



## Who Are We Working for Anyway? Avoiding Personal Agendas at Meetings to Better Support Individuals Across the Autism Spectrum

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*Gloria Smith goes into the conference room for a meeting about her son. As she enters, she is faced with nine professionals sitting around the table. Each one knows her child and who she is, but she is not sure who they all are. She has talked with the teacher, but has not contacted anyone else. Her son, Adam, is her first child and has autism. At this meeting, Gloria will be asked to discuss his IEP goals, and his behavior plan. Each professional has 10 or 12 other student meetings on their agendas. Time is important to them, but meetings have been run efficiently in the past. The agenda is set and the meeting begins.*

There are multitudes of meetings surrounding a student with an autism spectrum disorder (ASD) or, for that matter, any disability. Those meetings may include parents, school personnel, therapists, case managers, waiver representatives, other family members, and agency representatives who provide support to the child. Each person attending those meetings may enter the room with a personal agenda in mind. Each may believe his or her ideas are in the best interest of the child. Participants may have a hard time letting go of those ideas, adapting them, or even listening to others. Meetings can become long and involved, and can create tension among all participants. Tensions stem from each person's reactions to the student based on his or her personal experience and perspective. Personal agendas create needless power struggles and personality clashes that often result in the true needs of the person with autism/Asperger's being forgotten and excluded from any discussion or planning that takes place. Personal agendas cause participants to forget the main focus of the meeting... the student.

Personal perspective and experience can impact the manner in which people choose to look at and support individuals. Many times that unique perspective is skewed and does not allow one to see the whole person and what is happening to them. Herb Lovett illustrates this concept in his book, *Learning to Listen* (p. 130):

*The lives of people in distress (with disabilities) can take very different directions depending on who is asked for help. A common problem for people providing services is figuring out who to call when they are confused about what to do. For example, if Denise has started hitting people, any number of things can happen to her depending on who is asked to respond first. A medical practitioner might want to give her a drug, a psychologist might assign a behavior program or a therapy appointment, an occupational therapist might want to assess her styles of sensory integration, her family might want people to punish or placate her the program administrator might want to increase staff time with her, and her service coordinator might want to send her to a residential treatment center out of state. Much of Denise's future will rest on that first telephone call, but how do we know who to call first. Ideally, any one of these key people is comfortable with giving a preliminary opinion and asking for further consultation to help rule out (or in) other contributing causes, but sometimes consultants insist their expertise is the only*

*information needed and will try to 'own' Denise and her situation. Too often professionals work in isolation and rely entirely on a single way of understanding and responding to a behavior. When they proceed to personalize their struggle to 'conquer' a behavior, this narrow focus can lead to the excesses that have killed people in the name of therapy. At this point we recognize controlling and authoritarian ways of working for what they ultimately are...inhuman.*

To create an atmosphere of collaboration and cooperation, people must have open minds and be responsive to multiple positions. Open minds allow individuals to become a team working to create the best possible situation for the child with ASD.

## Stumbling Blocks

There are many areas where schools and parents both create tension and confusion during school meetings. Observations from actual meetings between schools and parents illustrate some of the stumbling blocks.

### For Schools:

**Meetings:** Meetings are short, rushed, and nothing gets discussed for any length of time. There are also times when the focus of the particular meeting is not clear to all involved. Meetings, whether formal or informal, may not happen often enough to help the team, which includes the parents, understand specific issues surrounding the child.

**Language:** All professionals use jargon (words related to that profession). Special education is full of jargon. Education professionals use this jargon on a daily basis, and assume that parents understand what is being said. Jargon is often like a foreign language to parents and other non-school personnel.

**Number of People:** There may be a number of education professionals at the school conference. Most of these professionals know each other and have already discussed the specific student. They may have already formed an "opinion" about the child and family. This sets a didactic versus supportive ('them and us') tone for the meeting that makes parents uncomfortable and less than trusting about what is being recommended.

**Assumption of Understanding:** Even if families have been involved with the special education system for a number of years, it does not mean that they always fully understand what is being discussed at the school meeting. Many times parents are not asked if they understand what is being said or recommended, or given the opportunity to ask questions.

**Parent Training:** Because parent education and training is often not a school priority, the annual conference may involve a steep learning curve for parents about special education services. Parents who have not received training may not understand the jargon or understand what is being recommended for their child. Yet they are still asked to provide "informed parental consent."

**Becoming Complacent:** Schools are responsible for coordinating and conducting numerous conferences for students receiving services. Because of time constraints, conferences continue to be conducted in the same manner year after year, and complacency ("the way we have always done it") is often mistaken for efficiency.

### For Family Members:

**Meetings:** Parents may not realize the time and effort it takes to coordinate a meeting that accommodates the schedules of teachers, therapists, administrators, paraprofessionals, and parents. When parents fail to show up for

their conference and do not contact the school in advance, not only is school staff time wasted but also other students have been denied access to their teacher and/or therapist.

**Language:** The family bears a responsibility for understanding the program and services being recommended for their child. The school team may assume that if the family does not ask questions, they must understand and be in agreement. Families who are not informed participants in their child’s conference may tend to make last minute changes or demands that create frustration and confusion that circumvent the benefits of the proposed program.

**Dependency:** It is important for families to take responsibility for making decisions about their child and not pass that responsibility off to the educational staff.

**Gaining Knowledge:** Parents may be asked by teachers to investigate certain important aspects of their child’s learning program by making phone calls, visiting sites, completing paperwork and using other methods. If there is no timely follow through by the family, the school may be unable to proceed with all aspects of the child’s program.

**Last Minute Changes:** Not attending a meeting or not voicing a concern as soon as they occur can create inconvenience and lead to unnecessary conflict. Changing one’s mind after the teaching staff have been investigating a certain curriculum, instructional technique, behavior plan, transition process or work site can create frustration, confusion, and anger and also create inconsistencies in the child’s program.

**Becoming Complacent:** Parents as well as teachers can become complacent. Not attending meetings, not asking questions, or letting things go without investigation because it is easier are all forms of parent complacency. Assuming things will get done simply because the school has to provide services is an ineffective way to monitor a child’s progress and sends the message that parents are not part of the ‘team.’

**Advocates with Personal Agendas:** Advocates are useful in many instances by helping parents understand situations, as well as assisting in reaching consensus in meetings. However, advocates who come to meetings with personal agendas and hostile attitudes rather than focusing on the needs of the specific student can create unfortunate situations for everyone involved.

**Threaten Lawsuit:** Sometimes tensions become so high that parents want to involve an attorney. The threat of a lawsuit creates incredible stress between and among school staff and family. Honest relationships will suffer and ultimately the child loses. Although legal alternatives are part of the due process guarantees of special education law, it should be used as a last resort.

It can be seen that stumbling blocks are not one sided. Schools and families both can and should work together to help solve problems instead of creating new ones.

Actually, school personnel and families each face other challenges that are quite similar. They all share frustrations when it comes to being able to do what is best for the child. The following table lists challenges that both families and schools face. Note the similarities.

SCHOOL	FAMILIES
Funding/money: To pay for materials, personnel training etc.	<b>Funding/Money:</b> To pay for services, insurance and to maintain family integrity.
<b>Standards:</b> Rules that must be followed are complicated. There are state and federal rules and regulations to consider.	<b>Standards:</b> Family rules or standards may be complicated by the views or opinions of extended family members.

<b>Class size:</b> How to provide individualized and intensive attention.	<b>Family Size:</b> How to provide individualized and intensive attention.
<b>Differing Priorities:</b> Different depending on each student's needs. Each has different priorities/needs that may conflict with the needs/priorities of others.	<b>Differing Priorities of Other Family Members:</b> Different depending on individual and sometimes may conflict with the priorities/needs of others.
<b>Environment:</b> Room size, materials, interactions.	<b>Environment:</b> House/room size, materials, interactions.
<b>Time:</b> Lack of time to do it all.	<b>Time:</b> Lack of time to care for all.
<b>Training:</b> Time and money is an issue to obtain information.	<b>Training:</b> Time and money is an issue to obtain information.
<b>Politics:</b> Differing beliefs and values.	<b>Family Culture:</b> Differing beliefs and values.

Working together to solve problems rather than placing blame requires that everyone realize multiple stressors and challenges faced by all. Instead of turning meetings into a situation full of barriers and obstacles in which the child is lost, the way to success is to support each other and build on individual strengths. It may be helpful to remember that all people have the best interests of the child in mind regardless of their perspective. Most people would not intentionally do something wrong or bad. Everyone wants what is best, but may have to overcome challenges in their job or family situation to do what is best. They simply may not always have the tools or support to do it.

## What Can Schools and Parents Do to Enhance Meetings?

How can meetings become more comfortable and create more meaningful educational goals and situations for each child? Here are suggestions for schools and parents to consider to help meetings become more productive and supportive of the student with an autism spectrum disorder.

### Suggestions for Schools:

**Come to meetings with open minds, instead of with preconceived ideas about the child or others who are attending the meetings.** There are always multiple perspectives in any situation whether it is in the classroom, therapy, at home, or in the community. Openness allows everyone to truly hear each other, and to learn about limitations and possibilities in each environment.

**Establishing a relationship between school and home is a crucial step.** This requires a joint effort between the teacher and the parents. It cannot be one sided. If a positive relationship can be established at the beginning of the school year and includes consistent open minded listening and communication, meetings have a better chance of being productive.

**Listening to each other is primary.** Realize that everyone has something to say from his or her perspective. At the same time, remember that each person's perspective is based on his or her experience and relationship with the student and is valid.

**Acknowledge issues that the child faces and set priorities for the learning experience.** Work together to see the vision for that particular student. Remember that each year's work should be focused on the ultimate dream or vision for that child.

**Discuss priorities and see what needs to be addressed in school as well as at home.** Be clear on what behaviors or skills need to be considered so everyone is thinking along the same lines and not spinning their wheels.

**The teacher should make an effort to contact parents and meet at the beginning of the year as one way to create a joint effort.** This informal meeting allows all players to get to know one another and set a positive tone for the beginning of the school year. Reaching out to each other is a wonderful first step.

**Ensure that parents are included in scheduling meetings and in the planning process by offering to call parents about dates and times prior to letters going out from the school.** This can help them understand the schools specific system for arranging meetings.

**Create a "safe" environment for families at meetings.** Realize the meeting room is filled with professionals who know each other and only one or two family members. Professionals all know the family but often the family does not know all of the professionals. That situation can be quite intimidating. Be sure the family knows ahead of time who will be there and provide introductions at the beginning of the meeting.

**Be sure parents understand what is being discussed throughout the meeting.** Professionals often use jargon during meetings and forget families may not use the same language. Be sure parents understand by asking what they have heard. Restate any information that appears confusing to them.

**Provide parent training both formally and informally beginning in early childhood through the transition years.** There is so much for parents to learn about the special education system and the adult service agency system. One meeting a year is not enough to truly grasp a situation. Remember that reading material is not always the best option for sharing information. Phone calls, informal meetings, home visits, or formal group instruction or monthly meetings may ultimately prove fruitful.

**If teaching strategies or behavior support plans are not working or achieving desired outcomes, they need to be refined.** Even if things have "always been done this way", it may be best to revisit common practices and make adaptations.

**Finally, remember that the dreams that families have for their child may be different from those of the school staff.** It is important for the school staff to hear family wishes, and then try not to push their views and values onto the family. Professionals can try to learn to value what the family dreams and help them meet those dreams or augment them to support the child in the best possible manner.

## Suggestions for Families:

**Families should share all necessary information about their child including information about medications, diagnosis, and illnesses.** If your child is on medications be sure to tell school staff so they can be alert for side effects or changes in behavior.

**Share the dreams for the future life of your son or daughter with the team.** Opening up and being totally honest is difficult for anyone. It is often more difficult when sharing with a group of professionals. Yet, sharing dreams and hopes, as well as fears, allows the team to understand family perspectives better. It creates a unique relationship that may increase the desire for working together toward those dreams. Other team members may be parents and also have dreams for their children; therefore they can empathize and understand the parent perspective better.

**When families do not understand what is being discussed, ask questions during the meeting.** Calling, e-mailing or writing to teachers at school can also dissolve any confusion or miscommunication that may take place. Realize that during the school day it is often challenging for teachers to make or take phone calls. It may be necessary to set up a phone date in order for discussion not to be rushed.

**Try to understand that your child's school may not always have the best PLAN, but try to start on common ground then adapt the plan as needed.** Know that sometimes the best PLAN may fail. After all, if the job of teaching students with autism or other disabilities was easy, anyone could do it and no meetings would be necessary. Often teachers need to try several strategies before finding one that works. It is frustrating for them, just as much as it is frustrating for the student and family. Allow them to try different techniques with the students and realize there may be some trials before there will be success. We all learn through our mistakes.

**Avoid threats or lawsuits if possible.** As stated, due process is a legitimate option and available for a reason. However, a lawsuit may or may not help. While it is important to advocate for your child, there may be better options than a lawsuit. Exploring mediation, parent advocacy, or informal meetings can be alternatives. Establishing a relationship with the teacher at the very beginning of the year and maintaining consistent contact can allow a more open and consistent dialogue between home and school.

**Finally, it would be wonderful for both the family and school staff to make and to receive calls or messages with a positive content.** So often the only time contact is made, other than to set a meeting date, is when some crisis has occurred. Sharing positive information can help in maintaining more trust and honest relationships between home and school.

The ultimate goal of collaborative meetings should not be How will you make this work or happen: but instead it should be **how can WE make this work together!!!** When parents and school personnel work together as a team, with respect and consideration for each other, severe disagreements are greatly minimized and ultimately, the child is the winner!!

## Reference

Lovett, H. (1996). *Learning to Listen*. Baltimore, MD: Brookes Publishing Co.

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Davis, K. (2003). Who are we working for anyway? *The Reporter*, 8(2), 5-10.