

## PLAY HEARTS, NOT POKER

By Jennifer L. Bollero, Esq.

As an attorney, arbitrator, mediator and loving mother of an autistic daughter, I have a unique perspective on the process by which families prepare their children's Individualized Education Plans (IEPs).

The IEP meeting, required by federal statute, is convened at least once a school year to plan an educational program that is tailored to the needs of each disabled child. The child's "team" attends the meeting: teachers, therapists, parents, school administrators, and any other invited parties.

So far, our family has had success with Amanda's education in our district. She has been fully enrolled in standard district programs - Early Childhood and then grade-school inclusion - and has made significant educational gains. We have been able to get the district to agree, with minimal or no conflict, to provide all the services we felt she needed in her IEPs.

Over the years, many parents have told me battle stories about their children's IEPs. They comment on how "different" Amanda's experience has been from theirs, even within the same district. Maybe so.

Certainly, my daughter's innate abilities have emerged, and in so doing, have given her more skills as she goes. Success truly breeds success. I can take no credit for the marvelous daughter God gave me.

However, Amanda would not have been able to be successful if the right opportunities were not available to her. This is where good advocacy can make all the difference.

### ADVOCACY V. PARENTING

Advocacy is by its nature, a cerebral activity and involves great thought and creativity. Parenting is by nature a visceral activity that involves great emotions and heavy decisions.

I know first hand how the feelings that come with children, especially disabled children, overwhelm and confuse us. No words can adequately explain the dread and anxiety that accompany us everywhere we go. We belong to a select club, an elite group of people, who speak a foreign language ("IEP", "OT", "PT") other

parents do not know. We emit sensitive radar that only those of our own kind can detect, often with one look.

For the sakes of our children, we must strive to be patient with those whose experiences have not given them access to our perspective. It is our duty to lead these people to a fuller understanding of the beauty and ability within our children. To do this, we must become effective advocates.

#### LEARNING ABOUT RULES AND STRATEGIES

Good advocacy often works like a game. I do not suggest that advocating for the needs of special needs children is trivial. It is just that the method of getting what you need from a school administration has rules and strategies that are often quite predictable.

If you learn and apply these rules, you can reduce the risk that is inherent when you negotiate for educational benefits. I liken this to the difference between poker and hearts.

#### PLAYING POKER

Poker is a stimulating game of wager. The fun, the skill and the whole game is in the bet. In truth, the cards make only a marginal difference to the outcome of the hand. It is not what you have in your hand that matters as much as what the other players think you have.

Every hand is a winner, and every hand is a loser. By manipulating the other players at the table, making them believe what you want them to believe, you win the bet. You do not really need to have a strategy for the cards: if you understand people, the cards will play themselves.

#### AND PLAYING HEARTS

Hearts is different. Hearts is all about having a strategy for the cards: how you play the cards given to you. What the other players think or feel is less important than getting them to play their cards in the order you want them to!

Yes, there is minimal bluffing, but at tremendous risk. This is because everyone is paying attention to the cards, not the players. However, the rules of the game give talented players a chance to unload their worst cards at little or no jeopardy to themselves.

In fact, the best hand at hearts is the worst hand played skillfully! If you have a wretched hand, and take every trick, you end up winning the round! Moreover, even if your round goes badly, the game keeps going, hand after hand, until all hands are played.

#### THINKING LIKE A POKER PLAYER

Many parents and advocates involved in IEPs use "poker" language to describe the process. They have come to believe that districts, overall, do not act in good faith when setting IEPs, and that they will cheat.

They do not want to "tip their hand" or "show their cards". They talk about the personalities of the school administrators and staff. Are they bluffing? What are their cards? Are they holding back? Do they care about my child? Do they care about disabled kids in general?

When parents feel like they have to battle educators for benefits, they lose confidence in those educators. When parents lose confidence in their educators, those educators (who are often acting in good faith to do an extremely difficult job) feel unappreciated.

A siege mentality sets in, lines are drawn, and the parties toss therapies and interventions onto the table like chips. They wager with the child's needs, but rarely does the child walk away with any of the pot. This is why playing poker at an IEP does not work for the children.

#### MAKING DEALS

Like hearts, advocating in an IEP might take many deals. The players, sometimes with competing goals, sit down year after year and look at their hands.

What progress has the child made in school? What skills does he or she have now? What are the demands of the next grade? How well equipped is the district or the staff to meet these needs? What resources do the parents have?

Most of the answers to these questions are known to most of the parties at the table. Unlike poker, which allows for more uncertainty to sweeten the bet, IEPs leave little to bluffing.

Either the child has abilities in certain areas, or he does not. Either she can attend in a regular education setting, or she cannot. Either the staff is prepared to deal effectively with this particular disability or they are not. And so on. A skillful advocate, like a skillful hearts player, knows when and how to play certain facts in the file so the child does not bear an undue burden in the education process.

#### EIGHT STEPS TO BETTER IEP MEETINGS

Here are eight steps for parents to learn. These steps will help the parent negotiator minimize conflict when dealing with good-faith district negotiators. They will also help you prepare a solid case when negotiating with district personnel who are acting in bad faith:

1. Make every attempt to sustain relationships.

Like the many hands in a hearts game, IEP negotiations play out over time. A game of cards is always more enjoyable when played in a group that likes and respects each other. Try to get to know and personally connect to the other team members.

Whether or not we personally like our child's teachers, school psychologist, school social worker, principal or other administrative personnel, we are stuck with them unless we move. If we move, we will be stuck with new school officials with whom we have conflict. Or new, difficult people will be promoted into established positions.

In any event, we have to learn to work with people we do not understand, agree with, or get along with. They are there, and will be there all year, year after year. Getting personally angry with them, even if they deserve it, lead to hostility down the line.

Now hostility can have its place, as in a lawsuit or a Due Process Hearing. However, if parties get that far in their fights, any chance for a working relationship is dead. Since it is in the best interests of our children to have a cohesive team working towards a common goal, we as parents must take a leadership role in sustaining the team atmosphere.

We cannot lead a team we do not join.

It is not enough to come into a meeting, periodically and make demands; even legitimate, legal demands. We must model the behavior we want to draw out in our children's IEP team.

If we want the other team members to be patient, prepared, and educated about our child's needs, we must set the standard.

We must be understanding of them and the demands on their time.

We must be patient with them as they learn our child's method of learning.

We must be prepared and secure helpful test results on our child's development, articles or other related materials, and then share them; and

We must be as or more educated about the objective realities of our child's disability so we can talk to other team members as peers.

Before we make any demands on a team member, we must ask ourselves, "Am I asking of this person something I have not done, or am not willing to do?"

If someone did something helpful, remember to say "thank you!"

When we can demonstrate that we are doing our part, it is more reasonable to press others to shoulder their responsibilities.

2. Keep the focus on the child's needs, not the district's resources or the parents' expectations.

Under the Individuals with Disabilities in Education Act (IDEA), Congress set forth certain protections for children with special needs. At its core, IDEA is designed to make sure that disabled children have access to a "free and appropriate public education" in the "least restrictive environment".

The United States Supreme Court has been relentless in their insistence that IDEA may not be used to force a school district to "maximize" a child's "potential". If a child is getting a "meaningful educational benefit" and making progress that can be objectively measured, then most courts will conclude that IDEA has done its job -even if most parents would consider the results basic or minimal.

Most schools pride themselves on doing more than passing work for their students, even their disabled students. Clearly, those with the highest expectations for children are the parents. This is why we are here.

Yet, many parents engage in the IEP process without having tangible educational goals, let alone a plan to accomplish these goals. Without a plan, the IEP, school staff, and parents will flounder.

Let me share an example. Our goal for Amanda is to teach her to function as an autistic person in a non-autistic world. We do not expect the District, or anyone else, to cure her autism. Each decision made for her - educational and otherwise - is shaped with this plan in mind. This simplifies things.

When we read a map, we have a starting point and a destination. We plan our routes and back-up routes from these two variables.

#### GET INDEPENDENT EVALUATIONS

How do you know where you are beginning? Get the child tested and find out! Parents must obtain independent medical and/or developmental assessments for their disabled children! Without clinical data, there is no reliable starting point for the journey.

Yes, these tests are often burdensome and expensive. Do them anyway. Our children's abilities and disabilities are the cards in our hands! How can we decide how to play them if we do not look at them first?

These evaluations bring parents on board. They force parents to understand the precise nature of their child's disability, and in so doing, obtain the necessary information to formulate a cohesive strategy for dealing with it. This is especially true if the nature of the disability has a hidden educational impact.

IDEA only requires school districts to pay for special services like speech, occupational or physical therapy if doing so gives an educational benefit, not just a medical one. In other words, the disability has to effect learning.

I emphasize the need to have independent clinical medical, psychological, and /or educational or evaluations done -not evaluations through the school district or by a practitioner selected by the district. Because IDEA has provisions, which, under certain circumstances, require school districts to pay for evaluations (ostensibly to make the field more level for low-income families), many parents who can afford an independent evaluation fail to get one.

However, school district evaluations are still school district material. If there is a hearing or lawsuit, these tests are crucial evidence. Parents will have more faith

in the truth of these tests when they choose the professionals who administer them. In the event that a test does not accurately reflect a child's abilities, parents who get these evaluations independently have a choice about whether to share this information with the district - something they could not control if the tests were done by the district.

These outside evaluations have another benefit in that they relieve the parties from subjective disagreements. The results speak for themselves. No one is to blame for this information. In fact, third-party reports give a willing school administrator a way to justify a difficult or politically unpopular decision to grant services.

When Amanda was going into kindergarten, I wanted her to a full-day program with kindergarten in the morning and Early Childhood in the afternoon. Our district had a "policy" (read "budget issue") against this.

When I took Amanda to her yearly reevaluation at the University of Chicago Developmental Disorders Clinic (a nationally recognized leader in autism diagnosis and treatment), I was able to persuade the U of C team that Amanda required the full-day program. They gladly made this recommendation in their report.

This relieved the sympathetic school administrator (who granted the request) from having to make the judgment herself. After all, if her boss disagreed with her, he would have a much harder time disagreeing with the University of Chicago!

With independent reports, everyone is off the hook and can bring themselves, defense-free, to the great task of addressing the child's problems. Once we know where we are, we can decide how best to get where we are going. Once everyone has an objective sense of a child's abilities, they can develop a plan to teach that child.

#### SPECIFIC, MEASURABLE, REALISTIC IEP GOALS

The IEP is designed to list specific educational goals for the child. Make sure the goals are realistic, specifically stated, and penned in layman's terms. As the school year unfolds, the team can look at these goals to objectively assess the child's progress. To this end, IDEA requires that the goals as they appear on the IEP form must be something that can be objectively measured.

Avoid generalized goals, as "Johnny will be able to attend in the classroom with increasing frequency". This phrase leaves Johnny's progress open to subjective evaluation. Disagreements about subjective evaluations lead to bluffing and defensive postures on all sides. Where does this leave Johnny?

If the goal read: "Johnny will be able to complete grade-appropriate class work during class time, up to 75% accuracy" the parties can evaluate what Johnny is doing in class and objectively measure this against the goal. If Johnny cannot finish a spelling test with his class with 75% accuracy, the team can agree on his inability to meet the goal.

This keeps the focus on Johnny and away from the other team members. When everyone can agree on the problem, it is much easier to brainstorm about new interventions that can help him learn, or whether the goal should be modified (e.g.: "É up to 50% accuracy", etc.).

#### PARENTAL EXPECTATIONS V. DISTRICT RESOURCES

A word about parental expectations and school district resources. These competing interests are present in every IEP. They represent an inherent tension in disabilities issues. Parents want the best for their children. School districts have to provide basic services within a clearly stated budget.

Never ignore these dynamics in an IEP. They are always there, even if districts are not supposed to consider budgetary concerns when they formulate an IEP.

In negotiations, emotions are often the problems to be solved.

Parents should never treat the school team as if they are sitting on limitless resources. School personnel should never forget the legitimate emotional investment each parent has in his and her child. Parents should attempt to occasionally see their child through the eyes of others. School personnel should try to be creative with what resources they do have.

Neither parents nor schools can wave a wand over a disabled child and make that child's problems disappear. Yet, the parties often treat each other as if this were true.

Parents sometimes have expectations of their schools that reach beyond academics. They want their kids to fit in, love learning, and have predictable,

pleasant school experiences. Often, kids with disabilities can do many of these things. Sometimes they simply cannot.

Schools, even the best of schools, can harbor frustrations that impede learning and fitting in. These frustrations should be whittled down until only those hurdles that cannot realistically be removed remain.

Similarly, schools have rhythms that cause unnecessary pain to a disabled child. Simply telling parents "this is how we do things" is an inappropriate attitude. Disabled children may not be penalized for bringing their disabilities to school. Teachers and students must make every reasonable accommodation to welcome them.

3. Always provide "face saving" ways out of a dilemma. Have a back-up plan.

Mediators know that this is the secret of successful mediations. We call it the difference between positional bargaining and principled bargaining.

Assume we have two parties who are arguing over one lemon. Each takes a position and insists on having the whole lemon. No compromises. They go to a judge who uses the rules of basic adversarial procedure to resolve their problem by dividing the lemon in half -to no one's satisfaction.

A mediator will ask each party what they want with the lemon. One party says they want the pulp for lemonade. The other wants to use the rind for zest. The mediator sees a solution the judge missed: peel the lemon and give all of the fruit to one party and all the rind to the other. A win-win solution.

Special needs children benefit greatly from principled negotiations. When parties know what their needs are, they can be more creative in finding solutions to those needs.

Often, parties simply assess their needs in private, and make unilateral decisions as to what they require to satisfy those needs. They then present only these conclusions as their positions in a negotiation: "I need the lemon."

Poker rules dictate that you will "tip your hand" and foul up your chances of winning if your opponents know what your plans are. Keep your cards close to your chest, and bluff it out. In negotiations, especially delicate negotiations, the goal should not be to win (which forces the other side to lose) but to achieve a particular objective.

Encourage brainstorming among all informed people at team meetings, especially before an IEP. When the collective resources of a group focus on a problem, the solutions that present themselves are amazing.

Have more than one approach to offer. If your initial suggestions cannot be implemented, you should have given some thought to your fallback position.

Sometimes a fallback plan contains a calculated failure. Failures, though unpleasant, are our greatest teachers. If you find yourself at odds with a school administrator's idea, and if this idea will not cause real harm to your child, set a trial period, then let the idea go forward and fail. Just let experience speak for itself.

No one likes to feel like a loser. No one likes to feel humiliated. No one likes to feel stupid, or to worry that if she makes a mistake, this will be held up for everyone to see. No one wants to worry over failing in front of a group. Moreover, everyone will fight tooth and nail to keep these things from happening.

I promise you, if an IEP becomes a contest of who is right and who is wrong, no one will roll over and play dead. Present a position (even a perfectly legal and legitimate one) in unnecessarily demanding terms, and you risk creating an atmosphere where the other side would rather eat steel wool than admit that they are wrong (and they certainly won't capitulate if their opponent is not wholly right on the facts in the first place!)

I am amazed at the number of parents who walk into a meeting and flatly accuse school personnel of professional incompetence - in front of their supervisors - then expect everyone to agree with them!

Sure, wouldn't you, if someone did that to you at your job?

4. Build your record.

What if you are right? What if school personnel are flatly incompetent? Do not say it. Show it!

Be reasonable and calm while you admit that you are concerned about how a situation is developing. Be prepared to show, objectively, how your child is not meeting his goals. Produce reports, articles or test results that will persuade an objective listener (like a due process hearing officer, or a judge) why your suggestions are reasonable.

If you can lay out a "court ready" case at this level, everyone will quickly read the handwriting on the wall. Threats and accusations are unnecessary. The facts speak for themselves. Of course, this assumes that you have some facts on your side.

Do not shy away from the damning evidence. Develop a strategy to deal with it. A good lawyer knows all the strengths and weaknesses of her case. We know where we expect to have trouble and prepare for this as best as we can. Again, objective data from non-school district personnel is the best place to start.

Independent medical, developmental and psychologist's evaluations and private therapists' reports and evaluations are crucial to setting up the facts. So are third party advocates or therapists who come to the school and observe your child in his school environment. You have to listen to what these reports and third parties tell you.

Parents must be willing to face the reality of their child's abilities!

If your child has tantrums when frustrated, do not demand that his day be frustration-free. Provide and document solutions how the frustrations and tantrums should be handled.

You are not being disloyal to your child by admitting his problem areas. You are being disloyal to your child if you do not prepare for them. Get the facts in writing. Do not rely on your own opinions and feelings.

This is not to say that parental opinions and feelings are bad. In fact, they are wonderful! In addition to what we may think or feel in our guts, we need to understand of what we can reasonably expect for our child in the classroom environment in a given timeframe.

Our best hopes and dreams come true one step at a time. Parental feelings are the most powerful thing on earth. Our insights are invaluable in setting goals, therapies, and just getting things done. They are not evidence!

We will fall flat on our faces if we indulge in the belief that our opinions, by themselves, will persuade an objective hearing officer or judge that we are right in any contested issue. Courts sympathize with parents but do not defer to parents.

As parents, we are expected to be many things for our children but "objective" is not one of these things. We are, by Nature's design, the least objective persons

in the room. Cull and collect objective evidence to buttress any argument you have. If you get caught off-guard on an issue in an IEP and believe you need written back-up for your position, adjourn the meeting and reconvene when you have a chance to have your child assessed by a qualified professional. IDEA does not require the parents to be rushed into anything.

#### 5. Walk a mile in the other side's moccasins.

It will not hurt to indulge your thoughts about how things are for the other side. In fact, experimenting with perspective is necessary to brainstorm solutions or to decide the order in which you will play your cards.

Spend sustained time at the school. Volunteer in your child's classroom and other classrooms. Watch the kids on the playground and in the lunchroom. What really goes on inside school? How tired are you at the end of a school day? How tired must the teachers, the aid, the principal, and your child be?

On the other side, encourage teachers and other school persons to visit you at home in different circumstances, so they know what your life is like, too.

Do not forget to sell your solutions. When we want interventions for our children that are designed to maximize potential, do not forget that IDEA will not support us. Find a way to make your proposal appealing for the school district.

When Amanda was in Early Childhood, the teacher (a wonderful woman) used her tried and true methods for disciplining Amanda. While these methods may work well with other kids, they were not appropriate for Amanda. Instead of objecting to this procedure, we offered a suggestion that we said would make things easier for the teacher. Framing our suggestions this way made it easier to implement.

Well-reasoned but abstract ideas about how things should be have little application unless you can offer practical advice about how they can be. It is not enough to know how you think things should be done, although this is an excellent place to start. To make workable suggestions, you need to understand how the people involved can do this job within the context of their day, training and budget.

Learn what they have to do and how they do it. Use that knowledge to advocate. Offer practical ideas about how to address problem areas.

It is harder to ignore the problem-finder if he or she is also the solution-giver. Conversely, it is easy to ignore people who do not know what they are talking about. Parents of special needs kids know this better than anyone else. We are constantly told how to do things by people who have no idea about the realities of living with our children. We rightfully ignore those people. School personnel will ignore you unless you understand the realities of what they do.

6. Listen actively, especially to the things you do not want to hear.

No one is all knowing. Really. As much as I know about my child, and I know an awful lot about her, I still have things to learn. To my knowledge, no one has yet descended from the sky.

Often the solutions we seek are stranded on the barren land of "What We Do Not Want to Hear", and are calling out to us.

Hear them. Listen to everything with a whole heart and a whole head. If you find yourself getting angry or defensive because you disagree with what someone is telling you, or because the person is talking to you in an offensive way, pay attention to your reaction. When we feel defensive, we stop listening. We begin to think about a rebuttal. Our thoughts are no longer on the issue, but how we will respond to it.

If you find your temperature rising, disengage your ego from what is happening. Breathe deep. Calmly restate what you heard like this: "I want to understand your position, Ms. Jones. Are you saying \_\_\_\_\_?" Then restate what you thought she said, not what you thought she meant.

She will confirm or deny your recollection. Keep at this until you are sure you understand her position. Only then can you calmly state your position. Often, what we think we hear, we did not hear. Or the other party innocently misspoke.

These oversights can be remedied easily. If not, then everyone at the table fully understands what the disagreement is about, and can try to deal with it. In addition, hearing all points repeatedly allows even the most uncomfortable of them to sink in enough to be objectively evaluated.

7. Encourage everyone to love your child, and then let them!

Pediatricians and child psychologists have a term of art called "gate-keeping". Gate keeping occurs when people set themselves up like watchdogs over a child, guarding the gate against intruders. Sometimes nurses and doctors will gate-

keep a particularly sick child. They become convinced that they are the only ones who can really act in the child's best interest and actively discourage others from helping.

However, no one can gate-keep over a sick or disabled child the way parents can. We are stunning in this ability. Nature has blessed us with innumerable instincts for just this task. When is gate-keeping appropriate? When it protects your child from a real harm. When is it not appropriate? When it gets in the way of loving or talented people who can help.

Parents must strive to maintain their sense of judgment. They must be able to tell the difference between real harm and potential or imagined harm. If we treat every person who disagrees with us as an enemy, we will dull our instincts so we will not be able to detect the real enemies in our presence.

A school speech therapist told the mother of a nonverbal autistic boy that there was no hope for him because she could not reach him. She told the boy's mother: "You know, these autistic kids just don't get it!" This statement demonstrated her dangerous ignorance about autism. She may as well have said, "You know those deaf kids? You talk to them, but they don't hear you!" This woman was a real threat to that boy. She would not help him. In fact, she caused him to regress. Gate keeping was a wonderful skill for his mother as she strove to get another therapist for her son.

However, if a knowledgeable educator has a different approach or opinion from ours, this does not make her the enemy. Do not gate-keep around those people - they are invaluable, untapped resources.

Let them close to your child to see the wonders and beauty you do. When they learn to love your child from their heart, they will be motivated to do what they can to help and will listen to what you have to say. If you push them away, they will never get a chance to find out what they and your child are capable of doing. Everyone loses that way.

I am convinced that children can never be loved too much or by too many people. Love will move mountains. Let it in.

8. Have a little faith.

As a lawyer, I have remarkable faith in the human spirit. I believe that most people are good at heart and will do their best if they are given an opportunity.

In the field of education, it makes sense to be optimistic. Think about it: No one becomes a teacher, an aid, an administrator or a facilitator because of the money, the hours or the Nike endorsements. They do this because they want to make a difference to children.

Of course, intelligent people will disagree about the proper way to make that difference. Those persons closest to the children will have a different perspective than administrators.

Very few, if any, of the people you will meet in your child's school is out to hurt anyone. Be alert for the occasional bad apple. Generally, give your child's team some credit for acting in good faith. If they need education, supply it. If you disagree, try to work it out without getting personal. Do not demonize well-intentioned people. Utilize them. Even if they have priorities that you cannot share, they can turn out to be of great help to your child.

#### SUMMING UP

Your child's IEP should never be a gamble. IEP meetings should not turn into a game of nerves with everyone trying to guess who is bluffing, betting or folding on the strength of their guess. An IEP should be a strategic meeting where a talented advocate need not lie about his or her hand, but can play any facts to the child's advantage.

Keep the game fair and in good spirits, when possible. Know what your goals are and work them. Many roads lead to the same place. Many different cards can win the game.

#### About Jennifer Bollero

Jennifer Bollero is an attorney in private practice in St. Charles, Illinois where she lives with her husband, Mike and two children, Amanda (who has autism) and Ben (who is not disabled). Her practice focuses on the needs of families with special needs children, especially those who need help securing appropriate educational interventions for those children. Her experience includes commercial litigation and trial experience, mediation, arbitration and some general practice.

Ms. Bollero graduated with a Bachelor of Arts from Northwestern University in 1985 and her Juris Doctor from Loyola University of Chicago Law School of Law in 1988. She has been admitted to the State Bar of Illinois and the Federal Bar for

the Northern District of Illinois since 1988. She externed for the Hon. Judge Aspen and for the American Civil Liberties Union.

Ms. Bollero is on the board of directors for two nonprofit organizations: the Kane-Kendall Services Coordinators (a point of entry organization for all persons with developmental disabilities in Kane and Kendall Counties in Illinois) and the Autism Society of Illinois. She is firmly committed to respecting the unique qualities of all disabled children, while encouraging all who raise and teach them to give them every opportunity to secure the skills and knowledge they will need in life.

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