having to seek funds from donors. Even when agencies put forth efforts to acquire funds beyond government allocations, long waiting lists for housing supports remains to be a great problem across the nation. When individuals are taken off a waiting list to receive housing supports, there are often limited choices when it comes to location of housing, types of living arrangements, level of support and integration into the community, and roommate selection. Thus, the narrow focus on service agencies needs to move to a more broad focus on community participation and public services (Lemon & Lemon, 2003).

**Microboards.** A fairly new approach for providing housing supports to individuals with I/DD is what is called a microboard. A microboard consists of a small number of family members, friends, advocates, and professionals who understand the individual's unique strengths and needs working collaboratively to provide housing supports to the individual with I/DD (Lemon & Lemon, 2003). When a microboard is established, government funds can be accessed to provide housing supports to the individual without the necessity of going through an established agency. This allows for a greater deal of person-centered planning as opposed to forced choices or no choices at all.

**Public services.** One of the greatest contributors to whether or not an individual with I/DD is enabled to live independently and experience true community integration is the quality of public services available in the geographical location in which the individual lives. Cities and towns that provide the following services and legislation to ensure access to services for individuals with disabilities create universal opportunities for the integration of individuals with I/DD (Lemon and Lemon, 2003):

- Public, cooperative, and private subsidized housing with legislation to ensure that an
  adequate amount of subsidized housing be dedicated specifically to individuals with
  disabilities.
- Affordable and accessible public transportation systems with legislation that guarantees that outlying areas be serviced with alternative transportation services as opposed to leaving certain rural areas without transportation services.
- Guaranteed employment projects that provides support to community-based entrepreneurial projects that target individuals with I/DD and/or legislation that requires employers to hire a certain percentage of individuals with disabilities.
- Incorporation legislation that allows community groups to develop innovative community projects that provide housing solutions for individuals with I/DD that do so in collaboration with individuals with I/DD and their caregivers.

It is essential that a broad perspective on community supports and public services be examined. Advocates should focus on initiatives to expand existing services and advocate for required legislation to continue to provide more equitable independent living options to individuals with I/DD.

# Main Themes Related to Supporting Independent Living

## **Self-Determination and Choice Making**

Choice making is an essential element of the self-determination movement (Wehmeyer, 2002), person-centered planning (Holburn & Vietze, 2002), and the Quality of Life approach (Stancliff, 1997, 2001). Specific housing choices for individuals with I/DD may include: 1) the choice to move out of a housing situation if the individual is unhappy, 2) the choice of roommates (if any), 3) the type of residence, and 4) the location of the residence (Stancliff et. al., 2011). The notion that individuals with I/DD should have opportunities to choose where, how, and with whom they live is widely endorsed but commonly denied. Research has shown that individuals with I/DD rarely choose where and with whom to live (Heller, Miller, & Factor, 1999; Lakin et al., 2008; Wehmeyer & Metzler, 1995). A recent study showed that 55% of individuals with I/DD do not choose where they live, 32% participate in the decision making process with support, and only 12% choose where to live without assistance. When examining the choice of living companions, 59% had no choice, and only 21% chose with whom to live without help (Stancliffe et al., 2011). Despite the fact that fewer individuals with I/DD are living in institutions and other group settings than ever before, since 1990 there has been only a 6% increase in individuals independently choosing where to live and 12% increase in choosing with whom to live (Wehmeyer & Metzler, 1995).

Individuals with I/DD are often restricted in their choice-making opportunities because of a lack of effective social networks (Mansell & Beadle-Brown, 2004). However, there is a very fine line between a supportive social network that enables choice making and a controlling social network that oppresses individual choice. Often, there is no clear distinction between the choices of the individual with I/DD and the choices of their family members. Case managers and administrators often accept the preferences of family members as representative of the preferences of the individual with I/DD (Wiesel & Fincher, 2009). It must be noted, however, that self-determination does not simply mean that individuals with I/DD always make their own choices without input or information from others. These individuals often benefit from the support from others during the decision-making process to assist them in making informed decisions as opposed to impulsive choices (Luckasson et al., 2002).

Individuals with I/DD may be limited in their choice making options related to where and with whom to live because of long waiting lists for residential services (Wiltz, 2007). Before individuals with I/DD ever visit potential homes or meet potential roommates, they are commonly placed on waiting lists (Davis, 1997). Polister (2002) analyzed how these waiting lists are managed and found that the factors considered when moving people off of waiting lists into residential accommodations include length of time on the waiting list, emergencies, risks in current living situations, severity of disability, potential service benefits, and age of care taker. Unfortunately, the individual's choice was not a considered factor.

Individuals with low support needs often have more available choices than individuals with high support needs (Fitzpatrick & Pawson, 2007; Stancliffe et al., 2011). Individuals living in their own home or an agency-operated apartment are more likely to have opportunities to choose where and with whom to live than those living in a group home (Stancliffe et al., 2011). Community living environments that are more individualized with fewer residents are associated

with more opportunities for choice making (Burchard, Hasazi, Gordon, & Yoe, 1991; Stancliffe, 1997; Stancliffe & Abery 1997; Stancliffe, Abery, & Smith, 2000; Stancliffe & Keane, 2000; Wehmeyer & Bolding, 1999). Individuals in supported living have more opportunities to choose where and with whom to live and also tend to rate higher in other areas of quality of life than those living in group homes (Emerson et al., 2001; Howe, Horner, & Newton, 1998).

Choice making is one aspect of self-determination. Self-determination also consists of the individual setting their own goals and evaluation their progress towards meeting those goals. According to Wehneyer, self-determination entails "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference" (Wehmeyer, 1996, p.18). Research shows that individuals with I/DD who have greater self-determination skills also have a greater quality of life (Lachapelle et al., 2005; Wehymeyer & Schwartz, 1998). Thus, those who provide supported living services need training related to enhancing the self-determination skills for individuals with I/DD.

## **Person-Centered Planning**

An important focus when supporting individuals with I/DD is to use person-centered planning protocols. This provides opportunities for individuals to share their dreams and set goals with their support teams so that a plan can be developed to assist the individuals in achieving the goals identified (Wigham et al., 2008). Several outcome studies have found that person-centered approaches can result in the individuals having greater choice, increased contact with friends and family, and more community participation (Holburn et al., 2004; Robertson et al., 2006). While goal setting and developing a plan is the basis of person-centered planning, a recent study demonstrated that the success of individuals with I/DD in achieving the goals they set often relies on how much assistance they get from support staff (McConkey & Collins, 2010). Individuals who provide independent living support services need training to understand how to involve people with I/DD when making housing plans, but they also need to develop expertise in setting up appropriate levels of supports to ensure the individuals can achieve their goals and continue to increase their independence through the supports provided.

#### **Needs/Social Mix/Choice**

Mainstream social housing allocations are made with three main considerations: 1) the financial needs of the individuals 2) the social mix of residents focusing on diversity of income levels and race), and 3) consumer choice (Wiesel, 2011). These same considerations should be made for individuals with I/DD, however, needs, social mix (diverse mix of residents), and choice entail more complex considerations for those with I/DD than other mainstream recipients of social housing. Needs is not simply a financial issue, but an issue of the independent living needs and supports the individuals will require. Social mix is not only related to income levels and race, but it is related to the mix of individuals with different levels of impairments associated with their disabilities and the social mix with individuals without disabilities. Choice entails not only the location and type of residence, but, in some cases, it also involves the choice of roommates who are compatible with the individual. Wiesel (2011) argues that an over-emphasis on any one of these considerations is problematic for the following reasons:

- When need is the main focus for housing allocations, there is a risk of having a crisisdriven system in which individuals with the most severe independent functioning and/or behavioral needs have priority over allocations than those with less support needs.
- When social mix becomes a main priority, individuals with I/DD lose the options to make roommate choices.
- When choice is the main focus without consideration of needs and mix, people with higher levels of needs may not have access to the supports and services they require due to inflexible funding structures and/or individuals with the highest level of needs may experience minimal social mix.

Unfortunately, there is no formula for how we should weigh the importance of needs, social mix, and choice. However, it is essential that decisions for social housing be made with carefully consideration of all three of these factors to ensure the most appropriate allocations are made.

## **Housing Accommodations**

An additional barrier faced by individuals with I/DD who also have physical impairments is the lack of housing options that provide the necessary accommodations they need for independent living. Lakin and Stancliffe (2007) describe a variety of accommodations to consider when examining ways to promote independent functioning:

- Physical modifications such as ramps and specially designed kitchens and bathrooms.
- Technologies such as alerting systems and one-touch phones.
- Modified supports such as periodic phone call check-ins, training in independent living skills, or living with a companion without a disability.
- Careful selection of environments such as choosing housing near shops, family, and/or work to decrease travel demands.

It is essential to determine what accommodations can be put in place to allow an individual with I/DD to live as independently as possible without necessitating full-time supervision and care.

# Housing Funding Sources for Individuals with I/DD

It continues to be a challenge to cover the cost of providing independent and integrated living options for individuals with I/DD. This section that follows provides an overview of federal and state funding sources available to individuals with I/DD to support housing costs including Medicaid and community-based waiver programs, the National Council on Independent Living (NCLI), and the Section 8 Houser Choice Voucher Program.

### Medicaid and Home and Community-Based Waivers

In 1965, the Medicaid program began to provide medical care for low income Americans. Initially, funding for individuals with disabilities was exclusive to those residing in institutions. Any funding for individuals in their own home or community based housing was limited to primary medical needs, such as doctor visits and hospital stays. Long-term care was only available for skilled nursing facilities (SNF) for individuals aged 21 and older. Due to the high costs of nursing care facilities, and public criticism that Medicaid favored

institutionalization, the government began to focus on cost effective methods such as home health services (see: <a href="http://aspe.hhs.gov/daltcp/reports/primer.htm">http://aspe.hhs.gov/daltcp/reports/primer.htm</a>).

In the 1980's, demand increased to fund individuals to stay at home or move out into the community. Congress approved the 1915(c) waiver program in 1981, which allowed states to provide services for individuals to avoid institutionalization. These services were not previously provided under Medicaid. Examples of waiver services included case management, homemaker, home health aide, personal care, sdult day health habilitation. and respite care. In order to meet the demands of their citizens, many states expanded their programs to include home and community-based housing. In the early 1990's states began to issue Home and Community Based Services (HCBS) waivers under 1915(c) (see http://www.pascenter.org/documents/PASCenter HCBS policy brief.php).

In 1999, the Supreme Court decided the *Olmstead v. L.C.* case. The case involved two women with developmental disabilities living in Georgia (Lois Curtis and Elaine Wilson). It was found that these women would be best served in the community instead of in an institutional setting. The state refused to move them into the community. Atlanta Legal Aide filed suit against the Georgia State Commissioner of Human Resources (Tommy Olmstead). The resulting Olmstead decision declared that persons with disabilities have a right to live in the community. The Court stated that the institutionalization of people is working under the assumption that they are not capable or worthy of public life, and individuals who were restricted to life in an institution faced isolation and limited social, family, work, and educational experiences and opportunities for independence. The Olmstead decision supports the right of persons with disabilities to leave institutions if they could benefit from life in the community. It challenged the government to develop and provide more opportunities through community-based services. The Olmstead ruling provided guidance for states regarding Title II of the ADA. It clarified the ADA "integration mandate" through the assertion that states had an obligation to ensure Medicaideligible persons did not experience discrimination by remaining in institutions if they would be better served in the community. If a person was unable to benefit or was not equipped to live out in the community, the Americans with Disabilities Act (ADA) would not prevent them from residing in an institution. Olmstead also found that state responsibility to provide community based treatment was not limitless (see http://aspe.hhs.gov/daltcp/reports/primer.htm).

The Olmstead ruling prompted states to create formal plans for more community integration. While there has been some guidance from the Centers for Medicare and Medicaid Services (CMS), there is a great amount of variation from state to state. States face a number of obstacles when it comes to community integration, including funding, labor shortages, and the lack of affordable housing (see

http://www.balancingincentiveprogram.org/sites/default/files/Thomson\_Reuters\_2011LTSSExpe\_nditures\_Final.pdf).

The Home Care Financing Administration (HCFA) approved 242 waiver programs in 2000. States may offer multiple numbers of waivers. In 1998, the average cost per waiver participant was \$14,950. The average cost of Home and Community Based waiver services for an individual with developmental disabilities was \$29,353. The average cost of HCBS waiver program for seniors was only \$5,362. Spending on long care community-based services has increased from

\$17 billion in 1999 to \$52 billion in 2009. In 2009, more than half of all Medicaid recipients received care in a community setting. However, there is still a greater demand for community-based services. In 2009, 1.6 million individuals remained in institutions while awaiting community-based services (see

http://www.pascenter.org/documents/PASCenter\_HCBS\_policy\_brief.php#c2). Presently, 28 percent of long-term care Medicaid spending is directed toward services for in home and community based services. The states have great flexibility when it comes to waiver services. Residential benefits and services may be offered through the states' standard Medicaid program or through home and community-based waiver programs. States may offer a variety of different programs to meet the needs of consumers. Due to the fact that states have extreme flexibility when it comes to Medicaid, there are fifty different states with fifty different Medicaid programs. Forty-eight states operate over 300 waivers. In 2009, 45 percent of all Medicaid spending on long term care was from HCBS services. This percentage varies from state to state (see <a href="http://www.hhs.gov/asl/testify/2010/06/t20100622a.html">http://www.hhs.gov/asl/testify/2010/06/t20100622a.html</a>).

## The National Council on Independent Living

The NCIL is a membership organization founded in 1982, and it operates on the premise that people with disabilities know what they want and know what is best for them. They believe that individuals with disabilities have a right to live in the community, and deserve equal rights and opportunities. Individuals with all types of disabilities have a common struggle and they have more political power as a group. NCIL represents individuals with disabilities, Centers for Independent Living (CILs), Statewide Independent Living Councils (SILCs), and other organizations that advocate for the rights of people with disabilities throughout the United States (see <a href="http://www.ncil.org">http://www.ncil.org</a>).

NCIL has two types of membership. The individual annual membership fee is \$35, with a reduced fee of \$10 for individuals under the age of 26. The dues may be negotiable if there is a financial hardship. Organizational memberships are based on the organization's annual budget, not including pass-through funds. Membership fees for a Center for Independent Living (CIL), Statewide Independent Living Council (SILC), or other organization with an annual budget between \$100,000 and \$200,000 would cost \$286 per year. An organization with an annual budget between \$900,000 and \$1,000,000 would pay fees of \$1,573 per year. Member benefits include voting rights to select board members, opportunities to join committees, action alerts for critical issues, reduced fees for the NCIL Annual Conference, and access to training sessions (see <a href="http://www.ncil.org">http://www.ncil.org</a>).

NCIL provides a directory for Statewide Independent Living Councils (SILCs). There are currently 56 SILCs nationwide. SILCs work with state agencies to develop and implement independent living plans for its citizens. They are consumer controlled, and the majority of the voting members are individuals with disabilities who are not employed by a CIL or a state agency. SILCs are responsible for monitoring and evaluating federally mandated state plans for Independent Living (see <a href="http://www.ncil.org/about/aboutil/">http://www.ncil.org/about/aboutil/</a>). Members are typically appointed by the Governor of each state, and most have disabilities and/or are knowledgeable about disability advocacy. SILCs are not for profit organizations (501 (c) 3). SILCs promote the independent living philosophy throughout the state and provide support and technical assistance to the

Centers for Independent Living (CILs). They promote the philosophy that all individuals have a right to live independently in society with self-determination and peer support.

NCIL provides a directory for Centers for Independent Living (CILs). Currently there are 403 CILs in the United States (see <a href="http://www.ilru.org/html/publications/directory/SILC.html">http://www.ilru.org/html/publications/directory/SILC.html</a>). According to Section 702 of the Rehabilitation Act of 1973, a Center for Independent Living means it is a, ".....consumer-controlled, community-based, cross-disability, nonresidential private nonprofit agency that is designed and operated within a local community by individuals with disabilities and provides an array of independent living services" (see <a href="http://www2.ed.gov/programs/cil/index.html">http://www2.ed.gov/programs/cil/index.html</a>). Individuals with disabilities make up 51% of the staff and 51% of the Board of Directors. CILs provide four core services including information and referral independent living skills training, individual and systems advocacy, and peer counseling (see www.ncil.org).

CILs are committed to being consumer controlled and including individuals across all disabilities. In order to qualify for federal funding for CILs, states must establish a Statewide Independent Living Council (SILC). States must also establish a statewide independent living plan approved by their SILC chairperson and the state director of Vocational Rehabilitation. Grant funding for CILs is based on population. The federal government oversees the awarding of grant funds. If the amount of state funding for the CILs exceed federal amounts, then the state may apply to oversee the awarding of all grant funds the following year. Currently, only three states manage their own grant money (see <a href="http://www2.ed.gov/programs/cil/index.html">http://www2.ed.gov/programs/cil/index.html</a>).

# Section 8 Houser Choice Voucher Program

The Section 8 Housing Choice Voucher Program is a federal program for assisting very low-income families, the elderly, and people with disabilities to afford housing in the private market. Participants are able to find their own housing, including single-family homes, townhouses and apartments. Housing choice vouchers are administered locally by public housing agencies (PHAs). The PHAs receive federal funds from the U.S. Department of Housing and Urban Development (HUD) to administer the voucher program.

An individual or family that is issued a housing voucher is responsible for finding a suitable housing unit of choice where the owner agrees to rent under the program. Rental units must meet minimum standards of health and safety, as determined by the PHA. A housing subsidy is paid to the landlord directly by the PHA on behalf of the participating family or individual. The family or individual then pays the difference between the actual rent charged by the landlord and the amount subsidized by the program. Under certain circumstances, if authorized by the PHA, a family may use its voucher to purchase a modest home (see <a href="http://portal.hud.gov/hudportal/HUD?src=/topics/housing choice voucher program section 8">http://portal.hud.gov/hudportal/HUD?src=/topics/housing choice voucher program section 8</a>).

Unfortunately, the wait list for this housing voucher program is extremely long, and they often close waiting lists if there are more individuals and families on the list than can be helped in the near future. Also, PHAs may establish local preferences for selecting applicants from its waiting list. For example, PHAs may give a preference to a family who is (1) homeless or living in

substandard housing, (2) paying more than 50% of its income for rent, or (3) involuntarily

displaced. Families who qualify for any such local preferences move ahead of other families and individuals on the list that do not qualify for any preference. Each PHA has the discretion to establish local preferences to reflect the housing needs and priorities of its particular community.

#### Conclusion

Fortunately, there has been a general trend of increased inclusion of individuals with I/DD related to independent living in communities across the nation and more thoughtful consideration of quality of life indicators when comparing different housing options. Likewise, there has been a more focused effort on person-centered planning and building self-determination skills of individuals with I/DD as they are more involved in identifying their unique strengths and needs, setting goals for themselves, evaluating their own progress towards meeting their goals, and they have many more choice-making opportunities related to their living options than in the past. Unfortunately, concerns remain in regards to meeting the varied needs of individuals with I/DD to support an increasing trend towards higher rates of independent living for this population. Lakin and Stancliffe (2007) discussed how the Medicaid scrutiny and cost-containment initiatives continues to pose a threat to sustaining and improving housing supports since Medicaid is a primary funding source for these efforts. There continues to be a great deal of competition and long waiting lists for housing supports considering the varied needs of individuals with I/DD, the positive move towards more community inclusion, and the steadily increasing ageing population. Another area of concern is research showing that individuals with more severe disabilities have less favorable outcomes on quality of life indicators than those with mild disabilities (Perry & Felce, 2003). This suggests that there needs to be a greater emphasis on providing a better quality of services and supports for those with more significant disabilities to enable them to experience a quality of life at least comparable to those with mild disabilities. To continue the progression towards equality in housing and independent living for individuals with I/DD advocates need to think creatively, pursue legislation to provide flexibility in funding for housing supports, develop initiatives to improve the training provided to staff who provide supported living services, and encourage the use of evidence-based practices when teaching independent living skills to youth and adults.

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# Using the "ASKED" Model to Contrive Motivations and Teach Individuals with ASD to Ask wh-Questions in Natural Settings

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#### Abstract

Individuals with ASD are less likely to engage in social mands, such as wh-question asking, even though this skill is demonstrated in those without ASD as young as 18 months. Therefore, teaching wh-questions to individuals with ASD is an important element in the development of any communication program. This is the third published study in a series of wh-question asking studies, and utilizes the ASKED model in order to teach two wh-questions to individuals with ASD in natural environments. The ASKED model describes a systematic procedure for setting up environments in order to motivate and teach question asking, including the use of prompts and data collection. This study employed naturally occurring communicative partners to implement the ASKED model in a variety of natural settings, and results showed positive effects across all seven participants.

# Using the "ASKED" Model to Contrive Motivations and Teach Individuals with ASD to Ask wh-Questions in Natural Settings

For individuals with autism spectrum disorder (ASD), mands or requests account for a large proportion of their communications. These requests generally are to obtain a concrete item, such as food and other preferred items, or to escape and get away from an aversive situation (Wetherby & Prutting 1984). They are less likely to engage in social mands, or mand for information in the form of questions (Hurtig, Ensrud, & Tomblin, 1982), yet neuro-typical children's language development involves wh-question-asking from as young as 18 months (Meyer & Shane, 1973; Ostryn & Wolfe, 2011a, 2011b; Trantham & Pederson, 1976). For instance, neuro-typical toddlers and young children will point to items and say "wat dat?" as the information-seeking mand "what's that?" or "where dat?" for "where is it?" Therefore it is important to include question-asking teaching in the early stages of a communication program to mirror typical language development.

There are two challenges to consider when teaching wh-questions to individuals having ASD. Firstly, in motivating them to want to ask an information-seeking question and secondly, for the communicative partner to provide the appropriate response/reinforcer. For instance, asking "what's that {item}?" or "where is it {item}?" should not automatically be reinforced by receiving the said item, but instead a response should include the information about the item. Responding to the questions correctly will ensure incorrect mands are not reinforced and, therefore, learned by the individual. In previous studies, investigators have successfully demonstrated environmental manipulations to motivate participants to ask the appropriate wh-

question, and documented these procedures using correct partner responding (Endicott & Higbee, 2007; Esbenshade & Rosales-Ruiz, 2001; Koegel, Camarata, Valdez-Menchaca, & Koegel, 1998; Koegel, Koegel, Green-Hopkins, & Carter Barnes, 2010; Ostryn & Wolfe, 2011a, 2011b; Sundberg, Loeb, Hale, & Eigenheer, 2002; Taylor & Harris 1995; Williams, Donley, & Keller, 2000; Williams, Perez-Gonzalez, & Vogt, 2003).

Careful consideration must be given to creating a situation in which a motivation for information arises and is arranged with the correct reinforcer in a behavioral chain. An example for a "where is it?" question may involve an individual who is hungry and knows that their favorite crackers are in the white cupboard, so they are motivated to open the cupboard and retrieve the crackers; a behavior they have performed many times. This type of situation can be arranged so that when the individual goes to retrieve the crackers, they are missing, thereby creating a motivating situation to ask the question "where is it/are they/my crackers?" The question itself is a mand for information, which will lead to getting the desired item of crackers.

In a similar vein, a motivating situation also can be set up to evoke the "what?" question. As individuals with ASD prefer tangible items, it is possible to use a variety of novel and attention-grabbing items (sound-producing items) that can be partially hidden in a bag or box, and placed near the individual. If the individual attempts to reach or open the bag or box to get the item, this is the motivating situation for s/he to ask "what's that?" then be shown the item and given the name, and then can mand to have the item.

Arranging situations, described above, for the wh-questions have been utilized in a series of question asking studies in clinical settings with generalization and maintenance phases taught by researchers (Ostryn & Wolfe, 2011a, 2011b). Based on the positive results of these studies, the ASKED model was developed. The ASKED steps are: (a) Assimilate (reinforcers), (b) Set up (environments), (c) Kick off and Encourage question-asking (by utilizing errorless teaching), and (d) Data (collect data). Figure 1 displays the model in an example data sheet that was used in the study to record the data.

The heading line shows the target question, setting, implementer, item featured in the question, the ASKED model steps, and the second person who will check the data. The first line of the chart would be explained as Jane, the SLP, decided to target the "what?" question in her speech session. She created a situation in which a new lighted bear toy would be hidden in a canvas bag on the side of the table during her session, so her student, L.D., would see the lights shining through the material bag and be motivated to ask about the item. During the session, when L.D. either attempted to grab the bag, or showed interest, but did not ask "what's that?" Jane prompted L.D. using the agreed upon prompt hierarchy. The data in the chart shows that Jane implemented a level 3 prompt, and then L.D. responded with an echoic. The student did not get this trial correct as the response was not independent. The trial was recorded and S.K. confirmed Jane's data was correct after watching the video clip.

The third line in the chart would be explained as D.R., the Para, decided to target the "where?" question at lunch. He created a situation in which L.D.'s lunch was not in the usual place, so his student would be motivated to ask "where is it?" During the time when L.D. followed his usual routine to get his lunch from his cubby, he found it missing, but did not ask the "where is it?"

question, so D.R. prompted L.D. using the agreed upon prompt hierarchy. The data in the chart shows that D.R. implemented a level 1 prompt, and then L.D. asked "where is it?" The student did not get this trial correct as the response was not independent, and the second checker, T.Y., who was present at the lunch table, confirmed D.R.'s data was correct.

The second line in the chart shows that L.D. did get the trial correct and independently asked the correct question as there is a zero in the prompting column, and 'yes' in the ID/Correct column. In the last line of the chart, the data shows that L.D. required a level 1 prompt (expectant look) and then asked the other question; he asked "what's that?" instead of "where is it?" These errors were recorded as they demonstrate discrimination learning. There was a two second delay between prompt levels.

The ASKED model is a systematic method educators can use to teach individuals with ASD how to ask questions using a model of Verbal Behavior, in which the functions of the questions-asking behaviors are correctly reinforced. It is critical that practitioners who work with individuals with ASD are able to implement evidence-based procedures for teaching wh-questions asking across all settings.

This is the first study to investigate the wh-question asking learning outcomes of individuals with ASD in generalized settings, by having their natural environment communicators implement the teaching using the ASKED model. This study was designed to remove any researcher/assistant involvement and investigate the effects of natural environment teaching on learning outcomes, as a step towards bridging the gap between research and real-life application.

In this current study, the first two questions of typical language development, "what's that?" and "where is it?" were taught to be discriminated solely in generalized settings by typical environment educators, such as teachers, teacher aides, and parents. Specifically, the following questions were addressed: (a) can natural environment implementers teach "what's that?" and "where is it?" to individuals with ASD using the ASKED model, and (b) what effect does utilizing the ASKED model in the natural environment with natural implementers have on learning and discriminating the expressive communications "what's that?" and "where is it?" for individuals with ASD.

#### Method

## **Participants and Setting**

Seven males participated in the study all with a confirmed diagnosis of ASD from DSM IV, from a licensed physician or psychologist. Leslie, 6 years old with ASD and global delays, and Kam, 7 years old, both attended a school for individuals with ASD and developmental delays. Their classroom had a ratio of eight students to two teachers and two floating aides. They also had pull-out sessions for speech and occupational therapy three times a week. Stewart, 5 years old with speech delays, Nigel, 7 years old also with speech delays, and Lee, 7 years old, all attended an ASD classroom in an elementary school. The ratio in their classroom was one teacher and five aides to ten students. They all had speech pull-out sessions once a week, and a social group once a week in which they would be matched with same age neuro-typical peers for games and activities. The last two participants were home-based participants. Will, 8 years old, participated

in the program during after school hours at home with his parents, and George, 6 years old also participated in this study in his home setting with his mother and private speech therapist.

# **Implementer Training**

The aim of this study was to implement the ASKED model in natural settings with typical communication partners. For Leslie and Kam, the implementers were the classroom teachers, aides, and speech therapist. For Stewart, Nigel and Lee, their implementers also were their classroom teacher, aides, and speech therapist, and for the home setting participants, Will and George, their parents and home therapists conducted the procedure. Prior to implementation of the ASKED procedure, the author of the study visited each location and presented a one-and-ahalf hour training on how to implement the ASKED model. This training included background information on questions-asking, the development of the ASKED model, how to set up the environments to evoke question-asking from the participants, individualized prompt levels for the participants, and how to collect and record data. The training involved a lecture-style training with visual slides, implementation modeling, and a practice activity with feedback. The author did not participate in the implementation of the procedure to ensure that the implementation occurred solely in the natural environments. However, the researcher was available for questions and concerns throughout the study if needed.

# **Experimental Design**

A multiple-baseline design across seven participants was employed for this study (Kennedy, 2005). The data were analyzed using visual inspection of graphs, and examination of changes in level and trend. The study was conducted in three phases: Phase I was baseline for asking "what's that?" and "where is it?" Phase II consisted of teaching "what's that?" using the ASKED model in the natural environment, and Phase III was a discrimination phase that involved teaching "where is it?" using the ASKED model in the natural environment.

*Independent Variable.* The independent variable was implementation of the ASKED model to teach "what's that?" and "where is it?" in natural settings by naturally occurring communication partners / implementers.

Dependent Variables. There were three dependent variables in the experimental phases, one in Phase II, and two in Phase III. The first dependent variable in Phase II, was the participants' response of "what's that?" for three consecutive instances, when presented with a novel item/sound/stimuli. The second dependent variable, in Phase III, was the participants' response of "where is it?" when presented with a situation in which something was missing from its location, along with discrimination opportunities to ask the "what's that?" question. During this discrimination phase, the implementers randomly selected the target question situation for the participants to avoid them learning a pattern of answering. The third dependent variable in Phase III was the participants' correct, unprompted, spontaneous, independent response of "what's that?" during the discrimination phase. Mastery criteria for the second and third dependent variables were three correct responses out of six responses for each question. Data was collected using event recording.

#### **Procedure**

ASKED Method. Implementers used the stages of the ASKED model in all three phases to plan and implement the question-asking opportunities. For the Assimilate and Set-Up stages, implementers prepared the necessary materials, such as moving the scissors from the usual boxes and placing them elsewhere, or taking a new flashing toy and hiding it in a box ready for social group, then they switched the toy on and made noise in order to get the participants' attention to the sounds. For the Kick-off stage, the implementers then ensured that they maximized the opportunities for question-asking, for instance, asking everyone to get a pair of scissors, knowing they were not in the usual box, or having the noisy toy disrupt the social group and have everyone attend to it. For the Encourage stage, the implementers also prompted the participants, depending on their responses, and prompt delivery occurred with a two second delay between prompts. The implementers then recorded the responses and prompts for the Data collection stage. For the baseline phase, the situations were set-up as described above, but no prompting was given and responses/non-responses were recorded. All participants that scored zero for baseline, Phase I, progressed to Phase II.

Typical situations that were set up for evoking the "what's that?" question included placing noisy, flashing, or moving toys in bags, boxes, and containers and having them situated on the table, floor, or close area to the participants. Situations developed for the "where is it?" question included hiding a favorite toy/reinforcer, play materials, snacks and drinks, and money in known or common places.

*Prompting.* An important part of this model was the prompting procedures for errorless responding. There were two prompting procedures utilized in this study, one for participants who communicated with vocal speech, and one for those who communicated using pictures. The vocal speech prompting procedure (denoted as a V on Figure 2) consisted of (1) vocal prompts of questions two times or more, with a 2-second delay between prompts, (2) vocal prompt of a question once, (3) vocal hint, but not the target question, for instance 'hmm, that looks cool,' (4) phoneme cue for first word, (5) expectant look, and (6) the participant gave the correct response. The vocal prompt was either "what's that?" or "where is it?" depending on the response that needed to be modeled. Participants who utilized the vocal prompting procedure were Kam, Will, and George. The picture communication prompting procedure (denoted as a P on Figure 2) consisted of (1) full physical hand on hand prompt to give/point to picture, (2) physical prompt of pushing elbow so hand moved towards picture, (3) partial physical prompt of tapping elbow, (4) gestural point to picture (5) expectant look, and (6) the participant gave the correct response. The picture prompt was either a picture for "what's that?" or "where is it?" depending on the response that needed to be modeled. During Phase II only the "what's that?" picture was available on the table, and during Phase III, both the "what's that?" and "where is it?" pictures were available. Other picture communications may or may not have been available in the natural settings during these phases, dependent on the individual situation. Participants who utilized the vocal prompting procedure were Leslie, Stewart, Nigel, and Lee. Data was collected using event recording.

*Materials*. Materials for the "what's that?" phases of the study were partially supplied by the investigator and partially supplied by implementers in the natural settings. In order to evoke the question "what's that?" it is important to ensure that the item/sound/visual is novel, so the

investigator supplied a range of noisy toys, and visually stimulating items, such as those with moving parts or flashing lights. Materials for the "where is it?" phases were generated by the implementers in the natural settings, as they were items that were familiar to the participants but had simply changed location. For instance, my lunch is always in my locker, I open my locker, it is not here, I am motivated to ask where it is as I am hungry and it is lunchtime.

# **Treatment Fidelity and Interobserver Agreement (IOA)**

Implementers were instructed to ask a fellow study implementer to either watch the question-asking interaction, or watch a video of the interaction later for scoring. The steps in the ASKED model that were assessed for treatment fidelity were, (S) setting-up the environment to maximize the opportunity for a correct response, (KE) prompting procedures were correctly implemented, and (D) data was correctly recorded. The (A) assimilation of reinforcers was not a step that was assessed with IOA data. A treatment fidelity and IOA activity were practiced with implementers in the initial training in which they had to independently score five question-asking situations with a minimum accuracy of 90%, which all implementers achieved. Implementers were asked to score a minimum of 60% of question-asking interactions for treatment fidelity and IOA, with a minimum of 80% agreement.

## **ASKED Model Implementation**

First, the implementers completed screener questionnaires that included information about preferred items as well as activities that participants enjoyed that could be used to set up the "what's that?" question-asking situations, and known items and schedules to prepare for items to be misplaced for the "where is it?" question-asking situations. The study was implemented for three months (December – March) for the participants who were in the school settings, and for two months (January – March) for the participants in the home settings. The participants who were involved in the study at school observed the regular school vacations and holidays, and the procedures were temporarily stopped until school resumed.

Because this procedure was to be undertaken in the natural settings, only guidelines were given related to implementers as to how many opportunities were to be presented to each participant. Firstly, implementers were informed that the contrived situations for question-asking should ideally occur when the environment is naturally set up for the situation, (for instance, it's modeling clay station time, and the modeling clay is empty so the participant can ask "where is the modeling clay?" or it is circle time and the new toy of the day can be hidden in a bag, so the participant can ask "what is it?") Secondly, implementers were to contrive situations for the participants' days across settings and communication partners to offer multiple opportunities for question-asking practice. Initially implementers were given guidelines of 6-8 opportunities per day, but as the study progressed, this number of opportunities was too difficult to achieve in the school settings, and therefore guidelines were given to decrease this number of opportunities to 3-5 per day for all participants in all settings, with an average of four per day. It was reported for all participants that the session days were not all consecutive due to holidays, breaks, weekends, illnesses, and social and family events.

#### Results

Acquisition and Discrimination. Figure 2 shows the prompted and independent responses for asking "what's that?" and "where is it?" for all participants. Each data point displays the highest prompt used for the total opportunities presented to each participant per day. For instance, session 7 for Nigel has a data point at 1. This indicates that Nigel was given four opportunities to ask "what's that?" on this day, and out of those four opportunities, the highest prompt he required was a full physical hand-on-hand prompt to give/point to picture. Nigel also had one data point for session 36 at number 6, which shows that out of four opportunities presented that day, he did not require any prompts and independently asked "where is it?"

None of the participants asked either wh-question in baseline. Participants with vocal communication mastered the "what's that?" question in Phase II, between 16-27 sessions, with an average of 22, which is 88 total opportunities to respond. These participants mastered both questions in the discrimination in Phase III between 15-25 sessions, with an average of 19, which is 76 total opportunities to respond. The participants using pictures for communication mastered the "what's that?" question in phase II, between 11-47 sessions, with an average of 26, which is 104 total opportunities to respond. These participants mastered both questions in the discrimination phase between 16-27 sessions, also with an average of 26, which is 104 total opportunities to respond.

Treatment Fidelity and Interobserver Agreement (IOA). Combining the scores for the treatment fidelity and IOA data from the study, implementers scored 68% of interactions with 89% accuracy for treatment fidelity and 92% for IOA. Reliability was calculated by dividing agreements by agreements + disagreements, and multiplying by 100.

Social Validity. After the study was completed, two Likert-type questions were given to the implementers working with the participants to assess the perceived effectiveness of the teaching method used in this study and changes in the participants' question asking behavior. Twelve out of 20 questionnaires were returned. The results of these 12 indicated that eight implementers agreed, and four implementers strongly agreed, that the teaching procedure could be used in natural settings. All 12 implementers rated the procedure as easy to very easy for a natural environment educator/parent to implement.

#### Discussion

The aim of this study was to investigate implementation of the ASKED model for individuals with ASD to learn and discriminate two wh-questions, "what's that?" and "where is it?" in natural environment settings, by natural setting implementers. These implementers consisted of teachers, classroom aides, parents, speech therapists, and in-home therapists, and they were instructed to infuse the teaching throughout the participants' typical day. Seven male participants, all with a diagnosis of ASD, mastered asking the "what's that?" question in the Phase II, and mastered asking "what's that?" and "where is it?" in the Phase III, (the discrimination phase), by communicating with speech or pictures. The natural environments in this study included a school for individuals with ASD and developmental delays, an ASD classroom in an elementary school, and two home settings.

The current study has extended the much needed research related to wh-question asking for individuals with ASD. Firstly, the results contribute to the replication of other studies that have taught wh-questions (Endicott & Higbee, 2007; Esbenshade & Rosales-Ruiz, 2001; Koegel, Camarata, Valdez-Menchaca, & Koegel, 1998; Koegel, Koegel, Green-Hopkins, & Carter Barnes, 2010; Ostryn & Wolfe, 2011a, 2011b; Sundberg, Loeb, Hale, & Eigenheer, 2002; Taylor & Harris 1995; Williams, Donley, & Keller, 2000; Williams, Perez-Gonzalez, & Vogt, 2003). Secondly, the results demonstrate that the ASKED model of teaching wh-questions can be successfully implemented by a variety of different educators and parents in natural settings. The results of this study demonstrate that the ASKED model can be included within the typical day of individuals with ASD and they can learn to ask and discriminate the two questions without pullout or formal one-to-one training. Thirdly, the results from this study indicate that this model can be successfully implemented with individuals aged 5-8 years old, and further extends the literature as the majority of past studies have involved younger children (Endicott & Higbee, 2007; Ostryn & Wolfe, 2011a, 2011b; Sundberg, Loeb, Hale, & Eigenheer, 2002; Williams, Donley, & Keller, 2000). Having the ability to apply an evidence-based model to different aged individuals with ASD is a progressive step towards standardizing question asking teaching. Fourthly, the successful implementation of the model by non-behaviorally trained implementers offer these educators the opportunity to understand and practice how to arrange the environment to evoke responses based on Verbal Behavior principles. In the ASKED model, for individuals to learn to ask the questions, the implementers had to arrange motivating scenarios to offer opportunities for expressive communications, and ensure that the function of the participants' behaviors were appropriate. For instance, the implementers had to set up situations using novel items in order to motivate the participants to ask "what's that?" In the case of "where?" questions, the implementers had to ensure they moved an item that was highly-preferred at a time when participants really wanted the tangible, or in a time of deprivation. Having non-behavioral educators and parents teach individuals with ASD using these behavioral principles is definitely an advantage of implementing the ASKED model in natural settings. Lastly, the results from this study replicate a previous wh-question asking study in which these two questions were taught and support the same discrimination findings that when a competing second stimulus-response is presented, after a period of just one stimulus-response has been presented, the correct responses typically decrease, as discrimination of the two responses is learned (Reichle & Sigafoos, 1991; Ostryn & Wolfe, 2011a, 2011b).

# **Natural Setting Considerations**

Before further discussion of this study, it is important to highlight some considerations of implementing the ASKED model in the natural environments. The overarching consideration is that the implementers were not overseen by a research assistant, and therefore it is possible that the data reported may not be absolutely accurate even though there was a second checker scoring a selection of the question asking interactions. Having said this, if the ASKED model was to be implemented in natural settings as a teaching tool, the implementers would not be overseen by anyone else, and would be implementing the procedures by themselves. This is the reason why the current investigation was developed with minimal help as a way to test the practicality of implementing the ASKED model in natural settings, and also to investigate if the participants could learn and discriminate the two wh-questions under possibly inaccurate conditions. Future researchers could investigate the model implementation by videotaping all the sessions, but as

the nature of this model is to be implemented in the natural environments, this may prove to be a cumbersome task. In addition, the implementers' behaviors will likely change as they know they are being watched and this will have an effect on their behavior and, therefore, the learning outcomes of the participants. However, it may be possible to record probe data for purposes of IOA.

## **Skill Acquisition**

All participants met criteria for learning "what's that?" in Phase II, and then discriminating between asking "what's that?" and "where is it?" in Phase III. On average, the participants who utilized speech mastered the phases quicker than those who communicated using pictures, but the differences were only four days and 16 opportunities for Phase II, and seven days and 28 opportunities for Phase III. There was some variability among the number of sessions required to reach mastery and exit the study, but these differences may be explained by several variables within the natural settings. Firstly, the sessions for all participants were not consecutive, as there were breaks for school vacations, holidays, and sickness. Secondly, there were several implementers per participant, as partner generalization was naturally built into the study, and by switching implementers, the introduction of variations in teaching and prompting would have occurred which may have lead to effects on participant responses.

In comparison to a previous study teaching "what's that?" and "where is it?" to younger individuals with ASD for discrimination in a clinical setting, the current participants in natural settings required on average 185 opportunities to exit the study. In the clinical study, participants on average required 163 opportunities to exit (Ostryn & Wolfe, 2011a, 2011b). The current participants required on average only 22 more opportunities than the clinical setting, and further the clinical participants were presented with 10 opportunities per session in Phase II and 20 opportunities per session, in a one-on-one setting with the investigator. Given these findings, and taking the procedural differences into account, it would be expected that the current participants would require many more opportunities to reach mastery with the absence of such strict procedures, but they did not. The current participants took many more days to reach mastery, but that was due to the fact they were only being offered between 3-5 opportunities per day. This is a very important finding as it demonstrates that individuals can learn question asking and discrimination in natural settings with natural implementers with similar numbers of opportunities to respond being presented as those in strict clinical settings with investigators. Furthermore, from a practical standpoint, initially setting up and offering between 3-5 opportunities to respond per day takes approximately 15 minutes, and therefore, constitutes very little teaching time in order to achieve question-asking discrimination for individuals with ASD.

## **Discrimination Between Wh-Questions**

As with previous studies (Ostryn & Wolfe, 2011b), the participants' previously mastered "what's that?" responses decreased when the second question, "where is it?" was introduced. This may be demonstrating the necessary learning for discrimination as the participants' response of "what's that?" was no longer the only correct question. Participants were now required to figure out under which stimulus conditions each question was required in order to achieve their function. Reichle and Sigafoos refer to this discrimination learning as "temporary decline" (1991). For all participants, except Will, the first "what's that?" data point in Phase III (the discrimination phase) was correct. However, with the introduction of the "where is it?" question,

there was a decrease in several subsequent "what's that?" responses for all participants. It may be for Will, that the introduction of the second question immediately started the discrimination learning, whereas for the other participants, they continued to give the previously reinforced response of "what's that?" until they were prompted on the "where is it?" question, indicating that their response was incorrect, and they started the discrimination learning. As with previous studies (Ostryn & Wolfe, 2011b; Sundberg, Loeb, Hale, & Eigenheer, 2002), and findings related to typical language development (Meyer & Shane, 1973; Trantham & Pederson, 1976), the participants practiced within this phase and learned to discriminate between using the two questions.

# **Implications of Current Study**

The ASKED model was developed to be easy to understand and implement, require very little set-up time, and produce effective results, so implementers' application behaviors would be reinforced by using it in natural environments. The results from this study support the ease of use in natural settings while still producing effective results. For this study, the model was implemented in three different settings with seven participants, two different prompting procedures, with over 20 implementers of differing ages, ethnic backgrounds, education and qualification status, experiences with individuals with ASD, and also differing lengths of time implementing the ASKED procedures, and yet, each participant successfully learned to ask and discriminate the two wh-questions. Results from this study suggest that this model can be implemented in natural setting with individuals with ASD up to age 8 years and could be an easy teaching model to include with minimal disruption in education and home settings.

#### **Future Research**

Future research should involve further replication of implementing the ASKED model in generalized settings with various age groups of individuals with ASD. Researchers could further extend the use of this model to involve teaching other wh-questions, such as "who?" or "when?" and involve participants of various ages or disabilities. A different direction for future research may involve investigating the various implementers in the natural settings and conducting research to examine the procedural integrity of the ASKED model.

In conclusion, individuals with ASD were able to acquire and discriminate between two whquestions when taught in their own naturalistic settings, by their everyday teachers, educators, and family members, by following the steps of the ASKED model. The findings of this study are very positive when accounting for the myriad of variables between the different implementation sites, indicating effectiveness for implementing the ASKED model in natural environment settings.

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#### About the Author

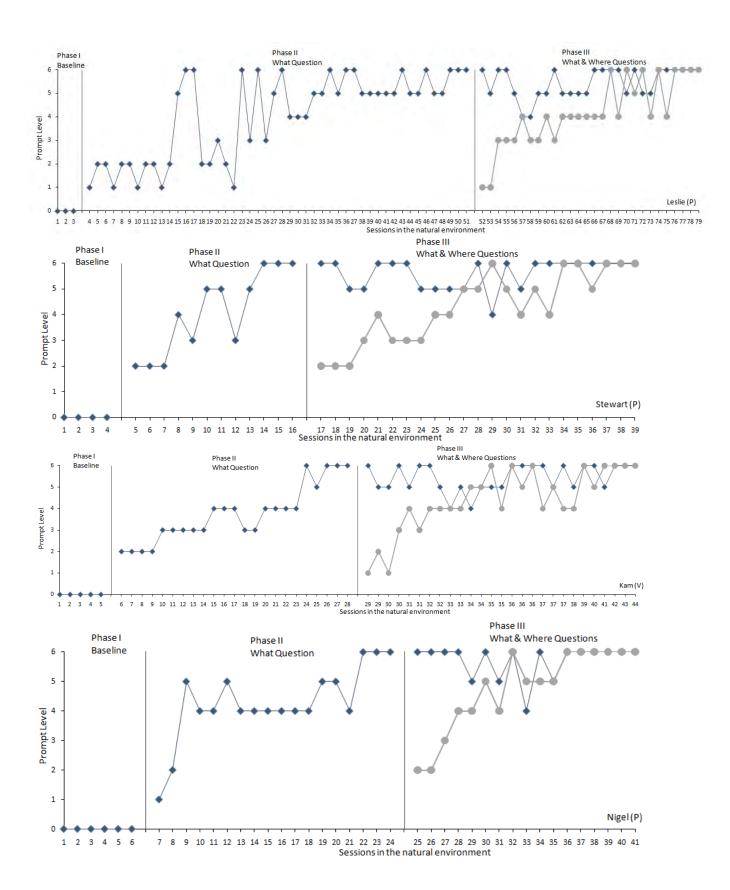
**Dr. Cheryl Ostryn** received her doctoral degree in Special Education (focus Autism and Applied Behavior Analysis) from The Pennsylvania State University and completed her post-doctoral work at The University of Colorado, Denver. She is a Board Certified Behavior Analyst-Doctoral (BCBA-D), a Professor of Applied Behavior Analysis at The Sage Colleges, and a board member of The Autism Society of The Greater Capital Region in NY. Dr. Ostryn has published in several scientific journals, the Young Exceptional Children Monograph series, the Autism Advocate, co-authored a chapter on functional academics, several grant-funded papers, and has presented her research both nationally and internationally. Her main research interests include teaching functional communication to individuals with autism using a model of Verbal Behavior.

# Appendices A

# Figures

Name: I	<u>LD</u>	Date: Nov	v 5, 2014	<u>1</u>	CIRC	CLE if the answer given i	s the opposite que	estion
Question	Setting	Person	Item	Assimilate	Set-Up	Prompting (KE)	ID/ Correct (D)	Second Check
What	Speech	Jane (SLP)	Lighted bear	Yes	Bear in canvas bag on side of table during session	3, then echoic	No	S.K. with video
What	Home	Mother	Flashy ball	Yes	Flashy ball in shopping bag in car	0	Yes	D.B present in car
Where	Lunch	Para D.R	Lunch	Yes	Lunch not in usual bag	1, then said qu	No	T.Y present in lunchroom
Where	Art	Teacher P.L.	Crayon	Yes	Have paper only	0	Yes	F.F. present at table
Where	Lunch	Para D.R	Lunch	Yes	Lunch not in usual bag	1, then said other qu	No	T.Y present in lunchroom
								Ostryn 2013

Figure 1. Example data sheet displaying steps in the ASKED model and sample data



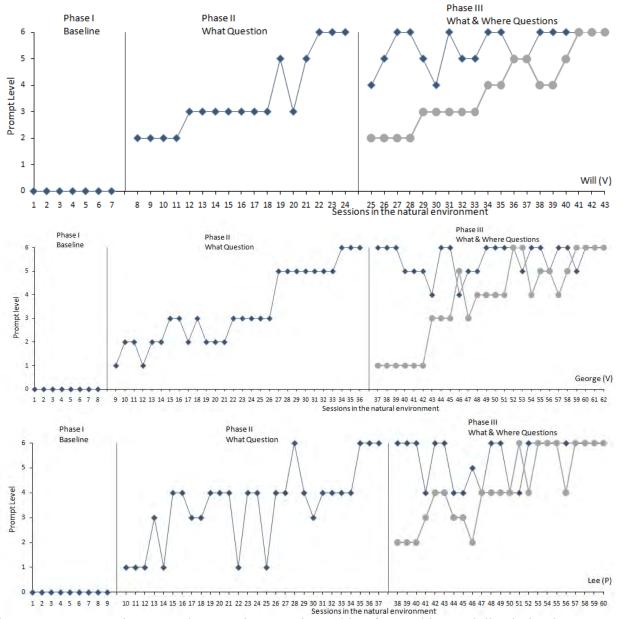


Figure 2. Correct and prompted expressive question-asking for teaching and discriminating "What's that?" and "Where is it?" ( What's that?" "Where is it?" (V) Vocal responses, (P) Picture responses; 0 - no response and no prompt; 1 - highest prompt to 5 - lowest prompt; 6 - independent response).

# An Analysis of Factors Influencing Low Enrolment and Retention of Girls with Disabilities in Integrated Primary Schools in Embu County, Kenya

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#### Abstract

This study investigated the factors that influenced low enrolment and retention rates of girls with disabilities in integrated primary schools. It further explored possible intervention measures that may be employed to mitigate the situation. The study was conducted in selected schools in Runyenjes (Embu East) and Manyatta (Embu North) sub-counties in Embu County. The location was purposely chosen in order to enable the researcher easy access to the respondents. Factors that limit enrollment and retention of girls with disabilities were worth investigating because the government of Kenya provides free primary education for all school going age children although the program does not address fully the education of children with special needs. Questionnaires, interview schedule and focus group discussion (FGD) were the tools adopted for data collection. The data collected were qualitatively and quantitatively analyzed; that is, thematically and frequencies and percentages. Poverty, long distances to school, negative attitude, time wasted by teachers, drug and substance abuse, security, household chores, boy preference, pregnancies and early marriages were the factors established to influence enrollment and retention of girls with disabilities in school.

# An Analysis of Factors Influencing Low Enrolment and Retention of Girls with Disabilities in Integrated Primary Schools in Embu County, Kenya

Women's education has come a long way. Earlier in Britain, only the daughters of the wealthy had access to education (French, 1990). They mainly learned at home, usually from a governess. Sometimes, they would share a tutor with their brothers at home, until the boys went away, as was customary, to one of the great public schools. Also "a daughter's" prospects would be cheerfully sacrificed to pay an expensive education for the sons: and while there were excellent day schools for boys, there were none for the daughters of the middle and upper classes (French, 1990). Moreover, the context of industrial development, population growth and social concern, the demand for a system of state education, free and fair to all began to grow. As late as the 1860s, there was a general feeling that education for girls in particular was socially and morally dubious as well as being a waste of time and resources. In Africa, however, there was low participation of women in colonial education compared with that of males. Usually, girls were not sent to school, and the few that were, received an education that prepared them neither for equal competition in the job market nor for self-employment in any way that gave them adequate economic independence, dignity or self-esteem. They were employed only as nurses, lady

physicians (not doctors), school mistresses and secretaries. However, even in these selected areas, women were denied access to any position requiring them to exercise authority over men, thus subordination of women in public positions of power and decision making. Education that guaranteed employment in the more prestigious and better paying jobs was exclusively for men and was logically closed up for the women (Robertson, 1986)

However, after the World Conference on Education for All (EFA), held in Jomtein, Thailand in 1990, many countries embraced universal education for all (UNESCO, 1996). Kenya was not left behind. This was evident from the various products by the government such as the Koech Report (1999), referred to as "The Totally Integrated Quality Education and Training" (TIQET), which emphasized ways and means of improving access, equity, relevance and quality with special attention to gender sensitivity, groups with disabilities and other disadvantaged groups; the Children's Bill of Rights (2001) which included education as a right to every child regardless of any kind of distinction; the Persons with Disability Act (2003) which stated that, "No person or learning institution should deny admission to a person with disability to any course of study by reason only of such disability; if the person has the ability to acquire substantial learning in that course, learning institutions should take into account the special needs of persons with disabilities with respect to entry requirements, pass marks, curriculum, examinations, auxiliary services, use of school facilities, class schedules, physical education requirements and other similar considerations.

Studies showed that even the few girls who enrolled in schools were in danger of dropping out than boys (UNESCO, 1996). The low enrolment and high dropout rates of girls was the reason why there was need for the removal of obstacles that hampered girls participation in education all over the world (UNESCO, 1996). A study carried out by the republic of Kenya in 1997 revealed that in Kenya, participation of girls in primary education was very low. According to this study of students entering standard one, only 80 percent of the girls reached standard four and 35 percent entered standard eight (Republic of Kenya, 1997). While these figures referred to students without disabilities, the rates could be even lower for students with disabilities. Hence, there is the need to investigate the situation for the girls with disabilities close to twenty years down the line.

# **Statement of the Problem**

Although the government of Kenya has committed itself to providing education to all school age children regardless of any kind of distinction, special education has not received much attention in terms of enrolment and retention of girls with disabilities. Girls with disabilities are often hidden from the public, and women with disabilities are absent from community activities such as social gatherings and political meetings (Muigai, 1998). A gender analysis report on disability in Kenya noted that disability limited educational opportunities more significantly for women than men, thus their enrolment and retention rates remained low (Mildred, 2002). The information sourced from the offices of the DEO and EARC showed that out of 30,268 girls enrolled in primary schools in Embu County as per 2008, only 219 had the four traditional categories of disabilities, (1) Mentally Handicapped (MH), (2) Physically Handicapped (PH), (3) Hearing Impaired (HI) and (4) Visually Impaired (VI). The number was quite minimal compared to the overall enrolled number of girls. This information clearly pointed to the significant gap between the enrolment and retention rates of girls without disabilities and those with disabilities. Minimal intervention has been undertaken to find out why girls with disabilities continued to register low enrolment rates. Thus, the current study investigated factors that influenced low

enrolment and retention rates of girls with disabilities in integrated primary schools in Embu County, Kenya.

# **Objectives of the Study**

This study sought to investigate the factors that influence low enrolment rates of girls with disabilities in integrated primary schools in Embu County, explore the factors that influence low retention rates of girls with disabilities in integrated primary schools in Embu County and establish strategies of improving enrolment and retention rates of girls with disabilities in integrated primary schools in Embu County.

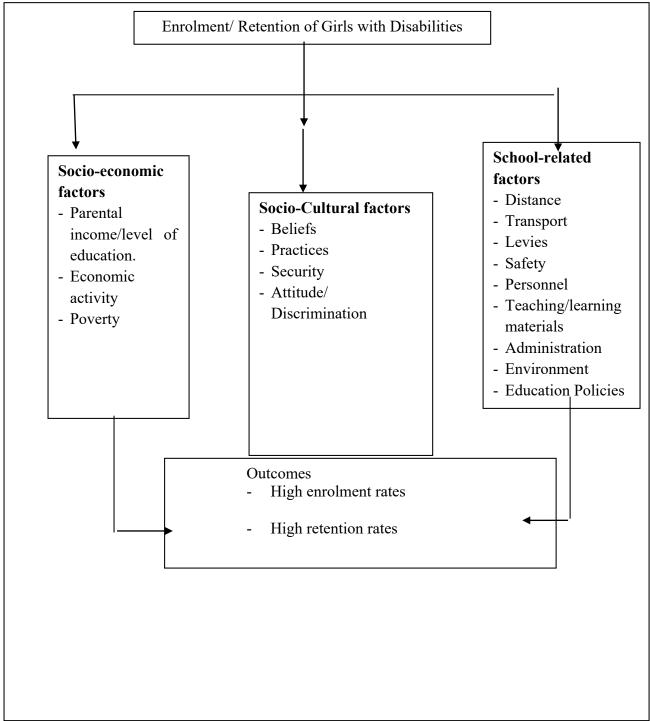
#### **Theoretical Framework**

This study was based on a theoretical model of learning by Chinapah Viyagum (1984). The model emphasizes equal rights to education irrespective of any distinctions among children and equal access to different types and levels of education. It urges that children should have equal treatment in terms of teacher behavior as well as teacher learner relationships and interactions. The model identifies school inputs such as teacher education, teacher training, political stability, class size, student-teacher relationship, school facilities, adequacy of teaching materials and resources as well as the school administration as vital factors in participation (enrolment and retention) of pupils in schools. The model summarizes the way the home and school environmental characteristics and processes interact to influence schooling. The home characteristics such as parental socio-economic status together with religious values predetermine a parent's beliefs and practices as well as attitudes towards education, especially girl child education and more so, the girl child with disabilities. These characteristics determine stereotypes that exist that pre-determine the fears of the parent and the girl's ambition as well as pre-occupation. Parental socio-economic status and home possessions directly influence the home processes such as the parents' support to the school in terms of paying fees, buying books, paying for examinations, feeding programs and so on.

# **Conceptual Framework**

The structural model ( see Figure 1) indicated was that the socio-cultural beliefs and practices such as causes of disability, religion, female genital mutilation (FGM), early marriages and attitudes towards persons with disabilities influenced enrolment and retention of girls with disabilities in schools. Furthermore, socio-economic background of the family and the community at large such as parental level of education and income, family size, economic activity, resource availability and allocation such as Community Development Fund (CDF), child Labor influenced enrolment and retention rates of girls with disabilities in schools. The model also indicated the school-related factors such as distance, personnel (staffing and qualifications/training), environment, curriculum, teaching/learning materials and transport levies influenced enrolment and retention of girls with disabilities in schools. The model, therefore, suggested that if the independent variables were geared towards positive influence by means and ways of improving the good ones and eradicating the bad ones, then the outcome would be high enrolment and retention rates of girls with disabilities in schools.

Figure 1: A Conceptual frame work based on the theoretical model of learning.



#### Review of the Literature

The literature reviewed concentrated basically on factors influencing enrolment of girls with disabilities in schools in Kenya. It focused on cultural beliefs (such as taboos, witchcraft and curses) which are viewed as outcasts (Barasa, 1997), where people with disabilities were seen as cursed, demon possessed and mad, which led to their discrimination. The net effect of this was the tendency by families to hide these children from public to avoid ridicule. Cultural practices such as female genital mutilation (FGM) and early marriages which lead to indiscipline and eventual dropout of school was also reviewed. The legal framework in education, security of these girls to and from school, distance between home and school, availability of teaching and learning facilities for the disabled, the parents' level of education, occupation and income levels were also looked into Also, information on pedagogical factors such as teacher attitude and classroom dynamics (for instance poor methods of delivery, inefficient teaching, lack of proper qualifications for some teachers handling children with special needs in the integrated programmes, lack of knowledge of the subject matter and lack of commitment of teachers) were reviewed.

# Research Methodology

The study was conducted in Runyenjes (Embu East) and Manyatta (Embu North) sub-Counties, Embu County, in Kenya. Descriptive survey was used to determine the causes for the current state of enrolment and retention rates of girls with disabilities in primary schools in Embu. The population comprised 169 learners, 118 teachers, 36 head teachers, and 165 parents from where a sample of 50 respondents was selected. Integrated programs for learners with disabilities in Embu County were stratified in accordance with the four main categories of disabilities namely the MH, PH, VI and HI. Simple random sampling was employed in selecting one program for MH and PH strata while purposive sampling was employed in selecting one program for VI and HI strata respectively. Questionnaires for teachers; interview schedules for head teachers and focus group discussions (FGD) for parents and students were used to collect data. To ensure validity of the instruments, assistance was sought from the supervisors. A Pearson's Product Moment formula for the test re-test was employed to compute the correlation coefficient in order to establish the extent to which the contents of the instruments were consistent in eliciting the same responses every time the instruments were administered. A correlation coefficient of 0.75 was established which was considered high enough to judge the instruments as reliable for the study. Analysis was done using SPSS. Narrative passages, tables and pie charts were then used to convey the findings of the analysis.

# Findings, Analysis and Interpretation

This section of the paper presents the results and discussion of the findings of the study. From the results of the study, 29% of the respondents were males while 71% were females. Among the parents who were interviewed, 10 (60%) were married, 4 (21%) separated, single (never married) (7%) divorced (7%), and widowed 5%. Findings on the education level of the parents showed that none of the parents had post-secondary education. The majority of the parents (53%) had primary education level while 5(27%) had secondary education and 3 (20%) had no education at

all. This reveals that illiteracy level in this region is high and therefore the fruits of education may not be known to many parents.

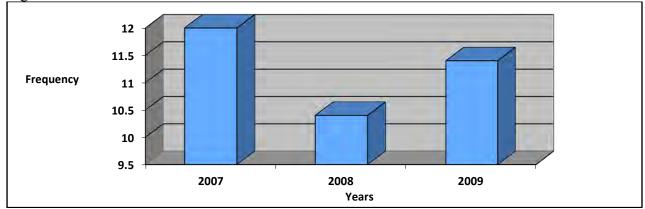


Figure 2: Enrolment of Girls with Disabilities from 2007 to 2009 in Embu

The enrolment of girls with disabilities was 12 in 2007 in the 4 sampled schools. There was a decline of 17% in the enrolment in 2008 whereby only 10 were enrolled as shown in (Figure 4.3) However, in 2009 the number rose to 11 (10%). No reason was given for the sharp decline in enrolment in 2008.

Table 1
Income Generating Activities for Parents of Girls with Disabilities

Activity	Frequency	Percentage
Farming	8	46
Business	1	7
Employments (Formal)	3	20
Casual Worker	5	27
Total	17	100

The income generating activities for the parents of girls with disabilities were established that 8 (46%) do farming, 1 (7%) in business, 3 (20%) in formal employment and 5 (27%) in casual Labor. The findings indicate that insignificant number of parents of the girls with disabilities had no formal employment and therefore relied mainly on low income from peasant farming, small business and working in the neighbors' farms as casuals. Such income is not enough to sustain basic domestic requirements like, food, medical expenses and school fees.

#### **Parent Analysis**

Parents, 7 (100%), concurred that their level of education, occupation and income were the major factors influencing participation of girls with disabilities in school. Parents with high levels of education struggled to ensure that their children attain better levels of education. They also understood benefits of education. Parents with professional occupations like teaching, masons, and doctors had stable income and could pay school fees for their children. This establishment is in line with an earlier finding by Tyler (1977) that educated parents enrolled their children in school, encouraged them to study by availing relevant and adequate learning materials such as books and ensured completion of their education due to their high income levels, while the case

was not the same for the socio-economically poor parents. Thus, in order to provide equity and quality to all regardless of any kind of social status, the government should make Special Needs Education free in totality.

Table 2
Rates of Children Given Education Priority with inadequate Family Resources

Children	Frequency	Percentage	_
Boys	12	73	_
Boys Girls	3	20	
Both	1	7	
Total	17	100	_

It was established that, 12 (73%) parents indicated strongly that, when resources were scarce, education of children without disabilities and especially boys would be considered first while 3 (20%) would consider girls with disabilities. However, as indicated (in Table 2), 1 (7%) would consider all children equally at whatever level of resources. The reason for giving boys preference was the belief that girls would leave the parents and get married, while boys would remain in the home to assist and take care of the parents in their old age. A study carried out by Chege & Sifuna (2006) cited the same. The fact that only seven percent (7%) of parents treated all children equally shows that a lot of advocacy is required to change their attitudes towards education for all categories of girls.

Due to the poverty levels of the parents, 14 (85%) were involved in household chores as compared to 3 (15%) who were not. The study established that 7 (42%) of parents did not enroll girls with disabilities deliberately but instead left them at home to do household chores and guard homes as they went about their daily activities. The reason given for not enrolling the girls with disabilities in school was that culturally the place of a woman was at home. It was believed that girls without disabilities would get married while those with disabilities rarely got married since they would not make good wives.

Table 3
Community Attitude towards Girls with Disabilities and their Parents

Attitude	GWD		PARENTS	
(N=17)	Frequency	Percentage %	Frequency	Percentage %
Negative	11	64	12	69
Positive	6	36	5	31
Total	17	100	17	100

The study established that 11 (64%) parents were of the view that the community had negative attitudes towards girls with disabilities while 6 (36%) viewed them positively. The study showed that the community had negative attitudes towards parents of girls with disabilities. However, 5 (31%) of the parents said the community had positive attitudes towards them (Tables 4-6). Those who had negative attitudes perceived girls with disabilities and their parents as outcasts, useless or hopeless as illustrated by studies of Barasa (1997) and Otiato (1996) which reported the

negative attitudes by communities towards disability. This study shows that 10 years down the line, the Embu community still holds on such negative attitudes.

Table 4
Community Perception towards Girls with Disabilities

Perception	Frequency	Percentage (%)	Their parents	Percentage (%)
N=17			Frequency	
Outcasts	10	59	12	71
Useless	5	29	-	-
Hopeless	2	12	5	29
Total	17	100	17	100

The results above clearly show that the perception of the community towards girls with disabilities and their parents was very negative. Of the majority of the parents interviewed, 10 (59%) said that girls with disabilities are viewed as outcasts whose parents had sinned hence they were punished through curse 9 (50%), witchcraft 5 (30%) or taboo 3 (20%) compared to 12 (71%) by the community as well as their own parents. A third of the parents 5 (29%) perceived the girls as useless. Two (12%) felt that the girls were hopeless while 5 (29%) felt the same for the parents.

Table 5
Reasons for Negative Perceptions on Girls with Disabilities

Reason $(N = 17)$	Frequency	Percentage (%)
Curse	9	50
Witchcraft	5	30
Taboo	3	20
Total	17	100

The results showed that 9 (50%) of the respondents believed in curses, 5 (30%) in witchcraft and 3 (20%) in taboos. The negative attitude towards disability was greatly seen to have influence on the participation of girls with disabilities in school.

Table 6
Parents Perception about themselves for being Parents of Girls with Disabilities

Feeling $(N = 17)$	Frequency	Percentage (%)
Embarrassed	9	53
Useless and worthless	8	47
Total	17	100

Findings of this study showed that about half 9 (53%) of the parents felt embarrassed of the situation they were in while 8(47%) felt useless and worthless.

Table 7
Impact from the Parents' Negative Perception on Education of Girls with Disabilities

N=17 Response	Frequency	Percentage
Hid the children for fear of ridicule	11	64
Enrolled the children in school	3	18
Viewed the children as useless and worthless	3	18
Total	17	100

The negative perceptions impacted negatively on education of girls with disabilities and made some parents 11 (62%) shy off and hide the children with disabilities from the public since they feared ridicule, 4 (23%) enrolled their girls with disabilities in school while 3 (15%) decided not to take them to school because they viewed them as useless and worthless.

Table 8
Why Girls with Disabilities of "School Going Age" not in School (as noted by teachers)

Response N=12	Frequency	Percentage (%)
Fear of ridicule	5	40
Poverty	5	40
Severity of disability	2	20
Total	12	100

Various reasons were given by teachers as to why girls with disabilities of "school going age" were not school; 5 (40%), cited fear of ridicule, 5 (40%) poverty and 2 (20%) severe disabilities. Ridicule leads to discrimination of children, Barasa (1997) and Otiato (1996). Community attitude towards disability and poverty level among parents had been reported by all the four categories of respondents (parents, pupils, teachers and head teachers) as major impediments in enrolment and retention of girls with disabilities in school. Muigai (1998), reported that girls with disabilities were hidden from the public and women with disabilities were absent from community activities such as social gatherings and political meetings.

Table 9
Place of Women in the Society

Place $(N = 17)$	Frequency	Percentage (%)
Home attendant	12	69
Outside the home	5	31
Total	17	100

Although this study established that the place of women in Embu community was considered in the home (as shown by 12 (69%) respondents), 5 (31%) felt that the trend was changing whereby today some women are being involved in activities outside the home such as formal employment, political involvement, business among others. From these findings, an affirmative action may be introduced to compel parents with girls with disabilities to enroll them in school when they attain school age.

Table 10 Security of Girls with Disabilities to, at and from School

Place $(N = 17)$	Type of Insecurity	Frequency	Percentage (%)
To and from school	Defilement /rape	15	90
	Others	2	10
At School	Sexual harassment	12	67
	Bulling	5	33

Parents highly attributed the participation of girls with disabilities in primary education on safety. About 15 (90%) of the parents felt that the girls with disabilities were insecure because they risked being defiled while on the way to and from school while 2 (10%) feared other forms of abuse like harassment or bulling (Table 10). The girls were also not safe in school as revealed by the parents interviewed. (Table 12) shows that 12 (67%) were sexually harassed while 5 (33%) complained of the girls with disabilities being bullied in school. The sexual harassment was associated with male teachers, school boys and other male workers. However, bulling was mainly done by male pupils.

#### **Distance Between Home and School**

Distance to school was one of the concerns by 60% of parents as a factor affecting enrolment and retention of girls with disabilities. A number of parents (27%) attributed it to communication, 7% type of school and 6% to severity of disabilities. This was because most of the integrated programs were quite distanced from one another ranging from two (2 km) to ten (10km). Some of the girls with disabilities could not walk to and from school alone and they had to be accompanied by their parents or siblings. Parents found it difficult to take their children to and from school every day due to the fact that they still needed to fend for the family.

The above finding concurs with earlier studies carried out by Hertz (1991) who established that in Ghana and Egypt, long distances to primary schools deterred girls' participation in education but not boys. The study showed that, some areas of Embu County had, and still have transportation hitches since most roads were not all weather friendly. This meant that even where the parents could afford fare for their children, there were no vehicles making them to remain at home. Bringing schools closer to villages will reduce distance covered and encourage more potential girls with disabilities to enroll. Parents who were economically endowed took their girls with disabilities to boarding schools and small homes.

Table 11 Policy Guidelines Awareness by Parents

Awareness $(N = 17)$	Frequency	Percentage (%)
Aware	7	39
Unaware	10	61
Total	17	100

The analysis showed that only 7 (39%) of the parents were aware of the policy guidelines in the education of learners with special needs as compared to 10 (61%) who were not aware. This lack of awareness could be a major contributor for low enrolment of girls with disabilities who have

attained school going age. Of parents interviewed, 9 (54%) confessed that they were aware of cases of girls with disabilities of school going age but were not in school.

Table 12
Reasons for not taking Girls with Disabilities to School

Reason $(N = 17)$	Frequency	Percentage (%)
Shame and ridicule	10	59
Ignorance	3	18
Useless and hopeless	2	12
Poverty	2	11
Total	17	100

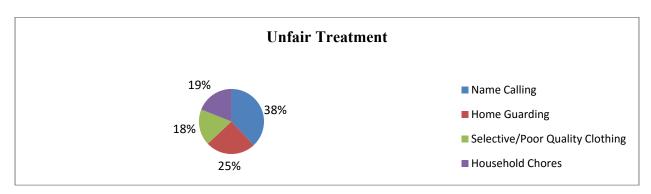
From the above results, 10 (59%) cited fear of shame and ridicule due to the negative attitude towards disability by the community, 3 (18%) ignorance, 2 (12%) viewed girls with disabilities as useless and hopeless hence no need to educate them. These parents need to undergo some seminars to realize that children with disabilities are still useful. According to Table 12, some parents (2; 11%) attributed their decision not to educate girls with disabilities to level of poverty in the area. Education facilities for girls with disabilities should be free so that even poor parents can access them for their children.

Table 13
Learners Family Characteristics

Ectivities I timitity Cital determines		
Type of family (N=17)	Frequency	Percentage (%)
Monogamous	11	63
Single parent	5	32
Polygamous	1	5
Total	17	100

Most of learners interviewed 11 (63%), came from monogamous families compared to 5 (32%) single parent family and 1 (5%) polygamous family. Polygamous families are sometime unstable and can affect children education; however such family setups are rare in Embu. Most of the learners 15 (89%) had their parents alive, while only 2 (11%) had no parents.

Figure 3: Level of Unfair Treatment of GWD by Families



Analysis of learners further showed that children with disabilities are not treated equally as other children. Of the interviewed learners, 7 (42%) indicated that girls with disabilities were treated unfairly. The unfair treatment included abuse such as, name calling consisting of 6(38%) of the respondents), home guarding and household chores contributing 4(25%) and 3(19%) respectively. On discrimination, 18% of the learners cited that when parents bought clothes for the family, those with disabilities would either not be bought any at all, bought fewer and or of low quality. The level of discrimination for children with disabilities as reported by learners in this study is very saddening. This concurs with Barasa (1997) and Otiato (1996) studies that people with disabilities were seen as cursed, demon possessed and mad, which led to their discrimination.

Table 14
Disability as a Hindrance to Participation in School for Girls with Disabilities

Hindrance $(N = 17)$	Frequency	Percentage (%)
Had to be taken to school	3	15
Distance	4	23
Speech problem	3	15
Hearing problem	3	15
Abuse (lack of concentration)	3	19
Not able to perform extracurricular activities	2	13
Total	17	100

From Table 14 above, 15 (86%) of the learners who participated in the FGD felt that disabilities hindered participation in education. They cited cases as: children with disabilities had to be taken to school (15%), others could not walk long distances (23%), some had speech problems (15%), while others had hearing problems (15%), were continually abused hence lacked concentration (19%) and could not perform some extra-curriculum activities (13%). It is not practical for members of the family members to be supporting the girls with disabilities to school daily, thus affecting the levels of enrolment and retention in education.

Table 15
Income Generating Activities to Meet Children's Education

Means	Frequency	Percentage (%)
Farming	12	72
Casual work	3	16
Business	1	6
Livestock sale	1	6
Total	17	100

Learners who took part in the study said that their parents met their educational needs through income generated from farming enterprise 12 (72%), engaging in casual work 3 (16%), doing some business 1 (6%) and income from sale of livestock (6%) (Table 15). These are carried out on subsistence level while the small percentage grown for commercial, the revenue fetched from it cannot meet the school fees requirements and purchase devices such as wheelchairs, glasses, hearing aids and white cane for the girls with disabilities. So, parents of children with disabilities have no resources to cater for their children's school fees and other necessities. This finding is in

agreement with that of Nkinyangi (1980) who observed that the inability of the family to pay the cost of education led to early withdrawals from school and that girls and especially girls with disabilities were the major victims.

# Special Unit Teacher Involvement in Teaching the Regular Classes

It was established from learners (67%) that the arrangements in the schools was that, special unit teachers also taught the regular classes. So when the special unit teacher was not in class, the learners with disabilities in the special unit were left alone 5 (30%), told to play outside 5 (30%), told to go home 2 (10%), asked to join the regular classes 2 (10%) or left with another teacher 3 (20%).

# **School Environment for Girls with Disabilities**

Most girls with disabilities (10; 59%) were happy with the school environment, terming it as disability friendly as compared to 7 (41%) who felt otherwise. However, 41% respondents were unhappy with the school environment due to inappropriate infrastructure, inadequate facilities and lack of equipment.

#### **Distance to School from Home**

According to the learners interviewed, schools were situated at average distance of three kilometers from the pupil's homes (standard deviation of two kilometers). The furthest learners (although very few) were ten (10) kilometers away from the schools. Just like parents report, the long distances to schools are challenges to girls with disabilities who have to walk or be taken to school by parents. All head teachers were in agreement that the integrated primary schools were located faraway and much distanced from girls with disabilities homes and that those who went to school walked an average distance of 3.4km to and from school. This distance was too long for a person with severe disabilities and therefore limited girls with disabilities who were potential learners from enrolment.

Table 16
Types of Insecurity Faced by Girls with Disabilities

Danger $(N = 17)$	Frequency	Percentage (%)
Drug Abusers	11	67
Crossing Rivers	6	33
Total	17	100

According to the learners interviewed, 10 (58%) noted that it was not safe to walk alone to and from school as compared to 7 (42%) who thought otherwise. The dangers expressed included fear of being attacked by drug abusers on the way 11 (67%). The drugs included miraa, alcohol and bhang. The other 6 (33%) feared crossing rivers (Table 16). The insecurity factor influenced participation in education. Parents were not sure whether to leave the girls with disabilities to go to school on their own, whether to accompany them or whether to let them remain at home altogether.

Table 17

Bullying in School

Response	Frequency	Percentage (%)
Yes	8	47
No	9	53
Total	17	100

The study established that in the 4 (100%) sampled schools, 8 (47%) girls with disabilities were bullied or sexually harassed as reported by learners. However, some learners 9 (53%), did not report any cases of bullying. The girls were harassed by the boys (88%) and school workers (12%) according to learner's analysis. However, whenever the harassment cases were reported to the school management, the administration responded positively. The culprits were either punished 10 (60%), cautioned against it 1 (7%) or created awareness 6 (33%) on living in harmony with girls with disabilities. This is a good indication that management has set up mechanisms for improving retention of girls with disabilities through penalty imposed on bullying offenders in schools.

Table 18
School Administration Response to Bullying

Response	Frequency	Percentage (%)
Punished	10	60
Cautioned against it	1	7
Created awareness on the need to live in harmony with	6	33
GWD		
Total	17	100

Table 19
Rating of School Administration by Learners

Rating	Frequency	Percentage (%)
Quite Good	12	71
Fair	2	11
Without Compassion	3	18
Total	17	100

The administration's treatment for girls with disabilities was termed as quite good as reported by 12 (71%), while some termed it fair (2; 11%). A few learners (3; 18%) however reported that school administration had no compassion toward girls with disabilities. Learners (11; 67%) had a feeling that their teachers wasted a lot of class time in the staffroom as compared to 6 (33%) who said that their teachers don't waste time. This (67%) concurs with an earlier study by UNICEF (1998) that teachers wasted pupil's time in the staffroom chatting or doing other things while the classes remained untaught and the syllabus uncovered. For those who did not like their schools and the teachers, the reason given was that some teachers did not know how to handle some disability cases such as the HI.

Table 20
Learners Policy Guidelines Awareness

Response $(N = 17)$	Policy Awareness	Awareness of girls with disabilities of school going age and are not in school (%)
Yes	47	67
No	53	33
Total	100	100

About 8 (47%) of learners were aware of the government policy on the rights of children, education included. The remaining 9 (53%) were not aware. The majority 11 (67%) of the learners were aware of girls with disabilities of school going age and were not in school and 6 (33%) did not know.

Table 21

Areas of Training for Teachers

Area of Specialization (N = 12)	Frequency	Percentage (%)
MH	1	9
PH	4	33
Inclusive Ed.	7	58
Total	12	100

The areas of specialization as per teacher's training in the sampled schools were as follows: MH 1(19%); PH 4(33%) and Inclusive Education 7 (58%) as indicated in (Table 4.31). According to the findings, all the 4 schools (100%) had at least 1 teacher trained to handle learners with special needs. Areas of specialization were mental retardation (MH), Learning Disabilities (LD) and Inclusive Education (IE). The head teachers indicated that there were times when they experienced shortage of teachers both for regular and special needs classes. The head teachers' information revealed that schools have some capacity to handle all children's needs and therefore low enrolment and retention of girls with disabilities could not be associated with SNE teachers. The substantial number of teachers trained in special needs shows that schools in the areas have capacity to handle girls with disabilities. So, the low enrolment and retention could not be attributed to lack of trained teachers but could be because of other factors like attitude, poverty and insecurity

Table 22
Assessment of School Environment by Teachers

Environment Status in Schools	Frequency	Percentage
Friendly	9	71
Unfriendly	3	29
Total	12	100

In this study, 9 (71%) of teachers felt that school environment was friendly to girls with disabilities as opposed to 3 (29%) who felt it was not friendly. The only issue raised by teachers in the schools was lack of essential amenities such as special toilets and pathways for the PH. Some degrees of physical disabilities require special facilities like toilets and chairs modified to

their comfort without which these parents hesitate to enroll their children in school where such facilities lack.

Table 23
Assessment of Teaching and Learning Materials by Teachers in Schools

Learning Materials	Frequency	Percentage
Enough	6	50
Not enough	6	50
Total	12	100

The above table shows that 6 (50%) of teachers did not have enough teaching and learning materials. They therefore felt that this negatively influenced enrolment and retention of girls with disabilities in schools.

Table 24
Reasons for Administrators' Inability to Girls with Disabilities in the Schools

Response (N=12)	Frequency	Percentage %
Over relied on special meetings resolutions	4	33
Lacked knowledge on special cases	4	33
Greed for money	4	34
Total	12	100

Out of all the teachers interviewed, 6 (50%) condemned the administration saying that it was not effective in handling children with special needs especially girls with disabilities. The reasons they gave were rated as follows: (33%) were of the view that the administration over relied on special meeting resolutions for various decision making, while (33%) felt the administration lacked knowledge on special cases and (34%) said the administration had greed for money. This meant that when the administration received money from the government, donors or any other sources for improvement of special needs education (SNE) in their schools; they usually spent it on other things rather than living up to the expectations of the money providers' objectives. It was noted that none of the school administrators sampled for the study had training in special needs education.

Table 25
Awareness of Policy Guidelines

Response $(N = 12)$	Frequency	Percentage %
Aware	7	62
Unaware	5	38
Total	12	100

The study found that, 7(62%) teachers were aware of policy guidelines on the education of learners with disabilities as opposed to only 5(38%) who were not aware. However, out of the 12 teachers, nine (79%) noted that these guidelines were not being implemented by schools. More than a half of the teachers 7(57%) interviewed said they were aware of cases of girls with disabilities of school-going age who were not enrolled in school.

#### **Cultural Factors**

Half of the head teachers (50%) pointed out that negative attitudes towards disability both by parents and the community has adversely affected enrolment of girls with disabilities in schools. The negative attitude was due to the causes associated with disability, some of which were cited as witchcraft, curse or taboo. This kind of community attitude was reported by Barasa (1997) and Otiato (1996) and over ten years later the communities still associate disability with taboos, witchcraft and curses. This contributes to the parents of children with disabilities shying off and hiding their children from public for fear of ridicule. The perception has not changed despite interventions by government, NGOs, churches and ministry of education among others pointing out that disability is not inability.

Table 26
Cultural Factors that Affected Enrolment of Girls with Disabilities in School

Factor $(N = 12)$	Frequency	Percentage %
Ignorance	3	27
Lack of value attachment to education	4	30
Safety/security	5	43
Total	12	100

According to the teachers involved in the study, cultural factors that affected participation of girls with disabilities in education were: lack of value attachment to education of girls with disabilities, 4 (30%), safety stood at 5 (43%) and ignorance was rated 3 (27%) as indicated in (Table 4.32). Negative attitudes towards girls with disabilities were an impediment to enrolment since the community had not seen the need to educate girls. Rape at which was 80% for girls with disabilities was cited as the major cause of insecurity. Any effort to address insecurity on the way and at school for girls with disabilities and positive change by community on perception towards disability will definitely improve enrolment and retention of girls with disabilities in schools.

#### **Household Chores / Home Guards**

Due to negative attitudes towards disability in the community, there was lack of value attached to the education of girls with disabilities. One (30%) head teacher said that parents of girls with disabilities therefore, let them remain at home and involved them in household chores as indicated in (Figure 4.4). They were also involved in household chores, including washing utensils, cooking, guarding homes and looking after younger siblings among others. Many studies have shown that parents use their daughters for household chores at the expense of their education (Chege & Sifuna, 2006). One (20%) head teacher revealed that the girls with disabilities were just let to stay at home because they were thought to be worthless and useless. The reason given as to why parents considered them worthless and useless was attributed to traditional beliefs that the place of a woman was taking care of the family. The parents of girls with disabilities felt that their girls with disabilities would never be married due to their conditions hence, no need to educate them.

#### **Lack of Qualified Personnel**

All the four schools in the study had at least one teacher trained to handle children with special education needs as reported by head teachers. This agrees with teachers' results as reported

earlier in this study. However, the areas of specialization did not match the varying types of disabilities in some cases. Those teachers trained in special education were either for MH or LD. This resulted in little or no enrolment for those children suffering from HI, VI, and Emotional Disturbance. By training teachers widely to cover the above areas will encourage more girls with disabilities to enroll because their needs are met and can receive better attention.

#### **School Levies**

The head teachers reported that parents of children with special needs were required to pay some levies to school when enrolling them. The PH who resided in the small homes were required to pay for boarding facilities and maintenance. Those in special units were also required to pay for meals but, some parents were unable to meet the charges due to their social economic standing. This meant that their children remained at home.

# **Pregnancy**

Pregnancy was mentioned by head teachers (80%) as a cause of school drop out for girls and more so girls with disabilities. Some of the pregnancies were as a result of sexual harassment/abuse to and from school, at school and voluntary sex. Voluntary in the sense that these learners come from poor families and can easily be lured with money by their teachers and other school boys or men within the community.

# Summary of Findings

#### **Parents' Education and Enterprises**

Education level among parents of the girls with disabilities in this study was found to be low. Few parents had primary education or secondary education. Even some had no formal education at all. In terms of economic activities, farming, business, formal employment and casual labor workers were established as the sources of income for the parents in the region. Therefore, parents of girls with disabilities were uneducated and also poor. Such factors can contribute negatively to enrolment and retention.

# **Security of Girls with Disabilities**

Security to and from school were reported by parents, learners, teachers and head teachers as not very good for girls with disabilities. Cases of sexual harassment and abuse to and fro and at school were common which has resulted into poor enrolment because of fear by parents and girls with disabilities themselves.

# Poverty and Priority Strategies in Embu County

Poverty level among parents of girls with disabilities versus levies demanded by head teachers in schools contributed significantly to low rates of enrolment and retention in schools in the region. Poverty was as a result of low income of parents who lacked good education to secure better paying jobs. The parents who were interviewed said that when resources were scarce, education of children without disabilities and especially boys was given priority. This was echoed by learners and teachers, who cited poverty among parents as the main setback in enrolment of girls with disabilities. According to the head teachers, some parents were unable to meet the charges due to their social economic standing.

#### **Distance to School**

According to the findings, learners in the study were of the view that some potential learners lived as far away as 1.5 to 10 km, while the teachers said they lived 1 -5km away and the head teachers felt they lived 2 – 5kmaway from the potential primary school for enrolment. Long distances combined with disability among these learners posed challenges in their bid to enroll and remain in schools. If boarding facilities could be available in schools or any arrangement to transport girls with disabilities to schools or providing them with wheelchairs the problem of long distance will be lighter and this will encourage enrolment and sustain it. This finding is in concurrence with an earlier study by Hertz (1991), that distance deters girls' participation in education but not boys. This finding is in agreement with earlier studies by UNICEF (1998) which observed that the proximity and access to primary education was a predetermining factor to participation in primary education.

#### **Shortage of Teachers and School Environment**

Shortages, time wasting and incompetence of some teachers in charge of girls with disabilities were mentioned as factors contributing to low enrolment. School environment was mentioned as another factor affecting enrolment and retention of girls with disabilities in schools. According to the findings, the environment in schools was not friendly to girls with disabilities although majority of learners liked their schools and teachers.

# **Culture and Attitude among Parents and the Community**

Negative attitude towards disability by both parents and community were seen as having adversely affected enrolment of girls with disabilities in schools. The community associated disability to witchcraft, curses and taboos. The results showed that community had negative attitude towards girls with disabilities and their parents as well. Some parents shied off and hid the children with disabilities from the public. Therefore, cultural belief attached to disability is one of the factors contributing to low enrolment and retention of girls with disabilities in schools.

#### **Unequal Treatment among Children**

The unfair treatment included abuse, name calling, home guarding while able brothers and sisters have gone to school. The learners cited that when parents bought clothes for the family, those with disabilities would either not be bought any at all, bought fewer and or of low quality. Unequal treatment among children with and without disabilities is contributing to low enrolment and retention of girls with disabilities in schools. Those with disabilities felt discriminated upon and therefore suffered from low self-esteem.

#### **Household Chores/Home Guards**

Girls with disabilities were involved in household chores at the expense of learning. Parents deliberately did not enroll their daughters with disabilities in school and instead left them at home to do household chores as well as guard homes. Head teachers said that parents of girls with disabilities normally left them at home and involved them in child Labor like washing utensils, cooking, guarding homes, and looking after their younger siblings, among others.

# **Pregnancies**

Pregnancy was a cause of school drop out for girls and so girls with disabilities to some extent while drop out was attributed for early marriage and therefore both thoroughly affects retention in school for girls with disabilities. Some of the pregnancies were as a result of sexual harassment/abuse to and from school, at school and voluntary sex. Imposing therefore, heavy penalty to the culprits especially those who forcefully impregnates girls with disabilities will be the only way out to improve retention.

#### Conclusion

The study established various factors contributing to low enrolment and retention of girls with disabilities in schools. The factors were low education status among parents of girls with disabilities, insecurity on the way to and at school for girls and women with disabilities, high level of poverty in the region among parents, prioritization of boy child education over girl child education, long distances to schools making it impractical for girls with disabilities, class time wastage and lack of skills by some teachers to handle girls, culture and attitude among parents and community towards disabilities, unequal treatment among abled children and those with disability, child labor among girls with disabilities and finally pregnancy, some through rape and forced marriages.

#### Recommendations

There is a need for more intervention to teach and advocate for equality in education access among all children in the community and at household level. There should be some organized learning forum in the community purposely for change of attitude so as to eradicate the community's perception of disabilities associated with a curse, bad omen or sin. The government may come up with a program to provide facilities like wheelchair and other supportive equipment so as to improve girls with disabilities mobility for them to easily access schools without having to be supported or guided by parents or siblings. Provision of boarding facilities would address mobility issues. Affirmative action should be introduced to compel parents with girls with disabilities to enroll them in school when they attain school age. The girls with disabilities are vulnerable group which needs maximum support from the parents, community and the government. Policies touching on child abuse if reinforced in this region would really protect girls with disabilities and eventually give them opportunities in education.

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# Employing Case Study Methodology in Special Educational Settings

# Angelise M. Rouse, Ph.D.

#### Abstract

In general, case studies are a preferred strategy when 'how' or 'why' questions are being posed, when the investigator has little control over events, and when the focus is on a contemporary phenomenon within some real-life context" (Yin, 2009). This article will examine the advantages and disadvantages of employing case study methodology in special educational settings. The appropriateness of a case study design will be evaluated when designing a study regarding special education programming.

# Employing Case Study Methodology in Special Educational Settings

According to Creswell (2007), a case study is an "in-depth exploration of an actual case." Additionally, case studies allow for observation of the day-to-day activities that provide the data need to explain the phenomena under study. Case studies also allow for identification of common themes in the daily activities, interactions, feelings and beliefs of the group being studied (Creswell, 2007).

Case studies provide an important perspective when trying to decipher human conditions, especially in school settings where respondents may not be willing or able to actively participate in the research (Popil, 2011). Case studies by design should measure true and natural results and not be disruptive to the environment researchers are exploring, both of which are intricate challenges when designing a case study. This paper will explore the history of case studies, the advantages, and disadvantages of employing case study methodology in special educational settings, as well as the human component involved when a researcher interprets it findings. Case studies are valuable tools in understanding the human condition. They are a notably, less definitive yet essential approach to understanding how our educational system both meets and fail the needs of special education students. A case study is a reliable way of conducting research in an education setting especially in special education. It has been used effectively acknowledging and assessing the needs of students in education. A case study is the best methodology when holistic, in-depth research is needed. It is an exhaustive study of a group, a level of human condition, an occurrence, or a community (Popil, 2011).

The French mostly used first used case study as a research methodology in Europe (Amy et al., 2008). In the United States, case studies were associated with the University of Chicago's department of Sociology from early 1900's to 1935 (Amy et al., 2008). The Chicago school was the best in the field of case studies because it had a great deal of literature and opportunity for new observation as it was the period of immigration (Amy et al., 2008). Professors and scholars there studied the various aspects of immigration such as unemployment, education, poverty, and other conditions related to immigration (Amy et al., 2008). Scholars there acknowledged that a

case study is conducted by considering totality in observation, restoration, and analysis of the cases under study. A case study is conducted in a way that integrates the views of the interviewer in the case under study (Amy et al., 2008).

The field of sociology is mainly related with case study research. During the 1900s, researchers raised concerns about the research process, in doing so, refined its process to be more scientific (Amy et al., 2008). Given that the Chicago School was best known for case study methodology, there were harsh attacks on their dominance (Amy et al., 2008). This led to the defamation of case studies as a methodology. Professors at Columbia University raised differences of opinion, and campaigned for their own scientific techniques (Amy et al., 2008). They "won" their campaign that contributed to the decline in research using pre-existing case study methodologies (Amy et al., 2008).

As the use of quantitative techniques became highly developed, the decline of the case study accelerated. Conversely, researchers were becoming apprehensive about the restrictions of quantitative techniques. For this reason, there was an improved significance in case study methodologies. Researchers developed new concepts and improved case study techniques (Amy et al., 2008). However, case study methodologies faced a recurrent disapproval by relying on a unit case that was often times unable to provide a simplified conclusion. That is, case studies generally lack an adequate quantity of consistent cases. Therefore, researchers learned that the objectives of the study should set up the factor, and they should be functional to all research. In that, a unit case is regarded as long as objectives and goals are developed (Bergen et al., 2008).

One useful tool in instances in case study is triangulation, which is the process of ensuring that a researcher carries out a study with accuracy and justifications. Triangulation can transpire with data, researchers, theories, and even methodologies. It can be a data source where the researcher collects information that remains the same in various circumstances. There are multiple ways to hone in and study a particular question. One way is investigator triangulation. This method is used when various researchers study the same subject. Theory triangulation is another method which researchers with varying opinions deduce the same outcome. Methodological triangulation uses different methods to increase strength in the analysis of the study (Karten, 2010).

Case study methodologies have been comprehensively used, predominantly in educational settings and in evaluative conditions such as efficiency of special education initiatives. One major disadvantage to case study in special education is in both areas of research, quantitative techniques have a tendency to obscure useful information that the researchers are required to reveal (McIntosh et al., 2013).

Unit or multiple-case designs are two ways case studies are conducted. Multiple designs follow a reproduction rather than sampling logic. However, in studies where no other cases are obtainable for duplication, the researcher is restricted to a unit case plan. Yin (2009) urges that an overview of outcome, from either a unit or multiple designs, "is made to theory and not to populations." Multiple cases reinforce the consequences by duplicating the pattern, hence increasing assurance in the strength of the theory (McIntosh et al., 2013).

Educators want suitable and consequential methods to capture time-framed assessments of students or aggregates. This method may be interpreted as a single unit or combined features. Of great importance is that the research has to be responsible to provide evidence and facts that can be easily understood by the readers, (Bergen et al., 2008). Many educational institutions have appreciated the reliability of case studies as they provide proof and illustration with which many educators can easily identify (Bergen et al., 2008).

#### **Case Selection**

The researcher often uses information oriented sampling when choosing a case for the study because the sampling does not have enough information to emerge with viable outcomes (Bergen et al., 2008).

#### **Requirements for Case Studies**

There is one essential prerequisite that the researcher has to possess when reporting case studies; that is, the obligation and commitment for the researcher to conduct the case study in a way that the outcome can be understood by the reader. However, various repercussions come with such responsibilities. Foremost, the reader must be capable of establishing the nature of the problem, question, or argument, and method of obtaining a conclusion. Next, the reader must also be proficient enough to determine the factual nature of the case and how the case study was developed. The proof must be credible, and, when presenting the case study, the researcher must avoid using opinion (Bergen et al., 2008).

# **Types of Case Study Methodologies**

Three types of case studies are as follows: descriptive, exploratory, and explanatory

#### Descriptive Case Study

Detailing the research is the beginning of the actual research. This method is most suitable in the study of special education because it list who or what particular aspects of special education that will be researched. Foremost one has to form premise of the association between the causes and effects (Bergen et al., 2008).

#### Exploratory Case Study

An exploratory case study involves the collection of data before the definition of research questions and hypothesis. It is suitable for social research. Pilot studies are very important in determining the ultimate procedure that will be used in these cases. Assessment questions are based on the results of the pilot study. In this type of case study, selecting cases is hard and the choice presents the chance to exploit what can be learned. For this reason, the cases that are chosen should be simple and agreeable issues (Mott, 2009).

#### Explanatory Case Study

An explanatory case study is most appropriate for doing casual studies that involves the use of pattern techniques such as the multiple cases. This type of study relies on theories such as knowledge-driven, problem solving and social-interaction (McIntosh et al., 2013). Knowledge-driven theory is involves the ideas and facts that are discovered from the research to become commercial products. Problem-solving theory tracks the same the trial but the only difference is

that they originate from an external source. The social-interaction theory asserts that researchers and consumers belong to the same professional networks and are in common communication (Mott, 2009).

# **Uses of Case Study Methodology**

Case study methodologies have widely been used in special education. Case studies have been applied to widen critical and creative thinking. This has been mainly helpful to students by expanding their knowledge and perspective, and helpful to teachers to provide a general line of expectations, guidelines, and a "norm" for their particular set of circumstances (Mott, 2009).

To elucidate complex links in real-life interventions, as for instance in special education, the research is able to determine causes and effects in special education. This provides a baseline springboard for educators, school administrators, and researchers to formulate effective programming for special needs pupils. It also allows opportunity to implement changes to ensure that facilities in special education programming are adequate and sufficient (Alberto et al., 2008).

#### **Designing Case Studies**

# **Study's Questions**

Study's questions are mainly the "how and why" questions. Therefore, the first thing the researcher has to consider is defining them. The use of these questions causes the research to be explanatory. For instance, in these cases: (a) why are disabled students secluded in special schools? (b) How can the facilities in special schools improve to ensure their quick recovery? and, (c) what are the benefits of integrating special students with mainstream students?

# **Propositions of the Study (Objectives)**

The study propositions are useful since they help define the study objectives and goals. The propositions are drawn from "how and why" questions. For example, in the area of special education, students with disabilities should integrate with mainstream students to help them learn and improve social interactions. Since they interact with general education students on a daily basis, this increases their confidence and helps them continue their formation of social relationships (Alberto et al., 2008).

#### **Conduct the Case Study**

Conducting research involves data collecting, distributing questionnaires, and conducting the interview.

#### **Data Collecting**

Data collection generally involves how data should to be gathered and the tools and techniques for collecting the data. Certification, archival reports, opinion polls, direct examination, participant observation, as well as physical artifacts are techniques used in the data collecting process (Alberto et al., 2008).

#### **Distribute Questionnaire**

Distributing questionnaires involves considering the people that would be involved in the special education program. They include teachers, parents, and students. Child study team members and special education administrators may also be included because they are the group that is directly

concerned with special education (Friend et al., 2012). These people may all offer viable information that could possibly be useful in the study (Alberto et al., 2008).

#### **Conduct Interviews**

Conducting interviews is how the researcher is going to carry out the interviews. The interviewer has to schedule a time to ask questions during working hours when teachers are at school and can function with minimal outside interference. The researcher has to consider how many interviews she is doing when constructing the case study (Mott, 2009).

# **Design the Case Study Protocol**

Case study protocols are developed by the researcher. The development of case study procedures requires the researcher to determine the required skills and review the procedures. As far as identifying the skills, the researcher has to be capable of asking questions, interpreting the responses, and be attentive and in charge. For example, researchers in special education must be well conversant within the subject matter and be unbiased by predetermined notions (Mott, 2009).

# **Case Study Questions**

Case study questions are the questions that the researcher will use as he or she collects information from various stakeholders. It is important that they remain consistent and do not contain any biased undertones. The order in which the questions are presented can also be important, as they should follow some semblance of order or logic (Mott, 2009).

# **Qualities of a Case Study**

All researchers, in spite of their beliefs about case study completion, must disclose the steps they followed so that others can identify the qualities of the fulfilled work. In order for these to happen, the reader has to be certain that case studies have value, and he or she needs to be capable of identifying the relationship between case and proof. Using the best practice strategy should help the reader define these purposes (Farrell et al., 2009).

### Advantages and Disadvantages of Using Case Studies

Case studies rely on participant-observer interactions and techniques. They are mainly expressive assessments, usually used in large schools and universities. The researcher uses available documents, holds informal and formal interviews with participants, observes enduring activities, and develops a study of both individual and group findings (Farrell, 2010).

In the theoretical study, case studies of the expertise of participants from different schools could be carried out. Selection of participants could be based upon types of students in school grouped together by a common factor (i.e., age, gender, or disability), experience, and training of teachers, or differences in institutional environment/supports (Gargiulo et al., 2010). Case studies can offer connecting, factual discovery of a project or its uses as it develops in a real-world setting. Researchers must be sensitive of these factors, as case studies are a difficult task that cannot be done through irregular brief site visits (Wnek et al., 2009). A Case study is an important method of research, with unique characteristics that make it best to answer questions for which there are no laboratory-controlled variables.

#### **Direct Observations**

An observational method is where an individual or individuals collect immediate data on the program or behaviors under study. They provide a researcher with a chance to gather data on a wide range program or behaviors and to investigate the assessment topic. By observing openly, the researcher can widen a holistic opinion, that is a thoughtful perspective regarding how the project will function. Observational techniques also allow the researcher to learn about facts the participants may not know (Gargiulo et al., 2010). Observations are important both in the formative and cumulative phases of research. Observation in the special education setting can be used to determine the extent to which participants understand the true concept of individualize special education which could provide important insights (McIntosh et al., 2013).

#### The Role of the Observer

There are several ways of collecting observational data depending on the type of the research. The most primary distinction between various observational approaches is the degree to which the observer will be a participant. The participant observer is entirely occupied in experiencing the project setting while at the same time understanding the setting through personal understanding, relations, and negotiations with other participants (Bergen et al., 2008).

#### **Recording Observational Data**

To carry out observation data the research means to follow a set of procedures and instructions. The observer goal is to obtain accurate information. Observations are normally guided by procedures that can take a variety of forms. The use of procedures guarantees that what the observer is doing is relevant. For instance, an observational approach is selected to collect data on special education, the process used would clearly guide the observer to scrutinize the participants' activities, duties of trainers, and materials provided and used (Bergen et al., 2008).

#### **Advantages**

Using a case study in special education research offers advantages. One advantage is that case studies provide open data about the behaviors of individuals and groups under study. It allows the research to enter into and understand the framework or condition of the area of study and the participants. It also provides a chance for identifying unexpected results that can be studied even further. Most of all, it is unstructured, and in a flexible setting, making for a unique and somewhat unpredictable experience each time, unlike the results of repeated testing in a controlled laboratory setting (Bergen et al., 2008).

#### **Disadvantages**

There are disadvantages when utilizing case studies in special education research. One disadvantage is its use of labor. Observation is expensive and time consuming as the observer has to spend many hours preparing and observing for each case and keenly take notes on all of the important events. Each case study presents a different set of variables so it is an ever-changing task of creating a new format and constantly re-locating the researcher.

Case study observation requires well-qualified, highly trained observers who can perform the duties with accuracy and objectivity. Human interpretation can be subjective and may not create an accurate baseline for the participants. Additionally, unlike lab work where science can be

measured by objective machinery, when a researcher has a bad day or clashes with the personalities of others, it may indirectly effect the results of the study (McIntosh et al., 2013).

Discriminatory perception by the observer may lead to changes in data because observers are selected as per their experience and often not screened for background indicators that would make them biased data collectors. Since the principal researcher has no control over the situation, the outcome might not be true. The behaviors or set of behaviors they observe may be different; making it difficult for the researcher to come up with viable results and therefore, may provide inaccurate conclusions (McIntosh et al., 2013).

Next, is the disadvantage of observing children who are ever-changing and sensitive people. Oftentimes, people modify their behaviors once they realize they are being observed, especially when they know their behaviors are being scrutinized (McIntosh et al., 2013).

#### **Interviews**

Interviews allow the researcher and his or her team to gather the perspective of project participants. There are various forms of interviews; open ended, focused, and structured. In open-ended interviews, the interviewer asks about the common events and can suggest solutions or provide insights into measures. However, the research should avoid dependence on one interviewer but rather seek information from as many people as possible to verify its accuracy (Yin, 2009). In cases where the respondent is to be interviewed a short time this type of interview is used. The focused interview is mainly employed where the respondent is to be interviewed for a short period. The aim here is to verify information gathered from other sources (McIntosh et al., 2013). The structured interview, also known as a survey, is used to collect information from neighborhood studies. The questions that are detailed in general interviews can be used in gathering adequate and sufficient information on special education. For instance, by the responses the researcher is getting, she can deduce whether these schools operate in the best way possible in reaching out to the students with disabilities. She may conclude the program is not adequate, does not meet or barely meets minimum requirements, is structured to look better than it performs, or simply benefits the management and not the students (Yin, 2009).

#### **Advantages**

Generally, the information gathered is detailed and specific, though the emergence of new or unanticipated events that can be discovered and studied further. Since the interview process allows face-to-face contact with the respondents, the researcher has an opportunity of understanding how her respondents feel about the issues at hand. Interviewing provides a chance to explore topics on a deeper level, which allows the information obtained to be further applied in other associated areas. The researcher is also able to identify whether the respondents understand the questions and in cases where they do not understand, he or she can clarify the question, thereby increasing the accuracy of the answers. Conducting interviews also allows the researcher to be flexible in carrying out the interview to meet a particular individual's needs (McIntosh et al., 2013).

### **Disadvantages**

The disadvantages of such are that they require additional time and funding to carry out interviews. Since the research has to cover travel costs to remote locations to afford the

researcher to observe in the natural environment, it can add expense to the process. It also requires highly qualified and well-trained personnel to carry out interviews. These activities require people who are amiable and personable so they can draw trust and honest responses from their subjects and interviewees (McIntosh et al., 2013). Chances of distorting the information are high because the researcher can easily misinterpret the respondents. When the volume of information is large, there is likely the problem that when reducing the data it will lead to results that get "lost in translation" and thereby produce an insufficient outcome (McIntosh et al., 2013).

#### **Focus Groups**

Focus groups provide a combination of both interviewing and observation. The focus group session is an interview and not a discussion group (McIntosh et al., 2013). It stresses group dynamics with the aim of gathering data. For instance, in special education, the stakeholders in the educational sector can form focus groups. They can include the local leaders, religious leaders, school administrators, and parents. This group can reveal their opinions about special education and how it is functioning today; express their views on experiences, present conditions, and future options. Focus groups also gives an opportunity for people to intermingle and work from each other's suggestions, including outside observations such as what people may have seen or observed in media, research, or other school districts that would be a benefit or detriment to their programming (McIntosh et al., 2013).

Focus groups are useful in classifying and defining problems in project implementation and identifying project strengths, weaknesses, and recommendations. It also allows researchers in assisting with understanding of quantitative results, achieving insights of project results and generating new ideas that can be used for further learning (McIntosh et al., 2013).

#### **Document Studies**

Documents are any written or recorded material not documented for the intention of the assessment. They include letters, memoranda, agendas, administrative documents, or newspaper articles. Documents can be either public or personal. Unrestricted repository is artifacts that have been made and stored for purposes of presenting a report of an occurrence that offers answerability. Public records are also useful when they pertain to the study. For the educational setting, significant internal records can be used to obtain important baseline information such as school operating procedures, students' transcripts and school records, annual reports, broad or specific results of standardized testing, and budgetary boundaries. They are certainly important in recounting institutional facades such as backdrops as well as the academic performance of learners, in determining and institution's potency as well as its weaknesses. From these documents, the researcher can understand the school's resources, mission, and visions (McIntosh et al., 2013). Historical or school documents reveal personal actions and experiences. Life documents can also help fill in the blanks and therefore it is important to consider externally recorded clues such as diaries, portfolios, photographs, artwork, or schedules. Personal records can help the research know her participant and help her formulate questions and challenges to the current norm, as well as help her devise the method(s) in which he or she wants to communicate (Deng et al., 2009).

### **Advantages**

There are several advantages for using documents in a case study research. Documents are locally available to everyone; therefore, acquiring them is not difficult. Documents are not expensive as compared to other sources like questionnaires. They are invaluable for determining the thoughts, ideas, setting, opinion, or historical sequences. Documents also provide a chance for study of tendency over time (Hess et al., 2007).

### **Disadvantages**

Utilizing documents may also provide disadvantages. Some of the documents may be in incomplete or "pencil-whipped" (filled in haphazardly or recklessly by the person recording the data), making it difficult for the researcher to rely on the information as accurate when conducting the study. Documents may not be accurate, forcing the researcher to look for other sources to acquire authenticity. Obtaining the appropriate documentation may be difficult and time consuming (Hess et al., 2007).

#### **Key Informant**

The key informant is the person that has a professional knowledge of distinct skill within the issue discussed. The person can also be someone who can capture the fundamental nature of what the respondents say and do. They aid in the evaluation to help the research group comprehend the issues at hand. They can offer knowledge beyond the research team. They are also very functional at assisting with the assessment of curriculum and related educational tools and materials (Cushing et al., 2009). Informants may be inspected or interrogated through focus groups or on an individual basis (Deng et al., 2009). Key informants in the theoretical project can help with developing student assessment questions, and answering formative and comprehensive questionnaires.

#### **Consultative Committee**

A consultative committee is a method of collecting information from key informants. The key informant in a special education setting includes teachers, child study members, and parents. Each of these people can supply valid and cruel information to the researcher. Consultative committees can be called together to represent attitudes and ideals of the community they represent (Dettmer et al., 2009).

#### **Advantages**

Since Consultative committee members represent the people, they provide information concerning causes, reasons, and best practices from an insider's point of view. Participant's advice and feedback increases the reliability of study, which may have residual benefits to solidify the relations among the researchers, respondents and other stakeholders (Popil, 2011).

### **Disadvantages**

It is time consuming selecting and obtaining committed informants. Relationships between researcher and informants may influence the type of data collected. For example, if two teachers or other staff members are not on good terms the informant is likely to give wrong information or hold information back that may lead to an inaccurate outcome. Informants may interpolate own biases and impressions. This may lead to differences among the parties involved leading to conflicts in research, outcome, and use of the final study (Yin, 2009).

#### **Performance Assessment**

Performance assessment emerges as the most popular technique in case studies because it gives emphasis to the advancement of evaluation tools that includes students in duties that are important. Such duties include critical and creative thinking skills and the harmonization of an expansive range of awareness. These assessments may entail qualitative activities such as interviews, group problem-solving skills, personal ability (poetry, artwork, stories) functional testing. A performance assessment in the theoretical project comprises of test techniques that require teachers to generate unit plans and evaluate students at various stages during training (Popil, 2011). This technique provides unusual prospects for gathering information that may cause some major troubles, For instance, observing a student with special needs can be difficult especially for a person who is not adequately trained in the field (Yin, 2009).

#### Conclusion

Through the study process, triangulation has been viewed as a conduit that warrants precision in substantiating research findings. Statistical data, hypothesis, as well as methodologies, have been established as key impetus that underpin triangulation. In special education for instance, case study is the best method in achieving a detailed research. Consequently, the case study comprises of a variety of functions that should be performed. These primarily incorporate interviews, questionnaire, focus groups, qualitative review, and observation. History shows that case studies have been widely employed in the previous century. The University of Chicago has been touted as the best institution that has widely published and documented social related issues though such methodology. Nevertheless, scattering attacks have been recorded against the case study protocols and results. Quantitative approaches were instead enhanced, as the case study was slowly being rebuffed.

This paper has delved into the viability, practicality, and pros and cons of case study research in the special needs school setting. Some might say that case studies are a valuable tool in evaluating how our educational systems meet or fail the needs of special education population. Others may see the fallibility of such studies and would proceed with caution and careful structure should they be a party to any case study research. Some value the debate that the researcher must unfold the perspective and expound upon how he or she have created validation through the research, and furthermore, how the published study must offer relevance, readability, integrity, and usefulness to its intended audience.

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#### About the Author

**Dr. Angelise M. Rouse** is an education writer and staunch special education advocate. Her interest focus is on creating a meaningful, lasting and empowering educational experience for students with disabilities. Her research examines the development of opportunities to learn in special education classrooms, and how these opportunities are negotiated differently by various groups of students.

Inspired by her doctoral dissertation topic, Dr. Rouse future research interests are in the overrepresentation of minorities in special education and the emotional development of African American young males. Dr. Rouse holds several educational certifications and has been thoroughly published on critical educational issues. She has worked in several educational arenas serving as a charter and public school teacher, school administrator and college faculty member. Her work ranges from all levels of education from middle school through college.

Dr. Rouse holds a Ph.D. in Special Education Leadership and received a Masters in Organizational Management and Special Education. Her first book, Especially 4 Me: A Student's Guide to Understanding the IEP, was written to help promote self-advocacy for special education students. She is currently working on her next publication which will encourage and motivate young African-American males to succeed and navigate life's challenges into adulthood.

Dr. Rouse believes everyone has captivating stories to tell and each story is as unique and individual as the strands on our heads. She believes that our personal insight gives substance and credence to our experiences and ideas to bring forth change. It's time more educators position ourselves to make positive changes to educating all students on new levels.

#### Retraction Statement

The Journal of the American Academy of Special Education Professionals (JAASEP) is dedicated to maintaining the highest level of integrity, validity and reliability in the research-based articles published in the our journal. At this time, based on information presented to us, we find it necessary to retract articles from a lead author that have been deemed questionable from our journal in order to maintain the level of peer review status that aligns with our commitment to our readers.

The following papers have been published in different issues of JAASEP between 2009 and 2013. Following an investigation by Nanyang Technological University, primary data are no longer available to be authenticated and we have been informed that there are serious concerns about the ethical environment in which the data were collected.

The authors (Noel KH Chia, Dorothy LF Wong, Angie GT Ng, Meng Ee Wong, Chiew Peng Kho, Stacey SK Tan, and Lay Hwee Wee) wish to withdraw the papers below published in JAASEP in order to protect the integrity of the research record. They apologize for any inconvenience caused, especially to the investigators, who have used these papers (Please note the authors have been unable to contact the first/lead author Pauline TC Poh of Paper #6 and the co-author Esther Yap of Paper #6 with regard to these retractions.)

- Chia, NKH, & Wong, DLF (Winter, 2009). The effectiveness of dimethylglycine (DMG) as a dietary supplement and adjunct treatment to P.E.C.S. approach in treating children with autism spectrum disorders and severe speech delay. *Journal of the American Academy of Special Education Professionals*, 4(1), 16-42.
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- Chia, NKH, & Ng, AGT (Spring, 2010). An investigation on the error patterns in computation of whole numbers committed by Singaporean children with dyscalculia. *Journal of the American Academy of Special Education Professionals*, 5(2), 5-37.
- Chia, NKH, Yap, E, & Ng, AGT (Spring, 2010). An analysis of verb pattern errors in active-passive sentence transformation made by upper primary Singaporean and Malaysian children with specific language impairment. *Journal of the American Academy of Special Education Professionals*, 5(2), 96-141.
- Chia, NKH, & Kho, CP (Winter, 2011). An investigation study on the learning difficulties in mathematics encountered by primary 4 children: In search of a cognitive equation for mathematics learning. *Journal of the American Academy of Special Education Professionals*, 6(1), 93-119.

- Chia, NKH, Ng, AGT, Tan, SSK, & Wee, LH (Fall, 2011). A comparative study on the correlation between (i) mathematics quotient and nonverbal intelligence quotient, and (ii) mathematics quotient and draw-a-person intelligence quotient in primary 3 children with selective mutism. *Journal of the American Academy of Special Education Professionals*, 6(3), 52-79.
- Chia, NKH (Fall, 2013). The effect of hypnosis on the academic performance of students with learning disabilities in school examinations: A single-group pre-test/post-test experimental study. *Journal of the American Academy of Special Education Professionals*, 8(3), 33-47.

Given the importance of this issue as indicated by evidence from Nanyang Technological University and the seriousness with which we take it here at JAASEP, let us walk you through what happened and our overall conclusions on this matter.

First, as a peer reviewed journal, JAASEP always assumes that the research and writing submitted by authors are gathered in the utmost professional and honest manner according to acceptable methodology and procedures. We will continue to maintain that stance. When university professors and professionals throughout the world submit research articles to JAASEP, it is never questioned as to whether the data are real or have been fabricated. There has been and will always be, the belief that what is being submitted is truthful in 100% of its wording.

With that said, we were contacted by Helmy Faber, Psychologist NIP, via an email questioning the veracity of the work by one of the lead authors, Dr. Noel Chia, on multiple articles in JAASEP. We immediately responded to her and to Dr. Chia.

Ms. Faber's allegations were premised upon her assumption of Dr. Chia having access to specific data and the people/organization who/which collected the data. According to Dr. Chia, he was not given access to the identities of the participants in the data collected because of a confidentiality clause. Ms. Faber's questions probed into the identities of individuals (e.g., parents and students) who collected the psychoeducational profiles (e.g., standardized tests and instruments) of pre-test and post-test results for analysis. These amassed data were then tabulated and sent to Dr. Chia for analysis. Dr. Chia reported that he was essentially working on secondary data where all participants' identities were coded to ensure anonymity. Besides Dr. Chia's questions about his knowledge of the participants mentioned in the articles, Ms. Faber's other questions were related to how the primary data were collected by the Malaysian organization Dr. Chia collaborated with at that time. According to Dr. Chia, since he did not collect the data, he could not supply specific details as to how the data were collected.

According to Dr. Chia, he referred Ms. Faber to contact the key individuals regarding her questions, but they had moved on and were unable to be contacted. He reported that this was perhaps due to the time lag (about 1 to 2 years apart) between the periods when these analyses of data were conducted and when Ms. Faber first contacted him.

Dr. Chia reported to us that he tried to contact the key individuals from the organization who supplied him the data, to liaise with and explain to Ms. Faber regarding her questions about the

primary data, but to no avail. He also checked up and found out that the organization had closed and its website was no longer accessible.

According to Dr. Chia, he informed Ms. Faber of his lack of success to contact the organization and its key individuals and he stated that she appeared not to believe him. However, he was able to provide evidence (e.g., email correspondence and a letter of appointment by the organization of him as their research consultant) of the existence of the organization and the individuals he corresponded with to the University Research Integrity Committee at his university, Nanyang Technological University in Singapore.

JAASEP reached out to Mr. Tony Mayer, Research Integrity Officer in the President's Office at Nanyang Technological University in Singapore. Upon correspondence with Mr. Tony Mayer, it was reported that a university group advising the President's Office completed a thorough evaluation on this matter and was reported to the Provost in line with university procedures.

Mr. Tony Mayer reported to JAASEP that the allegations of fabrication by Dr. Chia were found to be unsubstantiated.

### Mr. Mayer stated:

Thank you for informing me about the further complaints/accusations from Helmy Faber. As you know, the university group advising me completed its work last year and accordingly I have reported to the Provost in line with university procedures. Our conclusions were that no evidence was provided by Ms Faber that the data were fabricated or falsified. We also concluded that there is clearly an academic disagreement between Ms Faber and Assoc Prof Chia over the interpretation of the data and this is a matter which should be pursued as normal academic discourse through the medium of scholarly journals. Both parties to the dispute (Noel Chia and Helmy Faber) were advised accordingly in late November 2014.

#### He further reported:

The committee examined all the evidence presented to it by Helmy Faber and the responses from Noel Chia and, as I said in my earlier email, we could find no evidence to substantiate the allegations made by Ms Faber. The report is of course confidential to the University. We concluded that the dispute between the two persons was more one of interpretation and should be pursued through the medium of scholarly discourse. The dispute centres on the data used by Noel Chia. This had been provided by another organisation in Malaysia and Singapore, which no longer exists. There was no evidence to show that this data had been fabricated.

On May 12, 2015, Ms. Faber sent an email to JAASEP questioning the existence of Ms. Esther Yap. We will not repeat the details of the email content but after laying out her review, she stated:

Based upon all these facts it can be concluded that "Esther Yap or Esther Yap S.T. speech therapist" does not exist and the persona has been fabricated. Therefore the data in the paper "Chia, Yap & Ng (2010) 'An analysis of the verb pattern errors in active-passive/passive-active"

sentence formation in English made by Upper Primary Singaporean & Malaysian Chinese children with specific language impairment' have also been fabricated and this should warrant a retraction for your kind consideration. Furthermore, Noel Chia revealed in earlier emails that all the data from the 8 papers were provided to him by the PPC Consortium which was led by speech therapist Esther Yap. Since 'Esther Yap' was fabricated, the 'PPC Consortium' has been fabricated as well, so this should warrant a further retraction of all 7 other articles mentioned in the previous emails for you kind consideration.

In response to this email, we searched for Ms. Esther Yap and immediately found the following information on Google:

Yap, E. (2011). Oligolexia or what is it? *Journal of Reading and Literacy*, *3*, 52-56 <a href="http://www.srl.org.sg/www/downloads/JRL">http://www.srl.org.sg/www/downloads/JRL</a> Vol3 2011.pdf

About the Author: Esther Yap is a qualified speech language therapist currently in private practice in Malaysia.

Furthermore, we contacted Mr. Tony Mayer, Research Integrity Officer, and Professor Paul Teng on this issue. They responded with the following:

During the two investigative processes (one conducted by NIE and the second by a university-wide committee advising the Research Integrity Officer) into Ms. Helmy Faber's allegations against Dr. Noel Chia, we examined email and other correspondences between Ms. Esther Yap and Dr. Chia that date back to September 2007, and do not doubt that these came from a "real" person and an organization called the "Pusat Pembelajaran Cacat" (or "PPC" in short).

We also had sight of email exchanges between the PPC liaison officer and Dr. Chia, and between Esther Yap and other third parties. It is unfortunate that the organization which Esther Yap represented has ceased to exist but this is the nature of such voluntary bodies, especially when the funding support changes.

We did not feel the need to contact Esther Yap as we had no reason to doubt that the correspondence shared with us were genuine. Dr. Chia himself described his various meetings with Esther Yap and we had no reason to doubt her existence or that of the PPC.

On the matter of contacting Esther Yap, we don't have her current whereabouts. But a "google search" showed the following public information:

Oligolexia or What is it?
Esther YAP, <u>B.App.Sc</u>, MCSLT
Speech Language Therapist
EY Ucapan Klinik, Johor Baru, Malaysia
Journal of Reading & Literacy Vol.3, 2011: 52 - 56.
http://www.srl.org.sg/www/downloads/JRL Vol3 2011.pdf

At that point, based on our review of the evidence provided, and using the standard of "clear and convincing evidence", our conclusions were that Ms. Faber had not met the burden of proof that

Dr. Chia's data were fabricated or falsified. Ultimately, if Nanyang Technological University in Singapore, with its resources, did not find a need or a basis for a retraction of articles or evidence to support it, we could not see justified in doing so.

Then, on April 4, 2016, JAASEP received notification from Dr. Chia regarding his wish to withdraw the aforementioned papers in JAASEP (see beginning of this Retraction Statement). JAASEP did not have any information as to why this statement was now submitted by Dr. Chia nor were we given any forewarning of it.

JAASEP then reached out to Tony Mayer again with the following:

Our initial decision not to retract articles last year was based on the information you provided us regarding your investigation. It is very important for us to understand what has transpired. We saw on your website (http://research.ntu.edu.sg/ResearchIntegrity/Pages/Notice-On-Research-On-Children-With-Special-Educational-Needs.aspx) the statement:

"NTU has zero tolerance towards any form of research malpractice and will not hesitate to take action against anyone found to be lacking in research integrity. In accordance with its policy of research integrity, NTU conducted an in-depth investigation following allegations of research malpractice. This concerned research in the area of children with special educational needs carried out by researchers at the NTU National Institute of Education. Because of the non-availability of primary data we are unable to authenticate the data. Consequently, the University considers that coupled with doubts about the ethical approvals for the collection of the data, and in order to protect the integrity of its research record, the papers based on those data need to be retracted. Associate Professor Noel Chia and his co-authors have requested for the following papers to be retracted."

What does "Because of the non-availability of primary data we are unable to authenticate the data" actually mean?

What does "coupled with doubts about the ethical approvals for the collection of the data" mean?

We are respectfully requesting a response from you on this matter. JAASEP is issuing a formal response in its Spring 2016 edition. The more information we have, the better our understanding of the facts and the issues that led to the university's decision. Please let us know what happened that changed the decision of the university and warranted your formal response to the allegations.

Mr. Mayer then responded to us with the following:

Since we last corresponded the complainant produced new information which we have been investigating. In addition, other information was presented again which we have investigated and hence our change of stance.

The data for these studies was collected prior to A/Prof Chia joining NIE/NTU. It had been provided by an organisation called PPC/LDC from Kuala Lumpur. A/P Chia said that all data had been returned to LDC and had not been retained by him. Although the data collection was before he joined us – the analysis and writing had been carried out at NIE. The complainant has said that the PPC/LDC and its intermediary – a Ms Esther Yap – do not exist and so the data must have been fabricated as ere this organisation and this person. We have sworn Statutory Declarations of people who have met Esther Yap so that argument falls. However, we cannot trace the PPC/LDC in Malaysia.

In late 2015, some sample data sheets of child assessments carried out by PPC/LDC were presented to us by A/P Chia which had not been returned to PPC/LDC. We subjected this material to forensic examination and it appears that there may be problems over the signatures of the parental consents.

Because we cannot authenticate the data and because of our concerns about the ethical conditions in which the assessments have been conducted the University feels that we need to protect the integrity of the academic record and papers based on data from PPC/LDC in your and other journals should now be retracted. A/P Chia has agreed and has the agreement of those co-authors who he has been able to contact.

I hope this explains our change of stance.

### **JAASEP Conclusions**

The above stated information are the facts as presented to us at JAASEP. Based on this entire process, here are our conclusions:

- 1. JAASEP would like to personally and professionally thank Helmy Faber, Psychologist NIP, for her hard work and tireless efforts in this matter. She was clearly up against many professional roadblocks, yet she stayed true to what she believed and ultimately served the review process very well. We thank her for her professionalism and helping JAASEP maintain the integrity of our journal.
- 2. Based on this experience, Ms. Faber's work has made us realize that JAASEP needs its own independent review committee if a situation like this arises again. We hope it never does but we need to be prepared. JAASEP spent numerous hours examining all of the evidence presented to us by Ms. Helmy Faber and the responses from Dr. Noel Chia. It was a long arduous task, however, in order to do our professional due diligence in this matter and make such a significant and serious decision, we felt it essential that every document be reviewed and discussed.

JAASEP followed the lead of a university doing its own evaluation and ultimately, we were gaining access to information based on what it was telling us, not our own independent work. In the situation discussed, a university group advising the President's Office completed a thorough evaluation on this matter and was reported to the Provost in line with university procedures that the allegations were not substantiated. Then, new information was produced and other information was presented again which the university investigated and changed its stance.

JAASEP recognizes that we need to do our own independent investigation if a matter like this should ever materialize.

We want to thank Ms. Helmy Faber again for seeing this need and helping us move forward in the formation of such policy and procedure.

- 3. Based on the information presented, JAASEP has made the professional decision to retract all articles submitted by Dr. Noel Chia, not just the ones requested for retraction. Unfortunately, because of the uncertainty surrounding the prior research done that warranted the aforementioned retractions, JAASEP has made the professional decision to retract all of Dr. Chia's articles published in JAASEP in order to protect the integrity of our journal.
- 4. JAASEP has become a highly reputable peer reviewed journal in the field of special education. Every article submitted gets blind reviewed by multiple reviewers and the process for publication takes many hours. Our Editorial Board is exceptional and devotes itself to putting together a truly high quality journal and one that we are all very proud of publishing. It is JAASEP's hope that this retraction of articles by one lead author in no way impacts the outstanding research and writing done by all authors over the past 10 years for JAASEP. JAASEP will do everything possible to be sure that our integrity as a journal is maintained both now and in the future.

# Author Guidelines for Submission to JAASEP

**JAASEP** welcomes manuscript submissions at any time. Authors are completely responsible for the factual accuracy of their contributions and neither the Editorial Board of JAASEP nor the American Academy of Special Education Professionals accepts any responsibility for the assertions and opinions of contributors. Authors are responsible for obtaining permission to quote lengthy excerpts from previously-published articles.

Authors will be notified of the receipt of their manuscripts within 14 business days of their arrival and can expect to receive the results of the review process within 30 days.

All submissions must have a cover letter indicating that the manuscript has not been published, or is not being considered for publication anywhere else, in whole or in substantial part. On the cover letter be sure to include your name, your address, your email address, and your phone number

As much as possible, typescript should conform to the following:

- ➤ Method of Manuscript Submission: Send Manuscripts should be submitted electronically with the words "Submission" in the subject line.
- > Language: English
- > Document: Microsoft Word
- > Font: Times New Roman or Arial
- Size of Font: 12 PointPage Limit: None
- Margins: 1" on all sides
- > Title of paper: Top of page Capitals, bold, centered,
- > Author(s) Name: Centered under title of paper
- Format: Feature Manuscripts should follow the guidelines of fifth edition of the Publication Manual of the American Psychological Association (APA).
- Figures and Tables: All should be integrated in the typescript.
- Abstract: An abstract of not more than 150 words should accompany each submission.
- ➤ References: Insert all references cited in the paper submitted on a Reference Page

Submission of Articles: Submissions should be forwarded by electronic mail to the Editor, Dr. George Giuliani at editor@aasep.org

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