



***Early
Intervention
for
Young Children
with Autism***

***Part II:
Parent Proposal***

A Report to the Board of Education
by the Howard County Chapter
of the Autism Society of America



June 1998

Early Intervention for Young Children with Autism Part II: Howard County Autism Society Parent Proposal

June 1998

Authors: Ben Dorman and Anne Long, with assistance from:

Darren & Leslie Brooksby, Michael & Betsy Dooley, Valarie & Namso Dunbar, Steven Fine, Catriona Johnson, Leon & Claudia Igras, Robert McGillicuddy, Cheri Meiners, Paul Sesto, Sue Anne Shafley, Judy Terle and Steven Wampler.

Table of Contents

Table of Contents	i
Executive Summary	iii
Cost Estimates for Parent Proposal	vi
Parent Recommendations for the Autism Service Continuum	1
<i>Introduction and Motivation</i>	1
<i>Integrity of Services</i>	4
<i>Intensity of Intervention</i>	7
<i>Infants and Toddlers vs. Preschool/Kindergarten</i>	7
<i>Identification and Evaluation</i>	8
<i>Evaluation of Students</i>	9
<i>Program Evaluation</i>	10
<i>Continuum of Services</i>	11
<i>Infants and Toddlers Program</i>	14
<i>Preschool and Kindergarten Programs</i>	15
<i>Summer Services</i>	15
<i>Routines-based family intervention</i>	15
<i>Staff Development</i>	16
<i>Consultants</i>	19
Appendix A: The Case for Intensive Early Intervention	A-1

Early Intervention for Children with Autism – Part II: Parent Recommendations

Appendix B: Brief Description of A.B.A. Programs	A-5
<i>Behaviorally-Based Intervention</i>	<i>A-5</i>
<i>Discrete Trial-Based Programs</i>	<i>A-5</i>
<i>Flow Chart: The Early Stages of Learning in an ABA Program</i>	<i>A-8</i>
Appendix C: The Maryland Autism Waiver	A-9
Appendix D: A Critique of Current Classroom Practices within the Multiple Intense Needs Program	A-10
Appendix E: Critique of “Guidelines for Referral to a Multiple Intense Needs Class for Toddlers”	A-14
Appendix F: Outline of a Collaborative Initiative	A-15

Executive Summary

Introduction

The object of this statement of continuum of services is to propose a framework under which children with characteristics of autism or a diagnosis of autism (including PDD/NOS) will receive appropriate services that are acceptable to both parents and school system. Under this model, schools will have the freedom to recommend all services within the framework that fall within these guidelines.

In making the following recommendations to the Board of Education for the provision of appropriate services, we concentrate on four issues, as follows:

- **The creation of an open, collaborative, “user-friendly” process in which parents feel themselves a full part of their children’s education (Integrity of Services)**
- **The definition of an appropriate level of services (Intensity of Services and Continuum of Services; Program Evaluation)**
- **The use of successful intervention strategies (Multiple Intense Needs Programs and Discrete-trial based Applied Behavior Analysis Programs)**
- **The need for external guidance to and training for the program in the form of consultants from a nationally recognized autism program (Staff and Parent Training)**

Integrity of Service Recommendations

Process

Establish procedures that:

- a) ensure that services included in the continuum of services are recommended appropriately. Procedures guiding the continuum of services must
 - contain criteria for intervention intensity and methodology that are open to objective assessment
 - allow the possibility of meaningful external input from both parents and professionals into placement decisions
 - allow for a dispute resolution process that is invoked before the statutory rights of Mediation and Due Process
- b) give staff at individual schools the freedom to recommend services within the continuum as defined based on the needs of the child.
- c) ensure that both parents and school system personnel responsible for the education of children with autism are fully aware of policies issued by Central Office.

Early Intervention for Children with Autism – Part II: Parent Recommendations

- d) the process by which placement decisions are made for individual children is open, and takes place within the context of an A.R.D. meeting, in which parents are regarded as full participants.

IEP Goals

To accomplish the goal of providing challenging educational programs we propose the following:

- I.F.S.P./I.E.P. goals be drawn from an approved developmental checklist or other relevant documents.
- Both parents and school staff have access to the appropriate documents during the planning phase of the program

Continuum of Services

We propose that the service continuum comprises:

- Multiple Intense Needs (MIN) model classrooms
- inclusion in R.E.C. center special education classrooms with additional discrete trial therapy hours (“Extended Inclusion”)
- the option of home-based intervention for children with IFSPs
- home visits
- summer services for all children in the program.

In addition, we give a number of reasons why it is advantageous to place the MIN and Extended Inclusion models at the same site.

Intensity of Services

The recommended frequency of services for children with autism is

- At least 20 hours/week of intervention for children with I.F.S.P.s
- Full day (32.5 hour/week) programs for children in preschool and kindergarten.

Small variations from these service levels are possible for staff training, home visits and parent interviews.

As to intervention quality, staff, instructional assistants and aides will undergo the training program proposed below. The recommended staffing level for the program is

- Children with I.F.S.P.s will require 1:1 aides for their intervention hours.
- Children in MIN classrooms will have 1:1 aides as appropriate. The MIN model classroom will be staffed as recommended in the HCPSS proposal.

For children receiving discrete trial-based programs in preschool and kindergarten, the basic model of intervention is

Early Intervention for Children with Autism – Part II: Parent Recommendations

- 12.5 hours of inclusive classroom instruction
- 20 hours of discrete trial therapy.

For all children, the parents will be encourage to supplement the service hours with 10 hours of routines-based intervention in the home.

For children with I.F.S.P.s the service continuum should include the home as a primary site for intervention. A possible way of implementing such programs is through the CSAAC Intensive Early Intervention Program.

Staff and Parent Training

Frequent concerns of parents in the area of staff development are the level of knowledge and expertise that their child’s educators have; and the discrepancy of knowledge between various educators.

We propose a training model that features:

- **Training in behaviorally-based methodologies**
- **Providing personnel with hands-on experience in using techniques**
- **On-going training opportunities supervised by specialists**
- **Inclusion of parents in training opportunities**

Evaluation of Children

Children who are suspected to have autism should receive evaluations that

- provide an autism checklist
- assess the developmental level of the child
- attempt to determine which will be the effective educational approaches for that individual child. This may be done by testing possible intervention strategies as part of the diagnostic process.

Program Evaluation

The program should be evaluated under four distinct criteria, as follows:

- **Simple Inventory** — creating a simple database on the number of children and the intervention provided, including intensity and teaching strategies at each age
- **Staff Training** – the level of training of staff working with children with autism
- **Learning Opportunities**— documentation of number of opportunities for teaching, an important potential outcome indicator
- **Outcomes**– the outcomes achieved by children based on developmental goals and behavioral improvements.

Cost Estimates for Parent Proposal

We have attempted to provide an estimate for the costs of the services we recommend. The sample budget *arbitrarily* assumes an equal division of children in the Multiple Intense Needs model classrooms and in the extended inclusion (discrete trial-based) model. Our proposal can be seen as reducing the budget for MIN classrooms and explicitly including the costs for children served through existing R.E.C. programs.

We have assumed the same number of children requiring intensive intervention as in the HCPSS proposal: 40 children to be served in FY1999 (16 Infants and Toddlers; 24 Preschool/Kindergarten) and 64 in FY2000 (24:40). The budgets for related service professionals (Psychologists, SLPs etc) are identical.

Note that for FY1998 the stated program costs for children with autism in either proposal do not include the costs incurred by HCPSS for children outside the MIN program.

For completeness we have compiled the costs of the HCPSS proposal on the accompanying spreadsheets, with a couple of minor modifications for items that appear to be typographical errors (behavioral specialist FTE, FY1999 for infants and toddlers; cost of family intervention staff for FY2000).

Our budget for summer services is worked out explicitly on an accompanying sheet. It will be seen that for FY2000 our estimates are similar. However for FY1999 the figures provided in the HCPSS proposal seem arbitrarily low; we expect that these numbers correspond to grant proposal requests for funding for these services rather than the true costs. Given the similarity of our year 2000 figure to theirs, the HCPSS program cost for FY1999 must also be similar if the services are of the same intensity.

We have not taken into account in the budget the possibility that some services may be provided through CSAAC's home-based early intervention A.B.A. program. We understand that the annual cost for this program is approximately \$32,000. Under the forthcoming Autism Waiver, this cost would be subject to a 50% match from Federal funds for eligible children.

Finally, a note concerning the costs of training. As stated in the "Staff Training" section, we propose 35 consultant days for experts from a recognized autism consultancy to give intensive hands-on training to staff. To deliver the quality of training we seek, we expect 3-4 professionals to be engaged for a week each in the first year, ensuring a low professional:teacher ratio in the training program. The other consultant days will be used for regular follow-up training sessions by the consultants which will also involve hands-on training and potentially discussion of individual cases. During the two-week training course proposed, therefore, the hours required of HCPSS staff development personnel as presenters would be roughly half of what is in the HCPSS proposal. We have not budgeted any change in the staff development line item, although it may be necessary to increase the budget for training of temporary aides. We also endorse the HCPSS proposal to provide small stipends to parents attending the training workshop.

Services For Young Children with Autism - HCPSS Proposal

Direct Intervention through school year

Current FY98										Total
Multiple Intense Needs Classes		Teachers	Instructional Assistants	Temporary Employees		SLP	OT	Psychologist	Behavioral Specialist	
		FTE	FTE	rate/h for 36 wks	No.	Hrs/Wk	FTE	FTE	FTE	FTE
Item Cost		\$39,150		\$360			\$45,525	\$45,550	\$61,320	\$39,150
Infants & Toddlers		2.0	1.0	\$14,200	4.0	14	\$20,160	\$22,775	\$3,066	\$1,958
Preschoolers		3.0	3.0	\$42,600	4.0	20	\$28,800	\$34,163	\$3,066	\$1,958
\$425,401										

Proposed FY99										
		rate/h			rate/h			rate/h		
		No.	Hrs/Wk	No.	Hrs/Wk	No.	Hrs/Wk	No.	Hrs/Wk	No.
Item Cost		\$39,150		\$14,200	\$360	\$45,525	\$45,550	\$61,320	\$39,150	
Infants & Toddlers		3.0	1.5	\$21,300	6.0	15	\$32,400	\$68,288	0.75	\$34,163
Preschoolers		6.0	6.0	\$85,200	12.0	25	\$108,000	\$136,575	1.50	\$68,325
\$978,627										

Proposed FY00											
		Bs R/h		\$360		\$360		\$360		\$360	
		No.	Hrs/Wk	No.	Hrs/Wk	No.	Hrs/Wk	No.	Hrs/Wk	No.	Hrs/Wk
Item Cost		\$39,150		\$14,200	\$360	\$45,525	\$45,550	\$61,320	\$39,150		
Infants & Toddlers		6.0	3.0	\$42,600	12.0	15	\$64,800	\$136,575	1.50	\$68,325	1.00
Preschoolers		10.0	10.0	\$142,000	20.0	25	\$180,000	\$227,625	2.50	\$113,875	2.00
\$1,817,762											

Summer Services and Training - HCPSS Proposal

Summer Services and Staff Training							Current FY98	Total
Multiple Intense Needs Classes								
	Combined Summer Costs	Family Intervention & Support Teachers	Family Training Stipend	Professional Development	Presenter Stipends	Consultants		
Item Cost			FTE					
Infants & Toddlers	\$17,880						\$17,880	
Preschoolers	\$14,554						\$14,554	
Combined Cost	\$8,000			\$8,400	\$3,600	\$3,000	\$23,000	
Total							\$55,434	
Proposed FY99								
		\$39,150		\$150				
Infants & Toddlers	\$17,880						\$17,880	
Preschoolers	\$23,200						\$23,200	
Program Cost		1.5	\$3,000	\$23,040	\$4,800	\$15,000	\$104,587	
Total							\$145,667	
Proposed FY00								
		\$39,150		\$150				
Infants & Toddlers	\$76,120						\$76,120	
Preschoolers	\$123,400						\$123,400	
Program Cost		2.75	\$6,000	\$23,040	\$4,800	\$15,000	\$156,545	
Total							\$356,065	

Services For Young Children with Autism - Howard County ASA Proposal

Direct Intervention through school year												
Current FY98												
MIN and REC Classrooms												
	Teachers	Instructional Assistants	Temporary Employees	SLP	OT	Psychologist	Behavioral Specialist					Total
	FTE	FTE	Base rate/hi for 36 wks	FTE	FTE	FTE	FTE					
			No. Hrs/Wk									
Item Cost				\$45,525	\$45,550	\$61,320	\$39,150					
I & T - MINC	2.0	\$78,300	4.0 14	\$22,763	\$22,775	\$3,066	0.05	0.05	0.05	0.05	\$1,958	\$163,221
Pre-K MINC	3.0	\$117,450	4.0 20	\$34,144	\$34,163	\$3,066	0.05	0.05	0.05	0.05	\$1,958	\$262,180
see notes												
												\$425,401
Proposed FY99												
			Base rate/hi	FTE	FTE	FTE	FTE					
			No. Hrs/Wk									
Item Cost				\$45,525	\$45,550	\$61,320	\$39,150					
I. & T. - MINC	2.0	\$78,300	4.0 15	\$21,600	\$21,600	\$18,396	0.30	0.30	0.30	0.05	\$1,958	\$236,904
I. & T. - Inclusion/ABA	0.0	\$0	4.0 20	\$28,800	\$28,800							\$114,100
Pre-K MINC	3.0	\$117,450	6.0 25	\$54,000	\$54,000	\$18,396	0.30	0.30	0.60	0.60	\$23,490	\$460,836
Pre-K Inclusion/ABA	0.0	\$0	3.0 32.5	\$35,100	\$35,100							\$35,100
additional 1:1 aides			9.0 20	\$64,800	\$64,800							\$64,800
												\$911,740
Proposed FY00												
			Base rate/hi	FTE	FTE	FTE	FTE					
			No. Hrs/Wk									
Item Cost				\$45,525	\$45,550	\$61,320	\$39,150					
I. & T. - MINC	3.0	\$117,450	6.0 15	\$32,400	\$32,400	\$36,792	1.00	1.00	1.00	1.00	\$39,150	\$473,292
I. & T. - Inclusion/ABA	0.0	\$0	12.0 20	\$86,400	\$86,400							\$192,450
Pre-K - MINC	5.0	\$195,750	10.0 25	\$90,000	\$90,000	\$113,875	1.00	1.00	2.00	2.00	\$78,300	\$837,870
Pre-K Inclusion/ABA	0.0	\$0	5.0 32.5	\$58,500	\$58,500							\$58,500
additional 1:1 aides			15.0 20	\$108,000	\$108,000							\$108,000
												\$1,670,112

Summer Services and Training - Howard County ASA Proposal

Summer Services and Staff Training							Total
Current FY98							
Item Cost	Combined Summer Costs	Family Intervention & Support Teachers	Family Training Stipend	Professional Development	Presenter Stipends	Consultants	
		FTE					
Infants & Toddlers	\$17,880						\$17,880
Preschoolers	\$14,554			\$8,400	\$3,600	\$3,000	\$14,554
Combined Cost	\$8,000						\$23,000
Total							\$55,434
Proposed FY99							
		\$39,150		\$150			
Infants & Toddlers	\$56,990						\$56,990
Preschoolers	\$74,900			\$23,040	\$2,400	\$35,000	\$74,900
Program Cost		1.5	20	\$3,000	\$2,400	\$35,000	\$122,187
Total							\$254,077
Proposed FY00							
		\$39,150		\$150			
Infants & Toddlers	\$93,900						\$93,900
Preschoolers	\$117,500			\$23,040	\$2,400	\$20,000	\$117,500
Program Cost		2.75	40	\$6,000	\$2,400	\$20,000	\$159,145
Total							\$370,545

Parent Recommendations for the Autism Service Continuum

Introduction and Motivation

The object of this statement of continuum of services is to propose a framework under which children with characteristics of autism or a diagnosis of autism (including PDD/NOS) will receive appropriate services that are acceptable to both parents and school system. Under this model, schools will have the freedom to recommend all services within the framework that fall within these guidelines. The Department of Special Education will monitor school compliance with the guidelines and will set up a process for resolving disputes between schools and parents.

Programs for children with autism need to be specifically designed to meet their needs in order to be effective. This is because children with autism

- a) do not in general learn *incidentally* (i.e. they do not necessarily pick up cues from their environment or make easy generalization from one circumstance to another);
- b) have social deficits that prevent them from *learning from peers*; and
- c) tend to perseverate (focus repetitively upon) on objects or activities. This leaves them *tuned out* for much of the school day unless redirected back to the subject at hand.

The parents who have participated in the Education Committee have found that the specific techniques of Applied Behavior Analysis, especially discrete trial therapy, can indeed address their children's need to *learn how to learn*, and therefore should be part of the program offered to children with this difficult disorder. This approach needs to be followed within the framework of a comprehensive program developed in consultation with a specialist in the field.

In making the following recommendations to the Board of Education for the provision of appropriate services, we concentrate on four issues, as follows:

- **The creation of an open, collaborative, “user-friendly” process in which parents feel themselves a full part of their children’s education.**

This will obviate or greatly reduce the need for time and energy spent by HCPSS administrators in overseeing the ARD process. It will also reduce the need for expenditure on litigation costs by both school system and parents.

Perhaps most important is that parents are already dealing with the day to day responsibility of caring for a child with a severe disability. A truly open, collaborative process offers the opportunity to form an alliance with the schools for their children's care and future *instead of what is currently all too often just another burden to overcome*. We list a set of measures designed to ensure this below under “Integrity of Services.”

- **The definition an appropriate level of services.**

There is widespread agreement in the literature that children with autism require education that is “intense.” Intensity refers here both to the number of intervention

Early Intervention for Children with Autism – Part II: Parent Recommendations

hours and the staff/student ratio. Intensive intervention requires a minimum number of quality intervention hours by trained professionals with an *average* (time averaged students per educator) staff/student ratio approach approaching 1:1. Appendix A reproduces some recent findings by State Task Forces and other writings on this issue.

Intensity of services also touches on the issue of summer services. Children with autism often need to be engaged educationally for the full year: the 11-week summer break often causes regression in skills; it can stymie the development of delayed though emerging skills; and it can have severe consequences for the child's development and for the effectiveness of the fall term. Also, the services provided need to continue to ensure progress towards the child's education. Parents' almost unanimous experience is that children with autism who are not challenged and engaged are likely to become bored, non-compliant, and develop potentially severe behavioral problems. Thus summer services for children with autism must be the standard approach rather than a separately determined service.

- **The use of successful intervention strategies.**

The intervention strategies outlined in Part I of this report (the White Paper report presented to the Board of Education on January 8th 1998) summarized a number of strategies that form a continuum of services. Many of the strategies described in that paper, including incidental teaching techniques and discrete trial intervention are based on methods of Applied Behavioral Analysis; an appropriate continuum of services should include all of them as appropriate for individual children. *It is our experience however that currently, discrete trial-based programs are actively discouraged by HCPSS administration staff, except in rare instances.* Parents' requests for discrete trial based programs are often denied even when strong indicators of its effectiveness — as well as advice from professionals — exists.

By the use of discrete trial intervention we do not mean the use of discrete trial methodology as an occasional technique to teach a particular skill. Rather, the demonstrated effectiveness of discrete trial intervention relies on an intense program in which the methodology is used for much of the day. For children who do not easily learn in a less structured group setting, this is the method of choice. The inability to function well in a group setting is a characteristic shared by many children with autism, at least initially. Based on the continuum of services, these children should have the opportunity of benefiting from a discrete trial based program. At present, the HCPSS Service Coordinators recommend only a very small number of children for discrete trial intervention. We submit that the criteria under which such programs are currently employed are too narrow, and their reluctance to recommend it is symptomatic of an irrational bias against its use.

Conversely, children whose progress is satisfactory in the group setting, should be educated by appropriate techniques (many of which are still behaviorally-based) in that setting. But what is meant by "satisfactory progress?" Logically, the standard to measure progress includes *objective criteria of the child's ability to learn key steps along the developmentally appropriate sequence followed by typically developing peers.* Currently it is measured against I.E.P. goals which may be drafted by school staff with low expectations of children's abilities. These I.E.P.s are often signed by parents who are

new to the diagnosis and its consequences, and are as yet unable to assess their child's capabilities.

We propose that the HCPSS introduce a regime of discrete trial based programming parallel to the Program for Children with Multiple Intense Needs. The details of the implementation will appear in the section on Continuum of Services.

We also suggest criteria and standards for when children's programs should be discrete trial-based. These suggestions allow the accountability for decisions that parents need. We stress that we do **not** argue for the provision of discrete trial based programs for all children. *However, such programs can and should be available where they show promise for success with individual children, and be offered without prejudice.* Since discrete trial-based programs are the single most serious omission from the current continuum, we emphasize their importance by describing their operation in detail in Appendix B.

- **The need for external guidance to and training for the program in the form of consultants from a nationally recognized autism program.**

The provision of quality intervention services for children with autism is an expensive proposition, and both this proposal and that offered by HCPSS administration staff entail significant increases in expenditure. However, even seemingly high consultant costs represent only a small proportion (under 4%) of the total intervention cost, which is dominated by staffing expenses.

There are a number of consultancies that have specific experience in working with school systems to provide appropriate services for all children with autism wherever they fall on the spectrum of the disorder. The providers we list work with schools to design a mixture of center-based and home-based intervention (depending on age-group), and stress inclusive education and the importance to children of generalizing skills learnt in a 1:1 setting to peer interactions and daily living in the home.

Additionally, as promised in Part I of the White Paper Report, we give some potential sources for funding the additional costs of the program. Two immediate possibilities exist:

Autism Medicaid Waiver Services: In April of this year, the Maryland State Legislature unanimously passed and the Governor signed HB99 requesting that the Dept of Health and Mental Hygiene apply to the Federal Health Care Financing Administration (HCFA) for a Waiver for autism services. The text of the bill is given in Appendix C. The waiver is to be submitted to HCFA in June and should be approved in October. Under this waiver, services for family training and education and home-based intensive programming for children with autism will be reimbursable up to 50% for eligible children, where the service is provided by an approved Medicaid participant.

The Maryland State Improvement Grant: Under IDEA 1997, States will compete for funds to assist in improving services for children with disabilities. The current Maryland State Education Department Newsletter¹ lists as major goals of the grant as "collection and analysis of student data, effective instructional practices and the preparation of personnel working with children with disabilities." The last of these may possibly provide funds for the training program. Three Howard County parents of children with disabilities currently

¹ *Special Education: Planning for the Future.* MSDE, May 1998.

sit on the State Special Education Advisory committee, which will have input into the Grant Proposal. This source is, however, currently only a possibility.

Integrity of Services

Integrity of Service refers to assurance that the *process* of deciding services for individual children is fair and that Best Practices as recommended by experts are available to children. To be sure, a number of the following suggestions already exist within the County. However, making them explicit and available to parents is a key element to building trust in the interventions offered. A frequent concern of parents is that school personnel routinely state that the services that they have decided upon are adequate and appropriate for a particular child. These statements are “based on professional opinion” that often seems arbitrary.

Another important point is that the *goals and objectives* contained within the Individual Family Service Plan/Individualized Education Plan (I.F.S.P./I.E.P.) determines the schools’ legal obligation for services. If the objectives of these plans are not sufficiently challenging then children will not be given the opportunity to learn at a rate “tuned to their abilities”. Months may slip by before the Plan is modified, if this happens at all. Important barriers to challenging I.F.S.P./I.E.P.s arise from parent’s initial inability to judge their children’s potential accurately, and often low expectations on the part of school staff.

We address each of these issues in turn.

Process

Procedures should be established that:

- a) ensure that parents are confident that the services included in the continuum of services statement are assessed carefully and recommended as necessary. The continuum of services statement must
 - give criteria for intervention intensity and methodology
 - include criteria that are open to objective assessment
 - allow the possibility of meaningful external input, from parents and professionals, into placement decisions
 - allow for a process external to the Service Coordinators to resolve disagreements between parents and schools other than the statutory rights of Mediation and Due Process
- b) staff at individual schools are free to recommend services within the continuum as defined based on the needs of the child without the presence of Central Office personnel.
- c) ensure that both parents and school system personnel responsible for the education of children with autism are fully aware of policies issued by Central Office.
- d) the process by which placement decisions are made for individual children is open, as required by the recent IDEA Reauthorization. Placement decisions are to be discussed and made in ARD meetings with parents present. Many parents either know or sense

Early Intervention for Children with Autism – Part II: Parent Recommendations

that these decisions are often made by HCPSS personnel at the school and central office levels prior to scheduled ARD meetings.

- e) collaboration between parents and school system personnel implies parents are regarded as equal members of the teams involved in the process. In particular, note that this does not require that HCPSS accedes to parental requests automatically, rather that parents feel that their input is treated with respect and due consideration.

We take strong issue with two provisions in the HCPSS proposal that are directly relevant to the Process. These state policy on Family Participation in the child's program and of Methodology.

Family Participation: After affirming the School System's belief in the importance of parent involvement in the development of programs for children with autism, the proposal gives no role to parents in directly planning the intervention. Instead, parents are to be involved in the evaluation and assessment process by providing relevant information, and in the planning process by "identifying priority areas" for planning and development.

The omission of a potential parent role in planning the program² is serious because it contradicts the statements made in the White Paper, Part I, and runs contrary to the intent of the I.D.E.A. legislation and the relevant Supreme Court decision, that of Board of Education vs. Rowley³. The decision stated that

It seems to us no exaggeration to say that Congress placed every bit as much emphasis upon compliance with procedures giving parents and guardians a large measure of participation at every stage of the administrative process ... as it did upon the measurement of the resulting I.E.P. against a substantive standard.

To paraphrase, it is as important to ensure parents are fully part of the process as it is to ensure that the I.E.P. contains measurable goals.

Methodology: We are in agreement about the appropriateness of various educational strategies for young children with autism. However, given the history of discord between parents and schools regarding discrete trial-based A.B.A. programs (expressed in the introduction to this proposal), parents need an explicit commitment to the use of discrete trial methodology as a primary intervention strategy where it is warranted.

The process of selecting methodologies from a list of possibilities could indeed be complex. However, nationwide there are many programs that use discrete trial teaching as a primary methodology. Staff with adequate training, and with appropriate professional guidance, integrate other strategies as necessary. We think that truly deriving each child's program "from first principles" when selecting from a range of methodologies what each child requires for each individual skill - the implication of the HCPSS proposal - is highly unlikely to occur in practice. Basing the intervention on an established framework and a scheme for using the teaching strategies available within that framework appears to be far more workable and desirable.

Parents also require a much stronger commitment on the part of the school system regarding input from themselves and from other professionals such as psychologists,

² Indeed this omission is so glaring that we must assume it was a mere oversight.

³ 458 U.S. 176. March 1982

Early Intervention for Children with Autism – Part II: Parent Recommendations

behavioral psychologist, doctors and other therapists. The language in the current proposal by HCPSS merely promises to “review” this information, whereas schools should be required to give both due consideration.

In closing, we understand the prerogative of school staff ultimately to determine the methodology to be used for a particular child. However, the object of proposing an expansion of services will not be met if parents feel that their input to the process is effectively ignored by school staff who do not render decisions without prejudice.

IEP Goals and Objectives

Goals and objectives for a child’s IEP, or IFSP as appropriate, are developed by the ARD committee, which includes as equal co-participants, the child’s parents. The goals and objectives in the IEP/IFSP serve a number of purposes:

- They delineate the expectations that an ARD committee has for a child
- They serve as a tool to measure those expectations
- They serve as a guideline to school staff members as to how best approach particular skills
- They serve as a commitment on part of the school system as to what skills and tasks will be worked on, and
- They are the main consideration when determining specific individualized education services

As such, it is crucial that ARD committee members carefully and thoughtfully develop a set of appropriate goals and objectives for a child. A frequent concern of parents is that school staff members of the ARD committee propose goals and objectives that do not sufficiently challenge their children either in their scope and breadth, and occasionally even reject parent attempts to amend the plan. Parents are generally concerned that school staff members frequently set their sights on levels of functioning for their children that are just too low—a concern also raised by the U.S. Congress in the preamble to the recent I.D.E.A. Reauthorization Act⁴.

This is not to say that parents feel that school staff members deliberately endorse insufficient goals and objectives. However, parents are concerned that school staff members do not fully understand the growth and development potential that individuals with autism can possess. Through educational advances individuals are attaining higher levels of functioning and independence than were thought possible only a decade ago. Advances in autism research continue to raise general expectations of what constitutes an appropriate education for children with autism. It is important that ARD committee members have the necessary expertise or receive the necessary training that will enable them to develop IEP/IFSP goals and objectives that reflect these advances.

To accomplish the goal of providing challenging educational programs we propose the following:

⁴ P.L. 105-17, §602. The I.D.E.A. Reauthorization was signed into law July 1997, and all of its provisions become effective by July 1st 1998.

Early Intervention for Children with Autism – Part II: Parent Recommendations

- I.F.S.P./I.E.P. goals be drawn from an approved developmental checklist
- Both parents and school staff have access to appropriate checklists during the planning phase of the program

If these recommendations are followed then parents will be enabled to select appropriate goals for their child and may help the school staff in selecting those skills most important to them.

Intensity of Intervention

Intensity of Intervention refers to:

- a) the frequency, in terms of total number of intervention hours (referred to below as “service hours” provided by
 - school system personnel: educators, aides, and therapists providing related services (e.g. speech/language pathologists)
 - family intervention hours, delivered by family members of the child with autism under guidance from the schools and other professionals
- b) the quality of the intervention, referring to the staff student ratio and the level of training of the staff.

We feel strongly that given the available evidence and advice from professionals, the levels of service we propose below for Intense Needs cases should be standard operating procedure, with exceptions if necessary for any reason. Children with less severe deficits are still children with autism, whose future independence is possible with sufficient early intervention. Their needs are for intensive programs using teaching strategies that allow skill acquisition at the pace of which they are capable.

Adopting such a continuum of services model will remove the onus on parents to fight for additional services when they are perceived to be necessary, and avoid the needless waste of children’s educational pos

sibilities while they are very young and intervention is most effective.

Infants and Toddlers vs. Preschool/Kindergarten

The emphasis of programming is different for children who are covered by the infants & toddlers provision (IDEA, Part C), covered under §636 (Individualized Family Service Plan) which places more emphasis on a family support plan, compared to §614 (d) (Individualized Education Plan). The service requirements for IFSPs stress the importance of, among other things, providing a statement of the family’s resources, priorities, and concerns [§636(d)(2)] providing intervention services “in the natural environment” [§636(d)(5)]. For these reasons, services provided to children with IFSPs need to be at a sufficient level to provide effective intervention whether or not families are capable of supplying effective intervention themselves.

Just as at present, children covered by IFSPs in general require individual aides for their program, and thus our proposal budgets one aide for each child. This aide may be

either used in the classroom or alternatively to provide discrete trial therapy at school or in the home.

Identification and Evaluation

The initial identification and evaluation of a child who has autism or is suspected of having autism (including PDD-NOS) is completed in one of three ways:

- By a multidisciplinary team at one of the RECCs, for a child under three years of age
- By the Child Find Screening and Assessment Team at the County Diagnostic Center, for a child three to five years of age
- By an independent private source as procured by the child's parents (i.e., The Kennedy-Kreiger Institute, Children's Hospital, private practitioners)

For the first two county-provided means, the identification/evaluation is usually completed in an arena format by: early intervention specialist or special educators (as determined by the child's age), psychologists, speech/language pathologists, and occupational and physical therapists. Private evaluations sought by parents can and are provided also by neurologists, developmental pediatricians and psychiatrists as well as other professionals with equivalent qualifications to therapists working for the schools. In addition, each child is required to be re-evaluated, as provided for in IDEA, every three years, or more frequently if conditions warrant, or if the child's parent or teacher makes a request.

The Importance of Evaluations

The initial identification and evaluation process is crucial in that it can provide information to a child's parents as well as to school personnel and other ARD participants. The initial identification of a disability and the subsequent evaluation of the degree of severity are very important first steps for parents who are struggling to understand their child. Both parents and professionals need to understand how to assist each child effectively as he or she struggles with various developmental milestones. However parents, who are new to the realm of disability and special education services, are at a distinct disadvantage.

Parents and school personnel alike can only appropriately serve a child once they possess two critical components of information. Both need to have complete and accurate information that will allow them to:

- make good decisions as they work to design an individualized education program
- intervene, interact, engage and educate the child effectively.

To accomplish this, both need to be able to determine what needs to be done and to be able to do it. The purpose of the evaluation process is to provide the ARD committee with the necessary information in order to design an effective individualized educational program (IEP) for the child.

Evaluation of Students

Difficulties in Evaluating Children Suspected to Have Autism

Evaluating children, particularly young children, who are suspected to have autism is difficult due to the nature of the disability itself and due to the age of the child. All diagnostic measures used to evaluate individuals who are suspected of having autism require interaction, communication and sustained attention. However the abilities to interact, communicate and attend are the core deficits of autism.

A child's age can make diagnosis difficult because so many of the behaviors on the usual autism checklist are normal for a young child although to a lesser degree. For example, tantrums are a part of every two-year-old child's repertoire. The difficulty lies in trying to determine if the tantrums are normal or more "autistic" in nature. As autistic children become older their behaviors and their developmental deficits become more apparent in contrast to their same age peers. But early diagnosis is essential in order for intervention to have the greatest effect.

Therefore, it is essential that the evaluation process provide as much accurate and useable information as possible: important decisions that are especially dependent on the initial evaluation will later be made by the ARD committee. Evaluations that are based upon a few standardized measurement tools and autism checklists are insufficient.

Thorough Evaluations

Considering the difficulties faced in evaluating a child who is suspected to have autism, more thorough evaluations are indicated. Children who are suspected to have autism should receive the usual evaluations that 1) provide an autism checklist and 2) provide information about the child's developmental level. Children who are diagnosed with autism, however, *should subsequently receive evaluations that test the effectiveness of particular educational approaches for that individual child.*

In order for all evaluations to be accurate they must be administered by competent and trained professionals. In the case of the evaluations that will be used to indicate approach, the administering professionals must be trained in those approaches. Of course, meaningful data must be kept for each approach. Ideally, each educational approach might be tried over a period of time that allows for sufficient evaluation.

In the sections of IDEA that discuss evaluations (§300.530 – §300.536), evaluation data from five sources may be considered: information from the parents of the child; evaluations from independent professional, as procured by the parents of the child; classroom-based assessments and observations; observations by teachers; and observations by related service providers.

It is the charter of the ARD committee to design a child's IEP based upon the information that is provided by the evaluations of the child. The committee can use the following information for selecting educational approaches for an individual child:

- Documented progress in the child's home
- Documented progress in the child's school environment

Early Intervention for Children with Autism – Part II: Parent Recommendations

- Recommendations by professionals as documented by an individualized report/evaluation

An ARD committee, then, must have at its disposal accurate evaluations of a child's strengths and needs and of the potential effect that various educational approaches might have upon those strengths and needs. The ARD committee should use information that is gathered from a variety of sources and in a variety of locations. Logically and ethically an ARD committee must consider approaches that have demonstrated success when used for an individual child.

Program Evaluation

In proposing the following suggestions for programming guidelines, we have sought professional advice from two sources: Prof. L. Larson, Johns Hopkins University Special Education Department, and Prof. Martha E. Snell, Curry School of Education, University of Virginia. They made a number of suggestions we summarize below. We stress the need to build in a careful evaluation scheme at the outset of the program. The program should be evaluated under four distinct criteria, as follows:

- Simple Inventory
- Staff Training
- Learning Opportunities
- Outcomes

By "simple inventory" we mean that a record should be kept of

- a) The number of children in the program
- b) The hours of intervention provided
- c) The techniques determined to be successful for the child

We believe this is a very easy documentation requirement that would be accomplished simply by entering information from children's I.F.S.P/I.E.P.s into a central database, and keeping that database current. We believe that no such facility currently exists. Creating one would be little effort and would greatly improve both school and parents accesses to simple, non-controversial information.

Documentation on staff training appears also to be a simple requirement of keeping a central log of the degree of training under the program that each staff member and aide receives. The complication that arises, of course is deciding how to enter prior training that the staff member has received to date, but this does not seem to be an insuperable obstacle to keeping such a record.

Documentation on learning opportunities refers to evaluating the number of times individual teaching techniques are used. This information is potentially the best indicator of outcomes in general. However, we understand that this is potentially the most onerous of the evaluation requirements. It may be achieved as a part of data collection with appropriately designed forms. Noting that because of variations in children's functioning level, even the best practices applied effectively may not necessarily ensure that the children

learn, it is important to attempt to gather this information system-wide so that the patterns that arise may be understood.

Outcomes documentation requires documenting children's progress against educational goals. At the minimum this is performance on I.E.P. objectives. However it would be more desirable to assess against repeatable measures such as communication, social and basic academic skills on a developmental checklist, as well as measuring changes in problem behaviors.

Continuum of Services

This proposed continuum sets a standard operating procedure for hours and intensity of service such that:

- teaching techniques providing various types of educational opportunities may be implemented;
- 1:1 time for teaching crucial communication (and other skills) can be provided to assist in promoting a successful group instruction program;
- children who have moderate to severe deficits and who respond well to the program, may be provided with additional educational opportunities commensurate with their ability to learn.

There is a need to provide at least two distinct options of services for children with autism. The first is a modified version of the current program for children with multiple intense needs, which consists of a dedicated classroom which is designed to provide a program tailored to promote incidental learning. The modifications that are necessary include higher service hours as detailed below, and direct training of staff, assistants and aides in the appropriate techniques.

We recognize that the Multiple Intense Needs Classroom (MINC) model has achieved some success to date. This success is likely to be amplified by increased service hours, by increased staff training in behaviorally-based incidental teaching techniques, and by the provision of quality training to temporary aides.

However, it is important to provide an alternative model whereby children may also receive intensive services through a more traditional R.E.C. center environment. Some children may still require a high level of intensity, but be able to learn in the *less restrictive environment* provided in the R.E.C. center, if they will benefit from a higher ratio of typically developing peers to special needs children. Under this second option, it will be possible to provide A.B.A. based programs in which discrete trial teaching is the primary methodology. Classroom inclusion time is an essential part of this program for children capable of benefiting from it. The intensity/frequency of services recommended either for the A.B.A. option or the MINC option in the revised HCPSS proposal is similar.

- Designate centers with Multiple Intense Needs project classrooms as centers where children with autism receive early beginnings/preschool/kindergarten inclusion.
- Provide inclusive education for the children with other special needs children and typical peers. Classroom aides would be provided as needed to support inclusion.

Early Intervention for Children with Autism – Part II: Parent Recommendations

- Additional hours to the full day program prescribed can be used for discrete trial training or alternatively, additional inclusive education, depending on the needs of the child in question. We refer to this model as “extended inclusion.”

Points to note about this model are as follows:

- a) There is no difference between the transportation requirements between this and the HCPSS proposal. The same number of children would be attending the same schools.
- b) The training requirements are similar to the MINC program, apart from the need to train the larger number of aides who will be responsible for 1:1 intervention with the children. The special education teacher(s) and instructional assistants in the R.E.C. classroom will require the same training course as the teachers in the Multiple Intense Needs Classes.
- c) Each child essentially takes up two “slots” in the special education classes instead of one (i.e., morning and afternoon instead of one or the other). There will be an occasional necessity to increase number of teachers at the R.E.C. centers as a result depending on the desired staff ratios. The other costs are for 1:1 aides. There appears to be no direct need to budget an additional teacher and instructional assistant for every four children as in the MINC program.
- d) Locating the extended inclusion model with the MIN model classes will obviate the need to provide the same intensive training to all special education staff at all of the R.E.C. centers, which is likely to prove impractical and expensive.

The siting of two intensive intervention classes at each location has several secondary benefits:

- The R.E.C. classroom may occasionally provide substitutes to the MINC classroom in case of unforeseen absences of temporary aides.
- Children’s placements may be shifted as appropriate between the two models with relatively little bureaucracy (apart, of course, from the approval of the ARD committee).
- There is a need to concentrate expertise and also ensure that all staff involved in teaching children with autism can receive the required training. This implementation will allow an atmosphere where pools of expertise can flourish.

Providing an alternative outside of the MIN classrooms would also accommodate children in the infants and toddlers program (under 3), who may best be served *in the natural setting* of the home. Home service hours could be used for discrete trial interventions. Such intervention will in general be provided by trained temporary teaching aides rather than teachers.

We are aware of issues regarding personal liability that limits the HCPSS willingness or ability to provide significant home based intervention hours through a potentially large number of temporary workers. However, these issues may be mitigated by

- a) Providing intensive home-based intervention through an agency such as Community Services for Autistic Adults and Children (C.S.A.A.C., Rockville, MD). For funding purposes, C.S.A.A.C. is already an approved Medicaid service

Early Intervention for Children with Autism – Part II: Parent Recommendations

provider, and thus intervention through this is potentially possible for eligible children at 50% of the cost under the forthcoming Waiver.

- b) Changing the relationship between the aides and HCPSS so that the liability issue entails less of a risk, i.e. by direct hiring rather than hiring the aides through a subcontract.

Summary of Continuum

The program of services for each child is determined by the outcomes identified with the family in the child's IFSP/IEP. The continuum of services we propose thus comprises the following components:

- Program for Children with Multiple Intense Needs
- Discrete Trial Based Programming
- Provision of (1:1) assistance as necessary to assist with individual children's behavioral and attention problems and to support the use of behaviorally-based techniques.
- Home visits⁵
- Home Based Programming for Infants and Toddlers provided as service hours
- Routines Based Family Intervention under the direction of Family Support Coordinators and Parent Intervention Teachers.

The proper implementation of all parts of the continuum requires intensive training, and in some cases retraining of staff and aides.

Program for Children with Multiple Intense Needs

The program for children with multiple intense needs, including autism, has components for infants & toddlers, preschoolers and kindergartners. The model is considered for children who have a diagnosis of autism or who present with moderate to severe delays in cognition, social interaction, communication, or behavior. Services are delivered in geographically designated Regional Early Childhood Centers. Staff members include early intervention teachers, instructional assistants, and related service providers who have completed a specialized training series. Each of the sites serves four eligible children and their families. Typical peers attend school-based sessions. This program is described in detail in the HCPSS proposal.

However, we have a number of concerns about the current implementation of this program, which are detailed in Appendix D. Our criticisms largely involve how the teaching strategies are implemented, rather than of the program strategies themselves, and reinforce the need for direct hands-on training of the staff in the program. We believe that currently it is premature to project the opening of as many as 10 classrooms based on this model—another reason for our two-stream approach to intervention.

⁵ The term "home visits" generically refers to natural environments where children spend the majority of their time during the day. It may, therefore, include services at daycare.

Early Intervention for Children with Autism – Part II: Parent Recommendations

We also take issue with the Guidelines for Admission to this program as detailed in the HCPSS report, as detailed in Appendix E. Briefly, we hold that a number of the Guidelines appear to contravene the IDEA.

A. B. A. Programs (Discrete Trial-based Intervention)

As recommended in the White Paper (Early Intervention for Young Children with Autism, Part I), A.B.A. programs are part of the continuum of services offered by HCPSS. We propose the provision of discrete trial-based programs for children with autism or other multiple intense needs who have demonstrated any one of the following:

- (1) the likelihood of success with discrete trial based intervention during the intake diagnostic procedures
- (2) lack of progress on IEP goals using incidental learning techniques
- (3) significant progress on specific IEP goals through use of discrete trial techniques either at school or in the home

or

- (4) children who have been recommended discrete trial programs in independent medical and psychological evaluations.

Personalized programs developed with a discrete trial base will include a significant component of classroom intervention time to generalize skills and to facilitate social interaction. Children with autism may be served either in their assigned R.E.C.C. center or in geographically designated sites. The hours of service at different ages are listed below. Additionally, family-guided routines-based intervention is a necessary constituent of discrete trial based programs.

Infants and Toddlers Program

Service Hours

The range of service hours for the Infants and Toddlers Program would be 20-32.5 hours of school or home-based instruction, including 1—3 hours home based instruction and family training. The total level of intervention would be up to 42.5 hours if the family-guided program is successfully implemented.

For children covered by IFSPs, the location and mix of service hours between classroom time and discrete trials (where applicable) will be determined collaboratively between school and parents.

In some cases, parents may request a less intense educational program for their children (especially for the youngest children). The HCPSS will advise parents, given the child's present and likely future needs, as to what level of service is most likely to prove effective for their child. Nevertheless, it will be necessary in specific cases to retain some flexibility in designing a less intensive program on family request. Parents may be granted increases in services to the recommended level if this is found to be necessary at a later stage.

Preschool and Kindergarten Programs

Service Hours

The range of service hours available for this age would be 28.5 to 32.5 hours per week (28.5 hours school based, and up to 4 hours for family and staff training at home or school. The total level of intervention would be up to 42.5 hours if the family-guided program is successfully implemented

For children receiving A. B. A. programs, the service level is 12.5 hours of classroom time, plus up to an additional 20 hours per week of discrete trial intervention.

Notes for both age groups:

The IFSP or IEP will be designed as far as possible to reflect a child's individual needs and abilities. Other factors, such as the child's age and daily schedule are considered in the design of the family intervention part of the program. At all levels, additional hours of family-guided routines-based intervention may be designed at the family's request.

The primary difference between the program for infants and toddlers and preschool and kindergarten programs is that the "service floor" is lower for infants and toddlers. Also, the mix of home and school-based services is expected to be different in general with more service hours [i.e. provided by HCPSS] taking place at home as the natural environment for younger children.

Summer Services

The almost unanimous experience of parents we have consulted is the availability of summer services. However, at present, by attempting to apply a stringent reading of the prevailing law regarding the provision of Extended School Year services, the needs of children are not properly addressed. Children with autism have a great need to be engaged effectively even during the summer. A total of 6 weeks without educational programming is very problematical, as is a restrictive education program for the summer that does not challenge the child.

Therefore, we propose that the program will include a summer service component for *all* children with autism. Provided the program extends to all children with autism, we endorse the expansion of the summer intervention time to seven weeks and to 20 hours per day proposed by HCPSS, but add that:

- I.E.P.s for summer, as far as is practicable, indeed be considered a continuation of the years' education plan.

Routines-based family intervention

The focus of the home program is on a family-guided routines-based approach using appropriate methodologies including developmentally appropriate teaching techniques, relationship-based strategies, principles of applied behavioral analysis (in both naturally-occurring incidental teaching and discrete trial formats, as appropriate), positive behavioral supports, assistive technology, and sensory plans and intervention.

Early Intervention for Children with Autism – Part II: Parent Recommendations

The importance of a successful home-based family intervention component of the program cannot be overstressed, since the home is the most important environment in which skills mastered at school must be generalized. This program component will also function as family support, in that it will teach families useful skills in living with a person with autism. However, in order to ensure things to happen as intended, techniques must be taught to families to facilitate learning using specialized techniques for children with autism. The following list comprises tasks which will naturally be taught in the home and which the family-based intervention may target:

- Self-help skills (dressing, toileting, eating)
- Reading & listening/ attention
- Obeying simple instructions
- Behavioral support
 - Suppression of inappropriate behaviors
 - Displaying appropriate behaviors
- Peer/sibling interaction
- Communicating needs and desires
- Child initiated interaction

Family-guided routines-based intervention begins with identification of the family and child's schedule of the day, including typical routines. Intervention is embedded in identified routines to provide multiple opportunities to teach and practice skills. The Family Support Coordinator provides a variety of structured group and individual family support activities.

Staff Development

Frequent concerns of parents in the area of staff development are: the level of knowledge and expertise that their child's educators have; and the discrepancy of knowledge between various educators.

Parent reports indicate that school system staff members display a wide and troublesome range in their knowledge of specific autism intervention strategies and techniques, as well as the applicability and availability of those techniques. It appears that a child's ability to receive appropriate services has become increasingly dependent upon the particular staff members who work with that child. This pattern of deficiency is almost certainly related to the current provision of staff development where participation in some activities is not required. Instead, to some extent, participation is voluntary.

When staff members do attend voluntary staff development activities, the emphasis seems to be on staff collaboration and indirect training, instead of direct and hands-on training. The school system relies heavily on the train-the-trainer model, where one or a few individuals receive the actual training, to in turn pass the information on to colleagues. For some topics this can provide for adequate staff development. However, we contend that given the complexity of educating young children with autism, this model is unsatisfactory.

We do not consider it sufficient for staff development personnel to attend conferences and workshops on behavioral techniques in order to bring back the expertise and train staff

and parents in a “second-hand” fashion. First, the full level of professional guidance required cannot possibly be learnt by the staff development personnel in a few hours at a conference. Second, such opportunities do not give the chance for the hands on application of the techniques under discussion. Third, staff and parents undergoing training need to interact with the instructor so they may learn how to cope with particular concerns and deal with situations that have or may arise within their own experience. Fourth, training needs to be ongoing and throughout the year both to allow staff to receive practical suggestions for individual cases and because of possible staff turnover, for aides in particular.

School system administrators rely upon self-assessments on the part of classroom educators as a way to determine the need for training. To some degree, training is only provided after a staff member asks for it. Considering that other, exterior variables may be present - child care coverage for summer training, for example – this is not sufficient.

Elements of Successful Training Programs

We have consulted with professionals with expertise in designing autism programs and with working with successful inclusion strategies. We propose the adoption of a training model for the autism program that features:

- ***Training in behaviorally-based methodologies***
- ***Providing personnel with hands-on experience in using techniques***
- ***On-going training opportunities supervised by specialists***
- ***Inclusion of parents in training opportunities***

We stress the importance of behaviorally-based training as the most important omission we see in the current training of staff. Many, albeit not all, of the primary education strategies proposed in the White Paper, Part I are indeed behavioral in nature, while others (Sensory integration plans, augmentative communication techniques etc.) are covered by existing expertise within the County schools.

We also stress the need for hands-on training which involves the staff in gaining experience in the techniques being taught under the guidance of a professional. At the same time, we question the efficacy of the two week training series proposed, which appears to consist mainly of lectures on instructional strategies. It is possible that with careful scheduling the training can be delivered in a single week, reducing the cost significantly.

Possible Models for Professional Training

The Autism Partnership, based in Long Beach, CA has worked with a number of school systems and schools around the nation, and one of their consultants⁶ was asked informally to advise on training program models they have devised for schools. Our intention here is not to recommend that their services be employed, but rather to obtain some suggestions from a nationally recognized autism program specializing in A.B.A. what is necessary to train staff.

⁶ Our point of contact is Sanford J. Slater, Ph. D., behavioral psychologist. The Autism Partnership will be presenting a seminar at the 1998 Autism Society of America Conference on ABA techniques and implementing A.B.A. programs across school and home settings.

Early Intervention for Children with Autism – Part II: Parent Recommendations

They use two models, one now employed by the San Diego School District, and the other is being used by Knoxville, TN public schools.

In both models, a number of consultants run a training program over the summer months. In the “San Diego” Model, the training is two weeks, and is followed up by very frequent (bi-monthly) visits to the schools. In the “Knoxville” model the training consists of a 3-4 day workshop also followed by bi-monthly consultation. Both programs entail ongoing hands-on training and employ the consultants to design individual programs for children.

Consultants may also address a number of important issues such as dealing with particular family circumstances and personality issues that may if not considered impede the learning of the children. With parents present, the course can also address the issues arising from the generalization of skills from home to school and vice versa.

The number of trainees to participate in the summer training offerings, if both staff members and parents are involved, may exceed 60 individuals. For delivery of hands-on training for this number of people it will be necessary to call in several professionals. We estimate a single professional can train up to 20 individuals in a week; thus 3 or 4 consultants will be required.

Our cost estimates involve \$20,000 in consultant fees for the summer training course and a total of \$15,000 in consultant fees scattered over the year for follow-up visits. In budgeting this sum we have estimated the cost of a “consultant day” at \$1,000, which would include fees and expenses. Exact figures would require negotiation between school and consultancy; the Rutgers University Program, for example, negotiates contracts with Education Agencies and provides services at costs that are to some extent based on budgetary necessities. The funds in this line item constitute under 4% of the total budget, and would also be in lieu of reimbursements currently made by the county schools to parents running home programs which would no longer be necessary.

The benefits of the county working directly with an established autism consultancy would also include (a) a great deal of expertise being directly available to the schools and (b) a considerable streamlining in the relationship between the schools parents providing additional education at home and (c) the consultants will be of the schools choosing, although preferably with some input from parent advocates.

Parent Training

As co-participants in the IEP/ARD process, parents require information about their child’s disability and about intervention strategies and techniques. They require the information that will allow them to work with the other team members as the team collaborates to design an individualized education program for the child. They need the information that will allow them to participate in necessary decisions. Parents also require information and expertise that will allow them to effectively work directly with their child.

To date the emphasis of school system provisions has been more upon providing parent support than true information. Certainly parents need support mechanisms in place as they come to terms with a diagnosis for their child as serious as autism. However, parents are less effective as participants in the IEP/ARD process if they are uninformed about intervention techniques and strategies, and if they have unnecessarily low (i.e. uninformed) expectations for their child’s education. Parents can also be more effective in the time they spend with their child if they are trained in effective intervention techniques and strategies.

Early Intervention for Children with Autism – Part II: Parent Recommendations

The object should be to offer parents with the opportunity to participate in workshops with the professional consultancy used to undertake staff training. Parents currently running home discrete trial based programs currently receive training in appropriate methodology for those programs. Similarly providing for parents to receive training in whatever strategies are decided for their child will aid significantly in family guided intervention and generalization of learnt skills.

We also propose a collaborative initiative, which would be a series of provisions designed to educate as well as support parents receiving new diagnoses. Parents would obtain important emotional support, as well as being directed to training programs and useful educational resources. Details of these plans are in Appendix F.

Consultants

Historically, parents who provide their own home-based applied behavioral analysis program for their child do so under the guidance of an autism consultancy program. Such programs are usually provided through university based outreach programs. Program consultants typically teach skills that parents (and their home-based staff) need to implement programs for their young children. In addition, program consultants provide guidance in the form of curriculum and other input. Currently, the school system will pay for some consulting services if those services relate to the child's IEP.

Under the model of services we propose, a general consultant from an autism consultancy program would be engaged by the HCPSS both to train and to consult on specific cases. However, if this model is not approved, it will be necessary to allow within the continuum of services the facility to

- Reimburse parents for consultant fees
- Use the consultant's expertise within the school program

We stress that this is not the preferred model. It is both more cost efficient to designate a consultant to work directly with the schools who may serve a number of families simultaneously, and it gives the school system the prerogative to choose a consultant who is amenable to home-school cooperation. However, if it is necessary to continue the practice by which parents separately engage consultant expertise, the following issues arise from the stated policy on consultants in the HCPSS proposal. In any event, the object will be to coordinate home and school education programs to achieve the goals of the I.E.P. We have every expectation that this will be agreed to by parents, *provided the I.E.P. agreed to the full A.R.D. committee is sufficiently challenging for the child.* In this case the concern raised by the HCPSS proposal of home program goals not being related to the I.E.P. will not arise.

Under current guidelines, a decision for the school system to pay for consultant visits is made by the ARD committee. However, the school system instructs ARD committee members to follow a particular process if the committee agrees that additional expertise is needed for a particular child. Basically the process details steps to be taken, such as determining need and looking within the school system for expertise, before seeking outside consulting services.

Early Intervention for Children with Autism – Part II: Parent Recommendations

In principle this process sounds logical, but in practice it is fraught with difficulties because:

- consultation needs to be part of a regular schedule of training and program maintenance rather than called upon to address a specific need. Guidelines that require the identification of a specific need miss the point of program enhancement and maintenance
- imposing a requirement to pursue every option within the school resources will simply delay the scheduling of consultations
- consultant visits need to be scheduled months in advance rather than in some sort of “emergency” mode.

It remains a concern of parents that an apparent bias against using A.B.A. techniques has ensured that sufficient expertise in them is not available to young children with autism. We contend that the primary reason for the policy, its tone, and its restrictions is the emergence of ABA related requests for consultative expertise. We understand there might be a concern on the part of the schools that parents may choose an external consultant practicing dubious intervention techniques. We are not aware that this problem has ever arisen, however.

Conversely, we agree that it is perfectly valid to exhaust the expertise available within HCPSS before paying for external consultants to solve particular problems that may arise in other circumstances, and endorse the policy in those cases.

Appendix A: The Case for Intensive Early Intervention

This Appendix gives a number of recent writings and findings on the subject of intensive early intervention.

In the current monograph *Targeting Autism*⁷, In a section entitled “Moving Toward Better Answers,” Shirley Cohen directs schools to work on various strategies, including:

Provide intensive services to toddlers and preschoolers. The cost of intensive (one-to-one) services for every two-, three- and four-year-old diagnosed as having autism or pervasive developmental disorder would undoubtedly be extremely high. But the current, often feeble attempts at intervention for this population are unlikely to reduce the even greater cost of maintaining a very large proportion of autistic individuals as seriously disabled throughout their lifetimes. It is cost-effective to help as many autistic children as possible become part of mainstream society early in their lives, and we need intensive efforts to accomplish this.

Not every child diagnosed as having a pervasive developmental disorder needs thirty or forty hours a week of formal educational treatment services for an extended period of time; and some children who begin receiving intensive services at age two or three will, a year or two later, be able to learn effectively in small groups and benefit from supported participation in inclusive settings. *But premature limitation of service time and premature reliance on group instruction are counterproductive strategies that should be ended.* [our italics]

Summarizing the issues surrounding developing important components of programs for children with autism, Serena Wieder writes⁸:

How best to help children with severe communication and relationship difficulties at younger ages perplexes parents and professionals alike... Several important factors need to be considered when deciding on an intervention course. First, children with severe communication and relationship difficulties ... vary considerably and require integrated intervention approaches individualized to their needs rather than be fitted into various program philosophies. Second, all children, including those with special needs, learn within relationship-based developmental experiences that take into account the child's individual differences. It is essential to understand how individual differences impede the development of such core process as relating, attending, communicating, and thinking. Third, specific therapies, behavioral and technical strategies, and emerging treatment approaches should be added onto a foundation of family support and ongoing, consistent interactive relationships ... *Fourth, intervention must be very intensive and occur as soon as possible* [our italics].

⁷Cohen, S. 1998 *Targeting Autism* (U. California: Berkeley), p. 179

⁸ Wieder, S. 1996 *Integrated Treatment Approaches for Young Children with Multisystem Developmental Disorder, Infants and Young Children* 8, 24. Dr Wieder is a member of the Howard County Chapter of the Autism Society of America.

Early Intervention for Children with Autism – Part II: Parent Recommendations

That children with autism need a program that is intensive at an early age and especially designed to meet their specific needs has been stressed by Gail McGee, who writes⁹:

Moreover, despite widespread recognition that in treatment of autism, early is essential and more is better, the current state-of-the-art treatment in early intervention for autism is good preschool education. When children with autism enter treatment before preschool ages, they are usually provided with a diluted preschool curriculum. There is a void of information on what is most crucial to teach toddlers with (or at risk) for a diagnosis of autism, or how best to teach them. This is a critical problem, given the relatively short time frame in which early intervention must occur. In sum, it is important to know how to best lay a foundation for the growing number of effective preschool interventions.

An excellent overall summary of the issues surrounding Intensity of Services was provided by a recent Task Force report published by the State of Connecticut Dept of Education¹⁰, which listed eight components of educational programs. The fourth of these concerned Intensive Programming, and summarized, quoting a number of authorities, as follows:

Intensity has been a hallmark of effective education for children with autism since the late 1960's. Intensity of education must be considered on many levels, including duration of education (e.g. the number of hours per day or days per week that services are provided; the number of weeks of educational intervention per year); the number of environments in which the teaching occurs (e.g., classroom, general school environment, home, community); and the educational validity of the interventions provided. Each of these levels is discussed below.

There has been considerable debate regarding the number of hours per day considered appropriate for educating children with autism in the public schools. This debate has been particularly lively with respect to preschoolers, given the preconceived notions regarded the alleged inability of typical preschoolers to “tolerate” a longer day. The early intervention literature clearly identifies the need for a minimum of five to six hours per day of instruction with five day per week programming — supplemented by 10–12 hours by families— as being the most effective for delivering substantial and generalizable educational outcomes to children with autism.

In determining the number of hours of formal instruction in the school setting, parents and professionals on the planning and placement team should take into account the following: a) both the family's strengths and constraints vis-à-vis the implementation of the child's program, and b) the opportunities in other community settings which may also exist. For children after the age of five, the issue is more easily resolved because children with autism are, by law, entitled to the same amount of educational time per week as their typically-developing peers. It should be specifically noted, however, that despite notions regarding programming intensity for typical preschool children, those with autism require far greater intensity to reach a level of program effectiveness, than do their typical peers.

⁹ The Walden Preschool Program McGee, G., Daly, T., & Jacobs, H. A. 1994 in *Preschool Programs for Children with Autism* by Sandra L. Harris and Jan S. Handleman (Pro-Ed:Austin), Chap. 8.

¹⁰ State of Connecticut Dept of Education Bureau of Special Education and Pupil Services 1996, Middletown Connecticut.

Early Intervention for Children with Autism – Part II: Parent Recommendations

Given that problems in generalization and maintenance of learned skills are very common to students with autism, any change in environment, interruption of services (as during the summer months), or unplanned change in instructional staff, can lead to substantial learning breakdown. Research clearly indicates that students with autism who are provided full year programming (e.g., between 215 and 225 school days) fare much better than those who receive less.

In planning additional programming time, the needs of the child must be considered primary, and the specifics of the diagnosis secondary. As such, high functioning individuals with autism may well require a different type of summer experience than children who are very challenged by their disability and/or who are more cognitively impaired. An important note of caution, however, is that the attainment of age-appropriate academic scores with commensurate language ability does not negate the need for year-round services. Deficits in social behavior/relatedness, communication, and areas impacted by such deficits, constitute core problems for individuals with autism. As such they require intensive, substantive and sustained teaching efforts throughout the entire year.

Full day programs occurring across a full year do not necessarily ensure the delivery of effective educational services for students with autism. In order for instruction to be effective, educators must also understand the learning styles and unique needs of students with autism. Further, teaching must consist of high-quality instructional interactions, individualized to the child's learning styles and needs. Similarly, no single methodology in and of itself will guarantee that the targeted skills will be functional, socially valid, or age appropriate. On-going, individualized attention to these important elements is vitally important.

On the subject of intensive intervention versus degree of severity of symptoms of autism, Bryna Siegel writes¹¹

Many parents instinctively try harder and do more and basically add more stimulation when their child does not respond normally. With autistic children, however, just adding "more" is not enough. The special difficulties experienced by autistic children warrant a form of special education unique to their disorder.

Sometimes the most severely impaired children—those for whom even the most intensive services will not make a critical difference—tend to be offered more services than children who have fewer initial impairments or who may be more ready to tolerate intensive work. In fact, children with the mildest disabilities typically are offered fewer services than more moderately impaired children because it is felt they may improve eventually on their own. To the extent that there are any real data on who should get how much service, there is reason to believe that more intensive interventions for more mildly affected children may be particularly efficacious.

We close this section with a quotation, which neatly encapsulates our view of the use of individualized versus group instruction. Raymond Romanczyk writes¹²,

¹¹ The Importance of Very Early Intervention: How Much Early Intervention Is Appropriate? Siegel, B. 1996 in *The World of the Autistic Child: Understanding and Treating Autistic Spectrum Disorders* (Oxford:OUP) ch. 9

¹² The Children's Unit for Treatment and Evaluation Raymond G. Romanczyk, Linda Matey, and Stephanie B. Lockshin 1994 in *Preschool Programs for Children with Autism* by Sandra L. Harris and Jan S. Handleman (Pro-Ed:Austin), Chap. 10.

Early Intervention for Children with Autism – Part II: Parent Recommendations

The goal of integration into the typical school setting is unquestionably correct. However, for some children a normalized setting, even with extensive support services, may not be the least restrictive setting. Central to the issue is one's definition of 'least restrictive.' For some children, a strategy of a continuum of services, from an intense, focused, individualized, specialized setting to the more typical classroom with required support services, is the most appropriate. This allows for rapid acquisition of needed skills and for a choreographed approach to habilitation. Some children who are placed in the supposed 'least restrictive' placement do not progress at a rate consistent with their potential. There can be an illusion of progress as they are 'with their peers' and are present in various activities. This could be seen as the least restrictive placement, but from a different perspective, it is highly restrictive if one is sensitive to temporal factors. If a child is in an environment where learning takes place at some fraction of the pace that is possible in a more specialized environment, then this indeed represents a restrictive environment.

Appendix B: Brief Description of A.B.A. Programs

Behaviorally-Based Intervention

The most important change we feel needs to be made to HCPSS's program for children with autism is the use of and rigorous training in A.B.A. techniques. There is much evidence in favor of state-of-the-art implementations of Applied Behavior Analysis. These programs use various behaviorally-based methodologies including discrete trial therapy as a major part of an integrated program that first teaches children *how to learn*, continues by teaching them how to generalize their learning, and finally teaches them how to be part a society.

Any behaviorally-based, intensive intervention program requires a high level of training for all staff working directly with the children, be it in the classroom setting or in one-on-one situations. Without a *specific focus* on training in techniques of ABA—a focus which currently does not exist within the county—professional staff and temporary aides will be unable to implement the program necessary to educate young children with autism.

This appendix has two parts: first, we give an overview of Discrete Trial-Based Applied Behavior Analysis programs. Second, we give specific curriculum information, showing how skills are taught in a progression of phases, and how generalization and peer interaction are phased in after the children can best use these learning opportunities.

Discrete Trial-Based Programs

Discrete trial therapy (DTT) is a specific teaching technique used to maximize learning¹³. The technique consists of breaking down a skill into smaller parts, and then teaching one sub-skill at a time. Each teaching session involves numerous trials, with each trial having a distinct beginning (i.e., the instruction) and end (i.e., feedback). Each part of the skill is mastered before more information is presented. DTT is contrasted with “continuous trial” or more traditional methods of teaching which present large amounts of information before the child's response is sought.

In DT-based programs, children are presented with opportunities to learn necessary skills until they are performed successfully. Children are reinforced (rewarded/praised) for doing so, which provides motivation for the child to continue to learn. Therapists and paraprofessionals working with the children are trained to ignore negative behavior but to reinforce compliance and good behavior — “*praise the best, ignore the rest*”. Reinforcers include for example, candy, affection, free play, and are selected on the basis of what the child responds to best. The child's success is closely monitored by data collection at various degrees of detail.

Skills that the child has mastered (i.e. he/she is successfully performing with some stated frequency, e.g. 80% or better) are tested subsequently to ensure that the child continues to be proficient in them. New tasks are constantly introduced to expand upon the

¹³ The Autism Partnership Curriculum and Session Guidelines, December 1996

Early Intervention for Children with Autism – Part II: Parent Recommendations

skills already mastered. Once a student has mastered a particular skill, *steps towards generalization begin immediately* and are adapted to the specific needs of the child.

The use of discrete trials is common to behaviorally-based methods in a variety of contexts. DT-based programs are often referred to as Applied Behavior Analysis (A.B.A.) programs, although the term refers more generally to behavioral methods in a variety of circumstances. The term ABA is used here, however, to refer to a method of *teaching* designed to analyze and change behavior in a precisely measurable and accountable manner. In particular, the methodology can also be used in more natural circumstances as part of incidental learning. However, by themselves methods that rely solely on incidental learning (described as behavioral methods in naturally occurring situations, routines-based learning, and other milieu teaching techniques) *will not necessarily provide sufficient learning opportunities for children with autism*. Children often will not comply with a teaching activity (this is also the difficulty faced in educating children with autism within traditional special education programs). The Discrete Trial Therapy component of ABA programs is designed to ensure that children learn the tasks of the recommended curriculum. This is accomplished by persisting with teaching the tasks until they are mastered. Trained “therapists” learn a variety of techniques to deal with non-compliance and to get children back on task.

In order to implement the discrete trial component and to generalize skills learnt to other situations, an ABA program requires a large number of service hours. Full day programs are indicated, often with hours added at home. As the children progress, their education continues to require similar levels of service, but in the more natural environment of the classroom.

Approach to Teaching

The elements of the ABA programs we wish to implement are drawn from intervention techniques that have been described in Part I. They are:

- The use of Discrete Trial Therapy
- The use of a developmentally appropriate curriculum
- Generalization by teaching in progressively less structured settings
- Use of functional assessments for challenging behaviors
- Use of natural situations as teaching opportunities
- Inclusive education

Depending on the needs and age of the child the program can require *a range of placements*, from a program in which one-on-one intervention predominates to one which stresses group instruction in the regular classroom. A major one-on-one, structured component is indicated for children who do not interact with other children well enough to benefit from a group setting. In center-based programs, the children are included, first in smaller then in larger groups, as their ability to interact and cope increases. The best practices thus indicate a ‘phased approach’ in which the degree of intensive one-on-one intervention is highest in the early stages, and more time is spent in inclusive settings later. Tasks to be learnt are also introduced in phases and developmental levels, as explained in the curriculum section below.

A.B.A. programs can be highly tailored to the individual needs of the child. They allow for a continuum of placements depending on those needs, and are tuned to the child’s

learning pace. The usual necessity of performing at least some of the therapy at home—so that the skills learnt in the program can be generalized to what is the most important setting the child must cope with—implies a great deal of parent involvement and awareness. For these reasons, these programs contain many if not all of the strategies found to be most successful in treating children with autism.

Curriculum for A.B.A. Programs

Specific goals and objectives are established along a continuum of developmental milestones that begins with non-verbal imitation and continues to advanced conversation, peer socialization, and academic skills such as reading and math. An example of how an ABA program might proceed in its early stages is given in the flowchart on the next page.

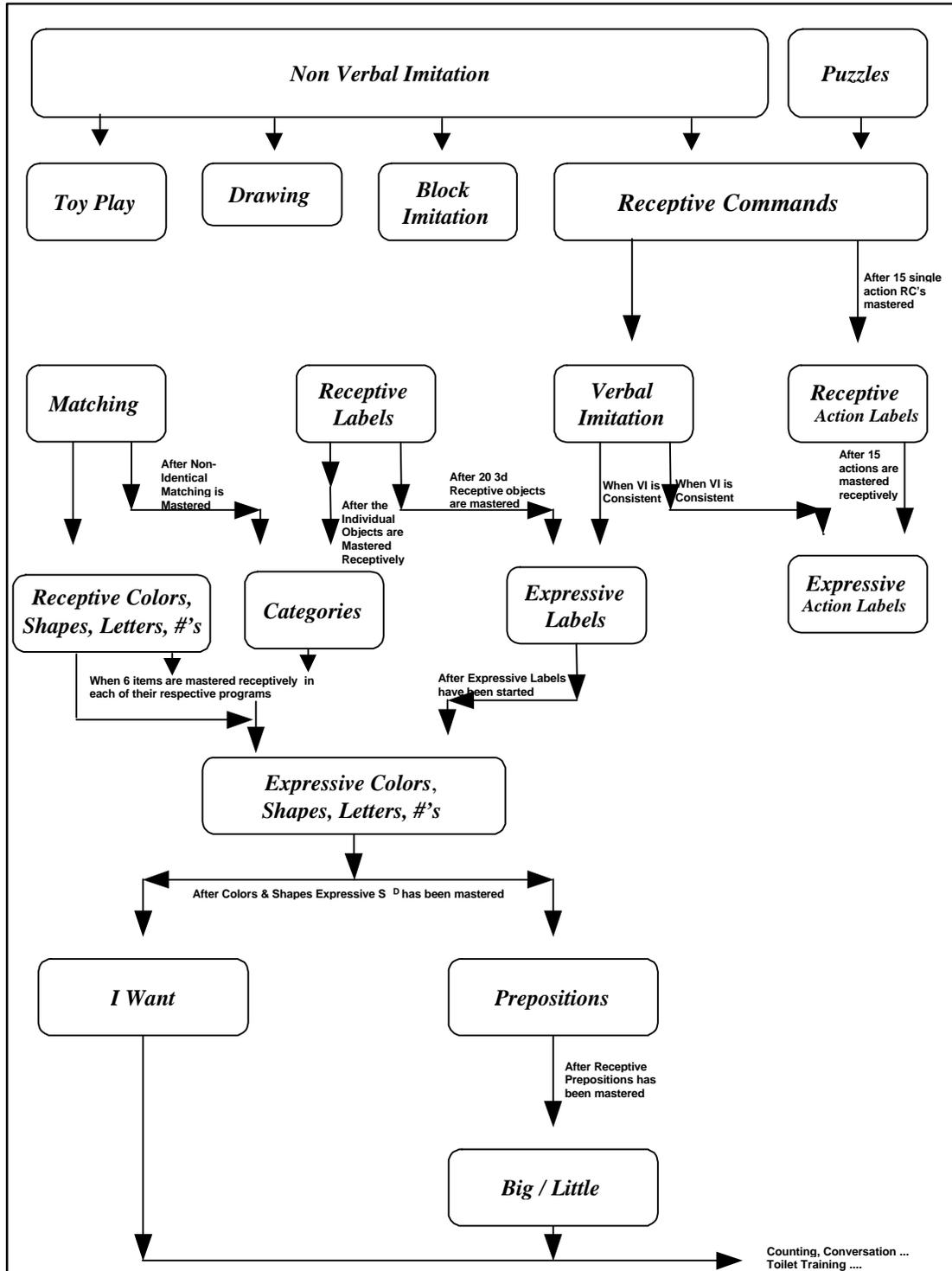
The developmental milestones or goals that make up a modern ABA program are those that typical children pick up effortlessly from their environment. We stress again that the autistic child must *learn how to learn*, beginning with very small and basic tasks, followed by increasingly complex tasks. In the context of the school system, IEP goals must be precisely specified and be measurable. Goals are typically written to cover the following areas (in alphabetical order):

- asking questions
- assertiveness
- attributes
- block imitation
- categorization
- cause and effect
- communication temptations
- conversation skills (basic, intermediate, advanced)
- describing
- drawing
- emotions
- expressive labeling
- functional communication
- general knowledge and reasoning
- “I don’t know”
- independent work and play
- joint attention
- matching
- motor skills
- negation
- nonverbal imitation
- observational learning
- peer interaction
- play, play scripts
- prepositions
- pronouns
- quantitative concepts
- reading
- recall
- receptive instructions
- receptive label requests
- same versus different
- self-help skills
- sequencing
- social awareness
- socialization skills
- songs
- stories
- verbal imitation
- “What’s missing”
- “yes/no”

Children using a discrete trial-based curriculum work through the “phases” of the curriculum at their own speed, entirely dependent on their skill acquisition rate. In addition, students may work on different phases simultaneously, especially if they have “splinter skills.”¹⁴

¹⁴ Splinter skills are those that children have that may be advanced of a child’s developmental age. The uneven pattern of development common to children with autism often produces such anomalies: thus a child may be unable to speak a complete sentence but able to add and subtract or read significantly above age level.

Flow Chart: The Early Stages of Learning in an ABA Program



Appendix C: The Maryland Autism Waiver

The following is an excerpt from the recently signed House Bill 99, signed into law in April 1998, concerning the application of the Dept. of Mental Health and Hygiene to the Federal Health Care Financing Administration for a Medicaid Waiver for services for children with autism. Under this waiver, children with autism will be eligible for certain services reimbursable by Medicaid irrespective of family income.

AN ACT concerning Home- and Community-Based Services for Autistic Children and Seriously Emotionally Disturbed Individuals - Medicaid Waivers

§1 (B) (2) The Department shall apply to the Health Care Financing Administration of the Federal Department of Health and Human Services for a Home- and Community-Based Services Waiver under §1915(c) of the federal social security act in order to receive federal matching funds for services to autistic children aged 1 through years who would otherwise require institutionalization in an institution for the developmentally disabled.

§1 (C) in accordance with subsection (B)(1) and (2) of this section, the services to be provided for seriously emotionally disturbed individuals or autistic children may include, but are not limited to:

- (1) Respite services;
- (2) Family training and education;
- (3) Day treatment services;
- (4) Therapeutic integration services
- (5) Intensive individual support services;
- (6) Therapeutic living services;
- (7) Intensive in-home intervention services; and
- (8) Specialized case management services.

§1 (D) The state matching funds required to cover the Medicaid costs under the waiver for autistic children shall be certified or otherwise provided by the Maryland state department of education, local school systems, and local lead agencies.

Appendix D: A Critique of Current Classroom Practices within the Multiple Intense Needs Program

The following section provides a detailed critique of current hands-on classroom practices in the MINC. The intent of this section is to show how actual day-to-day interaction with the children might be changed. The differences might appear to be slight, yet for children with autism they can be significant. We hold that some of these differences reflect an inappropriate level of understanding of the philosophies behind some of the methodologies the program is designed to employ. For these reasons, it is imperative that school staff members receive appropriate training that will allow them to recognize how significant these changes can be. Staff members need the knowledge and skills that will allow them both to determine what degree of intervention techniques is necessary and how to properly implement those intervention techniques.

The following comments are the result of observations by a number of parents who have observed the program in its current operation.

Verbal Commentary

Staff members have a tendency to talk for the duration of the class day describing situations and labeling objects and events. School staff members apparently believe that with enough exposure to simple language that a child with autism will develop some language skills of her own. An example of this exposure might sound like:

We are walking down the hall. Walk. Walk. Look, a door. Let's open. In we go. In. Time to hang up our coats. Coat off. Hang up coat. Look, a hook. Time to sit down. Pull chair. Sit down. Do you want me to scoot you in? Do you want Playdoh or blocks? Blocks or Playdoh? Blocks? Block. This is a block. Blue block. On top. On top of red block. Up. Up. Up. Stacking. Blue. Red. Blocks fall down.

This intense verbal input might appear to be positive stimulation, that when given with enough repetition might be of benefit for any young child.

The provision of labels and other descriptive information is unlikely to initially benefit most children with autism. To a young child with autism, this dialog might sound like, "Wah, wah, wah", much like the adult voices in *Peanuts*. This is not to say that a child with autism has a hearing disability. Most individuals with autism test to be within the normal range on standard hearing tests, however most have difficulties *processing* verbal input or language. Even if a child is able to pick out some words ("Wah, red, wah"), the reference may be lost on the child.

Children with autism do not learn concepts, including language, by exposure, as do typical children. Most must first be taught *how* to observe and *how* to imitate others—including language imitation. For typically developing children, imitation skills develop very early— months before first words are spoken. Children with autism must be specifically taught *how* to imitate and *how* to learn by observation and through exposure.

Single vs. Multiple Stimuli

When working directly with a child, school staff members tend to inadvertently and purposely provide multiple stimuli for a given task. The basis of this as a purposeful technique is that it is presumed to increase the chance that a child will be successful – the more cues made available to the child, the more likely she is to respond to one of them. However, for children with autism, a multiple-stimuli situation can be confusing and overwhelming. Some examples:

A child asked is asked to identify a picture, given simple requests such as “Touch cat” and “Touch dog”. The child might rely upon other cues, such as the orientation of the picture in relation to another picture (horizontal-vertical), the size of the pictures (small-large), or another feature of the picture (picture with worn edges).

A staff member is working with a child in a play situation with animals. The staff member might label the animal (“lion”) and then provide the sound (“roar”). The autistic child might be unable to discriminate the between what she understands to be two labels.

Instead, stimuli must be presented so that the targeted concept is clear to the child and as free from distraction as the child’s level warrants. The structure and complexity of the stimuli must be individually tailored to the needs of the child. As children progress stimuli is altered to be more natural and complex. It is the ultimate goal for children to respond to natural and unaltered stimuli, for example, the instruction of an elementary classroom teacher as she talks to the whole class.

Skill Generalization

School staff members tend to expect learned skills to transfer to more natural situations with little or no support. This is often confusing to the child for the multiple stimuli reasons described above. Planning for effective generalization is absolutely necessary. To teach a skill and then just hope that it will generalize to other contexts is unrealistic.

As described, skills must first be presented in a less distracting manner. Once skills are acquired in the context of one situation they must be supported in expanded situations. Situations must be contrived to appear progressively natural, until they are in fact natural. The timing for expanding a skill is important. If one expects the skill in a generalized setting too early, the child may not yet be able to understand the new context. Alternatively, if the skill remains in a specific context for too long, the child may associate that skill with just that context and not realize its application elsewhere.

Prompting

The use of prompting is almost universal among intervention strategies, however school staff members tend to incorrectly and overly prompt children with autism.

By definition a prompt is a support to the initial stimulus; a secondary stimulus, that is given to ensure a child’s success in completing a task, activity, etc. Correctly timing the prompt is crucial. Since a prompt is the secondary stimulus it must be timed so as not to actually become an initial stimulus. Prompting must be immediate.

Just as crucial is withholding the prompt. If a child is to learn to respond to the initial stimulus, at some point she must do so without it. Only through successful and independent

completion of a task or activity will a child learn to independently complete and generalize the targeted skill. Of course the prompt must be withheld at the right time.

Reinforcement

The use of reinforcement (sometimes called “contingency”) is also universal among intervention strategies, however school staff tend to under use this technique.

Reinforcement can be two conditions: positive and negative. (Negative reinforcement also includes the lack of any reinforcement, or the absence of the “reward”.) By definition, reinforcement is an event or situation that either increases (positive) or decreases (negative) the likelihood that a behavior will be re-attempted. For children with autism, reinforcement must be very clear *to them*, well timed and determined to be *individually* appropriate.

School staff members tend to use only natural reinforcement, which *is* preferred. However, if natural reinforcement does not provide incentive *for that child*, other reinforcement must be tried. For example, if a child does not clearly respond to verbal praise as reinforcement then other events or things need to be considered and applied until she has learned to respond to verbal praise.

Discrete Trial Intervention

When DT techniques are applied, school staff members tend not to follow appropriate protocol. Data is not recorded consistently. When various staff members work with a child on a specific skill they are often unaware of her immediate level of understanding without the notes and/or data from the previous session. Also, staff members do not appear to adhere to a definition of mastery that is more specific than an IEP/IFSP objective. When skill acquisition takes place in small steps, they must be measured in those same small steps.

In addition, school system staff members tend to fit the DT sessions into the day instead of making those sessions an integral part of the day. Sometimes DT accounts for as little as 10-15 minutes per day for a child. Sufficient time must be allowed so that a child can work on a range of skills, as well as to allow for repetition.

Adherence to a Classroom Routine

School staff members tend to place an emphasis on adherence to classroom routine, while at the same time children with autism tend to seek the comfort of routines. Staff members can mistake a child’s adherence to a routine as verbal understanding of the request. A child might learn the expected routine and therefore *appear* to follow verbal directions from the staff.

Routines should be used in such a way that they support the targeted skill, much as a prompt would. The routine should then be altered or faded so as to show true skill acquisition, as well as to foster skill generalization.

Appropriate Behavior for the Classroom

School staff members tend to mistakenly accept what appears to be active learning behavior when it is not. Appropriate behavior on the part of an autistic student can be misconstrued as participation. Some children with autism learn to sit quietly during an activity, appearing to be listening like their peers. In fact, that child might be quietly “stimming” (self-stimulation, or intense focus on an otherwise non-functional activity) and *not* focusing on the

lesson. For children with autism this quiet inattention is typically less frequent than active inattention, but is nonetheless present and more difficult to spot.

Seemingly attentive behavior that is actually *inattentive* is difficult to remedy. Active participation should be supported through a combination of positive reinforcement and prompting to ensure success to the degree that a particular child can attain.

Peers

Same-age peers currently attend school with disabled children to provide age-appropriate behavior models and to help foster the development of social behaviors. Peers tend to place multiple demands for attention upon staff. Typical children seek attention and affirmation of their accomplishments.

This in itself is a positive model for behavior. However, as the immediate and persistent demands of a peer are being met, situations arise where staff must choose between the peer and the disabled child. It is therefore imperative that staff ratios are sufficient to accommodate for the inclusion of same-age peers in the classroom without sacrificing the attentions paid to either disabled or non-disabled students.

Data Collection

Data collection is often delayed, sometimes until after the children leave, and sometimes absent. In addition, not all school staff members participate in taking data, i.e. instructional and temporary assistants often do not take data. Also, data collection is often taken only for one-to-one activities, to the exclusion of more group-oriented activities.

Data collection is an important part of any effective intervention strategy. It is important that data collection is accurate, immediate, simple and includes multiple and varied activities and behaviors. It is important that *all* staff members are trained in and participate in data collection techniques.

In addition, data must be interpreted and analyzed. It should be made available to all ARD committee members, including parents.

Accurate data is the basis for objective analysis, as subjective opinions and hypotheses may not always be accurate. For example, if the target with a child is to decrease aggressive behavior, a decrease from 50 aggressions to 30 aggressions may not “feel” different. But with statistical analysis 50 to 30 indicates a substantial decrease and an appropriate start for the intervention technique.

A Note About Flexibility

It is important to understand that some of these criticisms are for what would otherwise be considered strong, sound educational approaches for typical children or otherwise disabled children. As particular children progress, these criticisms may become less applicable. Given the autism continuum, staff must be properly trained to apply just the right measure of prompting, reinforcement, stimuli, routine, etc. for each individual child.

Appendix E: Critique of “Guidelines for Referral to a Multiple Intense Needs Class for Toddlers”

“Guidelines for Referral to a Multiple Intense Needs Class for Toddlers” (Appendices K and L, Part II of *Early Intervention for Young Children with Autism*) list criteria that are designed to help the ARD team to determine if placement in the MINC program is appropriate for a particular child. We have a number of concerns about these guidelines.

Our first concern is that they exist at all. The documents state that children who meet the “guidelines” may be “considered” for a MINC placement. This implies that *only* the children who meet the guidelines are to be considered. This is in violation to IDEA which states: “In conducting the evaluation, the local educational agency shall not use any *single procedure as the sole criterion* for determining whether a child is a child with a disability or *determining an appropriate educational program for that child.*” (emphasis added)

The most contentious criterion is that a child must have a “diagnosis or a strong suspicion of autism...or mental retardation or both” as related to a child’s particular score on the Childhood Autism Rating Scale or CARS (or on a standard IQ test, in the case of mental retardation). For a child to meet this criterion he or she must score within a certain range on a standardized test. For the CARS, it must be “moderate-severe”. A child who tests in the “mild” category on the CARS scale may simply not fit the criteria on that scale but may yet require intensive services. For example, we are aware of children with severe symptoms of autism who are extremely passive may who have received a CARS scale rating that underestimates his or her needs. Also, as noted by Bryna Seigel (see Appendix A) for children with more mild symptoms of autism, intensive intervention may be particularly effective.

Second, we object to the tone of the explanation portion that is included in the guidelines. The explanation clearly excludes the child’s family as members of the “team”. To quote from the guidelines (emphasis added): “The RECC Instructional Support Team will review the child’s record, conference with the team *and family*, and, if appropriate, observe the child. Final placement decisions are based on each child’s IFSP or IEP, the recommendations of *the school team* or Admission, Review, and Dismissal Committee, *and input from the family.*” This verbiage segregates parents and the ARD committee. As guaranteed by IDEA parents are co-participants in the ARD Committee.

Lastly, in addition to the initial criteria, the guidelines list a sub-criteria list, of which a child requires *four* to qualify for consideration in the MINC program. However, the choice of four criteria appears to be completely arbitrary. The only criterion that should be required is that a less intensive program is unable to meet the child’s needs for an appropriate education.

We note that according to the current proposal, not all children with autism will be placed in a MINC classroom. But by the year 2000 the HCPSS proposal appears to imply that all children with autism will be in these classes, and if four of these sub-criteria are required, then not all children with autism will receive intensive services.

Appendix F: Outline of a Collaborative Initiative

The following section is an outline for the development of a collaborative initiative that would strive to eliminate differences and conflicts between school system staff members and the parents of children with disabilities. This section remains in outline form because it represents only a beginning. It would be necessary for *all* interested parties – staff and parent representatives – to collaborate in the further development of such an initiative.

Overall Goals:

- To increase the participation of parents in the educational decisions affecting their children.
- To encourage and foster positive communication between parents and school staff.
- To increase parents' knowledge of their child's disability, the child's unique characteristics and learning style, and teaching and interaction techniques that might be applicable to their child.
- To increase school staff's knowledge of their students in the student's home and other non-school environments.
- To establish procedures to resolve minor conflicts before they are allowed to develop into more serious conflicts.

1. Parent Participation in Educational Decisions

The IDEA provides for parent participation in the process of making decisions that impact a child's individual education program (IEP). Parents need to have the knowledge that will allow them to participate in making decisions about their child's program. Parents need to be able to participate on par with other educational team members.

Goal - To increase the participation of parents in the educational decisions that effect their children.

Mechanism – A more user friendly system

Changes to the ARD process

Establish a regular parent- teacher conference schedule

Establish a regular communication systems between home and school

Encourage classroom visits or volunteering

Mechanism – Training

General information workshops (some topics: diagnosis, causes, characteristics; behavior management/positive behavior supports; effective education programs)

Early Intervention for Children with Autism – Part II: Parent Recommendations

Consultants (direct, child-specific training)

In-home training provided by school staff (child-specific, home and other non-school environments)

In-school training provided by school staff (child specific, school environment)

IDEA and COMAR training (co-sponsored with other agencies)

2. Positive Communication

Parents and school staff members need to be able to participate in the day to day communication exchanges that allow for the minor modifications to a student's educational program. Parents need to be able to expect to be included "in the loop".

Parents need to be informed of a child's progression or regression, while school staff will benefit from similar information as it pertains to the home and other environments, as supplied by parents.

Goal – To encourage and foster positive communication between parents and school staff.

Mechanism – Mutually Agreed Upon Expectations

School staff and parents to initially meet to discuss and agree upon communication options and preferences

Regularly scheduled meetings or phone conferences

Unscheduled meetings or phone conferences

Written communication system

Parents to be informed of conflict resolution procedures (#6)

3. Parent Knowledge

Parents need to have the knowledge that will allow them to provide effectively their own brand of intervention with their children in their home and other environments.

Parents need to have the knowledge that will allow them to participate effectively in the decision-making process for their child's educational needs.

Goal - To increase parents' knowledge of their child's disability, the child's unique characteristics and learning style, and teaching and interaction techniques that might be applicable to their child.

Mechanism – Parent Training

General information workshops (some topics: diagnosis, causes, characteristics; behavior management/positive behavior supports; effective education programs)

Consultants (direct, child-specific training)

In-home training provided by school staff (child-specific, home and other non-school environments)

In-school training provided by school staff (child specific, school environment)

Early Intervention for Children with Autism – Part II: Parent Recommendations

Mechanism – Parent Support Group

Sponsored by the school system

Co-sponsored with local support agencies

Goal – To increase parents' knowledge of the decision making process for their child's educational needs.

Mechanism – Self-advocacy Training

Sponsored by the school system

Co-sponsored with local support agencies

Referrals to organizations (MCIE, Arc, Parent's Place)

Referrals to services (Family Information and Training Center)

4. School Staff's Knowledge of Their Students

School staff personnel need to have useful knowledge of their students' abilities, challenges, behavioral patterns, etc, including knowledge of their students' tendencies in non-school environments.

Goal - To increase school staff's knowledge of their students in the student's home and other non-school environments.

Mechanism - Shared information

Observation (initial and updated)

Parent information form (initial and updated)

Parent interview (initial and updated)

Regular communication between home and school

5. Conflict Resolution Procedures

Parents and school staff need to be clearly informed of procedures to facilitate conflict resolution.

Goal - To establish procedures to resolve minor conflicts before they are allowed to develop into more serious conflicts.

Mechanism – procedures to be determined

Call or note to team leader? to principal? to supervisor?

Call or note to parent support representative?

Call or note to ombudsperson?

Early Intervention for Children with Autism – Part II: Parent Recommendations

Calls logged?

Period of findings?

Response meeting?

Written responses?

Conflict resolution training for some staff?