

# Advocacy for Systems Change

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## Abstract

Howard County Maryland, part of the commuter belt in the Baltimore/ Washington D.C. corridor, is an affluent school district with a strong reputation for general education. However, it had a reputation among parents of being extremely difficult to deal with regarding intensive services for children with autism. A group of parents from the Howard County Chapter of the Autism Society of America (HCC-ASA) and from Families for Intensive Autism Treatment (FIAT) entered into a dialogue with the Howard County School system. After two years of negotiations with special education staff, the Board of Education approved a programme of Intensive Early Intervention, including full day services for most children in preschool and kindergarten, using an Applied Behavior Analysis (ABA) based incidental teaching model, home-based discrete trial programs, summer services, ABA training for staff, and home intervention specialists. In this paper we will discuss the strategies used by the parents to achieve this goal. It included both unsolicited and solicited public testimony to the Board of Education and to the County Council; researching and writing a service model; extensive (and sometimes adversarial) negotiations with school administrators; effective networking among parents; and a measure of sheer good luck.

## Introduction

The object of this paper is to relate how strong, informed, persistent public advocacy by parents on behalf of young children with autism was instrumental in bringing about a total system change in special education services in Howard County, Maryland. The two year long process culminated in the approval in June 1998 by the Howard County Board of Education of a plan for intense early intervention (birth through five) for young children with autism. The school programme for children with intense needs, using behaviorally-based incidental teaching methods, includes a full school day for preschool and kindergarten ages, half-day services for infants and toddlers, and the provision of parent training through a home-based intervention specialist. Additionally, home-based Applied Behavioral Analysis (ABA) programs using discrete trial interventions are provided through a non-public placement arrangement with Community Services for Adults and Autistic Children (CSAAC). The Howard County Public School System (HCPSS) also launched a systematic effort to change the standard operating procedures of its Office of Special Education to adopt a high level of collaboration with parents around both the Individualized Family Services Program (I.F.S.P.) and Individualized Education Program (I.E.P.) process<sup>1</sup> and the education of children with special needs.

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<sup>1</sup> Under U.S. Federal Law, Individualized Family Service Programs must be devised for children with special needs under 3 years of age, and Individualized Education Programs (I.E.P.) for children of school age. In this paper we use the term "I.E.P." to signify both. Relevant legislation and regulations are the Individuals with Disabilities Education Act (IDEA, 1990), amended 1997, regulations issued 1999; in Maryland, the Code of Maryland Annotated Regulations (COMAR) governing special education, revised 1999.

Our principal thesis is that this turnaround should not be seen as an isolated instance of good fortune, but one that is repeatable elsewhere. This thesis is based on the assumption that Local Education Agencies are truly concerned about the services they offer to children with special needs, and if given the appropriate information can and will act in an enlightened manner. We believe that the attitudes and personalities of the key players in the drama—the Board of Education, senior administrators at the Superintendent level, and active, informed parents—are not unique to our County. We hope this account may work as a guide (rather than a definitive road map) to other parents wishing to see the same happen in their districts and a proof that however interminable the campaign may seem, it can be done.

Below we detail some of the specific strategies we and our fellow parents used to attain the goal. These included organizing a campaign of public advocacy by parents both to the School Board and the County Council containing factual information; conducting a collaborative dialogue with school administration staff; organizing concerned parents to be present at all related events; interesting local media in the story; writing detailed implementation plans for proposed services; and developing coherent public presentations.

This paper is organized as follows: we begin by describing the situation in the County before our initiative began. We continue by detailing the genesis of the initiative, with discussions with senior administrators, and with the initiation of the White Paper collaborative process of drafting a new service plan for children with autism. We then describe how the process finally came to a successful end, and close with an attempt at analysis.

Throughout we must stress that this initiative passed over what we perceive to be considerable resistance on the part of staff at the “implementation” level, those administrators whose task it is to represent the local Office of Special Education at I.E.P. meetings. We feel that it is important to bear in mind that to most parents the odds against succeeding in this endeavour seemed initially insurmountable.

## **History**

Special education in Howard County as of 1995 had a poor reputation with a sizeable minority of parents of children with special needs. The school administrators claimed that the majority of parents were satisfied with the services provided. However, parents who had informed themselves about current trends in special education for children with autism and requested services commensurate with what they had read often found themselves in a strongly adversarial relationship with the schools. Such disputes included but were not limited to arguments about the provision of Applied Behavioral Analysis as advocated by O. Ivar Lovaas and other researchers. Issues involving the intensity of services provided, including both the number of hours and the training of staff, and the provision of summer services were frequently controversial. For example, both of our children, Ben’s son Asher, diagnosed in the early part of 1995, received 5 hours of intervention services on intake and Anne’s daughter Eve, diagnosed in 1992, received under 3 hours. The early intervention programmes for toddlers were based on a modified form of the General Education High/Scope curriculum rather than on services specifically designed for the special needs of children with autism. Service levels generally rose to 10 hours for preschoolers and 12½ hours for kindergartners.

Services of this kind were standard for nearly all children in early intervention. Many parents thought that IFSP/IEPs had demonstrably little individualization in terms of the intensity of services, and were comprised in general of a set of goals—albeit often more quantifiable than in some other counties—that fell far short of challenging children with autism. The majority of parents entering the “special education maze” accepted the services that were prescribed for their children with little

dissent—and often, relatively little input. It was commonplace for the schools to expect parents to assent to IEPs without significant changes. While parents were explained their rights under the law, most parents declined to exercise those rights for fear of damaging their relationship with what was apparently their only resource in the care of their children with disabilities.

As is well known, in 1993 Catherine Maurice published an account, *Let Me Hear Your Voice*, of the exceptional progress of her children using the discrete trial teaching forms of Applied Behavioural Analysis (A.B.A., the application of which to systematic teaching of young children is also referred to as Intensive Behavioural Intervention, or I.B.I.) advocated by Lovaas amongst others. This became a ray of hope for parents struggling with children widely thought difficult or impossible to educate. Lovaas had demonstrated, albeit not without controversy, that children could progress using his methods up to becoming indistinguishable from their typically developing peers. However, the methods he advocated required a large number of service hours delivered to on a 1:1 basis, and thus had high attendant staff costs. Advocates argued that the long-term benefit to society of such intensive early intervention far outweighed the cost to school districts.

By late 1994 a number of families in Howard County had started A.B.A.-based home programs<sup>2</sup> with highly trained autism consultants as overseers. Many parents implementing such Intensive Behavioral Intervention plans in the county as elsewhere saw a meteoric rise in their very young children's vocabulary, and in their all-round ability to learn. To be sure, A.B.A. was also controversial amongst the local parent community. But to many parents the contrast between the poorly designed, low intensity services offered by the school system and the highly intensive, individualized —albeit costly—programme offered through the clinics and university departments consulting on A.B.A. programs was all too striking. Many parents were convinced that the education provided by the public schools was not appropriate, and were incensed at the ferocity and tactics by which some members of the school administration were prepared to defend programmes parents deemed to be totally inadequate and indefensible.

### ***The Brooksby Case***

Indicative of the HCPSS attitude towards discrete trial teaching methodology was the pursuit of the Brooksby case, which was initiated in early 1995 and finally settled late in 1999. Darren and Leslie Brooksby enrolled their son Lucas, at Bollman Bridge Elementary school. After initial satisfaction with the progress Lucas made at school, they discovered that his rate of progress increased markedly with the use of an intensive A.B.A. programme at home, and in June 1994 requested in writing that the schools provide such a programme. Their request was not answered for about 6 months, in clear violation of the law. There followed Due Process hearings at the local and state level, according to the procedures then in effect.<sup>3</sup> Although the initial ruling was sufficiently equivocal for both HCPSS and the Brooksbys to seek appeal, in both hearings the Brooksby family's contention that the schools did not have the legally mandated appropriate programme for children with autism was upheld. The family was to obtain reimbursement for ongoing A.B.A. programming at home until such time as the

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<sup>2</sup> Unless otherwise explicitly specified, in this paper A.B.A. refers to discrete trial teaching techniques, even though it is a much broader term that means other forms of behaviourally based intervention.

<sup>3</sup> Presently in Maryland there is no equivalent of the local hearing, and parents are able to request non-binding mediation hearings before an Administrative Law Judge, or file directly for State Due Process procedures also before a Judge.

schools could provide an appropriate programme. Subsequently the schools claimed that they had put together such a programme, but without either the training for the methodology or the oversight by an A.B.A. specialist that met the family's requirement. The family believed that this new programme was a sham, and continued to press for the reimbursement as granted in the original hearings. On the other hand, the school system maintained that their new programme was adequate and that it did not need to meet the standard of the maximal educational benefit for Lucas Brooksby that they saw the family as seeking. The irony is that legal wrangling over the amount of reimbursement due the Brooksbys and over attorney's fees continued until close to the writing of this paper, well after the HCPSS fully funded for many young children with autism a programme quite similar to the Brooksby's original request.

## **Beginnings**

In the fall of 1996 a number of parents of children with autism<sup>4</sup> in Howard County got together at meetings of F.I.A.T. (Families for Intensive Autism Treatment) and decided that they should advocate for changes in services. The Board of Education held a "Listening Post" at their meetings at which citizens could speak for three minutes about issues of concern to them, and the parents planned to address the Board, two at a time, at each successive meeting until they received an official response. Additionally the Board was sent a videotape of the successful application of A.B.A., and number of papers about its efficacy and its long-term cost effectiveness in assisting children to lead independent lives as adults as opposed to state-funded institutionalization.

In late November 1996, the Howard County Board of Education had a new Chair, Ms. Sandra French, and a new Vice-Chair, Mr. Steven Bounds. Bounds had a reputation as a fiscal conservative, and was therefore not regarded as receptive to increased special education funding. The Board considered the information supplied by the parents, and found it to have some merit. However the parents' views, backed up by the research articles they provided, were at variance with the views presented to them by the school administrators. The Board was also uncomfortable with the fact that, despite significant spending on special education services—about \$24m in 1996—there was a set of highly informed and vocal parents strongly dissatisfied with the existing programmes. Ms. French decided it was time for the Board to seek further information on special education issues, and so called a Special Education Focus session for January 1997, at which the Board requested the school administration furnish answers to a number of specific questions.

Also in November 1996, in direct response to the parent presentations at the "Listening Post," then Associate Superintendent with responsibility for special education, Dr. James R. McGowan, suggested a meeting with parents to discuss the issues more fully. The first meeting happened in late November, and meeting with McGowan became a monthly event. In January 1997 he requested that the parents write a paper detailing their arguments and plans for appropriate services in a proposal to the Board of Education by March of that year. The meetings became a forum at which McGowan and special education staff including Special Education Service Coordinator Sue Brown and Director of Special Education Sandra Marx discussed heard directly from parents about the need to adopt more intensive services, including A.B.A. Ms. Brown was a controversial figure among parents, on the one hand regarded by some as a strong advocate for effective programming, but on the other hand perceived by parent advocates as philosophically opposed to A.B.A. and intensive services.

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<sup>4</sup> Amongst others the group included Steven Fine, Anne Long, Ben Dorman, Catriona Johnson, Leslie and Darren Brooksby; Bob McGillicuddy, Steven Wampler, Norma & Paul Sesto, Michael Dooley, Luke and Stephanie Leonard, and Leslie Frazier.

## *The Focus Session*

The Special Education Focus Session held on January 16<sup>th</sup> 1997 included as speakers Sue Brown, Ronald Kaplan, Service Coordinator for Compliance, Sandra Marx, acting as facilitator, and Frances Wang, parent advocate and mother of a teenager with physical disabilities, and chair of the Special Education Citizens' Advisory Committee. The session came as somewhat of a pleasant surprise to the parents who had been instrumental in bringing it about (unbeknownst to themselves). During the session, Sue Brown made remarks that gave parents new hope, seeming sympathetic to the cause of improved services. She gave a sensitive appraisal of the problems facing parents of children with autism:

... a number of the students have multiple intense needs as a result of autism spectrum disorders (A.S.D.s), challenging behaviors and severe learning disabilities. Their patterns of behavior and learning needs are much more complex than we have seen in the past. During the past two years there have been between sixty and seventy infants and toddlers who have A.S.D.s. These children display behaviors that are on a continuum from mild to severe. They have disabilities in the areas of communication, cognitive, behavioral and social/emotional skills. Some children are nonverbal and have few skills. Some have disruptive, destructive or dangerous behaviors, including kicking, screaming spitting, hitting and biting. Some have limited social interactions with peers and adults. Children with autism also have a serious impact on family life and activities, as a result of challenging behaviors, communication difficulties, sensory disorders, sleep disorders, and activity levels. Parents are requesting intensive 1-to-1 behavioral training services of 40 hours/week in the school and home to address these needs. As the children turn 6, they have been and will continue to move into elementary schools, with serious needs in the areas of communication, behavior, social interaction and learning. In addition a number of students present with challenging behaviors which may or may not be related to a serious emotional disturbance or other disabilities.

However, at the same hearing, Kaplan, whose responsibilities include the legal aspects of the process, gave this appraisal of relations between school and parents:

...parental concerns take an inordinate amount of time to respond to. In reviewing the time needed to deal with parental issues, our office using some rough data concluded that about 2% of our parents take up about 80% of our time. It is difficult for our office to assist school personnel and provide the needed service coordination when so much of our time is taken with such few cases. I would like to address the issues associated with the 2% that I mentioned earlier. There are some parents who will only come to ARD<sup>5</sup> meetings or IEP meetings with attorneys or advocates, regardless of the issue. Their demands are great. Some want non—public-school placements at county expense for their child. Some want services within the public school system at great expense, which far exceeds education, which is reasonably calculated for their child to derive education benefit. For example, some parents want the Office of Special Education to pay for private therapy, or tutoring, or one-to-one assistance within the public school setting. Parental knowledge of special education [law] is great.

... for some parents, the concept of “more is better” permeates the ARD team process. They have at times shared their child's IEP, the Individual Education Program, with other parents. They will use the World-Wide Web to share recent court cases and to network with parents in other states. Advocacy organizations may hold monthly meetings and at times openly discuss their own child's IEP or ARD committee meetings and what services they received for their child as a result. At the next ARD team meeting, many parents come to that meeting requesting

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<sup>5</sup> Author's note: until 1999, I.E.P. meetings in Maryland were officially referred to as Admission, Review, and Dismissal (ARD) meetings.

compensatory services for their disabled child.

This testimony raised a number of themes which would surface regularly later. For example, Mr. Kaplan stated that it was only a small minority of parents who were dissatisfied with the levels of service. This view appeared to be widely held in the school system, judging by a recurring question throughout the negotiations we undertook, namely “Who did we parents represent, apart from a small number of malcontents?” Additionally, dissatisfied parents were seen as never satisfied (“more is better”) and even (perish the thought) making use of resources available to them from other counties and from advocacy and other support organizations in order to prepare for I.E.P. meetings. Administrator Kaplan made it clear: school staff were to prepare the I.E.P., and parents’ role was to accept what they were offered.

As a final comment, the Chair asked Mr. Kaplan what happened if the parents disagreed with the recommendations of the I.E.P. team. The reply was that

...when you talk about terms like Lovaas or ABA or specific placement, a decision has already been made that a whole group of individuals need that particular approach. Our premise is that an IEP is exactly that, an Individualized Educational Program, and that for every child who may have a disability that the services needed are going to vary from child to child, and as I stated in my presentation, what happens is that we will make a decision about one child. That information tends to be shared with other people and if they are not getting what they believe that the other parent got they will come back and say “well wait a minute, when we went through this process I got X. Now I found out it’s Y, so I would like to get X *and* Y” So the answer to your question is that we do whatever the IEP calls for, and that ranges from a small amount of service to an intense amount of service, and it’s driven by the goals and objectives on the IEP.

This exchange was instructive as an insight into how parent advocates were viewed by at least some school administrators, and how they in turn felt *their* position was consistent with their duties towards children with special needs. It was also clear that the School Board did not understand that the parent is, under law, an equal part of the I.E.P. team. We realized that the Board needed more education, too.

Frances Wang, speaking later, remarked that “... the cases that consume most of the staff’s time result only from the parents’ love and concern for what is best for their child, and take their toll on both parents and staff.” She advocated for a parent liaison with staff as a working intermediary for these contentious cases, an idea that was later taken up by the special education office.

We came away from this session feeling both hopeful and outraged at the same time.

### ***The Multiple Intense Needs Classroom Pilot Programme***

As Sue Brown said in the Focus Session, HCPSS, like other education agencies in Maryland, were continuing to see a steep rise in the number of children diagnosed with autism spectrum disorders. Howard County itself had seen no less than a 66% increase between 1995 and 1996. In response, HCPSS applied for and received a pre-school services grant from the Maryland State Department of Education (MSDE) to design a new autism programme. Of the 14 grant requests received by MSDE, ten were from counties seeking to develop programmes for the rapidly expanding population of young children with autism.

**TABLE: INCIDENCE OF AUTISM SPECTRUM  
DISORDERS IN HOWARD COUNTY 1993-1998\***

1993	1994	1995	1996	1997	1998
10	38	64	106	129	169

\*Students with autism as primary diagnosis ages 3-21. Source: Maryland State Department of Education

Planning for this new programme, called the Multiple Intense Needs Classroom, or MINC, was lead by Sue Brown and Instructional Support Team member Anne Hickey and began in 1996. The first children were placed into a pilot version in the fall of that year. The new programme was planned initially without parent input, at least to the best of our knowledge. For this programme, Brown, Hickey and others had extensively researched a number of school-based delivery models. They decided to base their programme on the Little Walden model, under development by Prof. Gail McGee at Emory University in Atlanta. This model has as its primary methodology behaviourally based incidental teaching techniques, by which learning opportunities among children with autism are delivered in a natural setting with assistance from teachers and typically developing peers. They regarded this methodology (also based on the principles of Applied Behavioural Analysis) as superior to discrete trial teaching as it implicitly promoted natural rather than rote learning. Nevertheless, Brown maintained that their goal was to produce an “eclectic” programme combining the best features of every approach. They visited the programme in Atlanta and came back to train Howard County teachers.

During the same period, the schools adopted a policy of increasing the number of intervention hours available for children with special needs in kindergarten from 12½ to 20 hours per week, often but not exclusively at parent request.

***Please to See the King***

Individual meetings of parent groups with administrators at the Superintendent level were relatively rare, and our group felt the invitation from Dr McGowan to be an important overture from the school system. The early meetings also gave some degree of hope. Encouragingly, on several occasions McGowan went out of his way to state that in his view the school system should be true to its stated goals of excellence in education for all children, including those with special needs. His request for a parent proposal however did not entail a commitment to anything other than studying the parents’ views. However, the forum provided by these early meetings gained us something new: an ability to open the seeming closed box of special education decision making. We were able to ask directly, for example, the nature of the new programme Brown and her team were planning, of which we were only dimly aware through parents with children in the pilot. We were also able to request information from the special education office to help write our proposal, and to ask questions about how far the schools were prepared to go in providing intensive services. However, for the first part of 1997, McGowan did not direct his staff to propose specific service levels.

McGowan’s original deadline of March was not met, partly because the information we requested from the special education office was never forthcoming, but perhaps mainly because we as parents could not fully agree on what our proposal should comprise (not to mention the problems associated with taking care of a few particularly demanding children!). Instead, after it became clear that both Brown and ourselves were working on service models, Dr McGowan asked director Marx to nominate staff representatives to a team which was to write a “White Paper” with the parents

proposing a new continuum of services. Brown also at the time had the aim of writing a document which was to be both a training manual and a guide to parents and teachers that described the characteristics of autism and the available treatments, for which she was interested in parent input. Thus, the new service plan became known as the White Paper Initiative, and the writing of it became the chief negotiating forum.

### ***What to Propose?***

The paper to be written at McGowan's request led to heated debates among the parents. What exactly would we propose? For guidance, we obtained copies of the results of a number of similar efforts from around the country, and talked to their authors. One faction amongst us held that the discrete trial teaching form of A.B.A. was the only scientifically proven methodology for young children with autism, and our paper should advocate that for all children. Many felt that the only way discrete trial teaching would be adopted was by legal means, through Due Process cases or possibly a class action lawsuit.<sup>6</sup> Another set of parents wanted to see the county schools provide a well trained, state of the art programme, whatever that might entail. Even those parents believed that such a programme would inevitably be an A.B.A. programme, and wondered what we would do if the schools chose something else. A third faction opposed concentrating on one particular methodology, but argued that we should advocate for services that were intensive in hours, delivered by well-trained staff, and had a large proportion of 1:1 time. Since most of the cost of intervention was in the staffing required for an intensive programme, if this were adopted there would be no strong cost incentive to deny A.B.A. services for children who responded to it. Also, if the County truly wanted to be treat parents as equals in the I.E.P. process, it was thought that, after due consideration, they would accede to parent requests for A.B.A. Another argument carrying weight was that it would be difficult to advocate successfully for a totally different programme from the one in which the schools had clearly already made an investment.

Despite a lack of consensus about the final shape of the programme to be proposed, we proceeded with writing those sections we could all agree on. In January, different groups of parents set about writing sections that characterized autism, advocated for A.B.A., roughed out service models, and researched potential additional sources of funds for pilot programs.

By the time we were called upon to write a collaborative paper with the school administration in about May of 1997, some plans for delivering A.B.A. services had been drafted. However, we had no real idea how to cost out such a programme. We were also not in a position to show how such services could be made to fit in with the schools' existing policies and procedures, which we realized was important from a pragmatic point of view.

Another important step was taken when the parent advocates became incorporated as the HCC-ASA education committee. This went a long way towards answering the question as to who we represented. The ASA chapter, with Ben Dorman as President, published a regular, widely-read newsletter, had a mailing list including about 120 families in Howard County, and offered a telephone support line which was frequently used. Over 60 parents had had contact with the chapter by the time the negotiations started, making us feel indeed representative of a fair fraction of the autism community. As negotiations progressed, our awareness that many in the community were counting on us, and that our success or failure would have immense future implications, weighed upon us heavily and forced our hand on a number of occasions.

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<sup>6</sup> Such a suit on this issue was actually filed in Westchester County, NY, during these negotiations

Ben Dorman and Steven Wampler, representing different viewpoints about the services to be provided, were to be the parent writing/negotiating team, although Wampler later stepped down to be replaced by Anne Long; later still, Sue Ann Shafley joined the team. Sue Ann's son Will who had been recently diagnosed was still young enough to require the intervention for which we were advocating, while Ben, Anne and Steve's children were already too old to benefit from new early intervention programmes.

## **The White Paper Initiative**

The writing of the collaborative paper began in earnest in June 1997, while monthly meetings with Dr McGowan continued. McGowan urged us to present to the School Board the programme we would like to see implemented. This contradicted Brown and Hickey's apparent goal of proposing their pilot programme as the new service model, and a debate ensued as to whether we could possibly ever agree on a joint programme. With our reservations that Brown was prejudiced against our aims, we felt that our efforts would have little chance of success without McGowan's direct intervention in the process.

Somewhat to our surprise, the initial discussions with Brown and Hickey were extremely cordial and apparently productive. We thought, judging by the way that school staff in general represented A.B.A. to other parents, that they rejected A.B.A. because they only knew about its older implementations. In particular, the versions of discrete trial programmes that were used in the seventies included the use of aversives, and in some incarnations gave little opportunity for children to generalize what they had learnt. We criticized such programmes based on the experience we had gained running our own home programmes. We insisted that we were interested in an approach which was both discrete trial-based and developmentally appropriate<sup>7</sup>, and allowed for generalization by being integrated into the classroom schedule.

It became clear also that we as parents were disadvantaged by a limited knowledge of the current literature on special education related to autism programming. We had heard much from the "pro-A.B.A." parent lobby, but little about the broad range of work that has been done in the field. Our collaboration with the school staff exposed us to a broader range of programming models, and also gave us key insight about how a school system puts a particular service model into practice. This included information about costing of services, and the logistics of running a programme for many children in a number of different schools. Brown and Hickey informed us about the theoretical basis of the Walden programme they were advocating, and pressed us to accept it as a base model. They noted that the type of "eclectic approach," they preferred was gaining favour in research circles (although we continued to point out that the service levels they favoured had little or no support). It became perfectly clear that we would fail if we insisted that they reject this programme and adopt a fundamentally different model as the only option. Further, we were aware that, either because A.B.A. programming had not been found to be effective with their children or because they were not properly informed, not all parents wanted discrete trial based programming. We were not about to narrow our base of support. We thus decided to adopt the third strategy mentioned earlier: to press

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<sup>7</sup> "developmentally appropriate" in this context means an education curriculum that teaches children with reference to the expected developmental stages of the typically developing child of the same chronological age. Discrete trial teaching programmes are sometimes criticized as not developmentally appropriate, since a child's progress in discrete trials through a phased curriculum of skills may sometimes exceed what a typical child would learn at the same age, and thus give the children the ability to recite information they are not capable of comprehending.

intensity and quality of services as our key demand for the new programme, leaving arguments about methodology aside for the moment. We pointed out that the Walden model itself included at least 30 hours a week of school-based direct intervention, well in excess of what the initial school system proposals offered.

Thus, in the summer of 1997 we asked McGowan and Brown to adopt a definite resolution about intensity of services: we requested they commit the schools to providing full day services (32½ hours per week) for all children. This they flatly refused to do: McGowan stated that such a commitment rested on “economic and political issues.” Brown said that such intensive services were not appropriate for all children. In addition to the other reasons why we insisted on a commitment to intensive services, we wanted a guaranteed service level which parents could opt out of, rather than a continuum of service levels in which all the decisions about intensity effectively rested with the schools. Our experience had been that only on request were children granted higher service levels. In contrast the model Brown was proposing at that time—and continued to advocate until later in the year—had services ranging between 5 and 18½ hours per week provided by the school with no clear, accountable guidelines as to how any child’s service hours should be determined. As for methodology, the “eclectic approach” to be followed would choose from among the various possible techniques available to teach a particular skill. Brown also added 10 hours to be made up by parents in an attempt to increase the apparent intensity of the model. These hours were referred to as “family routines-based intervention” and were planned as an extension of the incidental teaching model in use in the schools to the home.

After their refusal to commit to our key goal, we debated pulling out of the process altogether. The process appeared to be a dead end, in which our role was to endorse the plans offered by the school staff with little significant modification. Nevertheless, we felt that our other role in the process, of providing parent input into staff training, was valid. We also trusted McGowan to grant us the opportunity to present our own programme proposal directly to the School Board if we could not convince the school administration to incorporate our requests into their plan.

Meetings then continued for the rest of the year, taking place every two or three weeks. We were able to add language that explicitly recognized that parents had an equal role in the IEP process; stress that programming was designed to educate children based upon their potential; and explicitly included discrete trials as one of the options for teaching children with autism. Both sides worked simultaneously on descriptions of the characteristics of children with autism, short summaries of all the various available methodologies, and on service models. The object was to provide a description for staff of the full range of teaching “tools” of which they should be aware. Since the school staff ostensibly accepted discrete trial teaching as a valid option, the document had to describe A.B.A. We realized that it was crucially important how A.B.A. was presented to staff and parents. The attempt to agree on a description exposed the underlying tensions within the group, with the school staff proposing a rather negative assessment, and the parents insisting on incorporating the essence of their advocacy pieces into that definition. In the end, the HCPSS hired Prof. Andrew Egel of the Education Faculty at the University of Maryland, College Park, to attend our negotiation session and to write the A.B.A. description. Egel had devised a discrete trial based autism programme for neighbouring Montgomery County, and had standing as a local expert consultant on teaching methods for young children with autism. Egel pointed out that, as described in the draft document, many of the diverse methodologies, such as “normalized teaching methods” (meaning a developmentally appropriate approach to be taken with children in a classroom setting), were augmented by behaviourally based procedures. Others were actually behaviourally based, but not delivered using Lovaas style discrete trial methodology, programming and data collection methods. Perhaps unsurprisingly, Egel’s description which appeared in the finished document was similar to what the parents had written. Egel also recommended that if the school system wished to provide a Walden-style programme, they should bring in McGee from Emory as consultant and trainer.

## ***Off the Table***

While these negotiations were going on, for many parents nothing had changed regarding the adversarial climate they encountered at meetings with school staff. Parents of several children aged 2-3 and newly diagnosed with autism had started effective home-based A.B.A. programs and requested support from the school system, especially the use of discrete trials, as part of the Multiple Intense Needs programme. Such requests were routinely denied. Others expressed concern that the programme was not effective since, in the absence of more rigorous teacher training in new techniques, the new programme did not meet the children's needs any more than what it was designed to replace.

This placed us in a difficult position. On the one hand we were having ongoing, cordial negotiations with the very people who were denying to our constituents the services we were advocating. On the other hand, the behaviour of the school administrators removed any confidence that they would introduce any of our proposed programming ideas into the service model. Rather, it seemed that they were planning to institute their programme irrespective of our input, and parents unsatisfied with this would have the usual legal redress. If this was the final result, our whole initiative would be counterproductive in the long run. Under their proposal, some but not all children would receive more intensive programmes, and we believed that, in practice, these would be the children whose parents either were or could hire effective advocates. Even some of those families would only secure what their children needed after Mediation or Due Process challenges. The enhanced programme would be harder to challenge also, in part because the HCPSS could claim our endorsement. The Board of Education would not review its special education programmes for children with autism for a long time, and all possibility of obtaining our goal through public advocacy would be extinguished. In short, legal battles would rage, and children would continue to be denied the most effective services.

Also in the fall, the Board of Education offered to parents a less formal opportunity to meet with them and discuss matters of concern. These took the form of "coffee and conversation" sessions in which citizens were invited to open meetings with Board members. One of these sessions was attended by Anne Long and Leslie Brooksby, who asked the Board again whether they intended to provide A.B.A. services. The Board members said that they had been told that A.B.A. programs would cost about \$60,000 per child. Anne and Leslie informed them that the C.S.A.A.C. option, sanctioned by the State Education Department as a non-public placement that administered A.B.A. home programs, cost just over half that sum; that none of the parents they were aware of had paid that much to run a home base A.B.A. programme; and that our negotiating team's cost estimates, now based on some real numbers, fell far short of that sum. The Board also requested that we write to them, we believed in confidence, explaining how we really felt about the paper we were presenting and whether it would achieve the goals we sought.

This conversation redoubled the Board's efforts to find the truth about the economics of discrete trial programmes and to investigate why the staff still seemed so resistant to what many parents had found to be extremely effective with their children.

## ***How to Deal with an Impasse***

By early December, it was clear that parents and school system had not agreed on a new service model. The school negotiating team had modified their model. It now included full day services for some children of kindergarten age, and it included the hiring of home intervention specialists to work with families in the home or at school for a small number of hours per week. However, it did not promise an intensive programme for the majority of children. We thought that the incidental

teaching model had much merit in principle, although there were fewer studies demonstrating its effectiveness. If, however, the staff were not adequately trained in developing the incidental learning opportunities on which the programme depended, it would continue to be little different from what it was to replace apart from, perhaps, a modest increase in hours and some modifications to the classroom. There was no provision for staff training in the new plan other than the “train the trainer” model, by which administration staff would hold in-house training programmes to pass on knowledge gained elsewhere. We urged them to hire professional trainers and bring them in as consultants into the county schools. Finally, there was still a heavy onus put on parents to supply 10 hours of intervention themselves, which for some children would be the majority of the time. Placing the burden of implementing the kind of intervention proposed on a family likely in crisis, and with other children to take care of, had never been recommended by any authority on autism. Our proposal consisted of a scheme for incorporating large blocks of discrete trial therapy during full school days for many children, with classroom time built in to develop generalization. Training would be provided, like many parent run home programmes, by coaching workshops with professional consultants. We saw our programme as augmenting the service options provided by theirs, but in retrospect they may have seen our proposal as designed to be a replacement.

In the fall it had been announced that McGowan would be retiring at the end of January 1998, and thus we would have to finish our work by December. A presentation date at the Board of Education was set for mid-December, and later postponed to January 8<sup>th</sup> to allow additional time to finish the design of a service model.

Apparently, however, the school team were determined that the paper contain “data” that cast A.B.A. programmes in a poor light. In early December they presented to us for inclusion in the paper material that purported to show that the A.B.A. programming from their experience would be less effective than their offerings. The argument was that, of the children in the county who had undergone discrete trial teaching as young children, all still had individual aide support in the classroom in higher elementary school grades, while children in the school programmes did not. We argued that, first of all, many of the older children were profoundly autistic and would have needed individual support whatever they had received; and further, children who had undergone discrete trial teaching often had parents who were strong advocates who had ensured that the school kept an aide with them. Finally, no reference was made to the relative functioning levels of the children in either group.

We refused to sign our names to any document containing what we saw as disinformation. Thus it was decided to split the paper into two presentations. The first, henceforth to be referred to as the “White Paper, Part I” would be given at the January 8<sup>th</sup> Board meeting, and would contain the description of autism, of the HCPSS current programme, and of the teaching methodologies. The second would present the service model later in the spring, and would either be a joint presentation or two separate presentations depending on whether we came to agreement in the meantime. We were not sure at this point whether we had achieved anything really significant, but thought that the joint document we were to present contained a useful resource for both parents and teachers.

We had now been working with the schools for 15 months with no sign of achieving our original goal. Parents requesting A.B.A. or extended service hours still faced hostility; and we were about to appear in public in what appeared to be a collaborative relationship with the school system. We felt it was necessary to tell parents what was going on behind the scenes and to reassure them that we had not lost sight of our original goals. So, in a letter to parents encouraging them to attend the presentation, we gave our assessment of the situation as it was. We also had the impression from the “coffee and conversation” session that the Board had requested a frank assessment of our views. We thus wrote to the Board detailing our problems with the negotiations and with what still seemed to be inadequate service levels and insufficient staff training in the proposals we had seen to date.

Clearly also, attitudes had not changed sufficiently to remove the adversarial attitude and the future potential for legal action.

On the surface, the presentation was cordial, and the paper was well-received by the School Board. Over thirty families responded to our letter by turning out to hear the presentation. Many of them stayed afterwards, giving us an opportunity to gain input into the next steps in the process. However, the Board did not see our letter as confidential, and the school system administrators indirectly received copies of both letters. Needless to say, they were most displeased. Partly because of these letters, and also because both sides needed a break, meetings ceased until late January, after we were to meet with McGowan's successor, Sandra J. Erickson.

## **White Paper, Part II**

The first meeting with Erickson proved disappointing, although there were still faint grounds for optimism. At this meeting, we stated that we were looking for a framework of methodology under which intervention should take place: for example, if the basic teaching method used discrete trials, then other techniques (e.g. sensory integration, incidental learning techniques among typical peers) could be easily included in the schedule. We could not see how their eclectic approach could work in practice without a "backbone" based on an existing tried and tested programme. Erickson seemed to agree that this viewpoint should be explored, and directed us to produce a sample framework, which we provided in late February. During the meeting Brown also brought up the "data" that we had found objectionable in December, which Erickson dismissed more or less summarily as flawed.

Erickson told us clearly that she did not intend to supervise or mediate between us. She wanted us to go away and write a collaborative service model, or two if we could not agree, and bring it back to her for hers and the Board's review. We felt that we were now on our own, without guidance from the senior administration. But at least a fresh mind was, if not coming to the table, somewhere in the background, one that would consider our submissions without prejudice. But when would it be appropriate to involve her again?

There were two or three more meetings. Now attending were Hickey, Brown and Cynthia Johnson, also from the instructional support team. The parent team was comprised of Dorman and Long, who were joined by Shafley. Since we were still arguing about how to decide which was the most appropriate methodology to use in teaching an individual child, we proposed that this be done as part of an extended diagnostic process. Since the White Paper, Part I had now "blessed" discrete trial teaching as within the spectrum of services provided, we could not see any valid educational reason why it should not be tried. Given that their approach involved selecting among many methodologies to teach particular skills, we asked how they would select a particular methodology. Since there was no answer other than teacher's intuition, we suggested that they consider documenting how and when they selected teaching methods. Of course, our suggestions had a partly rhetorical intent, but they also were questions that were hardly unreasonable given the parameters of the programme the school staff were proposing. They were also questions that had well-defined answers for the kind of programme we were advocating.

### ***Endgame***

On the last day of March 1998, Brown presented us with the latest draft of their proposal for our review and assent. We gained the impression that if we were going to have any say in the contents of the collaborative paper it would at best be included in an appendix. Worse, this proposal was

virtually indistinguishable from the one we had rejected in early December. It contained no reference to the substance of any of our discussions since that time.

Meanwhile, away from the table relationships between the schools and parents requesting A.B.A. or extended services hours had, if anything, become worse. All during the previous year we had been listening to reports that came in through the HCC-ASA support line of denied A.B.A. services. There were two or three Due Process cases, and a number of requests for referrals to special education lawyers and advocates. We had also received various descriptions of the tactics of lawyers representing the HCPSS that we felt were inconsistent with the actions of a public agency, and wondered aloud whether the Board of Education truly knew what was being committed in their name. We kept silent about all of these matters during the negotiations, in order to keep the hope of final success alive. When one parent gave us a copy of a letter which appeared to us to quote the White Paper, Part I as supporting a denial of A.B.A. services, we felt we had to act.

At the following meeting, we told the school team that we would no longer be prepared to be part of the process unless the school administration undertook to cease and desist from dissuading parents from A.B.A. programs. We expected that they would never give such an assurance, for we felt it was time to appeal to the higher levels of the school administration. When they did so refuse, we walked out. We wrote to the Board of Education explaining that we had “lost confidence in the integrity of the collaborative process” and would be presenting to them our own separate proposal.

## **Resolution**

It was Sandra Marx who broke the impasse. Explaining that she wished to restart the process, she called Dorman a few days later, asking whether this was possible. Dorman replied that our overriding concern was that the programme needed fundamental change, including an expansion of service hours in line with our original request, removing the burden on parents in delivering intervention services, and the incorporation of discrete trial teaching into the service model as appropriate. She arranged a meeting with Erickson, at which we were to present a list of our concerns and programme suggestions. Erickson promised to assess our input and make a final decision as to what the HCPSS would propose in a new continuum of services plan to present to the Board.

In early May the County Council was deliberating the Howard County budget and was due to hold a public hearing into the fiscal year 1999 HCPSS operating budget. There was intense public interest. Superintendent Michael Hickey had proposed a significant increase in the budget, given that the economic situation in the county was now much improved and the previous years of austerity had not allowed for new programmes. The County Executive had proposed significant cuts in this operating budget, and under the Howard County Charter, the Council had the authority to restore the cuts. About 800 people attended and gave their input to this meeting. The public was nearly unanimous in support of the Superintendent and the Board of Education, who had publicly expressed deep displeasure at the Executive’s action. Our group of parents also gave testimony in strong support of the Board. Outside the meeting, Dorman encountered Superintendent Hickey, who greeted him and promised that we would see a change in attitude from their side. This was a strong hint that we had essentially won the battle. It implied that the Board of Education and the senior administration were all pressing the special education administration to endorse our programme proposals in some form.

By the time we met with Erickson a few days later, the school plan had been extensively revised. The difference in service hours between our two proposals had narrowed considerably, and the school proposal budgeted an increase in the funding for the program from the previous fiscal year (FY98) total of \$470,000 to almost \$1m in FY99, rising to over \$2m in FY2000. The parent-

delivered hours were no longer counted as part of the total frequency of services. Erickson had considered our arguments, and not only decided in our favour, but also apparently decided that now was a time to make unilateral decisions that would gain the confidence of parents and attempt to roll back the adversarial environment that had developed. We were asked at this meeting about various ways of implementing A.B.A. programmes, and the possibility of administering them through C.S.A.A.C., as done by other Maryland counties, surfaced as an option if the county schools could not provide A.B.A. in-house.

Erickson had requested that we present a full proposal to the Board in early June, and was to request a final decision from the Board on the new service continuum within two weeks. The plan we devised, “Early Intervention for Young Children with Autism, Part II – Parent Proposal” was duly presented. It focussed on four key issues:

- The creation of an open, collaborative, “user-friendly” process in which parents feel themselves a full part of their children’s education
- The definition of an appropriate level of services with guaranteed intensity.
- The use of successful intervention strategies including a commitment to fund discrete trial interventions
- The need for external guidance to and training for the program in the form of consultants from a nationally recognized autism program.

Our proposal suggested that the plan offered by the schools be implemented, but the number of children served be scaled back to allow some of the budget to go toward A.B.A. programmes. It added a detailed plan we had written using information gained during the negotiations for implementing a discrete trial teaching programme within the school, to operate side by side with the MINC programme at the same centres. It proposed committing \$35,000 for hiring professional consultants to come to Howard County to coach the staff in behaviourally-based methodologies, which was adopted in the school plan also. Further, it contained detailed suggestions on how to improve the confidence of parents in the special education process, and how to collect meaningful data on the outcomes of the programme. The proposal is available on the Web at [http://members.home.net/ben.dorman/hccasa/white\\_paper\\_2.pdf](http://members.home.net/ben.dorman/hccasa/white_paper_2.pdf).

At the presentation to the Board of Education, the special education administrators were asked for, and gave, a commitment that A.B.A. programmes would henceforth be supported by the HCPSS. Steven Bounds, now Board Chair, took the lead in questioning the special education staff. He commented that it was clear from what he had read that behaviourally-based intervention in some form was key. He said that it was clear also what type of services our plan comprised, but less so for the school proposal. He requested that we prepare a side by side comparison of the two programmes, and that the school administration highlight points of agreement and disagreement still present. Thus Bounds, whose ascendancy as Board Chair with fiscally conservative leanings we had feared, appeared to be our strongest advocate in the highest position.

Erickson directed her staff to study the feasibility of our plan. They determined that we had underestimated the costs, and as written would required an even greater budget request when fully operational in FY2000. Instead, she guaranteed that parents would be able to secure funding from HCPSS for A.B.A. programmes through C.S.A.A.C., as other counties were doing. We accepted this compromise, because it granted us everything we had requested apart from the guarantee of a teaching faculty fully trained and supportive of discrete trial teaching programmes. But we also felt that as more children who had received discrete trials entered the schools, A.B.A. would in time become a natural part of the early intervention services offered by HCPSS. The costs for the CSAAC programme were, because of state funding for non-public placement, actually *less* than the MINC programme, a fact Bounds pointedly noted.

In this form, with the MINC programme, the training budget, and the “C.S.A.A.C. option,” the plan won the unanimous approval of the Board of Education on June 25<sup>th</sup> 1998. In casting her vote, Vice-Chair Karen Campbell remarked that the Board’s role was to be responsive to parent input and to make the decision they thought in the best public interest; even though they could not satisfy all requests. But she encouraged us as parents to keep advocating for what we thought was best for our children, because that, after all, was *our* role.

## Conclusions

The object of describing our long and difficult negotiations here is not to point fingers at individuals about what seems now to be ancient history. Instead, we wished to give a sense to parent advocates that our persistent efforts did overcome stiff opposition, and thus give other parents advocates hope of achieving the same.

While our negotiations took place, the entire country was seeing a rapid rise in the number of diagnosed cases of autism, and also an increase in the number of legal challenges concerning the education of children with autism. As well, the reauthorization of the Individuals with Disabilities Education Act in April 1997, which passed the U.S. Congress nearly unanimously, emphasized the importance of parent input into the education of their children. Although the corresponding regulations were not issued until the Spring of 1999, the Act promised to put in place new measures for ensuring that special education achieved the result of granting children with disabilities the best possible chance for independence as adults. Also, no doubt an important factor, the economic climate in the late 1990’s was much more conducive to the initiation of new programmes than earlier in the decade.

The Board of Education showed responsiveness to parent input when it was delivered with factual information and backed up both by relevant research findings and videotaped documentation. Naturally there is no guarantee that similar policymakers elsewhere will be as responsive, but it seems fair to assume that a significant fraction would be. It seems a truism that, in the words of former Board Chair Sandra French, the Board of Education will always act on the advice given by its staff, in the absence of any other concrete information. In any school administration it is ultimately the responsibility of the policymaking body to set the policies of the special education department. Therefore, directing public advocacy efforts at those who are responsible for setting overall system policy offers the best hope of success in bringing about systems change.

Conversely, the immediate source of many parents’ frustration, i.e. the school staff most often encountered in their dealings over special education programming—even those representing the central administration—are not those responsible for setting policy. Thus they are not directly responsible for the parameters under which they are required to operate, although we as parents may sometimes take serious issue with the manner in which staff perform their administrative duties. The Board, however, could not discharge its policy responsibilities without a concrete proposal on which to make a decision, and thus could not be blamed for denying parents’ requests for improved services. In the normal course of events such a proposal would come from staff, although in our case, parent advocacy gave the Board pause to admit the possibility of a different viewpoint. Perhaps it happens often that those staff most likely to be charged with the responsibility of writing such a proposal are unable to see beyond the parameters of their everyday duties, which are to apportion

limited resources to children with great needs<sup>8</sup>. If so, then parent advocacy must play a crucial part if system change is to come about.

Our negotiations represented an opportunity to change the way the system operates, but the school staff, perhaps because of our clear philosophical differences over methodology, appeared to be unable to treat the situation much differently from that which they faced in the normal course of their duties. Perhaps also it is simply not (yet) in the culture for school systems to accept detailed input from parents such as we provided. To be sure, parents often also seem stuck in the same inability to see beyond the situation they are faced with in dealing with special education services. They may be informed about rights at I.E.P. meetings and the available legal recourses, but are unable to see how to work constructively for change when binding Due Process proceedings appear to be the only recourse to solve their individual difficulties. However, judging by the large number of accounts of poor relations between schools and parents of children with autism we have seen from across the country, few parents are given the opportunities and access to the school administration that we slowly developed over time. We think that school districts that demonstrate a real will to involve parents in a truly collaborative process to design new service models may often find that some of their more “troublesome” parents can be important allies.

From the beginning of the process onward, sometimes by trial and error, we developed a set of rules and strategies for effective negotiation. We offer these in closing.

- Keep focussed on influencing those with real decision making power. Additionally, try to determine who has the ability to think “out of the box” within the school system. Even if this person does not have decision making power, they may regularly speak to someone who does.
- Be prepared for a long haul. System change rarely happens quickly, if only because writing workable proposals is a detailed task.
- Advocate for the most radical agenda that is supported by a consensus of the literature. In our case, this meant leaving methodology considerations to one side and pressing for intensive services.
- Put it in writing. If you have an agenda for a meeting, type it up and distribute copies, even if they also have an agenda. Good manners will usually ensure the adoption of a joint agenda. Also, writing the agenda is an important step towards controlling it: you can be sure that this one will be used against you if you are not so prepared.
- Also, provide written materials expressing your position. In meetings these give the participants something concrete on which to base discussions, and so increase the likelihood that your issues will be those discussed in detail.
- Be open-minded. It is just possible that the position advocated by the other side has merits you were not previously aware of. If this is the case, suggest solutions that incorporate both sets of programming options. If you feel that this is not the case, be prepared to justify your reasoning with evidence [documentation, research studies].

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<sup>8</sup> As an aside, during our negotiations we developed a measure of sympathy and understanding for service coordinators who have to deal with this unenviable task on an everyday basis.

- Read the literature about the topics you are debating. Further, *read the sources cited in that literature* where they clarify points at issue. This will give you a deeper understanding of the issues in question as well as help you to anticipate possible objections to your stand.
- Consider what future actions are politically and psychologically possible. Suggesting that the other side drop everything and do as you suggest will invariably get you nowhere.
- Listen to what the other side is saying, and respond with paraphrases or questions. The chances are then better that they will in turn listen to you. Also, if they don't, the contrast will be all too obvious.
- Build upon areas of agreement and stress your intent to collaborate.
- Get to know the way the school system operates. It is difficult to work towards a program solution without some idea of the practicalities. Also, doing so entails collaborating with school personnel in a way that might become productive.
- Support the school system in every way possible about issues that do not conflict with yours. Advocate publicly for special education; you should see yourself not as an adversary but as a loyal opposition. In our case, as well as giving public testimony in support of school budgets, we wrote letters of support for the original MINC programme pilot. The object here is not to be effusive in order to win political capital. Rather, acting in support of special education is *always* in the best interests of your children, even if you don't like some of the school system's current policies.
- Negotiate in good faith, and grant the other side the courtesy of assuming that their actions are also designed to be in the best interests of the children.
- Don't assume that if you have been bested about an issue, that it can't come up for rediscussion. Think carefully about the last arguments you had, read more if necessary, and bring the issue back to the table until you reach an acceptable compromise. Sometimes, you may need to concede on matters of secondary importance and move on.
- Don't bother to defend your position on an issue unless it's actually challenged—in the worst case, you may expose a weakness or raise an objection to your position that had not previously occurred to the other side.
- Don't waste time insisting on consensus among your fellow parents. Bearing in mind all the above, you can't proceed to negotiate by holding the most extreme viewpoint—and those parents who do tend to the extreme have an important role in making you look moderate.
- Never descend into personal attacks. If you must criticize, do so obliquely "...these actions give the impression that..." This allows the other side to address those issues without getting defensive.
- Never threaten. Chances are your bluff will be called; school system people deal with what they regard as difficult parents all the time.

## Afterword

Since implementation of the plan started in the fall of 1998, Sue Brown and others in the county Office of Special Education have been instrumental in bringing about a sea change in the relations between parents and school staff. The HCPSS has made meaningful efforts to bring in consultants in collaboration techniques to help teachers, parents and administrators forge collaborative relationships. New documents have been written to assist in students' transitions from infants and toddlers to preschool programmes, and from kindergarten to first grade. The schools have asked parents to participate in presentations to staff about effective collaboration between school and parents. Parents were well-represented on a task force set up during 1999 to define programming for children with intense needs in elementary school.

HCPSS administrators and parents are represented on the Maryland State Department of Education's Task Force on Young Children with Autism, which is developing guidelines for local education agencies. The county Office of Special Education worked with parents to produce a new Strategic Plan for Special Education, and has recently issued a new, comprehensive set of policies and procedures. In the fall of 1999 Sandra Marx and Sandra Erickson held open focus groups for parents of all special needs children giving them the opportunity of expressing further concerns and suggestions for improved service delivery.

Of course, not everything is perfect. But it is greatly improved. The HCC-ASA information and referral line is now used more for resource referral than for receiving complaints. In the first six months after the new service plan was adopted, there were no new requests for mediation or Due Process, and no filings have been made concerning the provision of A.B.A. programmes or requests for intensive services. Also, during the 1998-9 school year, about 13 children were placed without difficulty in A.B.A. programmes.

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