# PARENTS' PERSPECTIVES ON INCLUSION AND SCHOOLING OF STUDENTS WITH ANGELMAN SYNDROME:  SUGGESTIONS FOR EDUCATORS

**Yona Leyser Ph. D.**
**Rea Kirk Ed. D**
*Northern Illinois University*
*University of Wisconsin-Platteville*

*This study examined perspectives on inclusion and schooling of a sample of 68 parents of children with Angelman Syndrome (a severe and complex disability), and solicited their suggestions and recommendations for educators.  Participants responded to a scale titled,* Perceptions of Parents of Children with Angelman Syndrome toward School *adapted from two instruments developed previously (Leyser & Kirk, 2004; Salend, 2001).  Parents also responded to several open-ended questions. Findings revealed not only a strong support of the philosophical and legal principles of inclusion, but also major concerns such as a lack of knowledge and skills by teachers and possible rejection of the child.  A sizable number of parents still supported the education of their child in segregated special education settings.  Most parents were satisfied with the child's schooling, but were concerned about the lack of services and difficulties of communication with the school and the district.  Parents offered helpful insights about their children and families.  A discussion of the study results and implications for pre-service and in-service training are provided.*

## Introduction

Educational systems around the world in developed and developing nations are undergoing school reforms. One of these reforms is related to the progressive inclusion of students with disabilities in regular classrooms and school environments (Ainscow & Miles, 2008; Mittler, 2002; Smith-Davis, 2002). The extent to which inclusive practices are implemented is influenced by cultural, political, social and economic contexts and by various interpretations of the concept.  Implementation therefore differs among nations, states, regions, and school districts (Friend, 2011; Gabel & Danforth, 2008; Jenkinson, 1998; Rouse & Florian, 1996; Vazins, 2009).  Parents have a major role in the development of successful inclusion programs. Indeed, special education reform acts and regulations in many countries provide guidelines for the active participation and involvement of parents in the education of their child.   For example, in the United States, the Individuals with Disabilities Education Act P.L. 94-142, most currently revised in 2004 as P.L. 108-446 (U.S. Congress, 1997; U.S. Congress, 2004) has strong provisions for parent participation.  Furthermore, research has demonstrated the benefits of collaborative relationships between home and school which include higher academic achievements, positive attitudes, improved behavior, and more successful programs (Yssel, Engelbrecht, Oswald, Eloff, & Swart, 2007). Parent reactions are also vital in the evaluation of inclusive programs. Their evaluation of curriculum, training of teachers and administrators, and their child's education can provide valuable feedback to schools (Garrick, Duhaney, & Salend, 2000; Leyser & Kirk, 2004; Seery, Davis, & Johnson, 2000). Results from studies which examined views of parents of children with disabilities about inclusion and integrated educational programs are mixed.   For example, several investigators examined the views of parents of children with mild or moderate disabilities in elementary and pre-school programs.  Several of these studies reported that parents were supportive of inclusion practices and were satisfied with these programs and the benefits for their child (Bennett, DeLuca, & Bruns, 1997; Miller, Strain, Boyd, Hunsicker, McKinley, & Wu, 1992; Seery et al., 2000).  However, results from other studies report less support (Fox & Ysseldyke, 1997).

Several studies of parents of students with severe disabilities in integrated programs from pre-school to high school supported their child's placement and expressed satisfaction with the educational outcomes, in particular the social benefits (Davern, 1999; Freeman, Alkins, & Kassari, 1999; Gallagher, Floyd, Stafford, Taber, Bronzovic, & Alberto,  2000; Hanline & Halvorsen, 1989; Palmer, Borthwick-Duffy, & Widaman, 1998; Ryndak, Downing, Jacqueline, & Morrison, 1995; Turnbull, Turnbull, Shank, Smith, & Leal, 2002).   A few investigators, however, suggested that some parents of children with severe disabilities do not favour inclusion (Palmer, Fuller, Arora, & Nelson, 2001).

Although the evidence presented suggests that many parents were in favour of inclusive education, they often expressed a number of doubts and concerns.  For example, Hanline and Halvorsen (1989) identified six areas of pre-transition concerns:  safety; attitudes of other students; staff and program quality; transportation; district commitment; and potential for failure.  Other concerns mentioned by parents included worries about possible verbal and physical abuse by peers, social isolation, and loss or reduction of services and of quality of instruction (Pivik, Mccomas & Laflamme, 2002; Runswik-Cole, 2008); Palmer et al. (2001) reported that parents were concerned that the severity of the child's disability precluded benefits from inclusion, that inclusion would overburden general education teachers or students, and that the child was too behaviorally disruptive and could hurt others.  Similar concerns by Australian parents were reported by Jenkinson (1998).

Some parents still harboured anxieties and concerns after their children were placed in inclusive programs.  These included worries about inadequate training, attitudes of general education teachers, lack of appropriate support and resources, and lack of specialized instruction, as well as concerns about the social integration and academic progress of their child (Bennett et al., 1997; Fox & Ysseldyke, 1997; Frederickson, Dunsmuir, Lang & Monsen, 2004; Garrick Duhaney, & Salend, 2000; Grove & Fisher, 1999; Pivik, Mccomas & Laflamme, 2002; Runswik-Cole, 2008; Seery et. al., 2000).

One of the areas of much concern often cited by parents of students with disabilities often cited is their unhappiness with the relationship, communication and partnership between home and school (Davern, 1999; Frederickson et. al., 2004; Lovitt & Cushing, 1999).  Parents were often found to express frustrations with the process used to develop the Individualized Education Program (IEP), reporting a lack of respect and receptivity toward their views, feelings of intimidation, and a lack of understanding of their needs.  They also reported the feeling of being less than equal partners (Childre & Chambers, 2005; Soodak & Ervin, 2000; Stoner, Bock, Thompson, Angell, Heyl, & Crowley, 2005; Tetreau, 1995).

Attitudes of parents toward inclusion are influenced by several variables such as satisfaction with the educational services their child receives and their beliefs about the educational goals.  While parents who are interested in socialization opportunities favour inclusion, parents who are concerned with academic goals favour a continuum of educational placements aimed at meeting academic standards.  Other variables related to attitudes include the child's age, parent socioeconomic status and educational background, years of experience with an inclusive setting, number of children, and marital status (Freeman, Alkin, & Kasari, 1999; Garrick, Duhaney, & Salend, 2000; Leyser & Kirk, 2004; Palmer, Borthwick – Duffy, & Widaman, 1998; Stoiber, Gettinger, & Goetz, 1998).

Most of the studies reported in the literature examined attitudes of parents of students identified as having mild to moderate disabilities, or of students with severe disabilities.  Some focused on a single etiological group of children or a particular type of disability, for example, parents of children with Down syndrome or with autism (Freeman et al., 1999; Kasari, Freeman, Bauminger, & Alkin, 1999), parents of children with a neuromuscular disease (Strong & Sandoval, 1999), and parents of children with mobility limitations (Pivik, Mccomas & Laflamme, 2002). The focus of this study was on parents of children with Angelman syndrome (AS).

The first three children with AS were diagnosed in England in 1965 by Dr. Harry Angelman.  In the United States the first reports of AS were in the early 1980s.  Most children however with AS have been diagnosed in the past 15 years.  Because AS is a relatively new diagnosis, and it is so rare, its prevalence is not precisely known.   It is estimated that between one per 12,000 and one per 30,000 people have AS. An incorrect diagnosis (usually of autism) has often been made.

For the majority of people with AS, the cause is a deletion in chromosome 15.  This is true for about 70% of those diagnosed with AS.  Another five to seven percent have a mutation of the chromosomal region in UBE3A.  Two to three percent have no deletion or mutation, but the person is still missing the active UBE3A gene.  Some have unusual chromosomal rearrangements and for the rest (about 15%), the cause is still unknown (Summers, Allison, Lynch, & Sandler, 1995).

Individuals with Angelman Syndrome are characterized by a developmental delay and intellectual disability.  Communication problems include diminished or absence of speech.  There are motor problems which include an inability to walk or walking with a stiff and jerky gait.  Hand flapping is another symptom.   EEG abnormalities and seizures are often reported.   Physical and sensory

characteristics include a large jaw, large mouth, and eye abnormalities.  A person with AS is also characterized by a loving, happy and excitable personality.  Frequent laughter is typical (Clarke & Marston, 2000; Richard & Hoge, 1999; Summers, Allison, Lynch, & Sandler, 1995; Summers & Feldman, 1999).

Although studies on parents' views regarding inclusion have been reported, their continued input and perspectives about inclusion and their educational experiences are crucial for the assessment and evaluation of inclusive school environments.  Perspectives may also change over time as more successful inclusive practices are implemented.  Furthermore as Kasari et al., (1999) reported, the diagnosis of the child impacted parent attitudes toward inclusive education.  Studies should therefore be designed of parents of children with different disabilities such as parents of children with AS whose perspectives have not yet been examined.

This study was undertaken to explore the beliefs of parents of children with AS about inclusion and their experiences, satisfaction and concerns related to the child's schooling.   The study was also designed to solicit parents' suggestions and recommendations for educators.   This study also examined the association between parent and child demographic variables, namely age, educational level, and extent of inclusion, on attitudes toward inclusion.

**Method**
*Participants*
Participants were 68 parents of children with AS who responded to a survey instrument about inclusion and schooling.  These parents were from across the United States who attended the Angelman Syndrome Foundation (ASF) conference and parents who responded to the on-line survey posted on the ASF website (see procedure).  Surveys were completed mostly by mothers (80%).  Over three-fourths (78.8%) were European American, and a similar percentage considered themselves to be middle income.  About one-third reported that both mothers and fathers were high school graduates and/or had some college education.  All others were college graduates.  Most (87%) were married.  The age range for children with AS was from three years to 18+.  One-fourth were in the three to five year old age range; about 40% were ages six through twelve; and about one-third were age twelve or above.   Fifty-six percent were boys.  Most (65%) were included in regular school settings.  Parents reported that about 45% were mainstreamed into regular classrooms for part of the day, 10% all day, 40% not at all, and 5% did not know.

*Procedure*
Permission to carry out the study was granted by the Angelman Syndrome Foundation (ASF).  They also provided assistance in carrying out the study.   Surveys were distributed in hard copy at the ASF conference held in 2007.  Forms were also available on-line on the ASF website.  A monthly reminder about the survey appeared on this website.   Consent forms were available both on-line and in hard copy.  The completed forms were submitted electronically or by hard copy to the researchers.  No differences in the responses on the hard copies (color coded in blue) or on the electronic mail (color coded in white) were noted.

*Instrument*
The instrument titled *Perceptions of Parents of Children with Angelman Syndrome Toward School* was administered.   It included a brief introduction indicating the purpose of the survey, namely to learn about parents' views, thoughts, and feelings and to solicit their input regarding inclusion and schooling of their child with AS.  In Part One of the instrument, parents were asked to provide background information (i.e., race, community, marital status, occupation, education level, age of child and degree to which the child was mainstreamed).
Part Two titled *Thinking About My Child's Education* included a 20 item rating scale examining attitudes toward inclusion and schooling.  The scale was adopted and slightly modified from a scale previously used by Leyser and Kirk (2004) and a scale developed by Salend (2001). This part had two sections. Twelve items explored attitudes toward inclusion, and eight items explored perspectives regarding their school experiences.
 Respondents were asked to rate each item on a five-point Likert scale ranging from 1 (strongly agree) to 5 (strongly disagree) with a midpoint at 3 (undecided).  Fifteen items were worded so that a response represented a favourable disposition toward inclusion and positive perceptions about the child's schooling.  Five items expressed a negative view about inclusion.  Scores of these five items were reverse-coded during the statistical analysis so that a low rating on each item was interpreted as a

favourable attitude regarding inclusion and schooling.  Cronbach alpha reliability analysis of the total scale (after item reversals) was .77.  The reliability for the 12 items measuring attitudes toward inclusion was .75.  The reliability for eight items measuring disposition toward schooling was .86.

In the third part, parents were asked to respond to four open-ended questions regarding the joys and challenges related to their child's education, their goals and dreams, and about what they would like teachers and school districts to know regarding the family and the child, as well as any other information they would like to share.  Ample space was provided for responses to each question.

**Data Analysis**
In this study both quantitative and qualitative data were collected and analyzed.  This allowed the researchers to elaborate on the findings in greater depth and provided a richer understanding of the data (Creswell, 2009).

*Quantitative Data*
Frequencies, percents, means, and standard deviations were calculated for the demographic variables and for each of the 20 items on the attitude questionnaire. Anova's and t- tests were carried out on the demographic characteristics and parent attitude scores.

*Qualitative Data*
The investigators used a modified form of the Critical Incident Technique, which involves the collection of real-world examples of behavior that characterize either very effective or very ineffective performance of some activity (Stano, 1983).  *The technique does not consist of a single rigid set of rules but rather should be thought of as a flexible set of principles…* (Flanagan, 1954, p.335; Stano, 1983, p.3).  According to Creswell (2009), during the data analysis, raters build their categories from a large specific base into more general categories, going back and forth between categories and database until a comprehensive set of themes is achieved.

The qualitative rich data garnered from the four open-ended survey questions allowed the investigators to generate information based on first-hand accounts of actual, personally meaningful perceptions of the parents.  By comparing the number of times each concept was cited, the relative importance of different factors was inferred.

Two raters, one of the investigators and a graduate assistant, independently sorted statements by grouping similar incidents together into piles.  Summary statements were developed for each pile for which a category was developed.  These categories were then collapsed into more general categories, again done independently by both the investigator and the graduate student.  This process was repeated a third time until no new categories emerged.  When the two raters disagreed, they met to determine the correct categorization of the disputed statements.  Disagreements only happened on placement of six statements.  As experts note, reliability of rating in this type of study by independent raters (or observers) is established when the use of the same procedures yields similar results (Flanagan, 1954; Yin, 1994).  This was accomplished here. Creswell (2009) noted that validity is established when the researcher, participants, or readers perceive the results as accurate.  Words such as authentic and credible establish validity.  The Angelman Syndrome Foundation's executive assistant and editor of *Voices of Angeles* (associated newsletter), after seeing the results of the study, indicated that she deemed this study to be accurate and credible.

**Results**
Table 1 refers to Part Two of the survey and depicts the mean scores and SD's of parents' rating of items exploring attitudes toward inclusion and schooling.  Responses to items about inclusion reveal that almost all (95.6%) believed that inclusion is a civil rights issue, namely that students with AS have the right to attend the same school as their peers without disabilities (item 1).  Similarly, more than three-fourths (77.9%) responded that children with AS should be given every opportunity to function in the general classroom (item 3).  A large majority (86.8%) felt that inclusion is advantageous for the socialization of their child (item 6).  Almost all parents (91.2%) responded that they would like to see their child have contact in school with peers without disabilities (item 9).  In addition, most parents

(92.7%) felt that inclusion is also advantageous for peers without disabilities by fostering acceptance of individual differences (item 8).

**Table 1:**
**Numbers, Percentages, Mean and SD's for responses to Attitudes Toward Inclusion and Schooling (N=68)**

| Item | 1 Strongly Agree | | 2 Agree | | 3 Undecided | | 4 Disagree | | 5 Strongly Disagree | | *M* | *SD* |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | *N* | *( %)* | *N* | *( %)* | *N* | *( %)* | *N* | *( %)* | *N* | *( %)* | | |
| 1. Students with AS have the same right to be educated in same school as other students. | 55 | (80.9) | 10 | (14.7) | 2 | (2.9) | | ----- | 1 | (1.5) | 1.26 | .66 |
| 3. Children with AS should be given every opportunity to function in general classrooms. | 33 | (48.5) | 20 | (29.4) | 7 | (10.3) | 7 | (10.3) | 1 | (1.5) | 1.87 | 1.06 |
| 6. Inclusion is socially advantageous for children with AS. | 39 | (57.4) | 20 | (29.4) | 6 | (8.8) | 1 | (1.5) | 2 | (2.9) | 1.63 | .92 |
| 9. I would like my child to have contact with typically developing children. | 45 | (66.2) | 17 | (25.0) | 3 | (4.4) | 2 | (2.9) | 1 | (1.5) | 1.49 | .83 |
| 8. The presence of children with AS promotes acceptance of individual differences. | 38 | (55.9) | 25 | (36.8) | 4 | (5.9) | 1 | (1.5) | | ----- | 1.53 | .68 |
| 4. Parents of children with AS prefer to place their child in inclusion. | 6 | (8.8) | 24 | (35.3) | 28 | (41.2) | 8 | (11.8) | 2 | (2.9) | 2.65 | .91 |
| 2. It is difficult to teach all students in a class if one student has AS.* | 4 | (5.9) | 19 | (27.9) | 11 | (16.2) | 18 | (26.5) | 16 | (23.5) | 2.66[1] | 1.27 |
| 5. The needs of students with AS cannot be met by a regular classroom teacher plus an aide.* | 15 | (22.1) | 14 | (20.6) | 12 | (17.6) | 4 | (25.0) | 10 | (14.7) | 3.10[1] | 1.39 |
| 7. Children with AS are likely to be | 9 | (13.2) | 8 | (11.8) | 11 | (16.2) | 31 | (45.6) | 9 | (13.2) | 2.66[1] | 1.24 |

| Item | 1 Strongly Agree | | 2 Agree | | 3 Undecided | | 4 Disagree | | 5 Strongly Disagree | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | N | ( %) | N | ( %) | N | ( %) | N | ( %) | N | ( %) | M | SD |
| isolated in inclusion.* | | | | | | | | | | | | |
| 13. My child has been teased in school.* | 1 | (1.5) | 6 | (8.8) | 23 | (33.8) | 22 | (32.4) | 16 | (23.5) | 2.32[1] | .98 |
| 20. Parents of children without disabilities resent children with AS in the classroom.* | 3 | (4.4) | 13 | (19.1) | 18 | (26.5) | 25 | (36.8) | 9 | (13.2) | 2.65[1] | 1.07 |
| 15. I like my child to be in inclusion next year. | 23 | (33.8) | 12 | (17.6) | 16 | (23.5) | 13 | (19.1) | 4 | (5.9) | 2.46 | 1.29 |
| 17. This school year is going well. | 22 | (32.4) | 28 | (41.2) | 13 | (19.1) | 4 | (5.9) | 1 | (1.5) | 2.03 | .94 |
| 12. I feel school has been positive for my child. | 32 | (47.1) | 29 | (42.6) | 4 | (5.9) | 3 | (4.4) | | ----- | 1.68 | .78 |
| 18. My relationship with my child's teacher and therapist is good. | 27 | (39.7) | 28 | (41.2) | 10 | (14.7) | 3 | (4.4) | | ----- | 1.84 | .84 |
| 11. I feel satisfied with school communication. | 15 | (22.1) | 26 | (38.2) | 11 | (16.2) | 12 | (17.6) | 4 | (5.9) | 2.47 | 1.19 |
| 19. My relationship with the school district administration is good. | 15 | (22.1) | 29 | (42.6) | 14 | (20.6) | 7 | (10.3) | 3 | (4.4) | 2.32 | 1.07 |
| 10. I feel satisfied with services my child receives. | 15 | (22.1) | 24 | (35.3) | 14 | (20.6) | 12 | (17.6) | 3 | (4.4) | 2.47 | 1.15 |
| 14. I feel school did a good job explaining services. | 15 | (22.1) | 31 | (45.6) | 4 | (5.9) | 16 | (23.5) | 2 | (2.9) | 2.40 | 1.16 |
| 16. The IEP process has been helpful. | 16 | (23.5) | 25 | (36.8) | 10 | (14.7) | 10 | (14.7) | 7 | (10.3) | 2.51 | 1.28 |

*Negative items. Scores should be reversed.
[1]Mean scores after reversal. Lower scores are indicative of a more positive disposition

Despite that strong support for inclusion, responses to several other items revealed parental concerns and reservations. For example, about one-third (33.8%) responded that it is difficult to teach in a class if a child with AS is included, while another 16% were not sure (item 2). Forty-three percent felt that the needs of a child with AS cannot be met by a regular classroom teacher with an aide, while another 18%

were not sure (item 5). One-fourth also felt that the child with AS is likely to be socially isolated in an inclusive school while another 16% were not sure (item 7). On the question whether their child has been teased by others in school (item 13), about one-third of parents were not sure. One-fourth felt that parents of classroom peers resent children with AS in the inclusive classroom, while another one-fourth were not sure (item 20). Would these parents want their child to be in an inclusion setting next year? (item15) One-fourth said, *No* and another fourth were unsure. Interestingly, on the question whether other parents of children with AS favour inclusion, (item 4), only about 45% gave an affirmative response while another 45% of respondents were undecided and approximately 10% did not think so.

These ratings by parents showing support for inclusion, on the one hand, yet also, revealing concerns and worries were echoed in the many written comments given to the open-ended questions. Categorization of these responses revealed that almost half (45.6%) gave support for inclusion. Examples of this view were, *I personally do not view inclusive education as a choice but as a human rights issue; segregation is wrong. A center program or self-contained classroom might have the best funded staff and intentions, but it's the wrong thing to do*; and *Child has severe AS--want as much school inclusion as possible so child meets a variety of students and they better understand her as much as possible.*

Other parents expressed concerns and were critical about inclusion. This was demonstrated in statements such as, *Elementary school was a nightmare, our son was included in regular education classes. Most teachers had no clue what to do, the* certified *staff ignored any input from parents*; *The greatest joy has happened within the last year when my son went to a special school out of the public school district … where other individuals are like* him; and *Center-based schooling offers the opportunity to hone in on the emerging skills and maximize the education process that highly trained special ed. teachers are familiar with. More emphasis needs to be put on the quality of the services and not on the location of services.*

A few parents expressed unhappiness with both inclusion and special education placements and chose to home school their child, i.e., *We have given home education to our daughter for six years, with the guidance and therapeutic recommendations of the National Association of Child Development. Her function is already higher than is expected of a child with Angelman syndrome. This repeatedly causes us to question the focus and materials of the traditional education and therapy systems.*

Responses to items about schooling showed that a majority (73.6%) felt that the current school year is going well for their child (item 17), and a large majority (89.7%) reported that school has been positive for their child (item 12). Most (80.9%) also reported good relationships with teachers and therapists (item 18). However, less satisfaction can be seen with school's communication (item 11) where about 60% expressed satisfaction, but one-fourth stated no satisfaction and another 16% were not sure. Parents were also unhappy with their relationships with the district administration (item 19) where 66.7% were satisfied while all others were unsure or not satisfied. Only 57.4% were satisfied with school services (item10) while all others were unsure or not satisfied. While many (about 70%) felt school did a nice job explaining the services (item 14), one-fourth did not think so. Finally, about 60% felt the IEP process had been helpful, yet about 40% did not think so or were unsure (item 16).

These ratings were supported by parents' comments on the open-ended questions. For example, *They always give my child every opportunity to succeed with any of his goals or our goals. I am thrilled with my son's achievement at this school, I have always been happy with his education, and he has always received services he needed. R. had teachers and therapists that cared for him and had his best interest in mind.* On the other hand, several were not satisfied: *I feel public schools should be able to provide more services and more semester hours of PT, OT, and speech. Many of the hours (my child receives) are on a consultant basis. I feel that is ridiculous.*

Several parents expressed dissatisfaction with their relationships and communication with school and the district: *District communication has been horrible since day one. District attentiveness to my daughter's needs has been negligent at best.* There were also some comments about positive communication: We have good communication with the school staff; we encourage them to treat her as normal [sic] as possible. She gets rewards and time-outs just like a regular eight year old.

*Variables Influencing Parents' Views about Inclusion*
T- tests and Anova's were carried out to examine the impact of two background variables on attitudes toward inclusion. The variables were attendance in a regular school building and extent of inclusion in a

regular classroom.   The attitude score was the mean score of 12 items exploring attitudes toward inclusion on the questionnaire.  Results are explained below.

*Attending a regular school building*
 Two groups were compared.  Group 1 was composed of parents (N=44) who reported their child attended a regular school building ( as opposed to a special school), and group 2 were those who reported their child attended a regular school only part of the time or attended a segregated setting (N=23).  The mean scores and SD's for group 1 were M=2.06, SD=.46 and for group 2, M=2.41, SD=.58. The t-test between groups was significant (t65=-2.69, p<.009).  Parents of children who were educated in regular public school buildings held more positive views about inclusion than those who reported their child attended a public school only part of the time or was educated in a segregated setting.

*Extent of inclusion in regular classrooms*
Two groups of parents were compared.  Group 1 (N=36) was composed of parents who reported their child was mainstreamed or included all day or part of the day in a regular classroom, and Group 2 (N=28) contained those who reported their child was not at all mainstreamed or did not know (only three stated they did not know).  The mean scores and SD's for Group 1 were M=2.07, SD=.48 and for group 2 M=2.31, SD=.58.  The t-test between the two groups was marginally significant (t62=-1.79, p<.078). Parents whose children were mainstreamed tended to hold more positive views about inclusion.  No significant differences on attitudes were found for gender, occupation of parents (two levels), schooling (two levels) or child's age (three levels).

*Analyses of Responses to Open-ended Questions*
*Parents' Goals and Dreams.*
Parents' comments regarding their goals and dreams for their children were grouped into several major categories.  Responses that were most common revealed that a major goal they wished for their child was to have social skills, a social life and friends (31 responses).  This was followed by the dream of happiness and enjoyment in life (22 responses).  Other common themes were:  be as independent as possible (22 responses); be able to communicate (17 responses); and be safe and secure (15 responses). Parents also mentioned future goals such as:  live independently or semi-independently or be taken care of by another person (16 responses); live in the community and be accepted and productive (16 responses); and live in a group home (seven responses).  Also mentioned was a goal of reaching his/her potential (11 responses).  These dreams were summarized by a parent who said, *We all have the same basic hopes and dreams for our child: health; happiness; and safety.*  A few responses revealed worries and concerns, i.e., *I don't know; I am living one day at a time*, and, *I hope he will have some kind of skill to participate in society.  He will never be able to live independently, but I'd like to hope that there will be a place for him in society.*

*What Educators Should Know about the Child and the Family*
The question regarding what parents want educators and administrators to know about the child and their family revealed that a majority want educators to know that the child is more than his diagnosis. These statements included: *do not underestimate, he/she can learn...is capable, more than the school realizes*; *has gifts; they are smart* (41 responses).  Additional remarks included, *child has special gifts to share* (five responses), *is doing his best*, *he does not have bad behaviors; he is just trying to communicate.* Other examples of statements by parents regarding the abilities of their children include: *Just because our son does not speak, he still has great potential to learn*; *She may not talk but does have much to say, so true is this statement*! and *He can teach other regular kids tolerance, joy and perseverance.*

In response to the question, *what should professionals know about your family*, the most often mentioned response was categorized as family devotion, love, and commitment (34 responses).  Telling responses included: *We love our son unconditionally and will do whatever we need to do to help him and give him the best life possible*; *I advocated relentlessly for my child because I know her needs and potential*; and *Our son was a blessing in the lives of our family members.  Not only are we learning a lot from him, but our family is learning a lot from each other.  We have become so creative and supportive of one another.*

Several parents addressed the needs of the family for help, support, and understanding, i.e., *We are not the* experts*; we are parents*; *We want you to help us to help our children*;  *Our life is hard, and they should not judge us*; and *We just want to be like everyone else.  But we're not, so don't make a big deal out of our special needs.*

*Information for District Personnel and Teachers*
Parents offered many suggestions and recommendations for school districts and teachers about their child's education. Their responses were grouped into two major categories. These categories were partnership and curriculum/instruction.

*Partnership*
A number of parents (12 responses) called for better partnerships and more teaming among the family, school, and other professionals. One parent reminded schools that, *Parent/guardian rights are not always respected*. Many stressed the need for staff development by districts (23 responses), and for school teachers to know what AS is and how to appropriately teach these students (26 responses), i.e., *All individuals with AS are unique in personality, abilities, and health issues. There is no one-size-fits-all method. An educator must take the time to know the child's uniqueness as a person and consider the disability secondary*, and *School districts need to train/educate all staff on how to work with and/or modify curriculum*. Some suggested an outline for training, i.e., *Characteristics of AS and specialness of the child. To what does the child respond most effectively (smiles, positive responses)? Understanding what child processes (not always easy) and to what she can respond*. Other suggestions for districts included *Communicate more with parents* (10 responses) and *Offer more services* (17 responses).

*Curriculum and Instruction*
 Parents also offered suggestions about instruction, curriculum and pedagogy. These included suggestions to provide opportunities for consistency and repetition (six responses), to have patience and love, to believe in these children (nine responses), and to be accepting of alternative methods (seven responses). Some examples were, *Talk to her - not down to her. Have lots of patience (and short hair, because she'll pull it!)*, and *Love working with these special children*. Comments about curriculum were mainly about the need to develop communication skills (25 responses). The importance of life skills rather than academics (15 responses) was also stressed. Another was the need to teach socialization skills (10 responses). Others were general suggestions, such as provide opportunities for success, get something out of the school day, and make progress.

Finally, some parents offered advice to other families. *Parents have to accept the special child they have. They need to accept the best in them and not disable them more. It's not the PT's, OT's, or teacher's responsibility; they are there to support repetition and consistencies. Love and hope will help you to raise your beautiful angels.*

**Discussion**
Results from the quantitative and the qualitative analysis revealed that a large majority of parents in this study were in favour of their child's inclusion in a regular school building and in regular classrooms for part of the day. Parents stressed that inclusion is a human rights issue, and segregation is wrong. Many mentioned the social benefit of inclusion, not only by providing opportunities for socialization and friendship for their child but also by fostering understanding and acceptance of individual differences by classroom peers. Similar findings were also reported in previous studies of parents of children with mild disabilities and especially children with more severe disabilities who value the benefits of socialization as an educational goal for their child (Freeman et al., 1999; Garrick Duhaney, & Salend, 2000; Leyser & Kirk, 2004; Palmer et al., 2001; Seery et al., 2000).

Despite the support for inclusion, parents expressed a number of concerns similar to those reported over the years in the literature. These included a concern over the lack of knowledge and instructional skills by general education teachers, lack of resources, and a fear that their child may be socially rejected and teased by classroom peers (Davern, 1999; Jenkinson, 1998; Leyser & Kirk, 2004; Lovitt & Cushing, 1999; Runswick-Cole, 2008). Some parents also expressed a concern about parents of students without disabilities who may resent the inclusion of their child. This concern may be related to a negative experience they have had at school with some parents or may be due to stressful encounters with members in their communities as reported by Worcester, Nelson, Raffaele-Mendez, and Keller (2008). Research studies on views of parents of children without disabilities about inclusion offer some mixed results. While these parents were often found to support inclusion, some parents were concerned that their children would not receive enough instruction from teachers. They also expressed concern about inappropriate behaviour of students with disabilities and that teachers were not trained to work with these children (Garrick, Duhaney, & Salend, 2000).

Interestingly, almost the same number of parents (about 45%) who thought that other parents of children with AS would favour inclusion responded that they were undecided. This response may suggest that parents of children with low incidence disabilities may have limited opportunities to interact with other similar families in their districts. Alternatively, it may be they are well aware that the decision whether to embrace inclusion by the family is based on a subjective evaluation of the attributes and needs of their child and on their values and experiences with school (Palmer et al., 2001). Indeed, findings revealed that a sizable percentage of parents did not think that inclusion is appropriate for their child, and they supported education in specialised settings. Several mentioned the benefits of specialised settings by observing that teachers are better trained, skilled, and more committed. Furthermore, they noted that their child will be with peers similar to him/her. Similar findings were also reported by other researchers (Kasari et al., 1999; Runswick-Cole, 2008).

However, findings also revealed that parents whose children attended a regular school building or were included in a regular classroom held more positive attitudes toward inclusion compared to parents whose children were mostly educated in segregated settings. Considering the views shared by many parents about the rights issue and the socialization benefits, this finding is not surprising. Still, as their responses revealed, many also shared concerns about inclusion. Other background variables were not found to be associated with more positive attitudes in this current study.

Input provided by parents about their feelings regarding their child's schooling and their experiences with the school system revealed a mixed picture. They expressed a high degree of satisfaction with their child's progress and the positive relationships with teachers they perceived as caring and committed, as well as with therapists. Yet, a sizable percentage (about 40%) of parents was critical about their relationships and communications with school and the school district administration. Many indicated that more services are needed. Parent dissatisfaction was also noted with the IEP process. These are further examples of unresolved issues and frustrations which parents continue to experience in their relationships with the school system that have been reported over the years in the literature (Davern,1999; Frederickson et al., 2004; Lovitt & Cushing, 1999; Pivik, Mccomas, & Laflamme, 2002; Runswick-Cole, 2008; Soodak & Ervin, 2000).

The study provided an opportunity for parents to share their personal feelings, thoughts, and insights about their child and about the family and to offer suggestions and recommendations for educators. Responses (some lengthy) revealed that their dreams and aspirations were not different from those of other parents of children both with and without disabilities (a statement made by several respondents). Most mentioned happiness, a rich life with enjoyment, having friendships, and being independent as much as possible. They also expressed the wish for their children to be safe and secure, to live and be accepted in the community, and to have people who will take care of them when they, as parents, will no longer be able to do so.

In their comments, parents wanted to send educators a message that their child is more than his/her diagnosis or label. They asked educators to not underestimate their children, that they are capable of learning, have a range of abilities, and should be treated as regular children. Most stated that the family has a strong commitment and love for the child, as well as high expectations, and will do all that is needed to provide the best care, education, and support. Only a few parents stated their own need to be accepted and welcomed, and their personal need for support. A number of other researchers are also reporting that many families of children with disabilities are resilient and cope effectively and positively with the demands of raising their child (Ferguson, 2002; McCloskey, 2010; Taunt & Hastings, 2002).

Parents provided suggestions and advice in several areas. They stressed a need for better communication and partnership between school and home and requested that schools and school districts provide better training about Angelman Syndrome. Many stated needs in the area of instruction and curriculum. For example, they called on teachers to be patient, to love and believe in their children, to have high expectations, and to accept alternative teaching methods. They suggested that more emphasis is needed in the curriculum on life skills, communication, and socialization.

*Implications*
Findings have several practical implications for pre-service and in-service training for educators and administrators. Although many universities and colleges offer some course work on disabilities for general educators, additional training in knowledge and skills is needed as more students with severe and multiple disabilities are educated in neighborhood schools and in regular classrooms. This knowledge

may be infused across the curriculum at the pre-service level and offered in workshops, meetings, and on the internet at the in-service level.  Examples include characteristics of students with severe and multiple disabilities and curricular alternatives (i.e., functional curriculum, community-based education, instructional accommodations, and strategies to promote positive peer interactions and friendships).  More emphasis is needed on family issues to facilitate more sensitivity and understanding of these families.  Inviting parent speakers to the college classroom may be a valuable experience.

In addition to their other responsibilities, during student teaching, pre-service teachers should be encouraged to attend school events and parent nights to meet families of students with disabilities.  If appropriate, students may also attend local meetings of parent organizations.  Strong and Sandoval (1999) reported that practicing teachers asked for more in-service training and support that included more frequent consultation from other staff such as experienced special educators.  As findings in this study also indicated, additional training on the needs of students with disabilities and their families should be required in programs preparing school administrators.  Parent input also indicated that professional development activities are needed at the district level for administrators and staff.

There are several limitations of this study which need to be considered.  The sample size of participating parents was relatively small.  Furthermore, a majority of respondents were European American parents who are from middle income, college-educated (many with advanced degrees), and who have higher level occupations.  These were parents who wanted to be heard and to share concerns and advice.  They may not represent many other parents who are a silent majority.

Future research should continue to examine the perspectives of parents of children with different diagnostic characteristics and educational needs regarding inclusion.  Furthermore, efforts by researchers should continue to explore strategies that will assure a higher response rate and a better representation of parents from different cultural backgrounds and socioeconomic levels.

**References**
Ainscow, M. & Miles, S. (2008). Making education for all inclusive: Where next? *Prospects: Quarterly Review of Comparative Education*, 38 (1), 15- 34.
Bennett, T. DeLuca, D., & Bruns, D. (1997). Putting inclusion into practice: Perspectives of teachers and parents. *Exceptional Children, 64,* 115-131.
Childre, A. & Chambers, C. R. (2005). Family perceptions of student centered planning and IEP meetings.
*Education and Training in Developmental Disabilities, 40* (3), 217-233.
Clarke, D. J. & Marston, G. (2000). Problem behaviours associated with 15-q Angelman syndrome.
*American Journal on Mental Retardation, 105* (1), 25-31.
Creswell, J. W. (2009). *Research Design: Qualitative, Quantitative and Mixed Methods Approaches.* (3rd ed.). Thousand Oaks, CA: Sage Publications.
Davern, L. (1999). Parents' perspectives on personnel attitudes and characteristics in inclusive school settings: Implications for teacher preparation programs.  *Teacher Education and Special Education. 22* (3), 165-182.
Ferguson, P.M. (2002). A place in the family: An historical interpretation of research on parental reactions to having a child with a disability. *The Journal of Special Education. 36* (3), 124-130, 147.
Flanagan, J. C. (1954). The critical incident technique. *Psychological Bulletin, 54* (4). 327-359.
Fox, N. E. & Ysseldyke, J. E. (1997). Implementing inclusion at the middle school level: Lessons from a negative example. *Exceptional Children, 64.* 81-98.
Frederickson, N., Dunsmuir, S., Lang, T., & Monsen, J. J. (2004). Mainstreaming-special school inclusion partnerships: Pupil, parent and teacher perspectives. *International Journal of Inclusive Education, 8* (1), 37-57.
Freeman, S. F. N., Alkin, M. C. & Kasari, C. L. (1999). Satisfaction and desire for change in educational placement for children with Down syndrome: Perceptions of parents.  *Remedial and SpecialEducation. 20* (3), 143-151.
Friend, M. (2011). *Special Education: Contemporary Perspectives for School Professionals.* (3rd ed.) Upper Saddle  River, NJ: Pearson.
Gabel, S. L. & Danforth, S. (Eds.).  (2008). *Disability & the Politics of Education: An International Reader.*  New York, NY: Peter Lang Publishing Inc.
Gallagher, P. A., Floyd, J. H., Stafford, A. M., Tabr, T. A., Bronzovic, S. A. & Alberto, P. A. (2000). Inclusion of students with moderate or severe disabilities in education and community settings: Perspectives from parents and siblings. *Education and Training in Mental*

*Retardation and Developmental Disabilities, 35* (2),  135-147.

Garrick Duhaney, L. M. & Salend, S. J. (2000). Parental perceptions of inclusive educational placements. *Remedial and Special Education, 21* (2), 121-128.

Grove, K. A. & Fisher, D. (1999). Entrepreneurs of meaning: Parents and the process of inclusive education.  *Remedial and Special Education, 20* (4),  208-215, 256.

Hanline, M. F. & Halvorsen, A. (1989). Parent perceptions of the integration transition process: Overcoming artificial barriers.  *Exceptional Children, 55* (6), 487-492.

Individuals with Disabilities Education Act Amendments of 1997 (IDEA) PL 105-17*,*   105th U.S. Congress. (1997)*.* Washington, DC: Author.

Individuals with Disabilities Education Improvement Act of 2004 (IDEA) Amendments PL 108-446*.*108th U. S. Congress.  Washington, DC: Author.

Jenkinson, J. C. (1998). Parent choice of the education of students with disabilities. *International Journal of Disability, Development and Education. 45* (2), 189-202.

Kasari, C., Freeman, S. F. N., Bauminger, N., & Alkin, M. C. (1999). Parental perceptions on inclusion: Effects of autism and Down syndrome. *Journal of Autism and Developmental Disorders, 29* (4), 297-305.

Leyser, Y. & Kirk, R. (2004). Evaluating inclusion: An examination  of parent views and factors influencing their perspectives.  *International Journal of Disability, Development and Education,51* (3), 271-285.

Lovitt, T. C. & Cushing, S. (1999). Parents of youth with disabilities: Their perceptions of school programs.  *Remedial and Special Education, 20* (3), 134-142.

McCloskey, E. (2010). What do I know? Parental positioning in special education. *International Journal of Special Education. 25* (1), 162-169.

Miller, L. J., Strain, P. S., Boyd, J., Hunsicker, S., McKinley, J., & Wu, A. (1992). Parental attitudes toward integration. *Topics in Early Childhood Special Education, 12* (2)*,* 230-246.

Mittler, P. (2002, July).  *Moving toward inclusion: The role of the United Nations:*  Paper presented at the

Third International Conference on Developmental Disabilities: Policy, Practice, and Research.        "Challenges

and Opportunities." Tel Aviv, Israel.

Palmer, D. S., Borthwick-Duffy, S. A., & Widaman, K. (1998). Parent perceptions of inclusive practices for their children with significant cognitive disabilities. *Exceptional Children, 67* (2), 271-282.

Palmer, D. S., Fuller, K., Arora, T., & Nelson, M. (2001). Taking sides: Parent views on inclusion for their children with severe disabilities. *Exceptional  Children, 67* (4), 467-484.

Pivik, J., Mccomas, J., & Laflamme, M. (2002). Barriers and facilitators to inclusive education. *Exceptional Children*, *69* (1), 97-107.

Richard, G. J. & Hoge, D. R. (1999). *The Source for Syndromes.*  East Moline, IL: LinguiSystems, Inc.

Rouse, M. & Florian, L. (1996). Effective inclusive schools: A study in two countries. *Cambridge Journal of Education, 26* (1), 71-85.

Runswick-Cole, K. (2008).  Between a rock and a hard place: Parents' attitudes to the inclusion of children with special educational needs in mainstream and special schools. *British Journal of Special Education. 35* (3), 173-180.

Ryndak, D. L., Downing, J. E., Jacqueline, L. R. & Morrison, A. P. (1995). Parents' perceptions after inclusion of their children with moderate or severe disabilities. *The Journal of the Association for Persons with Severe Handicaps. 20*, 147-157.

Salend, S. J. (2001). Creating inclusive classrooms: Effective and reflective practices. (3rd ed.). Upper Saddle River, NJ:  Merrill, Prentice Hall.

Seery, M. E., Davis, P. M., & Johnson, L. J. (2000). Seeing eye-to-eye: Are parents and professionals in agreement about the benefits of preschool inclusion? *Remedial and Special Education, 21* (5), 268-278, 319.

 Smith-Davis, J. (2002). World initiatives for inclusive education. *Teaching Exceptional Children. 35*, (1), 77.

Soodak, L. C. & Ervin, E. J. (2000). Valued member or tolerated participant: Parent experiences in inclusive early childhood settings. *The Journal of the Association for Persons with Severe Handicaps. 25* (1), 29-41.

Stano, M. (1983, April). The critical incident technique: A description of the method. Paper presented at the Annual Meeting of the Southern Speech Communication Association, Lincoln, NE. Retrieved from ERIC Database.

Stoiber, K. C., Gettinger, M.,  & Goetz, D. (1998). Exploring factors influencing parents and early childhood practitioners' beliefs about inclusion. *Early Childhood Research Quarterly, 13* (1), 107-124.

Stoner, J. B., Bock, S. J., Thompson, J. R., Angell, M. E., Heyl, B., & Crowley, E. P. (2005). Welcome to our world: Parent perceptions of the interactions between parents of young children with Autism Spectrum Disorder (ASD) and education professionals. *Focus on Autism and Other Developmental Disabilities, 20*, (1), 39-51.

Strong, K., & Sandoval, J. (1999). Mainstreaming children with neuromuscular disease: A map of concerns. *Exceptional Children, 65* (3), 353-366.

Summers, J. A., Allison, D. B., Lynch, P. S., & Sandler, L. (1995). Behaviour problems in Angelman syndrome. *Journal of Intellectual Disability Research, 39*(2), 97-106.

Summers, J.A., & Feldman, M.A. (1999). Distinctive pattern of behavioral functioning in Angelman syndrome. *American Journal on Mental Retardation, 104* (4), 376-384.

Taunt, H. M., & Hastings, R. P. (2002). Positive impact of children with developmental disabilities on their families: A preliminary study. *Education and Training in Mental Retardation and Developmental Disabilities.37* (4), 410-420.

Tetreau, D. (1995). A principal's personal view of navigating the special education system. *The School Administrator (52,* 27-29.

Turnbull, R., Turnbull, A., Shank, M. Smith, S. & Leal, D. (2002). *Exceptional Lives: Special Education in Today's Schools.* (3rd ed.). Upper Saddle River, NJ: Merrill, Prentice Hall.

Vazins, J. (2009, July 9). Changes urged in special education instruction: Too many students separated city

told. *The Boston Globe.* Retrieved July 13, 2009, from http:www.boston.com/news/ education/k 12/mcas/articles/2009/07/09/changes_urged_in_special_ed.

Worcester, J. A., Nelson, T. M., Raffaele-Mendez, L. M., & Keller, H. R. (2008). Giving voice to parents of young children with challenging behavior. *Exceptional Children, 74* (4). 509-525.

Yin, R. K. (1994). *Case Study Research: Design and Methods* . (2nd ed.). Thousand Oaks, CA: Sage Publications.

Yssel, N., Engelbrecht, P., Oswald, M. M., Eloff, I., & Swart, E. (2007). Views of inclusion: A comparative study of parents' perceptions in South Africa and the United States: *Remedial and Special Education. 28* (6), 356-365.