# Addressing the Needs of Parents and Their Children with Disabilities: Especially in Times of School Transitions

## By Yvonne H. Schermerhorn

#### **Introduction:**

This project was conceived out of concern for students with Angelman syndrome who typically are unable to verbally communicate their needs, feelings, choices, fears, pain or to demonstrate what they know. The reality and scope of this problem became highlighted in recent months as I witnessed a real life drama as it played out for a student and her family. Over the summer, several school personnel, who had worked with Jill (a pseudonym), resigned and moved on to other teaching positions. New teachers and teaching assistants with less experience and who were unfamiliar with Jill and her special needs, were hired in their places.

The end results were that in the fall, Jill would have a new special education teacher, a teaching assistant who had not worked in a school setting before, a new speech teacher, occupational therapist and the cursory new home room, and content area teachers. (Not directly related, but note worthy was the fact that several other school employees had retired, as well as a favorite office staff member who had moved and were to be replaced, thus dramatically changing the previous complexion of the building.)

We have all been known to say at one time or another, "Change is good". Unfortunately, as all special education teachers and parents of children/young adults with disabilities know, transitions can be extremely difficult for these students. Even in the best of times and situations, sudden changes in schedules, routines, directions, rules or other expectations cause students with disabilities some anxiety and may result in behavior problems or a lack of compliance to the established standards. Throw into the mixture, a change in most of a student's service providers and you have the ingredients for a nightmare! Student learning and safety become legitimate issues of concern for the parents.

In an honest attempt to prevent such a nightmare, and help Jill's transition into seventh grade, her parents made some simple requests and suggestions to the school administration. For example, Jill's parents suggested teaming the new teaching assistant with an experienced teaching assistant who had previously and successfully worked with their daughter, or perhaps to simply pair Jill with an assistant who had recently worked directly with Jill and therefore was familiar with her routines, needs and personality. These would be service providers that Jill knew, trusted and who had already demonstrated a rapport with Jill. It was the parents belief that if their suggestions and practical requests went unheeded, Jill would encounter a tough time adjusting to her new teaching staff. Over a period of several days, these exchanges became the norm while parental input was seemingly ignored and administrators continued to make decisions that would directly affect a child with whom they themselves had little personal contact.

Jill's parents and teachers would be left trying to "fix" the problems that would surely arise.

From the very beginning, Jill's parents had been highly supportive of all their children's schools and were active, reliable, productive members of several school groups, including parent representative for the Committee on Special Education (herein abbreviated as CSE), and the Parent-Teacher Association. Suddenly, they began to feel that their intimate knowledge of their child's needs and their ultimate, primary concerns for her safety and happiness were viewed as a challenge rather than as actions born out of a sincere effort to problem solve as they spoke for a child who had no voice except for theirs. What transpired were many phone calls, tears, loss of trust, hurt feelings, even bouts with physical illness that left the parents feeling they had no control. For a time, Jill's Mom even began experiencing migraine headaches, due to stress. Dad was taking time from his busy practice to make phone calls to administrators requesting clarification and support. It was both parents' hope that someone would listen to their worries as they advocated for their child's future and attempted to settle the matter in a civilized, professional manner as quickly and smoothly as possible.

Two weeks into school, and several of the parental predictions had come to light. Jill was not adjusting well to the new staff in her life. Each day Mom receives notes home about Jill's negative behavior, which include hitting and resistance to following directions. Jill was rebelling and speaking out in the only "voice" she had. It was well into October and Jill was still refusing to go to the bathroom for any of her new service providers. Advice was sought from previous teachers who had worked well with Jill. Behavior and health issues again surfaced as parental concerns. Jill was not settling in and enjoying school. By the spring of the year, Jill was more at ease with her new caretakers, but was still visibly upset and reluctant to attend certain general education classes, preferring to stay in the special education classroom where her comfort level was the highest. It seemed to her Mom that in the later part of the school year perhaps there had been a partial assignment shift in terms of who was working with Jill, placing her with those more accustomed to her needs and behavior. Jill never did completely adjust to the staff changes. All in all, it has been a difficult school year for Jill and her parents; adding stress to their already difficult role as parents of a child with special needs. Being realistic about Jill's academic ability, Jill's Mom feels it is more important for her daughter to enjoy attending school, interacting in an inclusive setting and coming home happy each day. Children, like Jill, depend predominantly on the rapport that is built between them and their teachers, teaching assistant and other service providers.

Events like this are not foreign to most parents of students with disabilities. Unfortunately, this story repeats itself over and over, all across the country as parents seek answers, make bonafide requests and suggestions to school administrators who affect their children's daily school life. The result is a lesion between home and school at a time in history when educators openly stress the desire for the positive effects of parental involvement and a building of relationships between home and school.

There is a need to help teachers and administrators become more aware and to respectfully and effectively work with parents in order to better serve students with disabilities, specially those who are non-verbal, like Jill. As Jill's former teacher, I questioned what I could actively do to help pave the way for future successful transitions during the coming school years, not only for Jill but other children with Angelman syndrome.

Many thanks to Dr. Janet Duncan, my masters project advisor, and to my dear friend, "Kate" (a pseudonym), mother of Jill (del. +), and above all to Jill, who makes me smile and continues to teach me what is really important.

# **Methodology:**

One way for me to assist in affecting change along these lines is to offer possible preventions and solutions in the form of a handbook for teachers and administrators, in order to make them aware of how parents feel, how they want to be treated and to suggest simple ways to best serve the needs of non-verbal students with concomitant disabilities, especially in times of major transitions. To meet this end, I have listened to their stories and enlisted the input of many parents of students with Angelman syndrome. (Angelman-l@ucsd.edu, personal communication)

### **Background:**

Angelman syndrome is a genetic disorder caused by abnormal function of the gene, UBE3A, located on a section of chromosome 15. In 80 % of the cases, it is caused by a deletion in this small region (q11-q13) from the maternally derived chromosome 15. In most of the other cases (20 %) of children with Angelman syndrome, genetic testing finds other disruptions and in a small percentage there are no genetic findings forthcoming, so the diagnoses are based on clinical findings alone. (As a point of interest, Angelman syndrome and Prader -Wili syndrome are both connected to disorders in chromosome 15.) Early on, it is not uncommon for an AS child to be wrongly diagnosed as having autism or cerebral palsy. Parents of children with AS readily admit that they have suffered through the ups and downs along the continuum of denial and acceptance while diagnostic testing comes up empty handed. Often it is through parental questioning and research that the genetic testing for AS is pursued.

Dr. Harry Angelman, an English pediatrician, first worked on this phenomenon in 1965 after he noticed similar characteristics in several of his patients: unstable, jerky (ataxic) gait, small head, happy demeanor and accompanying inappropriate laughter, seizure disorder, abnormal EEGs, lack of speech with sleeping problems, developmental delays, severe learning disabilities, and feeding problems in infancy. (Source: Touched by an Angel: The facts about Angelman syndrome, Angelman Syndrome Foundation, Inc. Newsletter, 1997.) These "Angels", as they are called, tend to have fair skin, blond hair and blue eye, or at least a lighter coloring than other family members. According to the goals of the ASF, "A major focus in education is communication, as children with AS seem to have much greater receptive language than expressive language ability." Some

researchers and speech-language therapists explain the lack of speech in AS children as a result of "apraxia", which is a developmental/acquired condition characterized by the inability to carry out the movements of oral, respiratory and larynx muscles associated with the formation of speech. It seems there is a disruption from the brain that tells the muscles how to coordinate these movements.

My personal interest in Angelman Syndrome came from the desire to learn all I could about a student that I was assigned to in my third year as a teaching assistant. I had the pleasure of working with Jill a year before in a local, inclusive summer recreation program and I made it known to my supervisors that I would welcome the opportunity to work with Jill in the upcoming school year. Bolstered with the practical knowledge gained in the six week summer program, I approached this new endeavor with excitement. This experience was further enhanced by communication with Jill's Mom in the form of daily written memos between home and school, occasional questions asked of Jill's previous teaching assistant, good old common sense, as well as literature on Angelman syndrome attained from their association's newsletters and a video purchased from an Angelman Syndrome National Conference, which featured a guest speaker, Dr. Steven Calculator. I also joined the Angelman Syndrome Foundation (A.S.F.) on-line group which is primarily comprised of a support group of parents and families of children with Angelman syndrome as well as other professionals interested in these exceptional children.

In the two years that I worked as Jill's one-on-one assistant, our mutual respect and rapport grew, and Jill became an ever increasing influence in my life. Eventually, her parents called upon me to "Angel sit", as I refer to it, and I was able to care for, observe and enjoy Jill in her home surroundings. Being with Jill and her siblings for several consecutive days at a time, broadened my insight into her personal interests, abilities, routines, and how she interacted with family members and even her pets. Not only did I learn more about Jill as an individual, strengthening our bond, but I also, over time, was blessed with the priceless gift of the friendship of her entire family. Somewhere in between, I had decided that Jill would be the focus of my masters project. It was with her Mom's permission, complete cooperation, and support that I began to write about an "Angel". The direction of the project has somewhat changed along the way. My initial interest centered on augmentative communication in students with Angelman syndrome. Then, as events presented themselves, I saw an example of the impact of communication, and narrowed the focus of my paper on one aspect of the effects of the absence of the ability to communicate and how it impacts students with Angelman syndrome and their families.

#### Rationale:

According to Marleen C. Pugach and Lawrence J.Johnson in Collaborative Practitioners, Collaborative Schools, (p. 225/227), "Developing a healthy partnership with families is one of the most important goals our schools can undertake" and "Likewise, what happens at school can affect the broader family unit". Schools that desire to be known for their family focus, need to have a plan of how to make family members feel included in the

educational processes that affect their children. This may include plans that draw parents and family members into the school by providing childcare and transportation to meetings which are scheduled for the convenience of both teachers as well as parents, utilizing parents as resource persons, providing medical information, social events and addressing the needs of the family as a whole.

Understanding that parents may view issues differently from teachers and administrators, helps prepare each to work through discussions and problem-solving in a collaborative framework, treating each other as equal partners who have the same goals in mind: serving the needs of the students. The James E. Briggs Early Childhood Education Center in Covington, Kentucky found that if the Center worked to first meet the needs of the family, then increased, positive involvement by the family followed. Their theme became one of regarding the school and family as a partnership.

Ysseldyke, Algozzine & Thurlow (Critical Issues in Special Education) point out that by the 1980s parents and teachers were recognizing the fact that many individuals with disabilities had trouble successfully making transitions within the school setting. Considering parents as partners and thus keeping home-school communication open and non-threatening, by safeguarding the components set forth in Public Law 99-457, ensures family empowerment rather than casting the school as the "experts" with all the answers who impose decisions on the passive family. Barriers that interfere with successful home-school collaboration may include any or a mix of the following: lack of understanding of each others views, differing expectations, language, daily stresses, desire for autonomy, time frame, and decision making processes. Successfully overcoming these and other barriers hinge on a collaborative style that incorporates mutual respect, building trust, directing energies toward a common solution, acknowledging differences of opinions, considering all options/alternatives, on-going clarification, reflective listening, defining goals and expected educational outcomes. (Katz & Lawyer. Communication and Conflict Resolution Skills) **Findings:** 

Parents want to be updated and including in schools' decisions that affect their children's education. Certainly parents are empowered by law to actively participate in establishing academic/social goals that are set forth in their child's annual Individual Education Plan (IEP), but for this to work, there needs to be a reinforcement by schools that they accept, welcome and encourage facilitation of these parental rights. Parents must be convinced of the schools' acceptance of their special needs children, and believe that the school considers parents and family members equal partners with a willingness and commitment to serve their children's varied educational needs. Following are some of the main points that parents wished to share with teachers and administrators.

# What parents want teachers and administrators to know about students with Angelman syndrome:

• My child is an *individual*, not just a kid with Angelman Syndrome. Spend time getting to know him/her.

Learn as much *factual information* as you can about my child's condition.

**Empower the family** rather than attempting to control situations.

Understand that any *change* in routine is very difficult for my child. Even small changes need to be well thought out and planned for. The biggest and most significant changes are those that deal with assigning *new teachers* to him/her.

*Talk* to my child and let him/her know when things will happen. Prepare him/her so s(he) knows what to expect next throughout the course of the day. This may make *transitions* go more smoothly. A simple change for us is a major change for my child and may cause big problems with *aggression*.

Don't equate lack of communication ability with *intelligence*. Students with Angelman Syndrome have a *high receptive language* ability. Don't talk down to them.

Give verbal and physical *prompts*, frequently

Since my child can't communicate with me, I need the teacher to *communicate* every day, if possible. I will write back as often as I am able.

Initiate communication with parents early on, when changes in my child's schedule, curriculum, staffing changes are anticipated.

Allow for carry over of a *familiar care giver* from year to year.

Do not *change* more than 2 *personnel* in the same school year. For example: Especially not the special education teacher and the teaching assistant!

Maintain the same *special area* teachers (music, APE, speech/language, O.T.) from year to year, when possible.

Accept *parents' wishes* for which care givers are assigned to their child. (I know best what type of personality clicks best with my child's learning style.)

Plan an *orientation period* in which the previous, more experienced assistant/care giver is able to work with the new care giver. Aside from the parent, they know my child the best. (This could be done in written or verbal form.)

If possible, have both seasoned and new assistant work for a day with the student to acclimate the student and teaching assistant to each other, to routines and nuances. This fosters an easier, shorter *transition period* for the student and care giver.

Keep the more *successful routines* in place from year to year. (Lunch, bathroom, snacks, bus time, etc.)

Keep the same "jobs"/responsibilities consistent. (e.g. Collecting the attendance cards, hanging up outer wear, cleaning the lunch table) This helps the student feel good about themselves.

Give my child *time to respond* to requests and to comply. It may take him/her a little more time to process the information and act on it.

*Novelty* is an important component to her learning style. Challenge him/her with new activities. Expect some resistance at first, however.

*Include* SPE students/classes information in school newsletters. These children are part of the school,/ graduating class, etc. Don't treat them as if they didn't exist.

*Involve* students in school plays, musical shows, etc.

Realize that often parents are their children's biggest or only *advocates*.

Understand that parents may be *struggling* with recent *diagnosis* (or years of misdiagnosis) of Angelman Syndrome. They may be grieving, battling bouts of denial and loss of hope. They look to you for help and understanding.

Realize that a *lack of the ability to communication* is often the child's/ student's *biggest disability*. It leads to isolation and frustration when not addressed! Finally, offer emotional and social support. *Reflective listening* on your part offers a therapeutic effect for the family and will be greatly appreciated.

• My child is an *individual*, not just a kid with Angelman Syndrome.

Spend time getting to know him/her. Engage in some fun activity with my child. Do the Hokey Poky, take a walk outside, or work on a puzzle together. Show him/her that you are interested in things that s(he) enjoys. Find out what makes him/her tick! Try to see things through his/ her eyes: laugh and smile with my child. This will build rapport.

• Learn as much *factual information* as you can about my child's condition.

Ask questions of the parents, they will love that you care enough to ask about their child's syndrome. Use the library, and internet to research about Angelman syndrome, for example, and sign up for the newsletter sponsored by their group. Join the Listserv (Angelman-l@ucsd.edu) and correspond with parents who have children with the same disability. Learn about their medical, practical, social, academic concerns. See how much they support one another and you will begin to have a strong sense of what their needs are and what their hopes are for their children. They will welcome you into the 'family', and answer questions you might generate. Parents of children with disabilities are individuals, also. This background will make you more understanding of where they are coming from, and help you discuss issues that they face every day.

• *Empower the family* rather than attempting to control situations.

Ask, don't dictate decisions that have already been made. When possible, include parents in decision making, ask for their advice. This does not mean that you are losing control, this shows respect and says loud and clear that you consider parents part of the team that is working to make all phases of their child's education more productive. They will bend over backwards to work with you, if they feel you are ready to consider and accept their input. At least be prepared to meet them half way.

• Understand that any *change* in routine is very difficult for my child.

Imagine then, that such things as new building construction, class schedule, room arrangements and personnel changes, seating arrangements, choices of bathrooms and the routine in the bathroom or at lunch time can all be overwhelming and confusing to my child. Try to maintain continuity from day to day and even year to year, when possible. For example: Make a habit of using the same bathroom at the same period of the day, as a matter of course. Sit at the same table at lunch, with the same friends, and

follow a certain routine for walking through the line, making food choices and paying for lunch. Offer the student the opportunity to make decisions and help out when possible. There is security in these routines and this tends to reduce anxiety and misbehavior.

• *Talk* to my child and let him/her know what and when things will happen.

Reinforce that the daily routine is going along as usual. As class periods or activities change, give a little advance warning. Talk the child through what to expect. Eg.: "It is time for music class now. It will be fun to sing our favorite songs with the class. Mrs. K. will be happy to see us. Let's stand up, push in our chairs and go to music, now." Especially help prepare students for what may be more unexpected. For example, arrange to have advance warning of times when the practice fire alarm bell will be ringing, so you will have time to prepare your student for the event. Quietly review how to proceed: "The fire bell might ring in a few minutes. We will stand up quietly, leave the class, and follow everyone outside." It is also important to allow time to put away one project before starting another: "It is almost time to go to lunch, let's put away your cuisinnaire rods. You did a good job with them and you will be able to use them again..." Always praise the student when they comply to your requests. Verbal 'rewards' are just as good as gold star stickers, and provide immediate input/ gratification. It shows you appreciate the child. Chat about everything throughout the day. Explain what you see: "Oh, someone is having a birthday today. I see that Jaime has a Winnie the Pooh balloon tied to her backpack." Make up songs that incorporate the student's name, use rhyming and the activity they are doing, or the colors of their clothing. Ask him/her to point to things for you to sing about. Not only does it reinforce receptive vocabulary, but it also takes advantage of those teachable moments. It makes your time together special and interactive.

• Don't equate lack of communication ability with *intelligence*.

Not being able to communicate verbally is not necessarily an indication of lack of intelligence. My child may not be able to vocalize with you, but this is not to say that s/he does not understand all or most of what is being said to them or in their presence. Proceed as if s/he understands all you are saying and you may be surprised at the results.

• Give verbal and physical *prompts*, frequently.

This ties in with talking to/with my child. Visually and verbally demonstrate how and what to do. This may include a variety of activities such as how/where to hang his/her coat, putting an item on a shelf, on holding the hand railing in the bathroom or when exiting or entering the school bus, or attempting any academic/ physical activity that may be difficult (due to vision or coordination problems) or in which the student has not yet acquired mastery. It may be a gentle support to their elbow or hand when maneuvering through the crowded school hallway or around desks. It may even be encouragement given from across the room when the student is participating in a class

activity (poetry recitation/music class) or in Adaptive Physical Education (APE) class ( where to put/find the exercise mat or other equipment, or which base to run to next in baseball).

• Since my child can't communicate with me, I need the teacher to *communicate*, every day, if possible.

Let's set up some form of daily communication system, so that we can inform each activities, health concerns, interests, appointments, successes, other of important behavior problems, etc. In this way we will be better able to connect with the child and keep on top of situations. For example, I may send you a Polaroid photo of my child sharing a happy family activity, so that you may talk with him/her about it. Display the photo in the classroom as a conversation/story starter with other students, teachers (especially helpful to the speech teacher). I will let you know when my child has not slept well or has been given medications (cold/seizure) that may affect behavior or alertness for the day. The more we share, the more we will be able to reinforce the positives, and praise the student and become involved with the child, holistically. See below an excerpt from the student's home-school communication notebook:

Oct. 5, 1999 (The teacher writes.) "Jill had a good day today. We took a walk and collected leaves for our next weekly art project. This also enabled Jill to practice walking on different surfaces (grass, sidewalk, pebble and brick walkway). She helped measure the ingredients when her cooking group made cookies. (Recipe enclosed) She also set the table and learned how to set up the sink for washing dishes. (Progress made in dealing with soap suds, no gagging, today!) We worked on story sequence in speech class. Jill did very well. Have a great weekend."

Oct. 8, 1999 (Mom writes.) "We had a quiet, fun weekend. Jill went to watch her brother's soccer game on Sat. She loved seeing the train go by on the nearby track! (Photo enclosed) Sunday, we had company for dinner- Grandma and Grandpa. Slept well last night. So did Mom! Ha Ha!"

• Initiate *communication* with parents early on, when *changes* in my child's schedule, curriculum, staffing changes are anticipated.

Alert parents in advance when major changes in personnel and schedules, etc. are expected. Work with parents to discuss possible repercussions, alternatives, and solutions before problems happen. Accept parental suggestions and input and consider their ideas before making decisions. Honor any legitimate requests for matching up their child with a particular teaching assistant or teacher, or matching the child up with an assistant that has worked with the student before, if at all feasible. This is just good business, and should not become a power play. The student depends highly on his/her teaching assistant and may become accustomed to one or two, and will work and behave better for a person that they have grown to trust and who understands them. This affords the student with a comfort zone, especially when they themselves are unable to communicate verbally and are completely dependent on another person

throughout the school day. Avoid several major changes at one time in the personnel who work directly with the student. One change — will be difficult enough for the student to handle. Limit the number of schedule changes from year to year, — keep in place the comfortable routines and responsibilities that my child has come to look forward to and — expect each day. Maintain continuity from year to year, when possible, with special service providers, like the Physical Therapist (PT),Occupational Therapist, (OT,) and Speech Language Pathologist (SLP). When — changes in personnel can't be helped, arrange time for meetings between the "old" and the "new" personnel.

This gives them an opportunity to exchange information, share curriculum ideas, behavior modifications (what works/what doesn't). Also, let parents and student meet informally with the perspective new personnel to break the ice. Maybe the new staff member could spend a day shadowing the student's routine with the former teacher/assistant as a model/guide.

- *Involve* students in school plays, musical shows, etc.
- *Novelty* is an important component to her learning style.
- *Include* SPE students/classes information in school newsletters

Find ways for students with special needs to participate in class/school projects. One mother wrote to me (personal communication) of her disdain when she and her child attended a school musical which seemed to have a part for almost every able bodied child in the building, but there were no special needs children included. Her own child, who was in a wheelchair, did not even have a place to sit as part of the audience, at first. It had been "assumed" by the teacher that he would not attend the event and no physical accommodations were made for his arrival. His Mom writes: "It was a production that could have easily had a kid in a wheelchair, stuck on the end of the chorus line with a buddy. My son would have given ten minutes with the water sprinkler\* to participate. It would have added to the production and now, all those kids will grow up and become principals and teachers who repeat the same ignorant practices".

\*Children with Angelman syndrome have a fascination for water and love any activity which involves water play.

- Understand that parents may be *struggling* with recent *diagnosis*.
- Realize that often parents are their children's biggest or only *advocates*.
- Offer emotional and social *support*.

The road for parents of exceptional children is often difficult. In the case of Angelman syndrome, the realization that something is wrong is not often apparent at birth and then when it becomes a concern, diagnosis is not always forthcoming. Due to the relative "newness" of the discovery of this syndrome, children are often

misdiagnosed as having autism or cerebral palsy. The testing process is not always conclusive. Some parents may struggle with denial, or hoping for the problem to be solved, as one Dad said, he looked for the doctors to discover what his young daughter had so the doctor could "fix" it. Putting a name to the syndrome means lack of hope to some and while it comes as a relief to other parents, who want to be able to learn all they can about their child's disability, so that they can be supportive and get on their family lives. Parents may automatically become the best advocates for their children. They know their children best and are willing to fight for them for needed services. As Jill's Dad explained, "We are her parents twenty four hours a day, seven days a week". These children can not speak in their own behalf. Parents may become more vocal in a struggle towards equity. They are not trying to make your job more difficult; quite the contrary.

• Realize that a *lack of the ability to communication* is often the child's/ student's *biggest disability*. It leads to isolation and frustration when not addressed!

Open your heart and your mind. Become part of the solution!

#### **Conclusion:**

Angelman syndrome is a complex chromosomal disorder. Its effects on the child as a family member, student, and member of the community is as varied as the children it touches. Teachers and school administrators who become as knowledgeable about this syndrome as possible, and who communicate openly with each other as well as with the parents and family members, using a team approach, are best able to serve the student. Taking time to listen and to treat parents and students with dignity is the corner stone that helps build success!

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