

Rhode Island Autism Project

***Final Report: The State of Services and Treatment for Children
with Autism Spectrum Disorders in Rhode Island***

Prepared by

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On behalf of the Rhode Island Autism Project Committee

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INTRODUCTION

Background On Autism

“Infantile Autism” was a term created originally in 1943 by Leo Kanner, a researcher at Johns Hopkins University. He used it to describe a group of children in his practice who were extremely solitary despite the presence of others, and who appeared caught up in repetitive movements and routines and had little or no speech or communication skills. Children that fit Kanner’s definition of Autism were generally severely impaired. During the same time in Germany a psychiatrist named Hans Asperger coined the term “Asperger’s Syndrome” to describe a higher functioning group of children who had normal rates of language development but social impairments similar to the children described in Kanner’s research. In 1980 DSM-III introduced the term Pervasive Developmental Disorder for Infantile Autism and all related conditions.

Autism Spectrum Disorder (ASD) is a term used to describe a group of developmental disorders which includes Autism, Pervasive Developmental Disorder Not Otherwise Specified and Asperger’s Syndrome. Throughout this report we refer deliberately to these syndromes collectively as ASD because this term accurately describes and includes a broad range of children.

The exact cause of autism remains unclear. In the past Kanner, Bruno Bettelheim (1967) and others originally thought that it was a kind of psychosis that resulted from being raised by cold or aloof parents. Some researchers insisted that autism was an early form of schizophrenia. These theories have since been completely disproven; virtually no reputable autism professional subscribes to either of them. Currently ASD is thought to be a biologically-based disorder that is caused by a variety of subtle abnormalities in brain structure and functioning.

Because these abnormalities come in many different forms and are often difficult to detect, there is no biological test or marker to prove the existence of ASD. Therefore, diagnosis of ASD is done by a qualified specialist through observations of a child’s behavior and examination of his or her social history. A variety of scales and tests are available to assist in reaching a diagnosis. This process can be difficult and at times imprecise.

There is a triad of symptoms that appear in all forms of ASD. First, children with ASD have difficulty with reciprocal social interaction; they may not show an awareness of feelings of others and demonstrate difficulty in making friendships. They may not seek help or comfort when hurt or sick, and they may not engage in imitative play or social play.

Second, children with autism may have marked difficulty with both verbal and nonverbal communication. They may have no speech, speech that is abnormally high, loud, or soft, or they may parrot back phrases without understanding their meaning (sometimes

referred to as echolalia.) Children with ASD who have speech often reverse pronouns. Nonverbal communication issues often include lack of eye contact, facial expressions, and body postures normally used in conversations.

Finally, children with ASD often show a restricted set of activities and interests. They may engage in repetitive body movements like spinning, hand-flapping or headbanging. Children with ASD may become preoccupied or abnormally fixed on a part of a toy or an object, or may have an obsessive interest in one area. They may also become severely panicked over a change in their environment and/or insist on following set routines or rituals.

Generally within the spectrum of ASD, children diagnosed with autism have the most severe symptomology, children with PDD-NOS more moderate symptomology and children with Asperger's Syndrome have mild to moderate symptomology. However, the degree of disability can vary widely, regardless of the label. One of the puzzles of educating a child with ASD is that s/he may function at mild to moderate level of disability in some areas and a severe and profound level in others.

History of the Rhode Island Autism Project

The Rhode Island Autism Project (RIAP) came about as a result of growing concern among special educators and parents of children with autism about the resources and programs available to children with autism, PDD-NOS and Asperger's Syndrome in Rhode Island. The Autism Society of Rhode Island (ASRI) formed an ad hoc committee of parents, therapists, administrators, autism specialists and educators in early 1997. The charge of this committee was to address issues concerning gaps in education for children with PDD and autism. ASRI and the Rhode Island Department of Education (RIDE) then arranged for and funded three meetings of the Ad Hoc committee which were held at the Department of Education and facilitated by Lesa Andreasen from Freeport, Maine. For the final two meetings the committee was expanded to include medical specialists, private agency staff, teacher union representatives and related service personnel. The purpose of these meetings was to generate a list of recommendations for improving services for children with ASD in Rhode Island.

The group noted at least 6 issues around education of children with ASD in Rhode Island. They were:

- Little or no coordination or consistency in programming across school districts for children with ASD
- No consistency in the identification and diagnosis of children in the ASD population
- No ongoing coordination between the medical professionals and Multidisciplinary Teams in schools
- Lack of knowledge about ASD among special educators in public schools
- Lack of information or training available on ASD
- Lack of support to regular educators serving ASD children in inclusionary settings

The group also reached consensus on a mission statement. It was to develop a *“comprehensive, coordinated system of services or resources for meeting the needs of people with PDD/Autism and their families including education, health, vocational/career, and social/community.”*

It became clear from issues raised in these meetings that Rhode Island needed to develop a system of educational services for meeting the needs of children with Autism Spectrum Disorders in the state. A separate committee was formed to pursue these issues. Over the summer the committee (which would soon become the Rhode Island Autism Project) developed a grant proposal and began designing a needs assessment. In September of 1997 RIDE awarded a grant to RIAP to pursue these issues. Our first step was to conduct a major needs assessment of children with autism in the state of Rhode Island. Data were collected through November of 1997 to April of 1998. These data include information from interviews with Special Education Directors, directors of private agencies specializing in ASD, Early Intervention Directors, diagnosticians who specialize in ASD and surveys of educators, parents and pediatricians. This final report is the result of that research.

METHODOLOGY

When we first began to design this study we considered the array of needs presented by children with ASD. Because they are serviced by a variety of providers in many different environments we knew it was important to survey or interview as many different groups of ASD professionals as possible. We also felt that including a variety of research populations would allow for a diversity of approaches and perspectives. In this section we will explain why we chose to include each source of data, describe it, describe methods of interview and survey design, address techniques for gathering data, methods of follow up and completion rates.

Special Education Director Interviews

We chose to include Special Education Directors and Assistant Directors for all Local Educational Agencies (LEAs) in our needs assessment because we wanted to get an accurate understanding of prevalence, classroom placements, and services for school aged children with ASD in Rhode Island. We felt that SPED directors, due to their administrative viewpoint, would be able to give us a succinct snapshot of their LEAs. In October of 1997 a letter which provided an introduction to the Rhode Island Autism Project was mailed to all Special Education Directors and Assistant Directors for all LEAs (please see Appendix I-A). In this letter we also requested an interview with each SPED Director. We chose to conduct interviews in person to 1) assure that we would receive accurate information on complex questions and 2) as a way of eliciting cooperation and involvement of LEAs in the project's future. Interviews were scheduled by telephone in the ensuing weeks. Interview questions were faxed at least several days prior to each meeting so that directors could do necessary preparation and background research. The interview protocol (please see Appendix I-B) for this group was designed in consultation with the RIAP committee and several special education directors of LEAs in Rhode Island.

All Special Education Directors chose to participate in the study with the exception of New Shoreham¹, for a total of 29 districts and response rate of 100%. Interviews were conducted from November 14, 1997 through January 8, 1998. I met with each SPED Director and/or Assistant Director at their office for each appointment². All interviews were tape recorded and ranged in length from 25 minutes to one hour, with an average time of about 40 minutes. Data from interview tapes were later entered into spreadsheets and were used to create a brief narrative on each LEA. A preliminary report and narrative were mailed to each LEA for final review and revision prior to issuing the final

¹ New Shoreham (Block Island) currently has no children with ASD, nor has the district served any in the recent past. Special Education Director Ken Andrew therefore chose, with our full support, not to participate.

² One interview was conducted over the telephone and another via mailed questionnaire, due to SPED Director time constraints.

report (please see Appendices I-C and I-D). It was necessary to issue preliminary reports to this population because a significant minority of interviewees did not have complete or accurate information on their LEA at the time of our interview.

Private Agency Director Interviews

By including interviews with directors of private agencies in our needs assessment, we hoped to 1) get an accurate understanding of the kinds of services that these agencies provided for children with ASD and 2) examine the differences between private agency and LEA ASD services. In November of 1997 a letter which provided an introduction to RIAP was mailed to all directors of private agencies in Rhode Island that identified treating children with ASD as a specialty and/or had at least several children with ASD in their current caseload. Agencies included Groden, Bradley, Trudeau, Sargent, Meeting Street and Northern Rhode Island Collaborative³. In this letter we also requested an interview with each agency director (please see Appendix I-E). We chose to conduct interviews in person for the same reasons that we did in person interviews with LEA special education directors. Interviews were scheduled by telephone and interview questions were faxed at least several days prior to each meeting so that directors could do necessary preparation and background research. The interview protocol (please see Appendix I-F) for this group was designed in consultation with the RIAP committee with special assistance from Pat Rakovic.

All Private Agency Directors chose to participate in the study for a total of 6 agencies and response rate of 100%. Interviews were conducted from December 29, 1997 through January 27, 1998. I met with the agency director and other staff members at their facility for each appointment⁴. All interviews were tape recorded and ranged in length from 30 minutes to two hours, with an average time of about 1 hour. Data from interview tapes were later entered into spreadsheets and were used to create a brief narrative on each agency. It was unnecessary to send out a preliminary report to each agency director due to the thoroughness with which they presented information at the time of the interview. Small points of clarification were addressed over the telephone.

Early Intervention Director Interviews

Our justifications for interviewing Early Intervention (EI) Directors are identical to those for the SPED director interview. In addition, we wanted to understand more about services available to the youngest children with ASD in our state. In November of 1997 a letter which provided an introduction to RIAP was mailed to all directors of Early Intervention regions. In this letter we also requested an interview with each agency

³ The Northern Rhode Island Collaborative is a public agency, but performs functions very similar to the private agencies in our state. It is for this reason that it was included in the private agency sample.

⁴ In two instances I interviewed the agency director only. In all other cases I conducted group interviews with several members of the staff and/or administration of each agency.

director (please see Appendix I-G). We chose to conduct interviews in person for the same reasons that we did in person interviews with LEA special education directors and private agency directors. Interviews were scheduled by telephone and interview questions were faxed at least several days prior to each meeting so that directors could do necessary preparation and background research. The interview protocol (please see Appendix I-H) for this group was designed in consultation with the RIAP committee with special assistance from Ruth Schennum.

All Early Intervention directors chose to participate in the study for a total of 5 regions and response rate of 100%. Interviews were conducted from January 29, 1998 through February 26, 1998. I met with each regional director at her office for each appointment. All interviews were tape recorded and ranged in length from 25 minutes to fifty minutes, with an average time of about 30 minutes. Data from interview tapes were later entered into spreadsheets and were used to create a brief narrative on each EI region. It was unnecessary to send out a preliminary report to each EI director due to the completeness of information provided at each interview. Small points of clarification were addressed over the telephone.

Diagnostician Interviews

We included diagnosticians in our needs assessment because we felt it was essential to understand how children with ASD were being diagnosed. What criteria were used? Did diagnosticians ever delay an ASD diagnosis? How were family needs, expectations and input incorporated in an assessment? To address these questions we conducted telephone interviews with the eight most often utilized diagnosticians and/or diagnostic health groups for children with ASD in Rhode Island. The sample is taken from the eight diagnosticians most often cited by SPED directors in their discussions of outside evaluations. The RIAP committee was also in agreement that these diagnosticians did the vast majority of ASD evaluations in our state. All eight agreed to be interviewed for a response rate of 100%.

We chose to conduct telephone interviews in order to afford ease and flexibility in scheduling⁵. The interview protocol (please see Appendix I-I) was designed in consultation with the RIAP committee and Barry Prizant. Questions were faxed to diagnosticians a few days ahead of time to allow for adequate preparation time. Diagnostician interviews were conducted in late spring of 1998 and were tape recorded. Interviews ranged from 8 to 20 minutes, with the average interview taking about 10 minutes. Interview data were later entered into a spreadsheet. Due to the completeness of answers, no follow-up was necessary.

⁵ On the whole, diagnosticians are an extremely busy lot; many of these interviews were done when they had a few spare moments between appointments and meetings.

Survey of Autism Professionals

We felt that we could not get an accurate picture of services for children with ASD in Rhode Island without surveying the people who were “in the trenches” as direct service providers. We therefore created a survey designed for a variety of ASD paraprofessionals and professionals⁶ which contained questions about caseload, diagnostic tests, educational interventions, home carryover techniques and preparedness to work with children with ASD (please see Appendices I-J and I-K). The same survey was distributed to paraprofessionals and professionals in LEAs, private agencies, and Early Intervention regional offices. The survey was designed in consultation with the RIAP committee and a pilot was tested by several professionals. The survey was designed to take no more than 20 minutes to complete. Care was taken to assure that members of the RIAP committee and those who participated in the pilot did not fill out the final survey; the survey was not sent to these groups and they were instructed not to complete one.

This survey was given to Special Education, Private Agency and EI Directors at the time of each interview⁷ with distribution instructions. Each survey packet contained a letter of introduction and instruction, the survey and a self addressed stamped envelope. Directors were asked to distribute the survey to up to 50 respondents including at least one complete MDT and other professionals and paraprofessionals who worked with children with autism. We limited the total number of respondents to 50 for each district so that large LEAs’ results would not skew the overall findings. Each survey packet and return envelope was numbered so that we could track response rates by district, agency or EI region.

The survey was distributed between December of 1997 and February of 1998. In total 914 surveys were administered. In late February and March at least one attempt at telephone follow up was made with directors of LEAs, agencies or EI regions with less than a 50% response rate. Followup attempts were limited by staffing and funding constraints. Surveys were catalogued, entered into spreadsheets and destroyed as they came in. The cut off date for survey return was May 1st. Response rates for individual school districts, EI regions and private agencies varied from a high of 100% to a low of 0%. The overall response rate was 40% with a total of 368 surveys returned.

⁶ Paraprofessionals and professionals surveyed included Classroom Aides, Early Childhood Special Educators, Educational Diagnosticians, Occupational Therapists, Physical Therapists, School Principals, School Psychologists, School Social Workers, Special Education Aides, Special Education Teachers, Speech Language Pathologists, Regular Education Teachers and Administrators.

⁷ For ten of the LEAs, surveys were mailed to directors after the interview because they were not ready for distribution at the time of the interview. For one LEA surveys were mailed directly to autism professionals by RIAP at the SPED director’s request.

Survey of Parents

We felt that parent perspectives were essential to understanding services for children with ASD in Rhode Island; it is parents who know their ASD child best and who have also had direct experience with a variety of service providers and agencies. The survey of parents (please see Appendix I-M) was created in consultation with the RIAP committee and leadership from the Autism Society of Rhode Island (ASRI). It was pilot tested by several parents and designed to take around 25 minutes to fill out. Care was taken to assure that members of the RIAP committee and those who participated in the pilot did not fill out the final survey; it was not sent to these individuals and they were asked not to complete the questionnaire.

The survey was administered to a total of 300 parents. Each survey packet contained a letter of introduction and instruction (please see Appendix I-L), the survey and a self addressed stamped envelope. The survey was administered between January and March of 1998. The sample was drawn almost completely from parent support organizations. 200 parents from ASRI, 40 parents from Families for Early Autism Treatment (FEAT) and 20 parents from Mothers Offering Support Together (MOST) were sent copies of the survey by each of those organizations. The remaining 60 surveys were sent to smaller support groups and to individual parents who called our office and requested participation. Care was taken to assure that duplicate names across organizations were eliminated, but some parents still reported receiving 2 copies of the survey.

This practice of recruiting from parent support groups allowed a simple solution to problems of recruitment and confidentiality, but it also meant that parents who filled out the survey were likely to be more informed and educated on ASD issues than is typical. The reader should remain cognizant of this fact when considering our results from this survey.

Due to issues of confidentiality, the researcher did not have access to the names of participants; therefore there was no means of direct followup. In early April parent organizations were asked to remind members to return their surveys.

Surveys were catalogued, entered into spreadsheets and destroyed as they came in. The cut off date for survey return was May 1st. A total of 87 surveys were returned for a response rate of 29%.

Survey of Pediatricians

The committee felt it was important to survey pediatricians because they are the first group of professionals who are likely to have contact with children with ASD. It is also pediatricians who must refer children with ASD symptoms out to diagnosticians who specialize in this area. We wanted to find out about their background in ASD, their general and ASD caseloads and the diagnosticians to whom they referred. The survey of pediatricians (please see Appendix I-P) was designed in consultation with the RIAP

committee and several area pediatricians. It was designed to take no more than 10 minutes to fill out.

The survey was administered by mail to selected members⁸ of the American Academy of Pediatrics and the American Academy of Family Practice in March of 1998. Each survey packet contained a letter of introduction and instruction on letterhead from the American Academy of Pediatrics or the American Academy of Family Practice and signed by the chapter president (please see Appendices I-N and I-O), the survey and a self addressed stamped envelope.

Follow up on the Pediatrician's Survey was not possible due to anonymity issues. Surveys were catalogued, entered into spreadsheets and destroyed as they came in. The cut off date for survey return was May 1st. In total, 68 surveys were returned for a response rate of 30%.

The response rates for all research populations are summarized in Table 1 below.

TABLE 1 Summary of Response Rates

	Interviews Requested/Surveys Administered	Interviews Granted/Surveys Returned	Response Rate
LEA Director Interviews	29	29	100%
Private Agency Director Interviews	6	6	100%
EI Region Directors Interviews	5	5	100%
Diagnostician Interviews	8	8	100%
Educator Survey	914	368	40%
Parent Survey	300	87	29%
Pediatrician Survey	230	68	30%

Comparisons of Met and Unmet Needs Across The Seven Research Populations

Finally, all research populations were asked three identical open-ended questions on met needs, unmet needs, and barriers to services for children with ASD (see for example Appendix I-P). This practice allowed us to get direct, comparable data across all populations and also gave participants an opportunity to present their concerns, ideas, and vision to us.

⁸ Several area pediatricians kindly went through membership lists for the Rhode Island chapter of each organization and eliminated names of practitioners who were no longer in practice, practiced out of state, or did not have a general pediatric practice as a part of their caseload.

Findings

Special Education Director Interviews

The findings for the Special Education Director interviews are summarized in Tables 2 through 10. In Table 2 prevalence of ASD by type and age for each LEA is presented. The majority of children with ASD are in preschool or elementary school and appear to be fairly evenly distributed across different types of classrooms and placements (with the exception of the Inclusion without Aide category). Perhaps the most striking finding in this table is that the total number of ASD cases reported by SPED directors is 420. This is about 3.5 times higher than the number of 120 cases reported in the latest RIDE Statistical Profile of Special Education. There are at least four reasons for this discrepancy. First, the RIDE definition of autism, which is based on Federal guidelines, does not necessarily allow for PDD and Asperger's cases to be included under the autism category; this limitation could result in an undercount of many cases. Second, twenty LEAs report placing all preschoolers with ASD in the category of Developmentally Delayed (DD) and another five reported placing some preschoolers with ASD in the DD category. Third, school districts report placing children with ASD in other census categories including Behaviorally Disordered (9 LEAs), Mentally Retarded (7 LEAs), Other Health Impaired (10 LEAs), Learning Disabled (6 LEAs), Speech or Language Disordered (5 LEAs) and Multi-Handicapped (3 LEAs). Additionally, SPED directors reported that they place some children with ASD in other disability categories because of parent resistance to an ASD diagnosis. Fourth, some SPED directors reported that when a child with disabilities is switched to an ASD diagnosis, their census category may not be changed when reporting to the state. Finally, some SPED directors reported a natural increase in the number of ASD cases since the last SPED census.

The remainder of the tables in this section are presented by collaborative⁹ and for the state as a whole. SPED directors report that the majority of children with ASD who are placed out of district are placed in Groden, Sargent, Bradley, Northern Rhode Island Collaborative and South Coast in descending order (see Table 3). The vast majority (69%) of directors report that their MDTs refer out for an ASD diagnosis, 21% report that the MDT refers out for selected cases and 10% report that their MDTs make an ASD diagnosis. The most commonly used diagnosticians or diagnostic groups in descending order are Child Development Center, Bradley, Groden, Dr Hirschberg, Dr Kiessling, and Dr. Walters (see Table 4).

⁹ In this report, the term "collaborative" refers to an aggregation of statistics for towns within each collaborative region; it *does not* refer to specific education programs that may be offered by a collaborative (ie. Northern Collaborative programs) unless specifically noted as such.

TABLE 2 Prevalence of ASD by Type and Age (1 of 2)

District (Director's Name)	Reported # of Autistic/ASD Children					Age Distribution					# in Different Types of Classrooms					
	Autism Cases Reported by SPED	PDD Cases Reported by SPED	Asperger's Reported by SPED	Total ASD Cases Reported by SPED	RIDE # of Cases	Difference	Pre-School	Elementary	Junior High	High School	Post High School	Full Time Inclusion with Aide	Full Time Inclusion without Aide	Self Contained Classroom	Combination of Inclusion and Self Contained Placement	Out Of District Placement
East Bay Collaborative																
Barrington (Ann Defanti)	3	10	5*	17	6	11	7*	2*	2	0	0	DU	DU	DU	DU	2
Bristol Warren (Judith Saccardo)	6	2	1	9	5	4	1	5	3	0	0	3	1	0	3	3
East Providence (Ann Carretti)	2	4*	3*	9	7	2	DU	DU	DU	DU	DU	7	0	1	0	1
Newport (Mary Connolly)	2	10	0	12	2	10	5*	5*	1	1		0	0	5*	5*	2
Newport County Regional (Donald DeCosta)	12	15	3	30	7	23	DU	DU	DU	DU	DU	8	0		18	5
Subtotal	25	41	12	77	27	50	13	12	6	1	0	18	1	6	26	13
West Bay Collaborative																
Cranston (Mary Carter)	DU	DU	DU	26	5	21	5*	5*	5*	0	0	4	2	10	7	2
Coventry (Michael Capalbo)	4	2	2	8	2	6	2	4	DU	2	DU	2	0	2	3	1
Northwest Special Educ. Region (Patricia Kline)	1	6	3	18	3	15	5	3*	1	1	1	1	0	9	6	2
Providence (Robert Lynch)	25*	22*	3	50	12	38	DU	DU	DU	DU	DU	10	0	20	5	9
West Warwick (Robert Sherman)	1	4	0	5	4	1	3	0	0	1	1	0	0	0	0	5
Warwick (Steve Lowery)	12	30*	6	48	6	42	6	4	6	6	DU	3	0	10	6	6
Subtotal	43	64	14	155	32	123	15	12	12	10	2	17	2	41	21	25
Southern Collaborative																
Chariho (Jeannette Roelf-Rothwell)	DU	DU	2	12	4	8	5	7	0	0	0	5	1	0	3	2
East Greenwich (Joan Colwell)	4	7	6	17	14	3	8	8	0	1	0	4	0	0	12	2
Exeter-WestGreenwich (Maureen Walekjo)	DU	DU	1	9	3	6	3	3	2*	1		1*	0	1*	1*	0
Jamestown (Helen O'Hara)	0	4	1	5	0	5	2	3	0	0	0	5	0	0	0	0
North Kingston (Daniel McGregor)	1	6	2	9	0	9	4*	5*	0	0	0	5	0	0	4	0
Narragansett (Sandy Keenan)	0	7*	1	8	1	7	6	2	0	0	0	6	1	0	0	1

District (Director's Name)	Reported # of Autistic/ASD Children						Age Distribution				# in Different Types of Classrooms					
	Autism Cases Reported by SPED	PDD Cases Reported by SPED	Asperger's Reported by SPED	Total ASD Cases Reported by SPED	RIDE # of Cases	Difference	Pre-School	Elementary	Junior High	High School	Post High School	Full Time Inclusion with Aide	Full Time Inclusion without Aide	Self Contained Classroom	Combination of Inclusion and Self Contained Placement	Out Of District Placement
South Kingston (Raymond Healey)	2	5	0	7	2	5	3	2				1	1	2	0	1
Westerly (Mark Hawk)	9*	5*	4*	18	3	15	6	10	1	1		16	0	2		0
Subtotal	16	34	17	85	27	58	37	40	3	3	0	43	3	5	20	6
Northern Collaborative																
Burrillville (Julian MacDonnell)	2	3	0	5	1	4	1	3	1	0	0	4	0	1	0	1
Central Falls (Arlene Garrison)	2	1	1	4	3	1	0	1	1	1	1	0	0	0	1	3
Cumberland (Jonathan Dyson)	6	7	3	16	7	9	4	7	3	2	0	0	1	0	8	2
Johnston (Steve Pereira)	1	4	2	7	0	7	5*	0	2	0	0	2	0	0	5	0
Lincoln (William Anderson)	2	6	2	10	10	0	4*	4*	0	1	0	0	0	6	0	4
North Providence (Robert Asekoff)	DU	DU	DU	12	4	8		DU	DU	DU	DU	DU	DU	4	DU	1
North Smithfield (Robert Fricklas)	1	1	0	2	0	2	0	1	0	0	0	0	0	0	0	1
Pawtucket (Cathy Fusco)	14	14*	2	30	5	25	2	9	2	1	0	14	0	0	4	4
Smithfield (Michael Moriarty)	DU	DU	DU	7	0	7	DU	DU	DU	DU	DU	2	2	0	1	2
Woonsocket (Denise Button)	9	3	0	12	4	8	6	6*	0	0	0	0	0	4	4	2
Subtotal	23	25	10	105	34	71	30	32	11	6	1	8	3	15	19	20
TOTAL	107	164	53	422	120	302	95	96	32	20	3	86	9	67	86	64

NOTE: DU is data unavailable; * denotes estimated #.

TABLE 3 Out of District Placements

	East Bay Collaborative	West Bay Collaborative	Southern Collaborative	Northern Collaborative	Total for Rhode Island
Bradley	4	2	0	1	7
Groden	3	8	2	8	21
Sargent	0	7	1	0	8
Trudeau	0	0	0	0	0
New England Autism Center	0	1	0	0	1
Boston Hegashi	0	0	0	1	1
May Institute	0	0	1	0	1
Rehab New England	0	0	0	0	0
Meeting Street School	0	0	1	0	1
Northern RI Collaborative	0	0	0	7	7
South Coast	6	0	0	0	6
Spurwink	0	0	0	2	2
Valley Community School	0	0	0	2	2
Meadow Ridge	0	0	0	1	1
Private Nursery School/ABA	0	0	2	0	2
Total for Each Collaborative	13	18	7	19	57

TABLE 4 Methods of Diagnosis and Use of Outside Diagnosticians

	East Bay Collaborative	West Bay Collaborative	Southern Collaborative	Northern Collaborative	Total for Rhode Island	Percentage
MDT Makes ASD Diagnosis	0	1	1	1	3	10%
MDT Refers Outside for Select Cases	1	2	0	3	6	21%
MDT Always Refers Outside For An ASD Diagnosis	4	3	7	6	20	69%
Dr. L. Hirschberg	2	1	3	2	8	28%
Dr. K. Cumoso	0	0	1	0	1	3%
Dr. A. Walters	0	0	3	2	5	17%
Dr. K. Plummer	0	0	0	3	3	9%
Dr. B. Plummer	0	0	0	1	1	3%
Dr. K. Kerman	1	2	0	0	3	10%
Child Development Center	3	3	6	2	14	48%
Dr. L. Kiessling	2	2	1	2	7	24%
Dr. K. Blane	0	0	0	0	0	0%
Blackstone Valley	0	0	0	2	3	10%
Bradley	3	3	5	3	14	48%
Groden	1	2	2	3	8	28%
Butler	0	0	1	0	1	3%
Early Intervention	2	1	0	0	3	10%
Newington	0	0	1	0	1	3%
Yale	0	0	1	0	1	3%
Dr. D. Tweekman- Collins	0	0	1	0	1	3%
Dr. Canton	0	2	0	0	2	7%
Dr. Hunt	0	1	0	0	1	3%
Sargent	0	1	0	0	1	3%

The vast majority of SPED directors (93%) report that each child's progress is tracked through IEP Goals and 72% also reported that IEP goals are used to link assessment to instructional strategies. Other linkage methods were ABA data (14%) and diagnostic testing (17%). 93% of SPED directors also reported that MDT shared information about ASD children through weekly meetings and/or informal communication (14%, see Table 5).

TABLE 5 MDT Procedures and Methods of Tracking Progress

	East Bay Collaborative	West Bay Collaborative	Southern Collaborative	Northern Collaborative	Total for Rhode Island	Percentage
Progress is Tracked Through IEP Goals	5	6	6	10	27	93%
Techniques Used to Link Assessment						
IEP Goals	4	4	3	10	21	72%
Data From ABA	1	1	2	2	4	17%
Diagnostic Tests	1	1	2	2	5	21%
Methods By Which MDT Share Information						
Weekly Meetings	5	5	7	10	27	93%
Informal Communication	2	1	1	2	4	21%

ASD treatment techniques used by Occupational Therapists (OTs), Speech Language Pathologists (SLPs) and Social Workers (SWs) are summarized by collaborative in Table 6. The most common techniques used by OTs with ASD children are Brushing, Swings and Trampolines. For SLPs they are Social Skills Groups and one on one instruction. The majority of school SWs work directly with families of ASD children, usually helping them to access services and other agencies.

In Table 7 the role of parents in assessment and IEP creation as well as methods of home carryover are addressed. LEAs report 100% involvement of parents in both IEP creation and diagnosis and assessment. The most common method of home carryover is a notebook between school and home (90%) followed by meetings at school (59%), visits to home by school personnel (45%), phone calls (34%) and home programs (34%).

Inservicing needs and current inservicing practices are summarized in Table 8. Almost all SPED directors (93%) noted a need for more inservicing of regular education staff on ASD and 83% noted a need for more inservicing of special education staff as well as an interest in personally receiving more information on ASD education models. Current inservicing procedures are also addressed in this table; 83% of directors report that their staff currently receive inservice training on ASD. The most common methods of inservicing are bringing in outside consultants (66%) and sending staff out to conferences or workshops (38% and 55% respectively). While many SPED directors expressed a wish to provide time off and reimbursement for training, in reality only 17% of districts reported providing time off for training and 34% reported funding training. This is clearly an area of unmet need.

TABLE 6 ASD Treatment Techniques Used by Occupational Therapists (OTs), Speech Language Pathologists (SLPs), and Social Workers (SWs)

	East Bay Collaborative	West Bay Collaborative	Southern Collaborative	Northern Collaborative	Total for Rhode Island	Percentage
OT Methods Used						
Trampoline	2	0	3	2	7	24%
Brushing Techniques	4	1	4	2	11	38%
Calming Techniques	0	1	1	0	2	7%
Swings	3	2	4	5	14	48%
Unsure of Techniques Used	0	2	0	4	6	21%
Noted Need for More OTs	0	0	2	1	3	10%
Speech Language Methods Used						
Social Skills Groups	4	2	5	7	18	62%
Communication Boards	1	0	1	0	2	7%
Work One-on-One With Students	2	2	6	4	14	48%
Unsure of Techniques Used	0	0	0	2	2	7%
Noted Need for More SLPs	1	0	1	1	3	10%
Use of Social Workers						
Work With ASD Students	1	2	5	3	11	38%
Work With ASD Families	4	4	5	6	19	66%
Noted Need for More SWs	1	0	1	1	3	10%

In Table 9 design of behavior and transition plans is addressed. Behavior plans are often designed by more than one individual, with school psychologists (62%), MDT/IEP teams (52%) and teachers (45%) the most likely to be involved. Transition plans include in descending order meetings (79%), child visiting the new school (72%), visits by new teacher to child's classroom (62%) and child spending time in both classrooms (41%).

Finally, Table 10 addresses specific educational techniques used by LEAs for children with ASD. Applied Behavioral Analysis (ABA) is the most commonly used technique followed by Picture Exchange System (PECS), Social Stories and outside agency programming.

TABLE 7 Role of Parents in Diagnosis, IEP Creation, and Home Carryover

	East Bay Collaborative	West Bay Collaborative	Southern Collaborative	Northern Collaborative	Total for Rhode Island	Percentage
Parents Are Involved in Diagnosis and Assessment	5	6	8	10	29	100%
Parents Are Involved in IEP Creation	5	6	8	10	29	100%
Phone Calls	2	1	4	6	13	45%
Notebooks Between Home and School	5	4	8	9	26	90%
Meetings at School	2	4	8	6	20	69%
Visits to Home By School Personnel	2	4	4	4	14	48%
Home Programs	1	3	4	3	11	38%

TABLE 8 Staff Inservicing Needs and Availability of Inservicing

	East Bay Collaborative	West Bay Collaborative	Southern Collaborative	Northern Collaborative	Total for Rhode Island	Percentage
Regular Education Staff Need More ASD Training	5	6	7	9	27	93%
SPED Staff Need More ASD Training	5	5	6	8	24	83%
Director Wants Information About ASD Education Models	5	5	8	6	24	83%
Staff Currently Receive ASD Inservice Training	4	4	6	10	24	83%
District Brings In Outside Specialists	2	5	8	5	20	69%
District Has Own Training Programs	1	2	6	3	12	41%
District Sends Staff Out to Conferences	4	3	5	5	17	58%
District Sends Staff Out to Workshops	3	3	4	3	13	44%
District Sends Staff Out to Private Agencies	2	2	2	3	9	31%
District Sends Staff Out to Classes or Courses	2	0	2	1	5	17%
District Pays for Training	1	3	4	4	12	41%
District Provides Time Off for Training	1	3	2	2	8	28%

TABLE 9 Design of Behavior and Transition Plans

	East Bay Collaborative	West Bay Collaborative	Southern Collaborative	Northern Collaborative	Total for Rhode Island	Percentage
Who Designs						
Behavior Plans						
School						
Psychologist	1	5	4	8	18	62%
Child's Teacher	1	2	4	6	13	45%
Occupational						
Therapist	1	1	0	2	4	14%
Social Worker	1	2	1	2	6	21%
MDT/IEP Team	5	4	5	4	18	62%
Outside Consultant	1	1	3	2	6	24%
Transition Plans						
Child Visits New						
School	5	6	5	5	21	72%
New Teacher Visits						
Child's Classroom	3	4	5	6	18	62%
Child Spends Time						
in New and Old						
Classrooms	2	4	3	4	13	45%
Transition Plan						
Meetings Are						
Held	4	5	7	7	23	79%

TABLE 10 Use of Specific Educational Techniques for Children With ASD

	East Bay Collaborative	West Bay Collaborative	Southern Collaborative	Northern Collaborative	Total for Rhode Island	Percentage
ABA						
Pre-School	3	4	4	4	15	52%
Elementary	1	4	4	2	11	38%
Junior High	1	2	1	0	4	14%
High School	0	1	1	0	2	7%
Social Stories						
Pre-School	2	0	1	2	5	17%
Elementary	1	0	2	2	5	17%
Junior High	0	0	0	0	0	0%
High School	0	0	0	0	0	0%
TEACCH						
Pre-School	0	1	2	0	3	10%
Elementary	0	0	2	0	2	7%
Junior High	0	1	1	0	2	7%
High School	0	0	1	0	1	3%
Picture Exchange System						
Pre-School	5	3	5	4	17	59%
Elementary	3	4	3	1	11	38%
Junior High	1	1	0	0	2	7%
High School	0	0	0	0	0	0%
Behavior Contracting						
Pre-School	1	0	0	2	3	10%
Elementary	1	0	0	2	3	10%
Junior High	1	1	0	1	3	10%
High School	0	1	1	0	2	7%
Outside Agency Programming						
Pre-School	1	1	1	2	5	17%
Elementary	1	2	1	1	5	17%
Junior High	1	1	0	1	3	10%
High School	0	1	0	0	1	3%

We end this discussion of findings with a brief narrative description of each LEA. These are provided in order to give the reader a qualitative understanding of the kinds of ASD programs and services available throughout Rhode Island. All data presented in these profiles are taken directly from SPED director interviews. Profiles are presented alphabetically.

Profile of Barrington

Barrington is a small town located in the east bay region of Rhode Island. The district serves about fifteen children with ASD.

The district utilizes as many resources as possible in meeting the educational needs of children with ASD. Special Education Director Ann DeFanti notes, "Whatever is available to us is what we will use. That's the nice part of being in Barrington." Applied Behavioral Analysis (ABA), PECS System (PECS) and Social Stories are used with children at the preschool level as well as a variety of augmentative communication techniques. These are all set within a highly structured framework. Interventions with older children are designed to address burgeoning social issues.

The district has a classroom for grades K-3 that serves only children with ASD. An occupational therapist (OT) and the entire IEP team use a variety of sensory integration (SI) techniques and tech access strategies. Children receive OT in the classroom. The district has recently started to use the Choosing Options and Accommodations for Children (COACH) approach as well. Speech language therapists and SWs run Social Skills Groups for ASD students. A school SW provides support groups to families of children with ASD. Home visits by the teacher and SW are conducted once a month.

Profile of Bristol-Warren

Bristol-Warren is made up of the towns of Bristol and Warren in the east bay region of Rhode Island. The district has approximately 9 students with ASD.

Goals are measured through the IEP process and baseline data. For example, when one child had issues with anxiety the teacher recorded all instances of anxiety. The district consulted with the Groden Center and used this data to create relaxation techniques. Data from discrete trials are also collected.

Bristol-Warren uses an eclectic combination of educational methods that are created in consultation with the Groden Center and are tailored to each student. The program is language based. Generally, picture schedules and home programs are used with preschoolers. These techniques are used with elementary students as well as Social Stories. Middle school students use related techniques and computers. At the middle school level teachers place a great deal of emphasis on the mastery of social skills through training in idiomatic language, peer tutoring and cooperative learning. The district also utilizes Social Skills Groups, communication boards, social scripts, activity schedules and a variety of forms of assistive technology. The treatment team designs behavior plans with occasional consultation from the Groden Center. Bristol-Warren has a close relationship with the Groden Center and consults with them continually on ASD children. Transition plans include inservicing for staff if it is needed, and are designed for the specific needs of each child. One way that the district has eased transition stress

for some students is through the practice of “looping” teachers and aides with ASD students up to their next grade level.

OT and SI are integrated into each child’s program as a part of a team approach. SLPs work one on one with children and use social scripts. They are an integral part of each child’s treatment team. They may also work with parents on carryover programs. SWs occasionally work with families and children with ASD. Generally families in this district are already well informed about their child’s diagnosis and well connected to the appropriate services. The district connects parents with the East Bay CAASP and helps to facilitate contact with other agencies. Carryover is accomplished through the usual “blue notebooks” and a home communication system which includes “picture notebooks” which contain photos of family members and familiar objects.

Special Education Director Judith Saccardo is proud of the effect inclusion has had on her district. She feels that inclusion is crucial to both regular ed and special ed children and that it has to do with “the belonging and acceptance of kids.” She recalls a conversation she had with a regular education teacher, “ ‘I just want to thank you for giving me the opportunity to have these kids in my classroom,’ she told me. ‘They are absolutely delightful. It has made such an impact on the regular ed kids. There is such a camaraderie and they look after one another.’”

Profile of Burrillville

Burrillville is a rural school district in the northwest corner of Rhode Island. The district has a total of five children with ASD, but its Special Education Director, Julian MacDonnell, suspects that a few students who just moved into the district may eventually be given an ASD diagnosis.

Methods for linking assessment to instruction strategies are tailored to each child’s needs and the goals of that child’s IEP. SI is used if the OT feels that it is needed for a child’s progress but there is a minimal amount of SI therapy in their district, largely because it is unnecessary. SLT is highly individualized and tailored to each student’s specific needs. SWs in the school system serve as a communication link between each family and the school system. They do not work with ASD students individually.

The IEP is designed so that lessons taught at school are also reinforced at home. Parents work in close collaboration with the MDT on the creation of their child’s IEP. Transition plans for when the child moves to a new school or classroom are quite extensive and include ongoing teacher conferences and classroom visits.

Mr. MacDonnell feels that there is an immediate need for improved regular ed teacher inservice training in Rhode Island on special education issues. Prior to his current position he worked in Massachusetts where extensive inservice training is mandatory. He feels that this is a more useful model. As a result of this, he already has background in ABA, TEACCH and other nationally recognized models for autism education. He

therefore does not feel he needs further education personally on ASD at this time. Currently special ed teachers in Burrillville receive extensive training on ASD teaching methodologies and therefore do not need further inservicing.

Mr. MacDonnell notes with great pride that special education programs in Burrillville are extensive and successful. The town has placed only two special ed students out of district. When asked why Burrillville has been so successful he responded, “There’s been a long time commitment to special ed here. And as a result special ed has been well received, it’s well recognized. There’s strong parent support here and I think that’s the key, because without the parents we’re just fighting the tide, but with them we can navigate the waters. It’s a big difference.”

Profile of Central Falls

Central Falls is a small urban school district in northeastern Rhode Island. There are approximately four students with ASD in the district and one preschooler who may be moved from the category of Developmentally Delayed to ASD.

Individual student progress is tracked through the goals set forth in the IEP as well as assessments by the student’s teacher and a school psychologist who then consults with the MDT. Goals are reviewed four times a year. OTs, classroom teachers and SLPs work together as a team to address each student’s specific issues. Special Education Director Arlene Garrison notes, “not just the speech therapist works on communication, or the OT on fine motor, it’s the entire group working on the same thing for the student.” Because their special needs classrooms contain children with different disabilities, there is limited use of OT and speech language interventions which are specifically geared to ASD. Generally, the student’s teacher designs behavior plans with a school psychologist or an outside behavioral specialist. Sometimes parents collaborate on the behavior plan as well.

A unique feature of special ed in Central Falls is the role of home visits. Because many families do not speak English, have telephones, and/or are reluctant to come into the schools, the school system’s four SWs make frequent home visits. In preschool and kindergarten programs teachers make monthly home visits as well. Each school also has a home-school liaison whose full time job is to communicate with families about school issues. Often SWs will go into the home to explain IEPs. Ms. Garrison notes that finding ways to explain disabilities in foreign languages and in terms that the parent can understand is an ongoing challenge that requires creative solutions. For example, she often calls parents and reads them a letter over the phone before mailing it in order to be sure they understand its contents. Because many families in this district are overwhelmed by poverty, home programs tend to focus on behavioral rather than academic skills. Because of families’ pressing social needs, staff often work to connect them with the local CAASP and other social service agencies.

Staff receives inservice training through a Professional Development Academy run by the city of Central Falls. While there are not formal programs in place there for ASD training, staff members can specially request them through the training academy. Specialists from Groden or Bradley operate these programs in which students are tuitioned out of district.

Profile of Chariho

Chariho is a rural school district in southwestern Rhode Island and contains the towns of Hopkinton, Richmond and Charlestown. The district has a total of 11 children with ASD, all of whom are in preschool or elementary school.

Preschoolers with ASD are taught with an integrated preschool population and the elementary population are taught in regular classrooms with support from an aide, as a way of assuring that they have as much exposure as possible to appropriate age models.

In educating children with autism, Chariho takes an eclectic approach. They use a variety of educational interventions that work with all children with special needs but also focus on interventions that are specific to children with autism such as communication boards and some behavioral programs. OTs design SI programs tailored to the needs of each student and advise classroom teachers on specific OT interventions. Chariho also has a special summer program for children with special needs who are recommended for Extended School Year program (ESY). This program includes therapeutic horseback riding and training on computers. Education of children with ASD in Chariho is a multidisciplinary effort that involves teachers, OTs, and SLPs collaborating together with the case manager to create the best possible programs for each student.

Case managers are a unique aspect of Chariho's special education program. Each case manager is special ed certified and is assigned a designated number of children. S/he designs behavior plans (in conjunction with the MDT), connects children with outside agencies and refers families to counseling when needed. Case managers are essential to transition plans; the old case manager meets with the new case manager in this lengthy process.

When creating a child's IEP, the MDT uses a COACH model. Prior to the creation of the IEP a survey is sent home to parents in which they can identify their priorities for their children. These goals guide the creation of the IEP. "It's a very lengthy process," Assistant Special Education Director Billie Jean Severi notes, "but we found it's well worth it...the parents really have great input."

Inservice training occurs in two different ways. OTs, physical therapists and case managers train incoming teachers, substitute teachers, case managers and aides on specific issues related to specific children. Chariho also does outside inservicing through consultants and workshops. Transition plans include inservice training of new teachers and staff. Because of this extensive training, Assistant Special Education Director Billie

Jean Severi feels that regular and special ed teachers do not necessarily need more training on ASD, though Chariho would not turn down the opportunity for more inservicing if it became available. Ms. Severi noted, "I don't think my staff is in dire need, but training is always important...if I could provide [inservice training] two days a month I would do that for my staff because they work very hard with all my kids."

Profile of Coventry

Coventry is a rural school district in the central part of the state with approximately eight children with ASD and another six with a different primary diagnosis who exhibit some autistic features.

Coventry's MDT makes an ASD diagnosis with the assistance of a consulting psychiatrist. After reaching an evaluation on a student the team meets with parents to inform them of the results of their child's evaluation. Parents are also pivotal members of the IEP team.

John Kotulo, Assistant to the Director of Special Education, notes that his district "takes a generic approach to disability and tries to keep things as individualized as possible." In short, they tailor programs to a child's needs rather than their diagnostic label. Specific techniques used with ASD students include PECS, a technique similar to Social Stories, use of transitional objects and elements of ABA. OTs working with ASD students design SI programs specific to each child's needs. SLPs use a variety of techniques including reversal and augmentative communication. SWs in the district often play the role of communication liaison/case manager between parents and the school.

Profile of Cranston

Cranston is a small urban school district located at the southwest boundary of Providence. This district serves about 26 children with ASD.

An integrated preschool, self contained half day, whole day, and extended day options are available to children with ASD. At the elementary school level the district's goal is to maintain students at their appropriate grade level with modifications which are necessary for ASD. These modifications include PECS and ABA programs which combine home and in-class instruction. The district uses outside consultants to assure the quality and consistency of these programs. At the middle school level children receive additional support on social skills. Cranston also utilizes an in class model for OT and SLT. SI is used as needed for individual children. The district encourages collaboration among team members as much as possible.

Cranston works to include families in their child's education. Parents do inservicing along with staff and an active Parent Advisory Board keeps the directors abreast of student needs. The district also informs parents of different options and makes

recommendations about what they perceive as most appropriate. At the primary school level SWs and school personnel make home visits one day a week to instruct parents in carryover skills. Parents also make visits to their child's school where they meet with the special education teacher, SLT and SW, observe classroom techniques and receive support. At the secondary school level a case manager oversees each child's interventions. The district has a school psychologist on staff who has postdoctoral training in ASD. She consults on specific behavior problems of children with ASD and does consulting for other school districts.

The district places an emphasis on inservicing at the time when teachers first encounter ASD students. While she acknowledges the importance of learning about ASD as a part of a degree program, Special Education Director Mary Carter also notes, "until you've got that kid sitting front of you every day you don't know the questions that you necessarily need to ask."

Profile of Cumberland

Cumberland is a suburban school district in northern Rhode Island with approximately 16 ASD students and another five students that exhibit some ASD features.

The district often refers children in need of an ASD diagnosis to outside diagnosticians, but occasionally uses consulting clinical psychologists on their staff to diagnose these students. Techniques used for instructing children with ASD are varied. Special Education Director Jonathan Dyson notes, "[We use] whatever works, I am not married to any one movement...I think that there are things that we find that work with each kid, because each kid is different." Techniques used include ABA, imagery, relaxation, role playing, Social Stories and in one case facilitated communication. SI is used with children at the preschool level. OTs also work with children on fine motor skills and stress management. SLPs do small group work with children with ASD in order to work on social skills. Reverse inclusion activities include combination homerooms. One unique aspect of Cumberland's inclusion programs is the use of an inclusion coordinator who prepares and educates regular education students and teachers about special education students.

SWs are not heavily utilized because there are only two to serve the entire district. Instead, Mr. Dyson uses his consulting clinical psychologists to work with families in designing home programs and working with ASD children directly. The clinical psychologist, school psychologist and occasionally classroom teachers also design behavior plans for children with ASD.

The creation of an IEP is a lengthy process that involves 3-6 meetings of the MDT. The MDT often meets more than once a week to discuss the progress of children with ASD. Home programs and carryover are designed to meet the needs of each child and the abilities of each family to carry out home programs. The school district has negotiated

with teachers' unions so that Teacher Aides go with a child to a new classroom setting. This practice eases the trauma of transition.

Overall, Mr. Dyson takes great pride in the programs available to children with ASD in Cumberland. He notes, "We provide kids with the supports that are necessary, with the instructional techniques that are necessary and we provide staff with the training that is necessary."

Profile of East Greenwich

East Greenwich is a town in the central bay region of the state. The district currently has 17 children with ASD. Student IEPs are created in consultation with the child's parents and the specialist who made an ASD diagnosis. A social history is taken by the school SW to aid the IEP process. Baseline data are taken each year to track each child's progress. MDT members create regular written reports of the student's progress and these are shared with parents and other team members.

Preschool students with ASD are included in regular preschool programs and receive support services through special education staff. Social Stories, comic strip conversations, PECS and picture schedules are used for children at the primary level. Fully mainstreamed children with ASD receive resource support, social skills training and OT if needed. The district's OT is fully trained in SI and is SIP qualified. SI equipment is available in both district elementary schools. The district also contracts out to Rehab New England as needed. SLPs in the district use Social Stories and at the primary level incorporate guided play; for example, one therapist in an elementary school goes onto the playground at recess to coach a child with ASD through normal peer interactions. The school SW provides family support and works with families who want to set up home programs and a school psychologist works directly with children with ASD.

Carryover is promoted through notebooks, staff-parent conferences, and occasional home visits from school staff to help set up home programs. Transition planning is extensive, but Special Education Director Joan Colwell feels that there is still a need to improve the area of consultation between the old and new teacher once the placement has been carried out.

Profile of East Providence

East Providence is a suburb on the eastern boundary of Providence. The district serves about nine children with ASD.

Educational interventions for children with ASD are designed according to each student's specific needs rather than his or her diagnostic label. Currently the school system uses PECS and ABA. The district also emphasizes mainstreaming children with ASD and

providing the aide and resource support to make this possible. OTs use SI as it is needed for each child and OT is provided in both pull out and in class settings, whichever is the least intrusive and most practical for the school system and the child. The district also has two inclusion specialists who are in constant contact with parents about their child's program and progress.

Because East Providence has 15 schools, scheduling MDT meetings presents significant challenges. The district has solved this problem by moving away from central-based teams for the elementary schools and instead creating building-based teams for the different sections of town. Typically the district brings in outside specialists to do inservice training with staff in afternoon sessions at the end of the school day. The district also has developed a 6 week afterschool inclusion training program for classroom aides. The class focuses on adapting materials, hands on exercises, behavioral intervention strategies and an introduction to OT and Physical Therapy.

Profile of Exeter/West Greenwich

Exeter/West Greenwich is a rural school district in the central part of Rhode Island. Currently the district serves five children with ASD.

Progress of children with ASD is tracked through the goals on the IEP as well as through baseline measures created through consultation with Barry Prizant and the Groden Center. The district uses elements of ABA, TEACCH, Social Stories and PECS in preschool and elementary school and for children who are academically mainstreamed provides social supports and behavioral contracting. There is an SI room for students at the preschool level. Once a child leaves preschool s/he receives SI in a small room in the school or his or her classroom. Teaching staff in the district have received inservice training on SI techniques. Exeter/West Greenwich takes an integrated approach in linking the different disciplines to treat children with ASD. For example, OT and SLT sessions are often combined, and the SLT and school psychologist often work together on pragmatic language skills. School SWs and psychologists often work together on strategies for teaching social skills. SWs also work with families of children with ASD and support them throughout the processes of diagnosis and IEP creation. Special Education Director Maureen Walejko worked at several RIARC organizations prior to her current position and therefore takes a "home-centered" approach to special education; families form an integral part of their child's educational team and are frequently consulted on their child's educational program. Home visits are an integral component of this approach. For example, in the intergrated preschool program staff make home visits to assist carryover every other Friday. On the remaining Fridays parents come in to school to observe their children's classroom program.

The school SW and each student's case manager (usually his or her classroom teacher) develop profile status sheets to summarize characteristics and issues for each special education student. These are shared with all involved team members at the beginning of each school year so that the child receives consistent and appropriate interventions.

Inservice training is accomplished through bringing in outside specialists from Groden, Bradley and other agencies and by using staff knowledgeable in interventions specific to autism to provide other team members. Ms. Walejko perceives inservicing as an ongoing issue because knowledge of the disorder is continually evolving. Transition plans include home visits by incoming staff and staff inservicing.

Ms Walejko is encouraged by the strides that her district is making in providing services to children with ASD. She notes, “[now I hear from staff] ‘we’d like to service that youngster and boy, we need to know more. When we have that information then we can develop [services].’ ...I think that’s a real positive thing, the recognition that [ASD] is not the same, that we have to look at this differently.”

Profile of Jamestown

Jamestown is a rural school district located on Conimicut Island in Narragansett Bay. The district has five children with ASD. The small size of the district presents both benefits and challenges.

Because the district is so small, Helen O’Hara, Special Education Director for the district, is involved with every child’s educational interventions. The district’s size also allows for frequent interaction between MDT members. Techniques used with students with ASD include peer models, modeling, ABA, picture reversal cards, scripted play, communication circles, reverse mainstreaming and Floortime. The district uses an eclectic approach tailored to the specific needs of each child. Ms. O’Hara credits most of her success to a dedicated staff who are willing to stay up to date on the latest autism teaching and treatment methodologies. Individual staff members who attend workshops or conferences share notes and information on these with all interested staff.

Because Jamestown is so small, it can only support a part time OT. Therefore, the district faces the continual challenge of trying to find a qualified OT who is willing to work limited hours. However, the district has found fully qualified OTs for the current year as well as next year.

The school SW is directly involved with older children with ASD and their families and currently the district is considering using school psychologists in a similar role for younger children. The primary liaison between the school district and an ASD student’s family is usually the case manager named on the IEP. Multiple staff members have some contact with families and parents are often encouraged to come into school to observe and learn carryover techniques from OT sessions. School personnel also make home visits.

Profile of Johnston

Johnston is a semi-urban school district abutting the southwest boundary of Providence. The district has about seven children with ASD.

Instructional and treatment methodologies for children in Johnston include individualized behavioral programs which are tailored to each individual child, PECS, and language based programs designed by speech language pathologists (SLPs) on staff. Behavior plans are designed by the school psychologist or SW and implemented by the classroom teacher for each child. The district has made a new commitment to SI and purchased an array of SI equipment to be utilized by the OTs on staff. In addition to regular MDT meetings, the district also utilizes an outside consultant from Meeting Street School to help coordinate MDT activities and promote carryover at home. School SWs meet with parents of children with ASD every other week to let them know about the child's progress at school and help with behavior management and carryover at home. Transition plans vary from child to child.

Steve Periera, Special Education Director for the district, feels that Johnston is in a period of transition and is moving towards meeting ASD children's needs more successfully. "We're in no way close to being perfect," he notes, "...but we have at least started to address their specific needs. And thank God I have very good parents who have been very cooperative because they want to keep their kids in the neighborhood school."

Profile of Lincoln

Lincoln is a suburban school district adjacent to the western boundary of Providence. The district has ten children with ASD.

Progress of ASD children is tracked through the goals listed in the IEP as well as goals and measures set forth by June Groden from the Groden Center. Teachers in preschool classrooms incorporate discrete trials, imagery and visual approaches laid out by Groden Center consultants. Children with ASD receive direct service in their classrooms from the district OT in a variety of SI techniques. The OT works hard to stay abreast of new developments in SI and SI techniques and also works with classroom teachers to reinforce SI. SLPs use Social Skills Groups and one on one instruction with ASD children if it is recommended in the IEP. SWs make themselves available to families of children with ASD to help coordinate services. Where needed, SLPs, OTs and Visual Therapists send home exercises to do with the child to promote carryover. The district does not recommend home programming as a rule, but Lovaas is offered through Bradley or the Groden Center if it is recommended by the Groden Center consultant. The school also works with parents to develop after school and weekend home Lovaas programs if they are interested. Most parents are deeply involved in the creation of IEPs as well. School transition plans always include the old and new teachers and may also include the school psychologist or SW as well. Staff inservicing is accomplished predominantly through bringing in outside consultants.

Profile of Narragansett

Narragansett is a coastal town in the south county section of Rhode Island. The district serves approximately 8 children with ASD.

The district has worked diligently to develop pilot models for educating children with ASD at the preschool level. A morning preschool includes 1) a teacher, 2) two aides, 3) an SLP who works with the students, teacher and aides, 4) an OT and 5) a physical therapist who all come on site to work directly with the children. Teaching methodologies include PECS and ABA. A few of the children are on EPSDT and therefore receive intensive ABA programs at home as well. For these children the school sets aside an hour each week for the home programming staff to observe the classroom and meet with the team to assure consistency between the two programs. The district also has a consultant from the Groden Center who consults with the team on each child. The consultant also reviews data and progress, tracking specific targeted behaviors on charts. There is one student in the district's elementary model. This child receives ABA at home for part of the day and then comes into school for the rest of the day. The other child in primary school has been fully mainstreamed into an inclusion classroom co-taught by a special education teacher and regular education teacher. Special Education Director Sandy Keenan credits the preschool program directly with that student's success.

The district's OT is SIP trained and certified. Large SI equipment is kept in a room at the district's elementary school. The OT oversees SI in the preschool and instructs teachers as needed on specific SI techniques. The SLT works directly in the classroom and coaches children through social situations. These professionals may also design home programs for children with ASD as well. The district's SW consults with the MDT team and ASD students, and is available to families for advocacy work, but this role may also be fulfilled by MDT team members. Behavior plans are designed by the classroom teacher and the entire MDT team in conjunction with the outside consultant. Any new paperwork on a child with ASD is reviewed weekly by all members of the child's MDT.

Staff development and inservicing is often informed by the specific needs of children in the district. Most inservicing is done by the outside consultant, but staff attend outside workshops as well.

Ms. Keenan is proud of the programs available to children with ASD in Narragansett. "If the feedback from staff, teachers and parents is the measure," she notes, "then I would say we're doing a great job...I don't think it should be interpreted that we're doing more than is appropriate. It's appropriate if it's working."

Profile of Newport

Newport is a small urban school district located on Aquidneck Island in the East Bay region of Rhode Island. The district has two children with an autism diagnosis and about another ten who exhibit some autistic-like features.

Educational programs are designed around the specific needs of each child. Special Education Director Mary Connolly notes, “As far as any specific technique, we really look at the youngster and how do they respond and how do we get them to respond more appropriately.” PECS is used with children at the preschool and early elementary levels. As children grow older the district takes a direct behavioral approach and places an increasing emphasis on modeling peer behavior and learning social skills. SI is introduced to children by an OT and carried through by the classroom teacher. SLPs go into classrooms and work with children in Social Skills Groups. SWs serve as a home to school liaison and work mostly with parents in promoting carryover of skills and learning. The MDT team and Ann Walters design behavior plans.

Newport places an emphasis on inservice training and takes advantage of the proximity of Bradley Hospital to the district; staff often go there to learn techniques for treating autism.

Ms. Connolly is proud of the individualized approach that her district takes with children with ASD. “I’m willing to meet each child as they come in and then work with them,” she notes.

Profile of Newport County Regional School District

Newport County Regional includes the towns of Little Compton, Tiverton, Portsmouth and Middletown, located in the coastal East Bay region of Rhode Island. The district provides services to about 30 children with ASD.

The district tracks student progress through the goals on the IEP and baseline diagnostic tests. OT is done almost completely in the classroom; children are pulled out only when the equipment is too big to bring into the classroom. SI includes an array of techniques such as brushing, balls and sensory boxes. Teachers, aides and parents are all trained in SI techniques. The teacher and speech language therapist run Social Skills Groups. PECS and ABA are the most heavily utilized teaching methodologies in this district. Older children also receive specific counseling and intervention to help them with social interaction. SLPs utilize picture systems to teach children social skills. Because Bradley Hospital is nearby, the district often consults with them about programs and individual students.

The district places an emphasis on collaboration with parents in areas such as SI, toileting, eating and problematic behaviors. SWs visit with families at home to do developmental screenings. Guidance counselors also provide some outreach. In some cases SLPs and OTs conduct home visits to instruct and educate families in specific methodologies. In order to assure that home carryover is being conducted correctly, the district videotapes sessions at school to be shared with parents. The district sponsors support and information groups for parents as well.

Profile of North Kingstown

North Kingstown is a central coastal school district with nine children with ASD. All of these children are in preschool or early elementary school. One special education teacher describes this sudden increase in cases as an “explosion.”

North Kingstown currently works in collaboration with a consultant from the Groden Center to set up behavioral programs for two first graders with ASD at their local elementary school. A representative of the Special Education office notes, “This is very new to us. Normally kids with this diagnosis have been placed out of district...if you had an autism diagnosis you were out. It’s just been in the last year or so that we’ve seen [the increase in numbers.]” The school district copes with these new challenges by bringing in outside consultants from Groden and Sargent Rehabilitation Center. North Kingstown is also considering bringing Social Stories and TEACCH into their curriculum for children with ASD. OTs provide SI as it is needed to individual students. SLPs work with ASD students in small groups and individually. SWs do some advocacy work for families. Transitions to a new school or classroom are eased somewhat by assigning the same aide to a student for up to three years.

Inservicing is arranged when the need arises. For example, last summer the district provided training to three aides to prepare them for the special elementary classroom. The district also brings in outside consultants and sends staff out to private agencies for inservicing.

Profile of North Providence

North Providence is a suburb of Providence. Currently the district serves about 12 children with ASD.

Most children with ASD in this district are mainstreamed in regular classrooms. Educational interventions for students in this district vary according to each child’s needs. The district uses Social Stories and behavioral approaches with many children with ASD and makes frequent use of outside consultants to create appropriate interventions for specific students. Children with ASD are typically enrolled in ESY programs as well. OTs in the district have received inservicing on SI and utilize these techniques when needed for children with ASD. The district has worked hard to integrate OT, SLT and Physical Therapy into the student’s regular program and is moving away from a “pull out” model. SWs assist families and the district with reaching out to other agencies and also address day-to-day emergencies as they come up. They also conduct Social Skills Groups in some classrooms. If a behavior plan is needed it is designed by the school psychologist and occasionally a consulting clinical psychologist.

Staff inservice training is usually conducted by outside consultants like Larry Hirschberg. At times the district also sends staff out to conferences. Special Education Director Bob

Asekoff notes that the inservicing needs are much greater for staff working with children with ASD than any other special ed population.

Mr. Asekoff feels that one of the district's growing strengths is its increasing ability to serve children with ASD in inclusive settings. He says, "Basically, we're just beginning to do this, within the last five years. It has a way to go and I am sure that it will get even better...regular ed and special ed staff are going gung ho to accommodate these kids to regular programs."

Profile of North Smithfield

North Smithfield is a rural school district in northeastern Rhode Island. At the time of the director interview the district had no children with ASD. Since that time two ASD children have been identified in the district.

Profile of Northwest Special Education Region

The Northwest Special Education Region is in the rural northwestern section of Rhode Island and includes the towns of Scituate, Foster, and Glocester. The district has about 10 children with ASD and another 8 that exhibit some ASD symptoms for a total of 18 possible cases. In meeting the needs of children with ASD, this district faces challenges of rural isolation.

The district uses "homemade" versions of PECS and ABA in its preschool and elementary settings. Higher functioning children with Asperger's Syndrome are academically mainstreamed, but still receive resource support to aid them in building social skills and controlling behavior. OTs utilize SI as it is needed for each child. SLPs work on social skills to the extent that these are needed for the acquisition and use of social language. SWs work with children with Asperger's Syndrome on social skills. Behavior plans are designed by several members of the MDT team with the assistance of a consulting clinical neuropsychologist.

The entire special education system is organized under a case management approach. The person assigned to case manage is the IEP service provider who has the most frequent contact with the student. As Special Education Director Patricia Kline puts it, "If one person can do it all, don't splinter the kid. We're not real territorial about titles, but, rather, every professional is expected to implement and carry over all IEP goals." Parents are encouraged to come into their child's school to observe specific teaching methods and strategies.

Professional development is accomplished through extensive inservicing and some of the cost is covered through an IDEA grant. Staff do inservicing by visiting private agencies and going to conferences and workshops.

Profile of Pawtucket

Pawtucket is a small urban school district adjacent to Providence. Currently Pawtucket serves about 30 children with ASD.

IEP goals and techniques used to link assessment to instructional strategies are shaped to each child's specific needs. Kevin Plummer is often consulted on the utilization of specific techniques. A variety of methodologies are currently in use in Pawtucket classrooms for children with ASD. These models include ABA, PECS and Social Stories. SI evaluations are done by an OT on staff and SI programs are created as needed. Pawtucket assures the quality of its Occupational Therapy programs through the utilization of exit and entrance criteria for OTs and collaboration with other members of each child's team. Pull-out is discouraged. Behavioral plans are generally designed by each child's IEP team in consultation with Kevin Plummer. Because the classroom teacher is the main contact and support for ASD families in the district, SWs serve only as occasional and peripheral support.

Last summer Pawtucket received a grant from Project Reach to fund a computer camp for children with ASD. The children created a web site. Assistant Special Education Director Ann Ritchie was thrilled with the results. "You have never seen autistic/PDD kids bond in your life," she enthuses. "This was truly amazing. We had goals of developing friendships...these children bonded with each other...one of the things they're not supposed to do is bond with people...and they bonded." The district is still looking for funding for the project for next summer.

Teachers and staff are inserviced on ASD issues and techniques as they encounter children with the disorder for the first time. The district holds monthly workshops on issues and techniques for a variety of disabilities.

Profile of Providence

Providence is an urban school district located in the capital city of Rhode Island. There are approximately 50 ASD students in this district. One of the challenges for this district is finding ways to serve children with a variety of cultural, linguistic and socioeconomic backgrounds.

Preschool students are integrated into regular settings with one-to one aides. Techniques which are utilized for linking assessment with instructional strategies are created on a student-by student basis and often include outside consultants such as Kevin Plummer and the Groden Center. Providence has several OTs who are extensively trained in SI techniques. SLPs emphasize relaxation techniques and augmentative communication strategies. Former Director of Special Education Pia Durkin describes her staff of 21 SWs as "the best in the state." They work directly with children with ASD on behavior plans and Social Skills Groups. SWs also help families with agency and counseling referrals. Providence also runs parent workshops at the preschool level. The district is

the recipient of a grant that pays for substitute teachers so that preschool teachers can go into the student's home three or four times a year to assist with carryover.

Part of the district's success in meeting the needs of ASD students is to rely heavily on interagency collaboration with the local CASP to help with funding respite and home training. Dr. Durkin also finds that because this district is so large they have the capacity and resources to offer some unique and creative interventions for children with ASD. "Is it perfect?" Dr. Durkin asks, "No. But I am proud of the fact that we are serving far more kids than we ever did."

Profile of Smithfield

Smithfield is a semirural community in North central Rhode Island with approximately eight children with ASD. Most of these children are in preschool and elementary school. Techniques used for children with ASD in Smithfield include Social Stories and circle of friends. Staff receive inservice training if they request it and funds are available to provide substitute teachers. In addition to the traditional blue book sent between home and school, Smithfield also uses communication books and homework pads.

Profile of South Kingston

South Kingston is a rural school district located on the south central coast of the West Bay region of the state. The district currently serves 5 children with ASD.

South Kingston utilizes both PECS and Social Stories for its youngsters with ASD. The district uses an eclectic approach for ASD because of the wide variation in the abilities and symptoms of its ASD population. OT methods include use of a trampoline, swings, Sensory Diet and a program called, "How does your engine run?" SLPs use social modeling, Social Skills Groups and one to one instruction with children with ASD in different settings. SWs serve on consulting teams and also run Social Skills Groups. The district has discovered that the most efficient way to instruct parents in home carryover techniques is through biweekly team meetings at the child's school.

Profile of Warwick

Warwick is an urban school district in the central coastal section of the West Bay area of Rhode Island. The district serves approximately 48 children with ASD.

Less severely involved children are fully included in mainstream classrooms and most of their support services occur within the regular classroom setting. Children with more significant impairments are placed in a combination placement of mainstreamed and self-contained settings. Educational interventions include Total Communication, PECS, picture cueing, structured visual approaches and programs designed by specialists from

outside agencies. Mainstreamed children with more mild symptomology are still provided with social skills coaching as it is needed. SI is a major component of Warwick's intervention for children with ASD at the pre and elementary school levels. SLPs use modeling, reverse mainstreaming and Social Skills Groups. SWs work with families to find appropriate systems and services. Behavior plans are designed by the child's teacher in consultation with the school psychologist and occasionally an outside consultant. At the preschool level teachers of ASD students travel once a week to the student's home to assist in home instructional programs. This methodology is also practiced to a lesser extent at the elementary school level. Warwick sends staff out to conferences for inservice training and also houses the PDD Discussion Group.

Special Education Director Steven Lowery feels that one of Warwick's greatest strengths is its commitment to inclusion. He asserts, "I've come to the opinion that Warwick is very strong when we keep our kids included and owned by the whole [school.]" He also feels that his district's greatest strength is its devoted staff. "With [children with severe autism] what's going well is based purely on the staff who are there," he notes. "It is not based on the system. The system is not doing anything extraordinary. The people working with the children are doing very extraordinary things. It is people contingent."

Profile of West Warwick

West Warwick is located in the central region of Rhode Island and has 5 children with ASD. All five of these children are in out of district placements. Special Education Director Bob Sherman chooses to place them out of district because he feels he lacks the staff necessary for meeting the needs of this population. However, the district has requested a program for children with ASD which is pending approval.

Profile of Westerly

Westerly is a small urban district in the southwest corner of Rhode Island. The district has a 15 children with an ASD diagnosis and another 3 under evaluation who are strongly suspected of having ASD, for a total of 18 cases.

General education and IEP goals are created for each child by the MDT team in consultation with Diane Twatchman-Collins. Techniques used to link assessment to instructional strategies include scripting, SLT, SI and instruction. TEACCH, discrete trials, some behavioral techniques and relationship-based approaches are used for children at the preschool level. Children in the elementary, middle and high school receive a program combining TEACCH, functional behavioral analysis, communication boards and augmentative communication strategies. The district relies heavily on teacher aides for its programs for children with ASD. Teacher Assistants are trained in SI therapy by an OT. SI is done in the classroom as well as a pull out program. The district provides workshops on SI. SLPs use Social Skills Groups and social prompts to coach

ASD children through social situations. The classroom teacher works with an outside consultant to design behavior plans.

Social Workers help families get access to appropriate resources and connect them with other families while classroom teachers assist with home carryover. At the preschool level each Friday is set aside for teachers to make home visits. In some cases teachers at higher grade levels also make home visits.

MDT members share information about children with ASD through reports and meetings. The district funds MDT collaboration time through a grant and also provides substitute teachers so that team members have sufficient time to collaborate. Staff inservicing is extensive and funded through grants and staff development credits.

Special Education Director Mark Hawk feels that the district's success in treating children with ASD is rooted in its dedication to serving children. He asserts, "We work real hard to get the services for kids. We don't look at a dollar and say, 'that costs too much'...we go forward with what we believe and we go with a passion and a commitment to children."

Profile of Woonsocket

Woonsocket is a small urban school district in the northeastern corner of Rhode Island. The district currently services about 12 children with an ASD diagnosis.

The MDT has a clinical psychologist on staff and therefore has the capacity to make diagnostic evaluations. However, every ASD child in the district's current caseload came in with an outside evaluation. The district uses a consultant from the Groden Center to find appropriate ways to link assessment to instructional strategies. Parents' needs are also considered when creating goals for each child. ABA and PECS are utilized for children with ASD in this district. The district owns an array of SI equipment and uses a variety of SI techniques. OTs also do consultations with classroom teachers and parents on SI techniques. SLPs work within the classroom with ASD students and use both one on one and small groups. School SWs' role with ASD students is generally limited to the initial social assessment and MDT meetings. However, they occasionally do more work with individual cases as the need arises.

The district emphasizes parent involvement; they are often consulted in the creation of behavior plans and also review and provide input on outside reports and assessments. Transition plans often include home visits by new teachers and parents are encouraged to visit different classrooms to explore options for their child's education.

Early Intervention Director Interviews

The findings for the Early Intervention (EI) Director interviews are summarized in Tables 11 through 17. In Table 11 prevalence of ASD by type and age for each EI region is presented. A total of 38 children with probable ASD are serviced through EI. It was often difficult for EI directors to give exact numbers because so many of these children are under the category of developmentally delayed and do not clearly exhibit all of the characteristics of the autistic triad. EI directors also report that ASD children treated in their regions fall between the ages of two and three, are consistently placed in the eligibility categories of Single Established Condition and Developmentally Delayed and are given ICD-9 categories of 299 or 315.

Four out of five EI regions report referring out children for an ASD diagnosis. Diagnostic groups utilized most often were CDC (4 cases) and Bradley Hospital (3 cases, see Table 12). All EI directors report using IFSP goals to link assessment to instruction strategies and four out of five report using diagnostic tests as well. All Early Intervention MDTs share information about children at weekly meetings. Behavior plans or goals are usually designed by the MDT and/or an outside consultant (3 cases each, please see Table 13).

Table 14 provides a summary of methods used by SLPs and SWs. Three out of five EI directors report that SLPs work with ASD children in Social Skills Groups and two reported one on one SLP instruction occurred in their region as well. Three EI directors report that SWs work with ASD students and two report that they work with families of ASD students doing case management, support and assisting in home carryover.

Results in Table 15, “Home Carryover Techniques,” indicate that all EI regions use notes, meetings at school, home visits by school personnel and home programs to promote home carryover. The level of home carryover for IE regions is more consistent and higher than that reported by LEAs.

Inservicing needs and current inservicing practices are summarized in Table 16. While four out of five EI directors reported that their staff need more ASD information, all five directors also reported that staff currently receive inservicing, that EI provides time off for inservicing and that EI pays for it as well.

Finally, in Table 17 use of specific ASD treatment models is presented. Currently, no one model is used consistently across EI regions.

TABLE 11 Prevalence of ASD By Type and Age

EI Region (Interviewee Name)	Reported # of Autistic/ASD Children				Age Distribution of Children with ASD (in years)	# in Different Types of Settings							Eligibility Category				
	Autism Cases Reported by Director	PDD Cases Reported by Director	Developmentally Delayed Cases That Are Suspected of Having ASD	Total Estimated ASD Cases		EI Center/Classroom	Family Child Care	Home	Hospital	Outpatient Service Facility	Regular Nursery School or Child Care Center	Residential facility	Other	Single Established Conditions	Developmentally Delayed	Multiple Established Conditions	ICD-9 Category
Groden (Leslie Wiedenmann)	3*	11*	2*	16*	2.5 – 3	Yes		yes						Reporting comes from regions			
Metro (Ann Moore)		5	5	10	2 – 3	1 - 5		yes		5	1 - 5			yes	yes		315
Northern (Anne Felice)	3	2	7	12	2.5 – 3	11		12		2	1			yes	yes		299
Central/Southern	2	14		16	2 – 3	6	1	2		1	1			yes	yes		315, 299
Eastern (Kathleen Cross)	0	0	0	0	2 – 3	Not Applicable							yes	yes			
TOTAL	5	21	12	38													

* Groden's #s are not included in column total because they are a referral agency.

TABLE 12 Methods of Diagnosis and Use of Outside Diagnosticians, All EI Regions

	Yes	No
MDT Makes ASD Diagnosis	0	5
MDT Refers Outside For Select Cases	0	5
MDT Always Refers Outside for Diagnosis	4	1
Outside Diagnosticians Who Are Used By District For Diagnosis		
Dr. L. Hirschberg	1	
Child Development Center	4	1
Dr. L. Kiessling	1	
Bradley	3	2
Grodén	1	4

TABLE 13 MDT Procedures and Methods of Tracking Progress, All EI Regions

	Yes	No
Techniques to Link Assessment With Instructional Strategies		
IFSP	5	0
Data From ABA	0	5
Diagnostic Tests	4	1
Methods MDT Share		
Weekly Meetings	5	1
Informal Communication	2	4
Phone Calls	1	5
Who Designs Behavior Plan		
School Psychologist	1	4
Social Worker	1	4
MDT	3	2
Outside Consultant	3	2

TABLE 14 ASD Treatment Techniques Used by Speech Language Pathologists (SLPs) and Social Workers (SWs), All EI Regions

	Yes	No
S/L Methods Used		
Social Skills Groups	3	2
Work One-on-One With Students	2	3
Use of Social Workers		
Work With ASD Students	3	2
Work With ASD Families	3	2

TABLE 15 Home Carryover Techniques, All EI Regions

	Yes	No
Phone Calls	2	3
Notes on What Happened in Each Session	5	0
Meetings at School	5	0
Home Visits	5	0
Home Programs	5	0

TABLE 16 Staff Inservicing Needs and Availability of Inservicing, All EI Regions

	Yes	No
Staff Need More General ASD Training	4	1
Staff Need More Training in Specific ASD Treatment Models	4	1
Director Wants Information About ASD Education Models	5	0
Staff Currently Receive ASD Inservice Training	5	0
EI Brings In Outside Specialists	1	4
EI Has Own Training Programs	3	2
EI Sends Staff Out For Conferences	4	1
EI Sends Staff Out For Workshops	3	2
EI Pays for Training	5	0
EI Provides Time Off For Training	5	0

TABLE 17 Use of Specific Treatment Models for Children With ASD, All EI Regions

	Yes	No
ABA	2	5
Behavior Contracting	1	4
Greenspan	1	4

We end this summary of EI findings with a brief narrative description of each EI region. These are intended to give the reader a qualitative understanding of the kinds of ASD programs and services available to very young children in Rhode Island. All data presented in these profiles are taken directly from EI director interviews. Profiles are presented alphabetically.

Profile of the Central and Southern Region Early Intervention Program

The Central EI region serves the communities of Cranston, Coventry, East Greenwich, West Greenwich, Warwick and West Warwick. The Southern region includes Charlestown, Hopkinton, Exeter, Jamestown, Narragansett, North Kingstown, New Shoreham, Richmond, South Kingstown and Westerly. Combined, these regions serve about 16 children with ASD. At this time these two EI regions are in significant transition. The regions are being combined into one and undergoing significant curricular and administrative changes as well. For these reasons, it is difficult to provide accurate and current information on these regions; much of the data collected in our interview is already out of date. We chose therefore not to provide a narrative description of the Central and Southern EI regions in this report. However, data from the interview was incorporated into the EI tables.

Profile of Eastern Region Early Intervention Program

The Eastern EI region includes the towns of Little Compton, Middletown, Newport, Portsmouth and Tiverton. Currently the region serves no children with ASD. However, Regional Director Kathleen Cross notes that this is not a typical situation; for example, last year the region had six ASD children. Data on treatment and interventions for ASD presented here are based on the previous year's experience. IFSP goals are identified by the child's family and assessed at formal 6 month reviews. The region uses an eclectic approach with elements of ABA training in teaching children with ASD. OT including SI is incorporated into structured play groups and the OT also instructs parents in methods they can use at home. Home carryover is reinforced through videotaping as well. The OT also makes home visits. SLPs work with children in groups on social skills. The region has no SWs, but other staff members have learned to perform many social work functions such as providing support and connecting families to other agencies. For example, the region has also had significant success in getting SSI for children so that they can receive additional services. A social work consultant is available for consultation on particularly pressing issues. Staff training is an ongoing process and is shaped by inservicing needs identified at an annual review. Transitions to preschool begin at 28 months. A late diagnosis is one of the transition challenges for ASD children; an ASD transition plan often begins within months of an ASD diagnosis.

Profile of the Groden Center Early Intervention Program

The Groden Center EI program is located in Providence, RI and currently serves 14 children with an ASD diagnosis and another 2 who center staff suspect will soon receive an ASD diagnosis. The average period of time that a child with ASD spends at the Center is brief, at only 7.4 months on average. Children are served through individual home visits by a Center therapist or through a center-based group for several hours a week. Children with ASD who receive services through Groden are also likely to receive EI services through their region as well. Children with ASD are referred to Groden by their EI region when regions determine that they need additional services. Progress is tracked through 6 month reviews of specific goals identified on the IFSP. The program is behaviorally oriented with communication based training as well. Parents are also taught carryover skills during home visits. SI is used if it is needed. OT in fine motor skills is also emphasized when there is a need. SLPs use picture exchange and emphasize choice making skills. SWs work with parents on specific concerns and help to connect them to other agencies and services. A parent support group meets at the Center once a week at the same time that the child's group meets. Transition plans into the school system are contingent on the cooperation of individual districts. All staff at the Groden Center go through an extensive center-based inservicing program when they are hired.

Profile of Metropolitan Region Early Intervention Program

The Metropolitan EI region encompasses the towns of Barrington, Bristol, Central Falls, East Providence, Johnston, North Providence, Pawtucket, Providence and Warren. This region serves between 5 and 10 children with ASD. The exact number is uncertain because several of the children have a rule out diagnosis. Children receive SI and OT through referral out to other agencies. Behavioral programming such as water play is used to reinforce mastery of skills. Behavioral goals are identified by psychologists on staff as well as outside consultants. SLPs and psychologists work on social skills through peer integration groups. SWs work with both children and families. Service coordinators work with families to identify support services and assist with home carryover. Families provide information during evaluations and identify IFSP goals with the assistance of their service coordinator. An allotment of money is set aside for each staff member to receive inservicing. Transitions typically begin at 28 months of age with several meetings and, with the parents' consent, assistance in the creation of the IEP.

Profile of Northern Region Early Intervention Program

The northern EI region includes the towns of Burrillville, Cumberland, Foster, Glocester, Lincoln, North Smithfield, Scituate, Smithfield and Woonsocket. This EI site currently serves five children with an ASD diagnosis and another seven with suspected ASD for a total of 12 children. Region staff works with the child's family to identify IFSP goals and these are assessed at formal 6 month reviews. Parents' input is sought at all stages of

the IFSP process. Teaching interventions for ASD children incorporate a multidisciplinary sensory approach including total communication, SI, open activities, social activity and tactile play. The program OT provides SI and the region also refers out. A team of professionals works with children with ASD in multidisciplinary therapy groups. SWs form a part of these groups and also provide support services and counseling to parents as needed. The case manager for each child is selected according to the child's needs; for example, a child with significant speech issues would be assigned an SLT. Transition plans begin at 30 months or earlier.

Private Agency Director Interviews

Findings from interviews with private agency directors are summarized in Tables 18 through 24. The prevalence of ASD by type and age is presented in Table 18. In total Rhode Island private agencies serve 340 children with ASD with Bradley Hospital serving the largest number of children followed by Groden and the Northern Rhode Island Collaborative. Children who are placed with private agencies as out of district placements come in with a diagnosis of ASD. Therefore, private agencies have little involvement in the formal ASD diagnostic process. In three cases agencies reported using CDC, Bradley, or Dr. Irwin Bennett for a second opinion on a diagnosis (see Table 19). However; the practice of referring out was generally rare due to the fact that most agencies have numerous diagnosticians on staff.

TABLE 18 Prevalence of ASD by Type and Age for Each Agency

	Groden (Susan Stevenson)	Bradley (Dr. Kevin Meyers)	Sargent (Marilyn Serra)	Trudeau	Meeting Street School	Northern Rhode Island Collaborative
Reported # of Autistic/ASD Children						
Autism Reported by Director		50	6	2	3	8
PPD Reported by Director		120	6	5	2	15
Asperger's Syndrome Reported by Director	1	80				3
Total Reported by Director	40	250	12	7	5	26
Total Caseload	68			26		87
% ASD	59	33	33	27	7	30
Age Distribution						
Pre-School	Evenly Distributed Across all Age Groups				1	9
Elementary				5	4	16
Junior High						3
High School				5		
Post High School						

TABLE 19 Use of Outside Diagnosticians For All Agencies

	Representative from CDC	Representative from Bradley	Irwin Bennett
All Agencies	1	1	1

All agency directors report using IEP goals and diagnostic tests to link assessment to instruction strategies and two report using ABA data as well. All private agency MDTs share information about students at weekly meetings and five out of six MDTs meet informally about students as well. Behavior plans or goals are usually designed by the MDT. All agency directors report that transition plans include visits to the new school by the student, visits by the new teacher to the old classroom, and the student spending time in both classrooms (please see Table 20).

TABLE 20 MDTs, IEPs, and Assessment Strategies, All Agencies

	Yes	No
Techniques to Link Assessment With Instructional Strategies		
IEP Goals	6	0
Data From ABA	2	0
Diagnostic Tests	6	
Methods MDTs Share		
Weekly Meetings	6	0
Informal Communication	5	1
Who Designs Behavior Plans		
Clinical Psychologist	2	4
Design As a Team	4	2
Transition Plans		
School Visits	6	0
Teacher Visits	6	0
Time in Two Classrooms	6	0

Table 21 provides a summary of methods used by OTs, SLPs and SWs. All agencies reported that OTs use a variety of SI techniques including trampolines (3 cases), brushing techniques (4 cases) and swings (4 cases). All agencies report that SLPs use Social Skills Groups and four out of six report that SLPs work one on one with ASD students. All agencies report that SWs work with ASD students' families doing advocacy, case management and support.

TABLE 21 ASD Treatment Techniques Used By Occupational Therapists (OTs), Speech Language Pathologists (SLPs), and Social Workers, All Agencies

	Yes	No
OT Methods Used		
Trampoline	3	3
Brushing Techniques	4	2
Swings	4	2
S/L Methods Used		
Social Skills Groups	6	0
Work One-on-One With Students	4	2
Use of Social Workers		
Work With ASD Students	2	4
Work With ASD Families	6	0

In Table 22 home carryover techniques are listed. All agencies report using phone calls, notebooks, meetings and home visits by school personnel to promote home carry over and all but one use home programs as well. The level of home carryover for private agencies is markedly higher than that reported by LEAs.

TABLE 22 Home Carryover Techniques, All Agencies

Carryover Techniques	Yes	No
Phone Calls	6	0
Notebooks	6	0
Meetings at School	6	0
Home Visits	6	0
Home Programs	5	1

Inservicing needs and current inservicing practices are summarized in Table 23. Only two out of four agency directors reported that their staff need more ASD training and all directors expressed interest in receiving information on specific ASD education models. All six directors reported that staff currently receive ASD inservicing and five noted that their agencies have their own training programs, provide time off for training and pay for training. There are marked differences in this area between the public and private sectors.

TABLE 23 Staff Inservicing Needs and Availability of Inservicing Training, All Agencies

	Yes	No
Teachers Need General Information	2	4
Teachers Need Specific ASD Information	2	4
Director Wants Information About ASD Education Models	6	2
Staff Currently Receives ASD Inservice Training	6	0
Facility Brings In Outside Specialists	4	2
Facility Has Own Training Programs	5	1
Facility Sends Staff Out For Conferences	3	3
Facility Sends Staff Out For Workshops	3	0
Facility Pays For Training	5	1
Facility Provides Time Off For Training	5	1

Use of specific educational techniques for children with ASD is addressed in Table 24. Currently no one technique appears to be favored by private agencies. Specific techniques are addressed in greater detail in the narrative profiles.

TABLE 24 Use of Specific Educational Techniques for Children With ASD, All Agencies

	Yes	No
ABA		
Pre-School	2	4
Elementary	2	4
Junior High	2	4
High School	1	5
Picture Exchange System		
Pre-School	4	2
Elementary	3	3
Junior High	1	5
High School	2	4
Picture/Word Books		
Pre-School	1	5
Elementary	1	5
Junior High	1	5
High School	0	6
Behavior Contracting		
Pre-School	3	3
Elementary	3	3
Junior High	4	2
High School	2	4

We end this discussion of findings with a brief narrative description of each private agency. Many agencies in Rhode Island are practicing unique and state of the art innovations in ASD programming; there is no way to convey these to the reader without a detailed qualitative description. All data presented in these profiles are taken directly from agency director interviews. Profiles are presented alphabetically.

Profile of Emma Pendleton Bradley Hospital

Bradley Hospital's main branch is located in East Providence, Rhode Island with another campus located in Middletown. Both of these branches serve clients on an outpatient basis. Additionally, the hospital has residential programs in its main branch and in a satellite in East Greenwich. Because of this programming versatility, Bradley serves children at all levels of ASD. 200 children are served on an outpatient basis, about thirty-five children receive in home IBT programs and another 15 are served in the residential facility, for a total of about 250 clients or about 33% of the total caseload. The ASD caseload is fairly evenly distributed across all age groups.

The agency serves about 60 students in its day program. The remainder of its outpatient clients are serviced in local school districts. Classrooms are set up across disabilities according to chronological age and developmental ability. The hospital provides an extended day program through EPSDT. Children who present with ASD must also present with a diagnosable behavioral difficulty which makes them unmanageable at their home or school in order to qualify for treatment at Bradley. At the request of school

districts, Bradley does emergency intensive residential 6-10 week long diagnostic evaluation for ASD children with specific at risk behaviors. Once the child's behaviors are stabilized s/he is placed in the outpatient program so that his/her progress and/or medications can be monitored.

At Bradley the psychologist or psychiatrist who is attending a specific case makes the diagnosis of ASD. A staff team in consultation with families designs treatment plans. A parent interview is included in every outpatient assessment. An interactional interview of the child with ASD is videotaped in order to assess the level of social functioning. Each treatment plan is designed to be as nonrestrictive as is appropriate to each child's level of impairment. Services range from traditional biweekly outpatient family therapy and parent education to 24 hour a day residential placement. Assessment is done through a variety of psychosocial evaluations and batteries.

According to Director Roland Barrett, Bradley's philosophy of care is "non-drug, non-aversive, but not antidrug, not antiaversive... It is family-centered, we're trying to improve the quality of life for the family as well as the individual kid." Arthur Mercurio adds, "It's a multidisciplinary team approach in the provision of care."

Specific educational techniques include an ABA program for 16 children from preschool through elementary school. This ABA program includes elements of Lovaas and functional analysis and contingency management. PECS is used at all grade levels. At the middle and high school levels staff also utilize behavioral contracting with students. Individual and group therapy (usually in the form of Social Skills Groups) forms an integral component of treatment for most children in this age group, especially higher functioning youngsters. Relaxation training is taught to children with ASD as it is needed. SI is utilized usually with younger children and is an integral part of both physical and OT programs. Sensory diet is an integral part of many students' daily routine. The hospital also uses a cotreatment model of combined SLT and OT and uses a classroom rather than pull out model. OTs also work with ASD students on fine motor skills and daily living skills. Speech therapists use picture systems, work on pragmatic language skills and coordinate social skills training.

SWs at Bradley primarily serve to teach families about ASD and provide them with appropriate support, family therapy, individual therapy and parent skills training. Families are encouraged to bring in their own advocates or consultants to the IEP process if they feel the need to do so. The SWs also do legal advocacy work and estate planning for some families. Through EPSDT Bradley provides up to 30 hours a week of in home training for many of its clients. Bradley has done parent satisfaction surveys and found that parents are very happy with the services they provide; the only parent complaint is the long waiting lists.

Public school districts utilize Bradley quite often for diagnostic evaluations. The most typical referrals are cases of high functioning Asperger's or PDD. School districts also utilize Bradley to do inservice training. Sometimes districts use Bradley consultants to

help with specific behavior management issues and to provide therapy services and social skills training.

Information about children is shared formally in weekly staff meetings and informally at shift changes. The psychiatry staff does rounds on residential clients daily. Inservice training at Bradley is extensive, including inservices for one hour once a week, as well as ongoing on the job inservice training. Professional staff at the hospital must go to ongoing continuing education in order to maintain their licenses. Roland Barrett notes, "It's different than a regular school system. All the docs here are Brown University docs and we have our own individual departments. This is what they do, developmental disabilities, it's not as if 90% of our kids are regular ed kids and we have this small special needs component. All we do is developmental delay."

Arthur Mercurio feels that Bradley's strength is in its eclectic approach to care, "We have not stuck to, or become opposed to a particular philosophy or treatment approach. We've been extremely open to considering on a case to case basis what it is that makes a difference for a child."

Profile of the Groden Center

The Groden Center is a private agency located in Providence, Rhode Island which serves about 40 children with ASD. Children with ASD make up about 59% of their caseload. The center serves all school-aged children but has a larger proportion of children at the junior high and high school levels because public schools find this age range particularly challenging and families are also attracted to Groden's vocational training program.

Groden's classroom size is determined by the degree of children's impairment; the greater the impairment the smaller the number of students. There is one special education teacher in each classroom, and one or more treatment teachers, individuals who have a bachelor's degree in psychology or a related social service field. The overall program ratio is one teacher for every 1.6 students. The center provides an hour-long extended day program for some of its residential clients funded through DCYF and for some of its day students funded through their local school district. Groden also offers a Saturday therapeutic recreation program for 35 to 40 students funded mostly through DCYF. The center has about 8 ASD children in residential group home placements and about 3 in therapeutic foster care.

If a child with ASD needs a diagnosis when s/he comes to Groden, a consulting psychiatrist does an assessment. In the first 4-6 weeks that a child is at Groden, center staff conduct an intensive behavior evaluation from which they create a functional program which includes intensive communication training and positive behavior supports. Agency Special Education Director Susan Stevenson notes that Groden has an excellent record of using functional analysis to find the underlying causes of problematic behaviors and creating solutions to them. Groden consults with parents for input on all components of the assessment. The Center also does an assessment of other kinds of

services that may be necessary to support a child in continuing to live at home. This includes a home assessment, extensive home visits and home programs and, if needed, intensive parent training and temporary staff placement in the home (funded through Medicaid). Progress is tracked through specific IEP goals, counting specific behaviors, baseline testing, and an annual administration of the Vineland to all students. Assessments include an examination of learning style, looking at strength and deficit areas, and environmental and sensory limitations. Groden places an emphasis on experiential learning; children go on community trips and get job training in the community. Generally Groden takes 3-4 weeks to plan an IEP prior to its formal meeting with the school district.

Groden's general philosophy of care includes taking a holistic approach to each student. Ms. Stevenson notes, "We're going to address all of a child's life needs. And in some ways that makes our job very difficult because we have only so many hours a day that we're trying to address a comprehensive set of needs for the children. That's why we feel interacting with the family is going to be very important because obviously much of the learning goes on in the home. That's a key piece of our philosophy, to link with the family and anyone else who comes into contact with that child. So that's a primary premise, that there are multiple providers and multiple teachers." Groden's philosophy also emphasizes acknowledging and responding to a student's strengths and interests in creating each child's educational plan.

Groden uses PECS and ABA at all grade levels. All staff are trained in discrete trial training at both individual and group levels. The Center is also known for its use of imagery and relaxation techniques to teach skills and lower stress. The basic technique includes using imagery to describe a scenario which typically precipitates a problem behavior. They then describe the individual engaging in an appropriate behavior and receiving a positive consequence. The Center has found that that this technique is effective with children at all ages and levels of cognitive development. Therapeutic foster care families are trained to use Social Stories with children who have been through traumatic experiences.

SI programs are designed by a contracted OT and carried out by center staff. In a few cases where a child needs intensive OT they receive it from an OT on staff or outside of Groden. OTs also work on fine motor skills, self help skills, basic domestic skills and skills related to specific vocational training. At Groden SLT is placed within a broader rubric of communication training. The center has a full team of SLPs who work with teachers in classrooms in areas such as snack programs, Social Skills Groups and one-on-one instruction. SWs serve as 1) case managers to each family, linking them to appropriate services and 2) counseling higher functioning children.

Home programming is carried out by Groden's teaching staff. "Our teachers don't stop at the end of the day," explains Ms. Stevenson. "They're looked at as a link to the family and they'll help the families design programs that they can carry out at home." Groden also has a home visitor who helps with intensive behavioral home programming and

coordinates respite care services and social services. The Center also does an informing interview for parents of children with complicated IEPs.

Groden has a community consultation services department that provides consultations to school departments, other agencies, and individuals. School departments primarily utilize the team for consultation on students with problematic behaviors. The team does a behavioral assessment, designs a program and teaches the staff to carry it out. Sometimes school districts ask the Groden team to do exams and profiles if they don't have specialists familiar with ASD students. Public school districts also utilize the Groden team to do inservice training on functional analysis, behavioral programming, relaxation training and imagery training. School districts also use Groden as a placement agency, but Ms. Stevenson is pleased to report that they are using the agency more often for shorter term placements with the goal of returning the child back to a regular education setting. Public school districts also ask Groden to do independent evaluations in situations where there is a dispute with a family about a child's diagnosis. Finally, Groden manages two classrooms in North Kingstown at middle and elementary school levels.

Groden has an ongoing staff inservicing program which includes a 3 month long 20 module training series with inservice training outside of the classroom. There is continual online inservicing as well; supervisors work alongside staff members in each classroom showing them how to implement various methodologies and strategies. The center brings in speakers from outside as well.

The Center makes intragency transitions during the traditional summer academic break. Transitions to a school district include time in two classrooms, teacher visits and school visits. Adult transitioning is long term and intensive.

Groden Center takes great pride in the services it provides to people with ASD. Ms. Stevenson notes, "It's not just [that we're] an agency that specializes in this population and providing what we think to be state of the art quality programs, we're doing it within a philosophical framework that is consistent with what is important for this population."

Profile of Meeting Street School

The Meeting Street School is located in East Providence and currently serves about five children with ASD. Another two children at the School exhibit autistic features as well. ASD clients makeup about 7% of Meeting Street's total caseload. The School primarily serves the therapeutic needs of all children with disabilities. Therefore the children who come to the School with an ASD diagnosis have other specific augmentative communication, OT or Physical Therapy needs that can not be met in settings that have a specific ASD focus.

Children with ASD are served in the same settings as other children at Meeting Street. Classrooms have six students, a teacher and a teacher associate. The School is divided

into Early Childhood, Elementary, Transition and Secondary units. The School works to use inclusive therapies and incorporate OT and SLT in the classroom. Meeting Street offers an afterschool recreation program for children ages 13 and over with disabilities. Children are referred to Meeting Street by their LEA. Once the School determines that its services are compatible with the child's needs each child is admitted and given 4 to 6 week of diagnostic screen. At the end of that period staff meets with parents for pre-IEP meetings and to create the child's IEP. Family input on diagnostic tests is an important component of shaping each child's program. Assessment of goals is an ongoing process with quarterly meetings to review each child's progress and ongoing weekly team meetings. Clinical Psychologist Joanna Futransky quips, "Meeting Street is aptly named because we meet a lot!"

Meeting Street's philosophy of care is moving towards a transdisciplinary approach, encouraging in class participation by therapists rather than a pull out model. This includes joint treatment and each professional working to carry out all of the goals for each child; not just the ones that are specific to their own discipline. The School does not use formal ASD programming currently. Educational and therapeutic techniques are driven by the IEP goals for each child. OTs play an important role at Meeting Street and design extensive SI programs for children with ASD as needed. They also work on augmentative communication strategies, self care skills and vocational training. One of the goals of the School is to develop a system of communication for every student; SLTs work to address this goal through a variety of techniques. School systems use Meeting Street for outside consultations on augmentative communication.

Home carryover is promoted through the use of notebooks, phone calls and an "open door" policy in which parents are encouraged to come in and observe their child's class at any time. The School also videotapes therapy sessions for parents to follow and learn from at home.

Profile of Northern Rhode Island Collaborative

The Northern Rhode Island Collaborative is a public agency that is made up of a consortium of the towns of Burrillville, Central Falls, Cumberland, Johnston, Lincoln, North Providence, North Smithfield, Pawtucket, Smithfield and Woonsocket. The collaborative's administrative offices are located in Cumberland with 28 classrooms throughout the region, many of which are in public school settings. It currently serves about 26 children with ASD

Generally, programs in the collaborative are designed for severe and profoundly disabled children and children with behavior disorders. The programs for children with ASD are language-based and very structured. At the preschool level the collaborative provides inclusion through Kinderpals, a program in which regular ed preschoolers come into special ed classrooms for a few mornings each week as well as a program with the YWCA of Woonsocket.

Children who are referred into the agency generally already have an ASD diagnosis, but the collaborative does further assessment measures to assist in making IEP determinations. The IEP goals are integrated to encourage a transdisciplinary approach. The agency is devoted to a team approach that includes parents in identifying goals and strategies. The assessment of each child drives the instruction, and ongoing data collection is at the heart of the program. Each child's progress is reported every six months in a formal review. In classroom educators place an emphasis on developing communication strategies appropriate for each child. SI is utilized in a variety of ways as well as behavioral approaches. Elements of TEACCH, ABA and PECS are incorporated into ASD programming when they are appropriate for individual children with ASD. As children grow older more of an emphasis is placed on functional living skills. For example, the collaborative rented an apartment to teach children daily living skills in a natural setting. OT and SLT is incorporated into classroom settings instead of a pull out model. SWs work primarily with families. Typically they help a family to ascertain IEP goals and needs and connect them with outside agencies. Job facilitators help place children in vocational settings as they grow older. The collaborative keeps track of its programs, staff, teams, classroom locations, classroom size and programming on a huge magnetic board with separate magnets for each staff member and administrator. This board allows the collaborative powerful visual representation of its entire program at a glance.

The collaborative is committed to integrating students back into public school settings as often as possible and uses extensive transition plans to assure success. Staff members also provide OT, Physical Therapy and SLT to students in local school districts.

The collaborative stays abreast of new interventions for ASD and incorporates them as needed. Inservicing is ongoing and extensive. Collaborative administrators work continually with collaborative staff to identify and meet training needs as they arise.

Profile of Francis B. Sargent Rehabilitation Center

The Sargent Center is located in Warwick, Rhode Island and currently serves 12 children with ASD who make up about 33% of the agency's total caseload.

Out patient services are available to children who remain in their local school systems. Usually around 10 to 12 children with ASD are served through this system.

Children come to Sargent with a diagnosis and then go through a formal 6 week long intake process in which the intake team determines the level of their eligibility for services and the type of services and educational interventions that will best fit their needs. The team includes teachers, a psychologist, a speech language therapist, a physical therapist, an occupational therapist and other professionals. The team's diagnostic work is geared towards further defining the diagnostic profile for each child.

Sargent was founded in the 1920s to serve the needs of the blind and deaf and eventually by the late 1960s took on the role of educating children with language and hearing disabilities. The school was formed around a multidisciplinary team approach. Teams meet weekly to discuss each child's progress. Extensive opportunities for inservice are available both within and outside of the agency. Sargent keeps a library of inservice information for its staff as well. Sargent staff feel that the school is constantly evolving and shifting as they incorporate new approaches and find different ways to use tested approaches with children from a variety of age groups.

The Center is organized into upper and lower school teams. Each classroom is designed to meet the needs of children with disabilities. Rooms are designed with specific color schemes, natural lighting, carpeting and visual cues designed to provide children with correct levels of stimulation. The school uses schedule boards with photographs and more visual cues in classrooms and smaller class size for its ASD population. Sargent uses metamusic, which is music that works on both hemispheres of the brain to sooth and focus children through different school activities. Director Marilyn Serra notes, "The facility is designed to be very user friendly for children."

The Center provides an extended year program and is looking into providing extended day services in the form of structured daycare for the younger children and community vocational training for the older children.

Progress of each child is tracked through four progress reports per year, written daily reports, weekly meetings of the direct service team and diagnostic tests. Acquirement of daily living skills and vocational skills is tracked as well. Sargent staff use Childhood Autism Rating Schedule (CARS) and a nationally scored SI profile to track progress of children with ASD.

Specific educational methodologies used at Sargent for children with ASD include PECS, Social Stories and specific behavior management techniques. Although the agency does not use ABA it has borrowed ABA approaches of data collection and discrete trials. The agency has a behavior management team of intragency and outside professionals that meets once a week to review individual cases and create individual behavior plans. Former Director of the Pediatric Program Pat Rakovic notes, "sometimes you're too close to the situation to see the solution" and that the team is a useful way to solve practical problems. The Center has been at the forefront of SI therapy in Rhode Island and utilizes a variety of techniques in each classroom. SLT makes up an integral part of the multidisciplinary team approach as well. As children grow older more emphasis is placed on social skills training and vocational skills. SWs work with children on play and social skills in the classroom and provide one on one counseling to some of the older children, as well as sibling and parent support groups. SWs make home visits and go over progress reports with parents and provide some family counseling. SWs also educate parents about other services available to them. Sometimes they will escort families to appointments to these agencies.

Families play an integral role at Sargent. Their input is included in progress reports and they offer formal assessment in the intake process; their goals, identified in a pre-IEP questionnaire, shape those of the final IEP. Sometimes parents even take the responsibility for writing large portions of the IEP. Ms. Rakovic notes, "From beginning to end they're an equal team member." If a family's assessment of their child's abilities seems at odds with the agency's, staff will conduct a home visit in order to understand and reconcile discrepancies in perception. Ms. Serra notes, "lots of times the child is different here than in the home and so for families to have access to what's working here is really important. Treatment goes on here, but it is also transferred into the home. And it would not be inappropriate for a SW to be part of the treatment team. OT and Speech will visit the home also in order to make the transfer occur." Videotapes of school sessions are also used to promote home carryover and parents are encouraged to visit the center to observe their child in the classroom. The SWs from Sargent teach parenting skills and do some advocacy. Sargent's staff try to tailor their expectations to parent's stress levels and ability to carry through with them.

School systems are asking Sargent staff to make an increasing number of diagnoses. LEAs also use Sargent staff as consultants on the MDT team. LEAs also utilize Sargent for extended school year programs and outpatient treatment of children who need supplemental programs. When a child transitions back to his/her local LEA, the Center does followup on his/her progress for several years. Transition plans typically include meeting with family about their goals, school visits, assessment of best placements and time in both classrooms for the child. Sargent staff find that the more formal this process is, the more likely it is that the transition will be a successful one. Ms. Rakovic notes "The community ends up having more questions, and they end up using us more as a consultant and then we develop a relationship that after the child is in the school and some problem comes up, they're more free to call us."

Profile of Trudeau Education Services

Trudeau Education Services is located in Warwick and currently serves seven children with ASD, making up about a quarter of the total caseload for the center. At the time of our interview the Center was in the process of transitioning to an ABA model of intervention for its ASD children.

At Trudeau children with ASD are served in classrooms that are similar to those for children with other kinds of developmental delay. The classrooms are set up to address the needs of children with multiple levels of intelligence and disability. However, the Center is currently in the process of designing two ABA classrooms. Director of Children and Family Services Katherine White notes, "I think as an agency we are just starting to recognize different strategies and different learning styles." She feels that the data are available now to support using different learning strategies for different developmental disabilities. An extended day program of extended structured play is provided for children up to age seven.

Trudeau refers out to CDC, Bradley and Boston Children's Hospital for its diagnostic evaluations. The Center currently uses standard general developmental delay matrices, but expects to cultivate new indices as it develops its ABA program. The Center is currently doing comprehensive reevaluations on each student with the revised IEP and taking a specific interest in their adaptive needs as well as their strengths and weak areas. From the MDT goals and objectives, Trudeau is developing an interdisciplinary overlay so that goals and objectives can be better integrated.

According to Director Kevin Leahy, Trudeau's general philosophy of care is "to respond to kids' needs and adults' needs where they are and to design our services based on their individual needs. Also, to provide the services within the kid's home community, to work real closely with families to make sure that there's a real good bridge between what takes place in the educational environment and in the home environment. [We also believe in] bringing therapists and a variety of other experts right into the learning environment. We really have been working very hard in the last couple of months to include families on the planning and design of the delivery of services. [We work hard] to develop the professional competency of our staff, we put a lot into the training of our employees and recruiting talented people." Ms. White adds, "by the nature of the beast, we're a self-contained facility but we're making a grand effort not to be self-contained because what we've found is that kids can stay here for a good 19 years and families and students don't have that experience of using outside services...[we need to get parents and students] used to using those services that will carry forward throughout the continuum of their lives that aren't necessarily connected to just one facility."

Currently specific teaching methodologies at Trudeau for children with ASD include PECS, circle of friends, queuing and specific visual strategies. Trudeau works to use a positive approach and does not incorporate aversive techniques. The collection of data is emphasized in measuring the effectiveness of specific methodologies. Trudeau staff believe that discrete trials and time for social play are equally important. SI techniques include deep massage and desensitization. SLTs work with children in both classroom and social contexts. They incorporate a thematic approach in teaching both language and social skills. A school psychologist designs the behavior plan for ASD children, trains staff in its implementation and tracks its effectiveness through data collection.

SWs in the agency work directly with families as case managers to ensure that respite care, afterschool programming and other social service needs are being met. SWs also do advocacy, run support groups for parents and siblings and run workshops. Ms. White notes, "It's a constant battle with Medicaid just to get something approved so the SW does the battle instead of the family." Trudeau emphasizes parent involvement and effective home carryover as a crucial component of its success. IEPs are not written until parents have met with the team and voiced their concerns. An MDT goes to each child's home to design home programs. Families are interviewed and a home assessment is done. Families are encouraged to prioritize what their needs are in designing the home program. For families who are particularly overburdened, a family mentor comes into the home to help implement and carry out the home program. Parents also make visits to the agency on open classroom days and receive some inservicing with the staff.

Additionally, parents have spearheaded the movement towards ABA classrooms. Center staff find that it is sometimes difficult to involve older families but they have found that keeping them informed of changes in the curriculum and scheduling conferences has helped to draw them in.

Trudeau emphasizes a collaborative relationship with public school systems. Local school districts usually refer children to the Center at the preschool level and Trudeau likes to transition children back into their local school district as soon as it is feasible. Trudeau is looking into the possibility of moving some of its classrooms into local school districts as a way to expand inclusion opportunities. Trudeau also receives increasing numbers of requests to do assessment for LEAs. Public school districts contract with the center for consultation on school to work transition programs. In describing Trudeau's changing relationship to LEAs, Director Paul Sherlock notes, "[Public school districts] used to farm students out and assumed that all was well. Somebody was doing their job so they didn't have to do it and that really took one advocacy element out of the mix. And now they're being included in that mix. The kid belongs to the family, the community and we provide the service. That's the underlying philosophy." Plans for transition s back to public school settings can range from simple to extensive; they are limited to the demands and needs of local LEAs.

Due to its current curricular and program transitions Trudeau has a large inservicing and training budget. Inservicing includes basic overall training on the agency's philosophy, specific training designed to address specific students needs, bringing in local experts and bringing in national experts. A monthly inservice release day allows Trudeau to train staff in techniques specific to their new approach.

Survey of Autism Professionals

The results of the survey of autism professionals are presented in Tables 25 through 38. Table 25 summarizes the occupation of respondents; in descending order, the top three categories were special education teachers (27%), SLPs (16%) and school or child psychologists (9%). Most of the surveys (66%) came from LEAs, but private agencies also had sizable participation at 29% (see Table 26). The age range of ASD children in each respondent's caseload (please see Table 27) for LEA collaboratives and private agencies tends to be skewed towards preschool and elementary school. However, it also appears that private agency respondents serve a disproportionate number of high school aged students (43%) in comparison to the collaboratives. This finding suggests that high school students with ASD are often placed out of district. Table 28, Total Caseload, indicates that the vast majority of respondents (79%) have from 1 to 10 students with ASD in their caseload.

TABLE 25 Occupation of Respondents

Profession	# of Cases	% of Total
Special Education Teacher	98	27
Speech/Language Pathologist	59	16
School/Child Psychologist	32	9
Special Education Aide	27	7
Early Childhood Special Educator	25	7
School Social Worker/Guidance Counselor	22	6
Occupational Therapist	22	6
Educational Diagnostician	21	6
Regular Education Classroom Aide	20	5
Physical Therapist	11	3
Regular Education Teacher	10	3
Administrator	8	2
School Principal	6	2
No Profession Listed	7	2
TOTAL	368	100

TABLE 26 Number of Cases by District/Agency/Region

District/Agency	# of Cases	% of Total
East Bay Collaborative	49	13
West Bay Collaborative	75	20
Southern Collaborative	57	15
Northern Collaborative	66	18
Private Agency	108	29
Early Intervention	13	4
TOTAL	368	100

NOTE: LEA subtotal is 247 cases; 67% of total.

TABLE 27 Age Range of ASD Children in Caseload, by Percentage

Age	East Bay Collaborative	West Bay Collaborative	Southern Collaborative	Northern Collaborative	Early Intervention	Private Agency	All Cases
Early Intervention	12	9	4	2	100	4	8
Preschool	41	56	49	33	0	32	40
Elementary School	65	52	74	79	0	56	61
Junior High School	31	21	9	23	0	33	24
High School	16	17	9	9	0	43	21
Postgraduate	8	3	5	2	0	12	6

In Table 29 settings in which ASD children are assessed or served are summarized. For all respondents the most common setting for assessment and service was a self contained classroom. However, EI respondents selected offices/clinics and child's home most often.

Table 30 summarizes the use of diagnostic tests by profession. This table reveals at least 3 striking findings. First, there are currently at least 44 diagnostic tests being used by practitioners throughout our state; this huge number could make it difficult to track and compare ASD children's progress across LEAs, agencies and EI regions. Second, 72 ASD professionals (including 21 special education teachers) reported that they do not use diagnostic tests, and therefore have no formal means of tracking student progress. This was the third most common response. Third, some of the tests listed are outdated and therefore of questionable validity.

Methods used to promote home carryover or implementation of home programs are summarized in Table 31. For all LEAs the most common methods used to promote carryover were phone calls (69%) and notebooks (72%). Consistently about 20% of all agency respondents reported using the various methods to implement home programs. EI and agency respondents consistently report a fairly high level of use for all methods for both carryover and implementation.

Tables 32a and 32b summarize methods of instruction by collaborative, region, or agency. There is a great deal of data in these tables, and the reader is encouraged to review them carefully. Three major patterns are apparent. First, the most popular methods overall in descending order are Picture/word boards, sign/gesture communication, PECS and SI. Second, agency respondents and EI respondents report overall higher levels of use of the methods of instruction listed than do the LEAs. Finally, over 20% of respondents reported a lack of familiarity with Social Stories, Greenspan, TEACCH and Miller; these are all nationally recognized models for ASD education and a broad lack of recognition of them indicates a basic need for greater ASD inservicing. Tables 33a and 33b present the same information organized by profession for the reader's further review.

TABLE 28 Total Caseload, by Collaborative and Agency

	East Bay Collaborative		West Bay Collaborative		Southern Collaborative		Northern Collaborative		ALL LEAs		Early Intervention		Private Agency		All	
# of Children	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total
0	11	22	7	9	3	5	5	8	26	11	1	8	0	0	27	7
1-10	35	71	54	72	51	89	60	91	200	81	6	46	86	80	292	79
11-20	3	6	7	9	1	2	1	2	12	5	4	31	13	12	29	8
21-30	0	0	2	3	1	2	0	0	3	1	1	8	2	2	6	2
More than 30	0	0	3	4	0	0	0	0	3	1	1	8	7	6	11	3
Blank/Missing	0	0	2	3	1	2	0	0	3	1	0	0	0	0	3	1
TOTAL	49		75		57		66		247		13		108		368	

TABLE 29 Settings In Which Children Are Assessed and Served

Setting	East Bay Collaborative		West Bay Collaborative		Southern Collaborative		Northern Collaborative		ALL LEAs		Early Intervention		Private Agency		All	
	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total
Self Contained Classroom																
Assess Children	19	39	27	36	14	25	23	35	69	28	0	0	38	35	121	33
Serve Children	21	43	39	52	27	47	38	58	125	51	3	23	61	56	189	51
Regular Classroom																
Assess Children	10	20	19	25	16	28	11	17	54	22	0	0	7	6	63	17
Serve Children	21	43	21	28	35	61	23	35	92	37	2	15	13	12	115	31
Private Facility																
Assess Children	1	2	6	8	2	4	1	2	10	4	1	8	41	38	52	14
Serve Children	2	4	3	4	1	2	0	0	6	2	3	23	63	58	72	20
Office/Clinic																
Assess Children	7	14	20	27	15	26	9	14	51	21	8	62	9	8	68	18
Serve Children	9	18	11	15	12	21	4	6	36	15	7	54	8	7	51	14
Early Intervention																
Assess Children	3	6	9	12	7	12	2	3	21	9	1	8	1	1	23	6
Serve Children	2	4	6	8	5	9	3	5	16	6	2	15	3	3	21	6
Day Care																
Assess Children	3	6	3	4	2	4	2	3	10	4	2	15	3	3	15	4
Serve Children	2	4	6	8	3	5	2	3	13	5	5	38	9	8	27	7
Child's Home																
Assess Children	6	12	6	8	15	26	2	3	29	12	7	54	12	11	48	13
Serve Children	6	12	6	8	6	11	2	3	20	8	8	62	27	25	55	15
Inclusion Classroom																
Assess Children	1	2	5	7	4	7	6	9	16	6	0	0	1	1	17	5
Serve Children	1	2	2	3	2	4	3	5	8	3	0	0	0	0	8	2
Resource Room																
Assess Children	1	2	8	11	3	5	0	0	12	5	0	0	0	0	12	3
Serve Children	2	4	8	11	3	5	1	2	14	6	0	0	0	0	14	4

TABLE 30 Use of Diagnostic Tests and Measures, by Profession (Page 1 of 2)

	Administrator	School Principal	Educational Diagnostician	School/Child Psychologist	School Social Worker/Guidance Counselor	Occupational Therapist	Speech/Language Pathologist	Physical Therapist	Early Childhood Special Educator	Special Education Aide	Special Education Teacher	Regular Education Classroom Aide	Regular Education Teacher	No Profession Listed	Total
Vineland	0	1	2	20	5	2	4	0	6	9	34	1	1	0	85
Brigance Comprehensive Inventory	0	0	10	4	1	3	3	0	9	7	38	1	1	0	77
Peabody Developmental Motor Scales	1	1	3	2	1	18	7	7	4	3	14	1	1	0	63
Woodcock Johnson	1	1	9	4	1	1	2	1	4	5	27	0	2	0	58
Preschool Language Scale	1	1	2	3	1	1	38	0	7	0	3	1	0	0	58
Mullens	2	1	10	3	0	6	6	0	12	1	9	0	0	0	50
WISC-III-R	2	2	3	23	3	0	2	0	1	2	10	1	1	0	50
CELF	0	0	3	2	1	1	38	0	2	1	1	0	0	0	49
Binet	1	1	0	18	1	1	1	0	2	5	3	1	1	0	35
WPPSI-R	1	2	2	14	0	1	2	0	2	1	3	1	1	0	30
Social Skills Inventory	0	0	1	4	3	0	3	0	2	4	11	1	0	0	29
Informal Observations	0	0	1	4	1	7	9	1	1	0	2	0	0	0	26
Bruinks-Oseretsky (BOTMP)	0	0	0	1	1	11	2	3	2	0	1	0	1	0	22
Bailey Scales of Infant Development	1	0	1	6	0	2	3	0	3	1	4	0	0	0	21
Sensory Integration and Praxis Test	0	0	1	1	0	8	3	0	0	2	5	1	0	0	21
TOPL Test of Pragmatic Language	0	0	0	1	0	0	13	0	1	0	1	0	0	0	16
PPVT-L	0	0	0	1	0	0	13	0	0	0	1	0	0	0	15
Pediatric Evaluation of Disability Inventory (PEDI)	0	0	1	0	1	5	1	4	0	1	0	1	0	0	14
Kaufman ABC	1	0	1	8	1	0	0	0	1	0	0	1	0	0	13
Miller Assessment Preschools (MAP)	0	0	2	0	0	6	0	2	1	0	2	0	0	0	13
WIAT	0	0	2	3	0	0	0	0	0	2	4	1	0	0	12
EOWPVT	0	0	0	0	0	0	11	0	0	0	1	0	0	0	12

TABLE 30 Use of Diagnostic Tests and Measures, by Profession (Page 2 of 2)

	Administrator	School Principal	Educational Diagnostician	School/Child Psychologist	School Social Worker/Guidance Counselor	Occupational Therapist	Speech/Language Pathologist	Physical Therapist	Early Childhood Special Educator	Special Education Aide	Special Education Teacher	Regular Education Classroom Aide	Regular Education Teacher	No Profession Listed	Total
Childhood Autism Rating Scale (CARS)	0	0	3	3	0	0	1	0	0	0	4	0	0	0	11
Rosetti	1	0	0	2	0	1	4	0	2	0	1	0	0	0	11
TACL	0	0	0	0	0	0	11	0	0	0	0	0	0	0	11
BATTELLE	0	0	3	0	0	0	1	0	3	0	2	0	1	0	10
PORTAGE	0	0	0	0	0	0	0	0	0	2	8	0	0	0	10
LAP	0	0	2	0	0	0	1	1	2	0	2	0	1	0	9
Leiter	0	0	0	5	0	0	1	0	0	0	1	0	0	0	7
TOLDP2	0	0	0	0	0	0	7	0	0	0	0	0	0	0	7
Transdisciplinary-based Play	0	0	0	0	0	0	4	0	1	0	0	0	0	0	5
Frosty Casual Perception	0	0	0	0	0	1	4	0	0	0	0	0	0	0	5
OWLS	0	0	0	0	0	0	3	0	0	1	0	0	0	0	4
CSPS	0	0	0	0	0	0	3	0	0	0	0	0	0	0	3
Goldman-Fristoe Test of Articulation	0	0	0	0	0	0	3	0	0	0	0	0	0	0	3
AGS Screening Profile	0	0	0	0	0	1	2	0	0	0	0	0	0	0	3
Token Test	0	0	0	0	0	0	2	0	0	0	0	0	0	0	2
VMI	0	0	1	0	0	1	0	0	0	0	0	0	0	0	2
PAB-R	0	0	0	0	0	0	0	0	0	0	1	0	0	0	1
Sensory Profile	0	0	0	0	0	1	0	0	0	0	0	0	0	0	1
Touch Inventory	0	0	0	0	0	1	0	0	0	0	0	0	0	0	1
Pragmatic Skills	0	0	0	0	0	0	1	0	0	0	0	0	0	0	1
Vort	0	0	0	0	0	0	0	0	0	0	1	0	0	0	1
DTUP-2	0	0	0	0	0	0	1	0	0	0	0	0	0	0	1
Developmental History	0	0	0	0	1	0	0	0	0	0	0	0	0	0	1
Do not use diagnostic tests	4	0	1	4	10	1	2	1	5	9	21	11	3	0	72
Am unfamiliar with diagnostic tests	0	0	0	0	2	0	3	0	2	4	2	7	2	0	22

TABLE 31 Methods Used to Promote Home Carryover or Implement a Home Program

Method	East Bay Collaborative		West Bay Collaborative		Southern Collaborative		Northern Collaborative		ALL LEAs		Early Intervention		Private Agency		All	
	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total
Phone Calls																
Carryover of School Skills	30	61	52	69	42	74	46	70	170	69	5	38	88	81	263	71
Implementation of a Home Program	9	18	20	27	9	16	11	17	49	20	7	54	47	44	103	28
Home Visit																
Carryover of School Skills	18	37	25	33	16	28	12	18	71	29	6	46	67	62	144	39
Implementation of a Home Program	8	16	12	16	11	19	7	11	38	15	9	69	59	55	106	29
Notes/Notebook																
Carryover of School Skills	35	71	51	68	44	77	47	71	177	72	6	46	104	96	287	78
Implementation of a Home Program	9	18	17	23	13	23	14	21	53	21	5	38	53	49	111	30
In-home Treatment By Educator																
Carryover of School Skills	8	16	14	19	7	12	1	2	30	12	6	46	40	37	76	21
Implementation of a Home Program	9	18	11	15	6	11	2	3	28	11	10	77	46	43	84	23
Home Program																
Carryover of School Skills	17	35	28	37	17	30	13	20	75	30	6	46	61	56	142	39
Implementation of a Home Program	9	18	20	27	12	21	10	15	51	21	10	77	63	58	124	34
No Communication																
Carryover of School Skills	1	2	1	1	0	0	2	3	4	2	1	8	2	2	7	2
Implementation of a Home Program	0	0	0	0	0	0	1	2	1	0	1	8	2	2	4	1

TABLE 32a Methods of Instruction, by Collaborative and Agency (Page 1 of 2)

Response	East Bay Collaborative		West Bay Collaborative		Southern Collaborative		Northern Collaborative	
	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total
	49	100	75	100	57	100	66	100
Sign/Gesture Communication								
I Use This Method	22	45	35	47	26	46	24	36
I Find This Method Effective	23	47	25	33	18	32	25	38
Picture Exchange System								
I Use This Method	19	39	30	40	24	42	19	29
I Find This Method Effective	18	37	26	35	19	33	21	32
Picture/Word Boards								
I Use This Method	24	49	37	49	30	53	31	47
I Find This Method Effective	24	49	30	40	25	44	30	45
Sensory Integration								
I Use This Method	21	43	29	39	26	46	26	39
I Find This Method Effective	19	39	27	36	21	37	22	33
Auditory Integration								
I Use This Method	8	16	4	5	2	4	3	5
I Find This Method Effective	6	12	7	9	4	7	3	5
ABA/Lovaas								
I Use This Method	3	6	7	9	11	19	7	11
I Find This Method Effective	3	6	6	8	10	18	7	11
Miller								
I Use This Method	1	2	1	1	2	4	1	2
I Find This Method Effective	1	2	2	3	2	4	0	0
TEACCH								
I Use This Method	0	0	0	0	0	0	1	2
I Find This Method Effective	0	0	1	1	0	0	2	3
Greenspan/Floortime								
I Use This Method	2	4	4	5	4	7	2	3
I Find This Method Effective	2	4	3	4	4	7	2	3
Social Stories								
I Use This Method	15	31	14	19	14	25	19	29
I Find This Method Effective	13	27	11	15	13	23	16	24
Comic Strip Conversations								
I Use This Method	10	20	7	9	2	4	11	17
I Find This Method Effective	10	20	5	7	3	5	9	14
Social Skills Groups								
I Use This Method	20	41	29	39	23	40	24	36
I Find This Method Effective	16	33	23	31	18	32	24	36

TABLE 32a Methods of Instruction, by Collaborative and Agency (Page 2 of 2)

Response	All LEAs		Early Intervention		Private Agency		All	
	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total
	247	100	13	100	108	100	368	100
Sign/Gesture Communication								
I Use This Method	107	43	10	77	81	75	198	54
I Find This Method Effective	91	37	12	92	77	71	180	49
Picture Exchange System								
I Use This Method	92	37	7	54	81	75	180	49
I Find This Method Effective	84	34	7	54	73	68	164	45
Picture/Word Boards								
I Use This Method	122	49	8	62	77	71	207	56
I Find This Method Effective	109	44	10	77	72	67	191	52
Sensory Integration								
I Use This Method	102	41	9	69	70	65	181	49
I Find This Method Effective	89	36	11	85	62	57	162	44
Auditory Integration								
I Use This Method	17	7	3	23	21	19	41	11
I Find This Method Effective	20	8	4	31	12	11	36	10
ABA/Lovaas								
I Use This Method	28	11	0	0	15	14	43	12
I Find This Method Effective	26	11	0	0	19	18	45	12
Miller								
I Use This Method	5	2	0	0	1	1	6	2
I Find This Method Effective	5	2	1	8	2	2	8	2
TEACCH								
I Use This Method	1	0	1	8	5	5	7	2
I Find This Method Effective	3	1	4	31	9	8	16	4
Greenspan/Floortime								
I Use This Method	12	5	5	38	3	3	20	5
I Find This Method Effective	11	4	7	54	4	4	22	6
Social Stories								
I Use This Method	62	25	1	8	22	20	85	23
I Find This Method Effective	53	21	1	8	20	19	74	20
Comic Strip Conversations								
I Use This Method	30	12	0	0	5	5	35	10
I Find This Method Effective	27	11	0	0	7	6	34	9
Social Skills Groups								
I Use This Method	96	39	4	31	56	52	150	41
I Find This Method Effective	81	33	4	31	47	44	127	35

**TABLE 32b Methods of Instruction, Unfamiliar or No Opinion:
By All Collaboratives and Agencies**

Method	Respondents Unfamiliar with Method		Respondents Expressed No Opinion of Method	
	# of Cases	% of Total	# of Cases	% of Total
Sign/Gesture Communication	14	4	8	2
Picture Exchange System	19	5	9	2
Picture/Word Boards	10	3	8	2
Sensory Integration	23	6	16	4
Auditory Integration	64	17	23	6
ABA/Lovaas	77	21	21	6
Miller	132	36	19	5
TEACCH	138	38	21	6
Greenspan/Floortime	130	35	21	6
Social Stories	72	20	19	5
Comic Strip Conversations	68	18	19	5
Social Skills Groups	20	5	16	4

TABLE 33a Methods of Instruction Listed by Profession (Page 1 of 4)

Response	Regular Classroom Aide		Regular Education Teacher		Special Education Aide		Special Education Teacher	
	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total
	20	100	10	100	27	100	98	100
Sign/Gesture Communication								
I Use This Method	14	70	1	10	19	70	52	53
I Find This Method Effective	9	45	2	20	10	37	51	52
Picture Exchange System								
I Use This Method	13	65	1	10	18	67	48	49
I Find This Method Effective	9	45	2	20	12	44	42	43
Picture/Word Boards								
I Use This Method	12	60	3	30	18	67	61	62
I Find This Method Effective	9	45	4	40	13	48	52	53
Sensory Integration								
I Use This Method	12	60	3	30	16	59	46	47
I Find This Method Effective	10	50	1	10	11	41	41	42
Auditory Integration								
I Use This Method	5	25	1	10	7	26	12	12
I Find This Method Effective	3	15	0	0	5	19	9	9
ABA/Lovaas								
I Use This Method	1	5	1	10	0	0	12	12
I Find This Method Effective	2	10	1	10	1	4	12	12
Miller								
I Use This Method	0	0	0	0	0	0	1	1
I Find This Method Effective	0	0	0	0	1	4	1	1
TEACCH								
I Use This Method	1	5	0	0	0	0	1	1
I Find This Method Effective	1	5	0	0	1	4	2	2
Greenspan/Floortime								
I Use This Method	1	5	0	0	0	0	4	4
I Find This Method Effective	1	5	0	0	1	4	4	4
Social Stories								
I Use This Method	5	25	1	10	9	33	23	23
I Find This Method Effective	5	25	1	10	6	22	18	18
Comic Strip Conversations								
I Use This Method	0	0	0	0	1	4	8	8
I Find This Method Effective	0	0	0	0	2	7	7	7
Social Skills Groups								
I Use This Method	6	30	2	20	12	44	52	53
I Find This Method Effective	5	25	1	10	9	33	34	35

TABLE 33a Methods of Instruction Listed by Profession (Page 2 of 4)

Response	Educational Diagnostician		Speech/Language Pathologist		Occupational Therapist		Physical Therapist	
	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total
	21	100	60	100	22	100	11	100
Sign/Gesture Communication								
I Use This Method	11	52	39	65	15	68	9	82
I Find This Method Effective	12	57	36	60	15	68	6	55
Picture Exchange System								
I Use This Method	8	38	36	60	11	50	5	45
I Find This Method Effective	9	43	36	60	14	64	3	27
Picture/Word Boards								
I Use This Method	13	62	41	68	15	68	8	73
I Find This Method Effective	14	67	41	68	14	64	6	55
Sensory Integration								
I Use This Method	9	43	30	50	18	82	8	73
I Find This Method Effective	9	43	26	43	18	82	8	73
Auditory Integration								
I Use This Method	2	10	4	7	2	9	1	9
I Find This Method Effective	2	10	5	8	2	9	0	0
ABA/Lovaas								
I Use This Method	3	14	8	13	4	18	1	9
I Find This Method Effective	2	10	5	8	4	18	1	9
Miller								
I Use This Method	1	5	4	7	0	0	0	0
I Find This Method Effective	1	5	3	5	0	0	0	0
TEACCH								
I Use This Method	1	5	2	3	0	0	0	0
I Find This Method Effective	1	5	2	3	0	0	0	0
Greenspan/Floortime								
I Use This Method	0	0	6	10	1	5	0	0
I Find This Method Effective	0	0	6	10	1	5	0	0
Social Stories								
I Use This Method	5	24	20	33	2	9	1	9
I Find This Method Effective	4	19	19	32	3	14	0	0
Comic Strip Conversations								
I Use This Method	2	10	14	23	3	14	0	0
I Find This Method Effective	2	10	14	23	3	14	0	0
Social Skills Groups								
I Use This Method	9	43	32	53	5	23	2	18
I Find This Method Effective	8	38	27	45	7	32	2	18

TABLE 33a Methods of Instruction Listed by Profession (Page 3 of 4)

Response	Early Childhood Special Educator		School/Child Psychologist		School Social Worker/ Guidance Counselor		School Principal	
	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total
	25	100	32	100	22	100	6	100
Sign/Gesture Communication								
I Use This Method	18	72	9	28	6	27	1	17
I Find This Method Effective	15	60	11	34	6	27	1	17
Picture Exchange System								
I Use This Method	17	68	11	34	5	23	0	0
I Find This Method Effective	16	64	11	34	6	27	0	0
Picture/Word Boards								
I Use This Method	17	68	9	28	4	18	0	0
I Find This Method Effective	17	68	10	31	6	27	0	0
Sensory Integration								
I Use This Method	19	76	7	22	6	27	1	17
I Find This Method Effective	15	60	11	34	7	32	1	17
Auditory Integration								
I Use This Method	2	8	1	3	2	9	1	17
I Find This Method Effective	2	8	2	6	2	9	1	17
ABA/Lovaas								
I Use This Method	7	28	5	16	0	0	0	0
I Find This Method Effective	7	28	6	19	2	9	0	0
Miller								
I Use This Method	0	0	0	0	0	0	0	0
I Find This Method Effective	0	0	0	0	0	0	0	0
TEACCH								
I Use This Method	1	4	1	3	0	0	0	0
I Find This Method Effective	1	4	4	13	1	5	0	0
Greenspan/Floortime								
I Use This Method	4	16	3	9	0	0	0	0
I Find This Method Effective	4	16	2	6	0	0	0	0
Social Stories								
I Use This Method	7	28	5	16	3	14	1	17
I Find This Method Effective	7	28	7	22	3	14	0	0
Comic Strip Conversations								
I Use This Method	1	4	4	13	1	5	0	0
I Find This Method Effective	1	4	4	13	0	0	0	0
Social Skills Groups								
I Use This Method	7	28	15	47	7	32	1	17
I Find This Method Effective	10	40	15	47	8	36	1	17

TABLE 33a Methods of Instruction Listed by Profession (Page 4 of 4)

Response	Administrator		Blank		All	
	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total
Sign/Gesture Communication	9	100	5	100	368	100
I Use This Method	3	33	1	20	198	54
I Find This Method Effective	5	56	1	20	180	49
Picture Exchange System						
I Use This Method	5	56	2	40	180	49
I Find This Method Effective	4	44	0	0	164	45
Picture/Word Boards						
I Use This Method	4	44	2	40	207	56
I Find This Method Effective	5	56	0	0	191	52
Sensory Integration						
I Use This Method	4	44	2	40	181	49
I Find This Method Effective	4	44	0	0	162	44
Auditory Integration						
I Use This Method	0	0	1	20	41	11
I Find This Method Effective	3	33	0	0	36	10
ABA/Lovaas						
I Use This Method	1	11	0	0	43	12
I Find This Method Effective	2	22	0	0	45	12
Miller						
I Use This Method	0	0	0	0	6	2
I Find This Method Effective	2	22	0	0	8	2
TEACCH						
I Use This Method	0	0	0	0	7	2
I Find This Method Effective	3	33	0	0	16	4
Greenspan/Floortime						
I Use This Method	1	11	0	0	20	5
I Find This Method Effective	3	33	0	0	22	6
Social Stories						
I Use This Method	1	11	2	40	85	23
I Find This Method Effective	1	11	0	0	74	20
Comic Strip Conversations						
I Use This Method	1	11	0	0	35	10
I Find This Method Effective	1	11	0	0	34	9
Social Skills Groups						
I Use This Method	4	44	2	40	150	41
I Find This Method Effective	5	56	0	0	127	35

**TABLE 33b Methods of Instruction, Unfamiliar or No Opinion:
All Professions**

Method	Respondents Unfamiliar with Method		Respondents Expressed No Opinion of Method	
	# of Cases	% of Total	# of Cases	% of Total
Sign/Gesture Communication	14	4	8	2
Picture Exchange System	19	5	9	2
Picture/Word Boards	10	3	8	2
Sensory Integration	23	6	16	4
Auditory Integration	64	17	23	6
ABA/Lovaas	77	21	21	6
Miller	132	36	19	5
TEACCH	138	38	21	6
Greenspan/Floortime	130	35	21	6
Social Stories	72	20	19	5
Comic Strip Conversations	68	18	19	5
Social Skills Groups	20	5	16	4

Tables 34 through 38 are attitude scale items on several statements about ASD education. Items are broken down by grouped professions, all LEAs, EI and private agencies. For Table 34, a summary of responses to the statement “I feel I am well prepared to perform evaluations on ASD children,” the majority of respondents (44%, excluding those who selected the “not applicable” category) chose “agree strongly” or “agree somewhat” and only 25% chose “disagree strongly” or “disagree somewhat.” For Table 35, a summary of responses to the statement “I feel I am well prepared to treat children with ASD,” the majority of respondents (53%) chose “agree strongly” or “agree somewhat” while only 18% chose “disagree strongly” or “disagree somewhat.” For Table 36, “I feel I am well prepared to teach children with ASD,” again a majority of those responding (48%, excluding the “not applicable” category) chose “agree strongly” or “agree somewhat” with only 16% of respondents choosing the combined disagreement categories. For Table 38, a summary of responses to the statement “I have adequate opportunities for continuing education in the field of ASD,” the majority of respondents chose “agree strongly” or “agree somewhat” (40%) but a sizable minority (32%) chose “disagree strongly” or “disagree somewhat.” However, for responses to the statement “I feel that the present structure of education for children with ASD in Rhode Island is appropriate,” “disagree strongly” and “disagree somewhat” have higher responses (33%) than the combined agreement categories (22%, see Table 37).

The results from the attitude scale items are a bit puzzling. In the open ended items on barriers to services and unmet needs many respondents described severe problems with ASD inservicing and access to information on ASD. However, these same respondents would then go on to select agreement categories on their ability to teach and serve ASD

students. For example, one regular education teacher stated in her discussion of unmet needs, “I was assigned to an inclusion classroom containing three autistic children with no training or preparation of any kind” but then went on to choose “agree somewhat” for all Likert scale items. Our project research assistants catalogued numerous similar (though less dramatic) examples. It is therefore the conclusion of the researcher that some of the positive attitudes presented in these scale items are due to socially desired response effects. This conclusion is further reinforced by the fact that items which did not appear to be statements of individual competence (Tables 38 and 37) garnered more negative responses.

On the whole, educators did not provide additional comments on their surveys. However, those who did add additional comments consistently noted a lack of time for IEP/MDT meetings, concern about parents, problems with inservicing and problems with access to information on ASD. We conclude this section with a quote from one SLP from the Northern Collaborative who summed up these issues rather eloquently.

The greatest barriers to service for children with ASD appears to be haphazard planning for these children. We have no standards to go by, no clear criteria as to who should be working with children with ASD and what their programs should look like. It seems that some children are lucky if they happen to live in a district, or attend a school with personnel that have experience and expertise. A child with similar needs will be receiving very different programs and services depending on where he lives, or what school he attends. School teams are also dependent on the administration to support their recommendations. Support is usually granted if parents are well informed and can advocate for their children.

TABLE 34 I Feel I am Well Prepared to Perform Evaluations on Children (1 of 2)

	All Administrators		All Special Educators		Regular Educators		Occupational and Physical Therapists		Speech/Language Pathologists		Diagnosticians and Psychologists	
Response	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total
Agree Strongly	2	14	15	10	3	10	11	33	13	22	11	21
Agree Somewhat	3	21	41	27	2	7	16	33	24	41	17	32
Neutral	0	0	9	6	1	3	2	6	9	15	6	11
Disagree Somewhat	2	14	28	19	1	3	3	18	11	19	13	25
Disagree Strongly	1	7	18	12	1	3	1	3	1	2	4	8
I Don't Know	0	20	2	1	2	7	0	0	0	0	0	0
Blank/Missing	2	14	12	8	2	7	1	3	1	2	1	2
Not Applicable	4	29	25	17	18	60	0	3	1	2	2	4

TABLE 34 I Feel I am Well Prepared to Perform Evaluations on Children (2 of 2)

	School Social Worker/Guidance Counselor		All LEAs		Early Intervention		Private Agencies		All	
Response	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total
Agree Strongly	3	14	28	11	2	15	27	25	57	16
Agree Somewhat	4	19	60	24	5	38	38	35	103	28
Neutral	1	5	20	8	1	8	7	6	28	8
Disagree Somewhat	2	10	50	20	2	15	11	10	63	17
Disagree Strongly	3	14	27	11	2	15	2	2	31	8
I Don't Know	1	14	1	0	0	0	3	3	4	1
Blank/Missing	1	5	19	8	0	0	3	3	22	6
Not Applicable	6	29	41	17	1	8	17	16	57	16

TABLE 35 I Feel I am Well Prepared to Treat Children With ASD (1 of 2)

Response	All Administrators		All Special Educators		Regular Educators		Occupational and Physical Therapists		Speech/Language Pathologists		Diagnosticians and Psychologists	
	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total
Agree Strongly	3	21	40	27	6	20	11	33	19	32	9	17
Agree Somewhat	3	21	38	25	2	7	16	48	25	42	13	25
Neutral	1	7	8	5	4	13	2	6	6	10	6	11
Disagree Somewhat	1	7	16	11	3	10	3	9	5	8	8	15
Disagree Strongly	1	7	9	6	2	7	1	3	1	2	7	13
I Don't Know	0	0	0	0	0	0	0	0	0	0	1	2
Blank/Missing	2	14	11	7	1	3	0	0	2	3	4	8
Not Applicable	3	21	28	19	12	40	0	0	1	2	5	9

TABLE 35 I Feel I am Well Prepared to Treat Children With ASD (2 of 2)

Response	School Social Worker/Guidance Counselor		All LEAs		Early Intervention		Private Agencies		All	
	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total
Agree Strongly	2	10	35	14	4	31	51	47	90	25
Agree Somewhat	4	19	68	28	6	46	28	26	102	28
Neutral	3	14	27	11	0	0	3	3	30	8
Disagree Somewhat	2	10	33	13	1	8	5	5	39	11
Disagree Strongly	2	10	22	9	0	0	2	2	24	7
I Don't Know	0	0	0	0	1	8	0	0	1	0
Blank/Missing	2	10	20	8	0	0	4	4	24	7
Not Applicable	6	29	42	17	1	8	14	13	56	15

TABLE 36 I Feel I am Well Prepared to Teach Children With ASD (1 of 2)

Response	All Administrators		All Special Educators		Regular Educators		Occupational and Physical Therapists		Speech/Language Pathologists		Diagnosticians And Psychologists	
	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total
Agree Strongly	1	7	58	39	6	20	3	9	15	25	8	15
Agree Somewhat	3	21	45	30	8	27	3	9	19	32	7	13
Neutral	3	21	12	8	3	10	2	6	9	15	6	11
Disagree Somewhat	0	0	14	9	1	3	4	12	6	10	7	13
Disagree Strongly	0	0	7	5	4	13	2	6	1	2	3	6
I Don't Know	0	0	0	0	0	0	0	0	0	0	2	4
Blank/Missing	3	21	10	7	0	0	6	18	6	10	3	6
Not Applicable	4	29	4	3	7	23	12	36	4	7	17	32

TABLE 36 I Feel I am Well Prepared to Teach Children With ASD (2 of 2)

Response	School Social Worker/Guidance Counselor		All LEAs		Early Intervention		Private Agencies		All	
	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total
Agree Strongly	2	10	37	15	3	23	53	49	93	25
Agree Somewhat	1	5	54	22	6	46	26	24	86	23
Neutral	0	0	30	12	0	0	4	4	34	9
Disagree Somewhat	3	14	30	12	1	8	4	4	35	10
Disagree Strongly	3	14	18	7	0	0	3	3	21	6
I Don't Know	0	0	2	1	0	0	0	0	2	1
Blank/Missing	2	10	32	13	1	8	3	3	35	10
Not Applicable	9	43	44	18	2	15	15	14	60	16

TABLE 37 I Feel that The Present Structure of Education for Children with ASD in Rhode Island is Appropriate (1 of 2)

Response	All Administrators		All Special Educators		Regular Educators		Occupational and Physical Therapists		Speech/Language Pathologists		Diagnosticians And Psychologists	
	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total
Agree Strongly	0	0	9	6	2	7	2	6	3	5	1	2
Agree Somewhat	1	7	32	21	5	17	6	18	8	14	6	11
Neutral	1	7	27	18	5	17	8	24	17	29	7	13
Disagree Somewhat	6	43	33	22	6	20	10	30	8	14	21	40
Disagree Strongly	1	7	11	7	3	10	1	3	8	14	6	11
I Don't Know	3	21	23	15	4	13	4	12	9	15	10	19
Blank/Missing	2	14	11	7	2	7	2	6	5	8	3	6
Not Applicable	0	0	4	3	3	10	0	0	2	3	0	0

TABLE 37 I Feel that The Present Structure of Education for Children with ASD in Rhode Island is Appropriate (2 of 2)

Response	School Social Worker/Guidance Counselor		All LEAs		Early Intervention		Private Agencies		All	
	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total
Agree Strongly	0	0	6	2	0	0	11	10	17	5
Agree Somewhat	5	24	34	14	0	0	30	28	64	17
Neutral	4	19	40	16	6	46	23	21	69	19
Disagree Somewhat	4	19	69	28	6	46	14	13	89	24
Disagree Strongly	0	0	27	11	1	8	4	4	32	9
I Don't Know	5	24	38	15	0	0	20	19	58	16
Blank/Missing	1	5	26	11	0	0	3	3	29	8
Not Applicable	2	10	7	3	0	0	3	3	10	3

TABLE 38 I Have Adequate Opportunities for Continuing Education in the Field of ASD (1 of 2)

Response	All Administrators		All Special Educators		Regular Educators		Occupational and Physical Therapists		Speech/Language Pathologists		Diagnosticians And Psychologists	
	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total
Agree Strongly	2	14	24	16	3	10	3	9	10	17	5	9
Agree Somewhat	4	29	36	24	10	33	11	33	16	27	14	26
Neutral	1	7	17	11	2	7	3	9	11	19	8	15
Disagree Somewhat	2	14	30	20	1	3	9	27	11	19	13	25
Disagree Strongly	2	14	16	11	4	13	6	18	8	14	8	15
I Don't Know	1	7	12	8	2	7	0	0	3	5	2	4
Blank/Missing	2	14	8	5	2	7	1	3	1	2	2	4
Not Applicable	0	0	7	5	6	20	0	0	0	0	2	4

TABLE 38 I Have Adequate Opportunities for Continuing Education in the Field of ASD (2 of 2)

Response	School Social Worker/Guidance Counselor		All LEAs		Early Intervention		Private Agencies		All	
	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total	# of Cases	% of Total
Agree Strongly	2	10	17	7	1	8	31	29	49	13
Agree Somewhat	7	33	51	21	7	54	40	37	98	27
Neutral	2	10	31	13	0	0	13	12	44	12
Disagree Somewhat	2	10	53	21	3	23	14	13	70	19
Disagree Strongly	2	10	44	18	2	15	1	1	47	13
I Don't Know	3	14	19	8	0	0	3	3	22	6
Blank/Missing	2	10	19	8	0	0	2	2	21	6
Not Applicable	1	5	13	5	0	0	4	4	16	4

Survey of Parents

Data from the survey of parents is presented in Tables 39 through 69. A total of 87 surveys were returned. In addition to answering survey questions, many parents provided lengthy comments on their experiences. These comments are quite extensive and could form the basis for another full report! These data are still being analyzed and considered. However, we do intersperse some quotes from the comments in our findings here in order to give the reader a better understanding of parents' experience.

Mothers filled out 78 of the surveys while fathers filled out 6 of them (Table 39). The race of respondents was overwhelmingly white (92%, see table 40) and all families reported that English was the language spoken most often in their homes. The sample was generally well-educated, with 76% of fathers and 82% of mothers reporting some college education or better (Table 41). Survey respondents reported that 57% of fathers and 46% of mothers had professional/managerial or office/clerical jobs. The most common occupation listed for mothers was homemaker (34%, see Table 42.) Overall, our sample of parents is probably more affluent and more educated than the average parent of an ASD child.

TABLE 39 Person Filling Out Survey

Person	# of Cases
Mother	78
Father	6
Mother and Father	1
Other	1
Blank/Missing	1
TOTAL	87

TABLE 40 Parent's Race

Race	# of Cases	% of Total
White	80	92
Hispanic	1	1
Other	2	2
Multiracial	2	2
Blank/Missing	2	2
TOTAL	87	100

TABLE 41 Parent's Education

Level of Education	Father		Mother	
	# of Cases	% of Total	# of Cases	% of Total
Less than High School	2	2	0	0
High School Graduate	17	20	15	17
Some College	19	22	27	31
College Graduate	23	26	26	30
Graduate or Professional Degree	24	28	19	22
Blank/Missing	2	2	0	0
TOTAL	87	100	87	100

TABLE 42 Parent's Occupation

Occupation Type	Father		Mother	
	# of Cases	% of Total	# of Cases	% of Total
Professional/Managerial	41	47	29	33
Office/Clerical	9	10	11	13
Skilled Labor	26	30	4	5
Unskilled Labor	6	7	6	7
Homemaker	0	0	30	34
Student	1	1	3	3
Blank/Missing	4	5	4	5
TOTAL	87	100	87	100

As is typical with ASD, the majority of children with ASD in families who participated in our survey were boys by a ratio of about 3.5 to 1 (see table 43). ASD children of families in the survey ranged in age from 2 to several over 21, with an average age of 9 years (see Table 44). The age of most parents was clustered between 31 and 45 years of age (Table 45). For parents' marital status, 85% reported that they were married and 11% that they were divorced (Table 46). 76 families reported that there were one or two other siblings in their household (Table 47) and 21 families reported the presence of other siblings with disabilities in the home (see Table 48 for an exact breakdown of these).

TABLE 43 Children with ASD, by Gender

Gender	# of Cases	% of Total
Male	62	71
Female	17	20
Blank/Missing	8	9
TOTAL	87	100

TABLE 44 Children with ASD, by Current Age

Current Age (in years)	# of Cases	% of Total
2	2	2
3	5	6
4	9	10
5	13	15
6	12	14
7	9	10
8	2	2
9	7	8
10	2	2
11	3	3
12	5	6
13	2	2
14	1	1
15	1	1
16	2	2
17	3	3
18	1	1
19	1	1
Over 21	6	7
Blank/Missing	1	1
TOTAL	87	100

TABLE 45 Parent's Current Age

Age	Father		Mother	
	# of Cases	% of Total	# of Cases	% of Total
15-20	0	0	1	1
21-25	1	1	1	1
26-30	2	2	3	3
31-35	15	17	18	21
36-40	20	23	24	28
41-45	25	29	25	29
46-50	12	14	7	8
51-55	5	6	4	5
56-60	2	2	1	1
61-65	1	1	1	1
Blank/Missing	4	5	2	2
TOTAL	87	100	87	100

TABLE 46 Parent's Marital Status

Status	# of Cases	% of Total
Married	74	85
Separated	1	1
Divorced	10	11
Never Married	1	1
Blank/Missing	1	1
TOTAL	87	100

TABLE 47 Presence of Other Siblings in the Home

Number	# of Cases
One Sibling	49
Two Siblings	27
Three Siblings	2
Four or More Siblings	2
No Siblings/Blank	7
TOTAL	87

TABLE 48 Presence of Siblings With Other Disabilities

Incidence and Type of Disability	# of Cases
Yes	21
ASD	4
Developmental Delay	6
Learning Disability	6
Mental Illness	2
Congenital Disability	3
No	58
I Don't Know	2
Blank/Missing	6

In Table 49 the age of children at the onset of symptoms is compared to age of children at time of their first ASD diagnosis. The average age at which parents first notice ASD symptoms is 1.5 years. The average time between this initial observation and receiving a formal ASD diagnosis is 2.8 years, suggesting that it is very difficult to get an autism diagnosis. The average age for an initial ASD diagnosis is 4.3 years. Many autism experts feel that there is a critical window of time for children with ASD between the ages of 2 and 5; children who receive disability-specific interventions at this age are more likely to make rapid gains and be successfully mainstreamed (Powers and Cohen 1996). The average age of 4.3 years at diagnosis represents a missed opportunity for these crucial interventions.

TABLE 49 Child's Age At Onset of Symptoms and Initial Diagnosis

Age (in years)	At time Parent First Noticed ASD Symptoms		At Time of First Diagnosis	
	# of Cases	% of Total	# of Cases	% of Total
0.50 to	20	23	0	0
0.5 to 1.0	7	8	0	0
1.1 to 1.5 ^a	28	32	2	2
1.6 to 2	19	22	7	8
2.1 to 2.5	8	9	12	14
2.6 to 3 ^b	4	5	30	34
3.1 to 3.5	0	0	7	8
3.6 to 4	0	0	6	7
4.1 to 4.5 ^c	0	0	1	1
4.6 to 5	1	1	3	3
5.1 to 5.5			1	1
5.6 to 6			3	3
6.1 to 6.5			0	0
6.6 to 7			5	6
7.1 to 7.5			0	0
7.6 to 8			1	1
8.1 to 8.5			1	1
8.6 to 10			0	0
10.1 to 10.5			1	1
10.6 to 11			1	1
11.1 to 11.5			0	0
11.6 to 12			1	1
12.1 to 12.5			0	0
12.6 to 13			2	2
13.1 to 13.5			0	0
13.6 to 14			2	2
TOTAL	87	100	87	100

^a1.5 years is average age when symptoms are first noticed.

^b2.8 years is average time between observation of symptoms and actual ASD diagnosis.

^c4.3 years is average age at time of diagnosis.

The range of formal initial diagnoses is presented in Table 50. Parents were asked to report the exact, written diagnosis as it was given to them by their child's diagnostician. This table indicates that while the majority of diagnoses are taken directly from formal DSM labels, there are many other diagnostic labels that are unclear and may not adhere to DSM categories. Use of ambiguous labels can make it difficult for children with ASD to qualify for necessary programs or to receive disability specific interventions. Diagnosticians who made each child's initial diagnosis are enumerated in Table 51. The Child Development Center of Rhode Island Hospital and Bradley Hospital did most of the diagnoses. Other health impairments for children with ASD are listed in Table 52. Seizure disorder, Obsessive Compulsive Disorder and Attention Deficit Hyperactivity Disorder were the most common secondary diagnoses. Finally, in Table 53, parents' experience in getting an ASD diagnosis is summarized. A majority of parents found it

somewhat or extremely difficult to get a diagnosis (55%) while 30% reported that it was somewhat or extremely easy to get a diagnosis. When commenting on the diagnostic process one mother noted, “I found the whole process difficult and I’m white collar/economically privileged. Imagine how poor people must feel!”

TABLE 50 Range of Initial Diagnoses

Formal Initial Diagnosis	# of Cases	% of Total
PDD-NOS ^a	25	29
Autism	17	20
PDD	15	17
Asperger's Syndrome	5	6
Developmentally Delayed	2	2
Infantile Autism	2	2
PDD with Autistic Tendencies	2	2
PDD/Autism	2	2
PDD/Autistic Disorder	2	2
PDD-NOS, Asperger's	2	2
Asperger's and Attention Deficit Disorder	1	1
Asperger's/ADHD ^b	1	1
Autism Spectrum Disorder/Autism	1	1
Autism Spectrum/PDD	1	1
Autism/Profound Retardation	1	1
Autistic-like tendencies and Mental Retardation	1	1
Mild to Moderate Autism	1	1
Mild to Severe Autism	1	1
Partial Autism	1	1
PDD with Autism	1	1
PDD-NOS/Autism	1	1
No Formal Diagnosis	1	1
Blank/Missing	1	1
TOTAL	87	100

^aPDD is Pervasive Developmental Disorder; NOS is Not Otherwise Specified

^bADHD is Attention Deficit Hyperactivity Disorder

TABLE 51 Name of Diagnostician or Diagnostic Health Group Who Made Initial Diagnosis

Name	# of Cases	% of Total
Child Development Center	25	29
Bradley	13	15
Other, outside of New England	5	6
Dr. Deborah Labato	5	6
Dr. Daniel Marwil	4	5
Dr. Laurence Hirschberg	4	5
Dr. Barbara Sherman	3	3
Boston Children's Hospital	3	3
Dr. Karen Kerman	3	3
School Psychologist	2	2
Dr. Karen MacGee	2	2
Meeting Street School	2	2
Dr. Ann Walters	1	1
Dr. Aspel	1	1
Dr. Barry Prizant	1	1
Dr. Carlos Canton	1	1
Dr. L. Kiessling	1	1
Dr. Kevin Plummer	1	1
Dr. Marjorie Pelouin	1	1
Dr. May	1	1
Dr. Robert DeLong	1	1
Dr. Sharon Parnes	1	1
Dr. James P. Curran	1	1
Dr. M. Christopher Bordon PhD	1	1
Umass Medical Center: Dr. Scheiner	1	1
UMass Worcester: Dr. Paul Shonkoff, Developmental Pediatrician	1	1
No formal diagnosis	1	1
Blank/Missing	1	1
TOTAL	87	100

TABLE 52 Other Health Impairments

Condition	# of Cases
Seizure Disorder	6
Obsessive Compulsive Disorder	6
Attention Deficit Hyperactivity Disorder	6
Asthma	3
Tourette's Syndrome	2
Mental Retardation	2
Bipolar Disorder	2
Verbal Apraxia	2
Oral Motor Dyspraxia	2
Attention Deficit Disorder	2
Brain Damage	1
Motor Difficulties	1
Depression	1
Other	8
Blank	45

TABLE 53 Experience in Getting a Diagnosis

Experience	# of Cases	% of Total
Extremely Easy to Get a Diagnosis	9	10
Somewhat Easy to Get a Diagnosis	17	20
Neither Easy or Difficult to Get a Diagnosis	12	14
Somewhat Difficult to Get a Diagnosis	30	34
Extremely Difficult to Get a Diagnosis	18	21
Blank/Missing	1	1
TOTAL	87	100

Tables 54a and 54b address current and past receipt of Medicaid for ASD children. 64% of ASD children of parents surveyed currently receive Medicaid, and 26% received it in the past. Some parents (11%) did not know about the existence of this program. Tables 55a and 55b present findings on current and past receipt of EPSDT service. 47% of ASD children of parents surveyed are currently receiving these services and 9% received them in the past. The most common response, however, was that parents did not know about the existence of this program. Table 56 summarizes parents' experience in getting Medicaid and EPSDT services for their child with ASD. Only 12% reported that it was extremely or somewhat easy to services while 43% found it somewhat or extremely difficult. One frustrated mother commented, "As a parent I didn't know what services my child was entitled to. Then when I became aware of the services I didn't understand how to get agencies to provide the services. No one just steps forward and says, 'here is what we can do to help you.'"

TABLE 54a Child with ASD: Current Receipt of Medicaid

Response	# of Cases	% of Total
My Child Receives Medicaid Through SSI	13	15
My Child Receives Medicaid Through Katie Beckett	42	48
My Child Receives Medicaid Through RIticare	1	1
My Child Does Not Qualify for Medicaid	13	15
I Choose Not to Participate in Medicaid	5	6
I Was Not Aware That Medicaid Existed	10	11
I Don't Know	3	3
TOTAL	87	100

**TABLE 54b Child With ASD:
Received Medicaid in the Past**

Response	# of Cases	% of Total
Yes	23	26
No	53	61
I Don't Know	3	3
Blank/Missing	8	9
TOTAL	87	100

TABLE 55a Child With ASD: Current Receipt of EPSDT Services

Response	# of Cases	% of Total
Child Currently Receives EPSDT Services	29	33
Child Does not Qualify for EPSDT Services	12	14
I Choose Not to Participate in EPSDT	5	6
I Was Not Aware That EPSDT Existed	31	36
I Don't Know	9	10
Blank/Missing	1	1
TOTAL	87	100

**TABLE 55b Child With ASD:
Received EPSDT Services in the Past**

Response	# of Cases	% of Total
Yes	8	9
No	63	72
I Don't Know	12	14
Blank/Missing	4	5
TOTAL	87	100

TABLE 56 Experience in Getting Medicaid or EPSDT Services

Response	# of Cases	% of Total
Extremely Easy to Get Program	1	1
Somewhat Easy to Get Program	10	11
Neither Easy or Difficult to Get Program	15	17
Somewhat Difficult to Get Program	19	22
Extremely Difficult to Get Program	18	21
Blank/Missing	24	28
TOTAL	87	100

Tables 57 through 65 address educational programs for children with ASD. Current classroom types for children of parents surveyed are reported in Tables 49 and 50. The sample is almost evenly divided between children in public schools (42 cases) and private agencies /private/parochial schools (45 cases). All LEA collaboratives are represented as well as some EI regions. East Bay and West Bay collaboratives have the greatest representation (60%.) The remainder of the findings are presented separately for children enrolled in public and private settings. Twice as many parents of children in private settings report that their children are receiving home programming and/or services compared to parents of children in public settings (see Table 59). A small number of parents report that their children are receiving alternative therapies at home (see Table 60 for a complete list). About 67% of parents with children in public schools and 78% of parents of children in private schools report that they currently receive home carryover. Conversely, 19% of public school parents and 13% of private school parents reported that they did not know home carryover was possible (see Table 53). Many parents with children in public schools commented on how difficult they found it to get home carryover programs. One mother noted, “Our school doesn’t do carryover willingly, I have to put everything in the IEP; we have a notebook to write in daily [for carryover]. This is always a struggle. Teachers do not have time but I have to insist so that I can have information to converse with my son. Our school does not like parents to be a part of things.” In Table 54 methods of home-school communication are summarized. The results are nearly identical for both public and private in the first three categories (phone calls, home visits and written notes) but parents of children in private agencies report a higher rate of home treatment (20%) and programs designed for families to do at home (20%).

TABLE 57 Child's Current Educational Program

Type	# of Cases	% of Total
Public School		
Regular Classroom w/ Aide Support	14	16
Regular Classroom w/o Aide Support	9	10
Self Contained Classroom w/ some Regular Classroom Academic Time	10	11
Self Contained Classroom but Mainstreamed for Specials and Lunch	5	6
Completely Self Contained Classroom	5	6
Private Agency		
LaPlante Center	1	1
Bradley	7	8
Groden	14	16
Meeting Street Center	1	1
Rehab New England	2	2
Sargent Center	3	3
Other agency, outside of Rhode Island	3	3
Blank/Missing	1	1
Private or Parochial School		
Private or Parochial School	8	9
Blank/Missing	4	5
TOTAL	87	100

TABLE 58 Child's Collaborative District

Name	# of Cases	% of Total
East Bay Collaborative	21	24
West Bay Collaborative	31	36
Southern Collaborative	16	18
Northern Collaborative	10	11
Northern Early Intervention Region	2	2
Central Early Intervention	1	1
Metro Early Intervention	2	2
Blank/Missing	4	5
TOTAL	87	100

TABLE 59 Education Received at Home

Program Type	Public	Private
OT/SI	5	8
Speech Therapy	8	7
ABA Home Program	2	7
EPSDT Programming, Type Not Specified	3	0
IBT Home Program	0	7
Other Home Program Designed by Private Agency	0	7
TOTAL	18	36

TABLE 60 Alternative Therapies Received at Home

Therapy	Public	Private
Allergy Treatment	2	0
Vitamin Therapies	4	2
Other	2	1

TABLE 61 Opportunities for Home Carryover

Response	Public			Private		
	# of	Cases	% of Total	# of	Cases	% of Total
Yes	28		67	35		78
Yes, But I Choose Not To Be Involved	0		0	0		0
No, I Was Not Aware That This Was Possible	8		19	6		13
I Don't Know	2		5	0		0
Blank/Missing	4		10	4		9
TOTAL	42		100	45		100

TABLE 62 Methods of Home-School Communication

Method	Public			Private		
	# of	Cases	% of Total	# of	Cases	% of Total
Phone Calls	21		50	23		51
Home Visits by School Personnel	10		24	14		31
Written Notes Between School and Home	25		60	29		64
Treatment in the Home by School Personnel	3		7	9		20
Program Designed for Families To Do at Home	4		10	9		20
Blank/Missing	11		26	9		20

NOTE: Totals exceed 100% where more than one method used.

About 93% of parents of children in public schools and 89% of parents of children in private schools report being involved in their child’s MDT and IEP teams (see Tables 63 and 64). However, 7% of parents in both private and public settings reported that they have not been included or did not know that they could be involved in the IEP or MDT team. Additionally, some parents who were involved on these teams felt unwelcome and that the team did not consider their input. One mother noted, “The IEP team obviously does not value our opinion. We were at all IEP meetings but they did what they wanted, not what we wanted!” Another parent commented, “We met initially with the MDT, what a farce! They knew very little and had nothing to offer.” Although these findings represent only a small percentage of families, they also directly contradict LEA and private agency claims that all parents are involved in MDTs and IEPs and that their input is valued and considered.

TABLE 63 Parent Involvement With Multi-Disciplinary Team (MDT)

Response	Public		Private	
	# of Cases	% of Total	# of Cases	% of Total
We Are Involved with Our Child's MDT	39	93	40	89
We Choose Not to be Involved with our Child's MDT	0	0	0	0
We Requested Involvement, but Have Not Yet Been Included	1	2	3	7
We Were Not Aware That This Option Existed	2	5	0	0
I Don't Know	0	0	0	0
Blank/Missing	0	0	2	4
TOTAL	42	100	45	100

TABLE 64 Parent Involvement with Individualized Educational Plan (IEP)

Response	Public		Private	
	# of Cases	% of Total	# of Cases	% of Total
We Are Involved with Our Child's IEP	39	93	40	89
We Choose Not to be Involved with our Child's IEP	0	0	0	0
We Requested Involvement, but Have Not Yet Been Included	1	2	3	7
We Were Not Aware That This Option Existed	2	5	0	0
I Don't Know	0	0	0	0
Blank/Missing	0	0	2	4
TOTAL	42	100	45	100

Finally, we leave the discussion of education on a more positive note. In the final education table (Table 65) parent satisfaction with their child's current educational program is addressed. 60% of parents of children in public school and 71% of parents of children in private settings report being extremely or somewhat satisfied with their child's current educational program.

TABLE 65 Parent Satisfaction With Current Educational Program

Response	Public		Private	
	# of Cases	% of Total	# of Cases	% of Total
Extremely Satisfied	10	24	14	31
Somewhat Satisfied	15	36	18	40
Neither Satisfied or Dissatisfied	5	12	1	2
Somewhat Dissatisfied	7	17	5	11
Extremely Dissatisfied	5	12	5	11
Blank/Missing	0	0	2	4
TOTAL	42	100	45	100

The remaining tables address forms of support available to families of children with ASD. In Table 66 use of respite care is addressed. Currently only 15% of parents surveyed use respite. A nearly equal percentage (14%) state that their child does not qualify for respite. Perhaps the most striking finding is that 44% did not even know about the existence of respite! Many parents commented extensively on their frustrations with respite. One perturbed mother stated, "The question about respite really bothers me. Its phrasing suggests that respite care of children with autism is readily available for the asking. In my experience that just isn't so! I spent a grueling year getting government sponsored respite care." Another parent noted, "We were told we had to be 'over the edge' to qualify for Respite." This is a clear area of unmet need. 75% of parents report current or past involvement in a parent support group (see Table 67). Table 68 summarizes the use of sibling support groups. Only 18% of siblings are involved in support groups or have been involved in the past while 38% of parents reported that siblings chose not to be involved (often parents commented that siblings were too young to participate) and 22% reported that they did not know of the existence of sibling support groups. Finally in Table 69 forms of support listed by parents in an open ended section of the survey are listed. The most common sources of support listed were family (40%), support groups (32%) and friends. 11% of parents explicitly state that they have no support.

TABLE 66 Use of Respite Program

Response	# of Cases	% of Total
We Use Respite	13	15
No, Child Does Not Qualify for Respite	12	14
We Have Applied for Respite but Are Wait Listed	2	2
We Choose Not to Use this Program	19	22
We Did Not Know That This Program Exsisted	38	44
Blank/Missing	3	3
TOTAL	87	100

TABLE 67 Use of Parent Support Group

Response	# of Cases	% of Total
I am Involved in a Parent Support Group	43	49
I Was Involved in a Parent Support Group in the Past, but Not Now	23	26
I Choose Not to Be Involved	11	13
No, I was Not Aware That This Program Existed	7	8
Blank/Missing	3	3
TOTAL	87	100

TABLE 68 Use of Sibling Support Group

Response	# of Cases	% of Total
Siblings are in a Support Group	3	3
Siblings Were Involved in a Support Group in the Past, but Not Now	13	15
Siblings Choose Not to be Involved	38	44
No, I was Not Aware That This Program Existed	22	25
Blank/Missing	11	13
TOTAL	87	100

TABLE 69 Forms of Support

Type	# of Cases	% of Total
Family/Relatives	35	40
Support Groups	28	32
Friends	15	17
Private Agency Where Child is Enrolled	13	15
Child's Teacher or Therapist	12	14
Other Parents of Children with Disabilities	11	13
Parent Explicitly Stated That They Had no Support	10	11
Church/Clergy	8	9
Child's Doctor	7	8
Local SPED Parent Advisory Committee	4	5
Blank/Missing	13	15

NOTE: Totals may exceed 100% where more than one form of support reported.

Survey of Pediatricians

Findings from the pediatrician's survey are presented in Tables 70 through 75. Table 70 summarizes years in practice for the sample. The sample is clustered between 0 and 20 years with the average at 17.10 years. The timing of actual and desired training on ASD for pediatricians is examined in Table 71. There is only a .1060 correlation between when pediatricians actually received their ASD training and when they felt it would be most helpful to receive their ASD training. In their comments many pediatricians noted the need for better ASD training for physicians. One doctor noted, "Like most things in medicine, training needs to be regularly reinforced."

TABLE 70 Pediatricians Survey: Years in Practice

Years in Practice	# of Cases	% of Total
0-5	13	19
6-10	6	9
11-15	13	19
16-20	12	19
21-25	5	7
26-30	3	4
31-35	3	4
36-40	1	2
41-45	0	0
46-50	3	4
Retired	4	6
Blank/Missing	5	7
TOTAL	68	100

NOTE: Average = 17.10 years.

TABLE 71 Timing of Training in ASD for Pediatricians: Actual and Desired

Actual			Desired		
of Training	Timing	# % of Total of Cases	of Training	Timing	# % of Total of Cases
Medical School		3 4	Medical School		2 3
Internship		1 2	Internship		1 2
Residency		18 26	Residency		29 42
In Practice as a Pediatrician		23 34	In Practice as a Pediatrician		0 0
No Training on ASD Received		5 7	Not Sure		1 1
More than One of the above		7 10	More than One of the above		25 37
Blank/Missing		1 1	Blank/Missing		7 10

Correlation between when pediatrician received training and when they believed training should occur = .1060

Tables 72, 73 and 74 summarize total, developmentally delayed (DD), and ASD caseloads respectively for all respondents. The average total caseload for respondents was 2,783 patients and the most common caseload reported was between 1501 and 2000 patients. The average DD caseload was 112 cases and ranged from 0 to 750 patients with the sample fairly evenly distributed across that range. 68% of pediatricians reported having between 1 to 10 children with ASD in their caseload for an average ASD caseload of 6 patients. A correlation coefficient test was run between the number of ASD cases reported by each respondent and the number referred out. The result of .9984 reveals that virtually all pediatricians who have ASD children in their caseload refer them out for outside diagnosis and treatment.

TABLE 72 Total Patient Caseload

# of Patients	# of Cases	% of Total
1-500	2	3
501-1000	5	7
1001-1500	5	7
1501-2000	13	19
2001-2500	2	3
2501-3000	6	9
3001-3500	2	3
3501-4000	2	3
4001-4500	1	1
4501-5000	4	6
5001-5500	0	0
5501-6000	2	3
6001-6500	0	0
6501-7000	2	3
Blank/Missing	22	32
TOTAL	68	100

NOTE: Average = 2,783 patients.

TABLE 73 Total Developmentally Delayed Caseload

# of Patients	# of Cases	% of Total
0-10	4	6
11-20	4	6
21-30	5	7
31-40	4	6
41-50	8	12
51-100	7	10
101-150	2	3
151-200	8	12
201-250	1	1
300-750	4	6
Blank/Missing	21	31
TOTAL	68	100

NOTE: Average = 112 developmentally delayed patients.

TABLE 74 Total ASD Caseload

# of Patients	# of Cases	% of Total
0-5	34	50
6-10	12	18
11-15	1	1
16-20	2	3
21-25	1	1
Blank/Missing	18	26
TOTAL	68	100

NOTE: Average = 6 ASD patients.
Correlation between Total ASD Caseload and
Number of ASD Cases Referred Out = .9984.

In the final table on the pediatrician's survey use of outside diagnosticians is reported (Table 75). CDC is most often used followed by Bradley Hospital, Dr. Kerman, Dr. Marwil, Boston Children's Hospital and the Groden Center. Several pediatricians commented on the high quality of CDC's work. One wrote, "Child Development Center at Hasbro Hospital should be available to all children of Rhode Island. These kind of organized comprehensive services result in most well coordinated care plans. Multidisciplinary clinical approaches are very helpful. It is discouraging that certain insurance companies refuse to recognize the importance of these kinds of services." Other pediatricians noted that they did not know what diagnostic resources were available in Rhode Island. One physician stated, "I am not fully aware of the extent of resources available in Rhode Island. In fact 3 years ago, I could not find anyone to refer a patient for evaluation, he was eventually seen at Boston Children's Hospital."

TABLE 75 Outside Diagnosticians Used for ASD Diagnosis

Name	# of Cases
CDC/Hasbro/Rhode Island Hospital	32
Bradley Hospital	22
Dr. K. Kerman	8
Dr. Marwil/Meeting Street Center	7
Boston Children's Hospital	7
Groden Center	6
Early Intervention	4
Dr. Canton	3
Dr. Kiessling	3
Dr. Rivinus	3
Butler Hospital	1
Delta Consultants	1
Highland Children's Hospital	1
Dr. Hunt	1
Dr. Lobato	1
Providence Center	1
Dr. Yunez	1

Diagnostician Interviews

Tables 76 through 79 contain information gathered from the diagnosticians' interviews. Table 76 provides a summary of diagnostic criteria used by each diagnostician or diagnostic group. All report using DSM-IV criteria although some did not find it fully satisfactory. One diagnostician asserted, "I use the criteria in DSM-IV, but I also emphasize to virtually everyone I talk to that [autism is] a spectrum disorder and the world is not nearly as neat as DSM IV would have it." A few diagnosticians reported using the Childhood Autism Rating Scale (CARS) and other diagnostic tests as well. The amount of time it takes diagnosticians to get a written draft of their report on an ASD child to parents is reported in Table 77. On average it takes them about a month to prepare the report, but all reported that they gave immediate verbal feedback at the end of the evaluation.

TABLE 76 Diagnostic Criteria Used

Diagnostician	DSM-IV	CARS	Mentioned the Use of Other Diagnostic Tools
Dr. Irwin Bennett/Butler	yes		
Dr. Karen Cammuso/Bradley	yes		
Dr. Lucia Fratantaro/CDC	yes	yes	yes
Dr. Laurence Hirschberg	yes		
Dr. Karen Kerman	yes		
Dr. Louise Kiessling	yes		
Dr. Kevin Plummer	yes	yes	yes
Dr. Anne Walters	yes		

NOTE: 100% of diagnosticians interviewed said that parent input was an important part of the diagnostic process and that they were able to customize their evaluations to parents' needs and expectations.

TABLE 77 Average Time to Send Parents a Written Draft Report on Their ASD Child

Diagnostician	Average Time (in weeks)
Dr. Irwin Bennett/Butler	1 to 2
Dr. Karen Cammuso/Bradley	4 to 6
Dr. Lucia Fratantaro/CDC	3 to 5
Dr. Laurence Hirschberg	4 to 6
Dr. Karen Kerman	2 to 3 ^a
Dr. Louise Kiessling	3 to 4
Dr. Kevin Plummer	4 to 8
Dr. Anne Walters	4 to 5

^aIf a report is requested by parents.

In our interviews with diagnosticians we asked them about the kinds of information they shared with parents at the time of an ASD diagnosis. The results are presented in Table 78. Virtually all diagnosticians report telling parents about support groups, medical interventions and educational interventions at the time of diagnosis. Two diagnosticians interviewed reported that they or their agency had a standard informational packet that they gave to parents as well. Three diagnosticians reported telling parents about respite care, but three also reported that they did not tell parents about respite. Of the three diagnosticians that reported not telling parents about respite care one told me, “I really haven’t [told parents about respite] because respite is really so confusing,” another noted, “I’m not that knowledgeable in that area” and the third was openly challenging, stating “Is respite available now? I don’t tell parents about it because they can’t access it.” If respite care is this confusing to medical professionals, how does it appear to parents? Finally, three diagnosticians reported that they told parents about their legal rights as parents of a child with a disability at the time of diagnosis. Most others noted that they only told parents about their legal rights if there appeared to be a need or a problem with receiving services. Several of these providers also noted that this kind of information could overwhelm parents who were still trying to take in an ASD diagnosis.

TABLE 78 Information About Services That is Shared With Parents at Time of Diagnosis

	Yes	No	Sometimes	Often
Parent Support Groups Or Other Parents	8	0	0	0
Medical Interventions	7	1	0	0
Educational Interventions	8	0	0	0
Respite Care	3	3	2	0
Their Legal Rights As Parents Of A Child With A Disability	3	1	0	4

Finally, the use of delayed diagnosis is summarized in Table 79. Three diagnosticians report delaying diagnosis if the child is extremely young (under the age of two). One of them notes, “The pro of delaying a diagnosis is that very young children can change. Many things affect behavior and I think to give a very heavy duty diagnosis of a lifelong disorder before we’re really sure can really do a number on parents and caregivers. So it’s not a diagnosis that we want to give lightly, it’s not something that’s just thrown out. I just wouldn’t want to put anyone through that unless we’re pretty darn sure.” Two stated that they delayed diagnosis if the child’s symptoms did not clearly indicate ASD and three noted that they sometimes delayed an ASD diagnosis in order to rule out an underlying health problem that could cause ASD like symptoms. Four diagnosticians stated that they never delay making a diagnosis. One asserted, “I don’t think that there are any pros to delaying a diagnosis. I think that the value of the child getting rapidly the exact right kinds of help vastly outweighs the possibility that in fact the child turns out [to have something else].” Another diagnostician who worked within an agency that used to delay ASD diagnoses reflected on why they stopped this practice. “In the past there were times when we delayed a diagnosis because all of us felt that the boundary between communication disorders and PDD is pretty blurry under age 5. I think we didn’t want to make a call on a diagnosis that was as devastating to parents as that unless we were very

sure. What changed my opinion about that was that for many kids (but not all) when we delayed making a diagnosis those kids didn't get as intensive services as they would have if they had the diagnosis."

TABLE 79 Use Of Delayed Diagnosis

Do You Ever Delay Diagnosis?	
Yes, if Child is Extremely Young	3
Yes, if Child's Symptoms Do Not Clearly Indicate ASD	2
Yes, in Order to Rule Out Another Underlying Cause	3
No	4

Comparison of Met Needs, Unmet Needs and Barriers to Services Across the Seven Research Populations.

Finally we turn to a brief exploration of met needs, unmet needs and barriers to services described by the seven research populations. Each research participant was asked to list up to four areas of met or unmet need; some listed less than four and some listed a great many more. These findings are summarized in Tables 80 (met needs) and 81(unmet needs/barriers to services¹).

Special education directors for Local Educational Agencies (LEAs) noted a general gradual improvement in services for children with ASD across the state, indicated that some good interventions were being done by private agencies specializing in ASD and described instances of some good ASD classrooms in some LEAs. However, they also noted significant problems with a general lack of knowledge on ASD, an inability to access information on ASD, pressing needs to expand and improve staff inservicing opportunities, inconsistency in programming across LEAs, unmet funding needs, understaffing and a general lack of support for parents.

Directors of Early Intervention (EI) Regions also observed gradual improvement in ASD services and intervention. When describing unmet needs they echoed concerns of lack of knowledge and access to information, inservicing needs and inconsistency in programming across LEAs, but placed specific emphasis on issues of understaffing and problems created by delays in diagnosis.

Private agency directors also noted that there has been a gradual improvement in services for children with ASD in our state as well as instances of good programming in some LEAs. However, they also echoed LEA Directors' concerns about lack of knowledge, lack of access to information, consistency, and the need for greater inservicing in LEAs. In addition, many private agency directors noted that their facilities are profoundly oversubscribed; these facilities are continually expanding services and have long waiting lists that never get shorter.

Autism professionals surveyed felt that there were some good individualized interventions in place for children with ASD, some good outside consultants, good interagency and IEP team collaboration and some good interventions for some individual children in LEAs. However, 82% of all survey respondents noted the need for more inservice training and/or that current inservicing was of low quality. 38% of educators surveyed reported that lack of parent involvement and outreach was a significant barrier to ASD education.

Parents surveyed noted that special services such as OT and SLP and programs like EPSDT were very good in our state when available. Parents also reported that they found

¹ We asked separate questions on unmet needs and barriers to services but invariably respondents presented the categories together in their answers. We therefore collapsed them into one category for our analysis.

support groups helpful and that the private agencies in Rhode Island were excellent. However, parents also presented numerous unmet needs and barriers to services including 1) a lack of access to information on ASD, 2) inadequate inservicing, 3) lack of services and programs, 4) long waiting lists and 5) lack of money or funding for ASD services.

Pediatricians reported that met needs included good interagency collaboration, good support to parents, good EI and improvement in the ability to make an early diagnosis. Unmet needs reported by pediatricians included lack of funding, inadequate health insurance, inadequate parent support and inadequate ASD inservicing for pediatricians.

Diagnosticians noted a general improvement in the awareness of ASD in our state, but also voiced concerns about the appropriateness or effectiveness of educational programming and delays in referral for diagnosis.

TABLE 80 Summary of Met Needs Across Populations

	Director Interviews	Educator Survey	Parent Survey	Pediatrician Survey	Diagnosticians
Some Good Programs/ Interventions Are in Place	48% Good Programs w/in Director's LEA, Agency or EI Region 15% Some LEAs Have Excellent Programs	12% Some Good Individualized Interventions	15% Local School District Is Doing Good Things For Kids w/ASD		
Growing Awareness and Acceptance of ASD/ General Improvement	25% Growing Awareness/ Acceptance of ASD			10% Ability To Make An Early Diagnosis Is Improving	6 Growing Awareness and Knowledge of ASD 7 Programming For ASD Is Improving
Good Private Agencies/Consultants/ Professionals	25% Good Private Agencies	20% Good Outside Consultants	43% Good Private Agencies		
		12% Some Good Professionals In The Field	31% Good OT/SI and Speech Therapy Where Available		
All Others		24% Good Interagency/IEP Team Collaboration	26% Parent Support And Information Groups Are Helpful	28% Good Interagency Collaboration	
		16% Good Inclusion	20% EPSDT, Medicaid/Katie Beckett Are Good If You Can Get Them	23% Good Support to Parents	
		11% Good Early Intervention		18% Early Intervention Is Good	

TABLE 81 Summary of Unmet Needs/Barriers to Services Across Population

	Director Interviews	Educator Survey	Parent Survey	Pediatrician Survey	Diagnosticians
Lack of Money or Funding Problem	38% Lack of Money/Funding	30% Lack of Money/Inadequate Funding	50% Lack of Money/Lack of Funding	33% Lack of Money/Funding 13% Health Insurance Inadequate for ASD	5 Lack of Money/Funding
Lack of Parent Support or Outreach	33% Not Enough Parent Involvement, Outreach or Support	38% Parents Not Involved in Child's Education Or Getting Adequate Support or Information		28% Not Enough Parent Involvement, Outreach or Support	4 Respite is Inadequate
Training and Inservicing Issues	50% Need More Training/Current Inservicing Inadequate	82% Need More Training/Current Inservicing Inadequate	48% Not Enough Training of Educators	15% Training on ASD is Poor or Nonexistent For Physicians	
Lack of Knowledge, Lack of Access to Information	50% Lack of Knowledge/Lack of Resources on ASD		51% No Single Place To Get ASD Information or Learn About Interventions/ No Advocacy 44% General Lack of Knowledge of ASD Among Educators and Administrators		7 Lack of Knowledge/ Understanding of ASD
All Others	30% Understaffing 23% Inconsistency In Programming Across LEAs	14% Limited Collaboration Between Doctors, Teachers and Parents 10% Limited IEP Team Collaboration Time 6% Misdiagnosis	28% Need More and Better OT, SI, PT and Speech Language Therapies 26% Waiting Lists For Programs Are Too Long	18% Misdiagnosis or Late Diagnosis of ASD 13% Limited Collaboration Between Doctors, Teachers and Parents	8 Programming Inadequate or Ineffective

REVIEW OF FINDINGS

Major findings for each of the seven data sources are listed below.

Special Education Director Interviews

- There are 422 school aged children with ASD in our state. This number is 3.5 times higher than the census estimate of 120 children with autism.
- Both quantitative and qualitative data indicate that a wide variety of programming for ASD youngsters is available in our state. This finding may indicate a general commitment to tailoring ASD programming to the individual needs of each child, but it may also suggest a lack of consistency in ASD programming across LEAs.
- SPED Directors identified inservicing as an immediate need in both qualitative and quantitative data.

Early Intervention Director Interviews

- In Rhode Island there are currently an estimated 38 children with ASD between the ages of two and three.
- There is a high level of consistency across regions in home carryover techniques, support to parents, transition plans, commitment to inservicing, and reporting of children with ASD.
- Uses of specific therapies and educational interventions do not appear to be standardized at this point.

Private Agency Director Interviews

- Private agencies in Rhode Island currently serve about 340 children with ASD.
- Private agencies consistently report higher levels of inservicing, home carryover, home programs and advocacy for parents than do LEAs.
- Directors consistently noted that there were chronic long waiting lists for agency services.
- Programming for children with ASD in these agencies appears to be extensive and varied.

Survey of Autism Professionals

- Most autism professionals in our state reported a caseload of 1 to 10 children.
- Survey items on the use of diagnostic and assessment measures and scales revealed that over 44 measures are currently in use in our state, many of which are outdated and/or inappropriate for use with children with ASD. Additionally, approximately 20% of respondents explicitly stated that they were unfamiliar with diagnostic and assessment measures.

- Methods of instruction used by autism professionals surveyed included picture/word boards, sign/gesture communication, PECS and SI. Agency respondents and EI respondents reported overall higher levels of use of the methods of instruction listed than did the LEAs.
- For survey items on ability to teach, assess and serve children with ASD most respondents reported feeling competent. However, qualitative data from the survey suggests that most respondents feel unprepared in these areas.

Survey of Parents

- For families surveyed the average period of time between first observation of ASD symptoms and an initial ASD diagnosis was 2.8 years.
- The average age at diagnosis reported in the survey was 4.3 years, which is too late for many of the early forms of intervention that are considered crucial to helping these children.
- Survey findings revealed that parents had extreme difficulty in accessing information on ASD services for their child. For example, 36% of parents surveyed reported not knowing about the existence of (EPSDT) Early and Periodic Screening, Diagnosis and Treatment and 44% reported not knowing about the existence of Respite Care.
- On a positive note, a majority of parents reported general satisfaction with their child's educational program.

Survey of Pediatricians

- Pediatricians surveyed reported an average ASD caseload of 6 children. Pediatricians also reported referring out 99% of their ASD caseload to ASD specialists for formal assessment.
- The single greatest need identified by pediatricians surveyed was for greater and more appropriate training of pediatricians on ASD. For example, there was only a 10% correlation between when pediatricians received training on ASD and when they felt they felt it would be most appropriate to receive training on ASD.

Diagnostician Interviews

- All are using DSM-IV criteria in making ASD diagnoses.
- Half (4 cases) do not delay making an ASD diagnosis, but half also reported delaying a diagnosis of ASD in some instances.
- Most diagnosticians interviewed reported that they do not routinely tell parents about Respite Care at the time of diagnosis because it is so difficult to access.
- Diagnosticians do not consistently tell families about their legal rights as parents of a child with a disability at the time of diagnosis because they do not always consider it necessary and because they do not want to burden them with too much information.

Comparison of Met Needs, Unmet Needs and Barriers to Services Across the Seven Research Populations.

Across the seven research populations, common met needs as well as unmet needs/barriers to services were consistently identified.

Met needs included (in descending order of emphasis):

- Good private agencies in Rhode Island, as well as some good professionals in LEAs.
- A growing awareness of ASD and gradual improvement in ASD services.
- Some good programming in some LEAs.

Unmet needs/barriers to services included (in descending order of emphasis):

- The need for more inservicing and improved inservicing.
- A lack of knowledge of ASD and lack of access to information on ASD.
- A lack of parent support and outreach.
- Funding and money issues.

POLICY RECOMMENDATIONS

Educational Initiatives

We suggest several areas for improvement on the quality and amount of educational services for children with ASD in our state.

Improvement of Tracking of ASD and Special Education Census Definitions of ASD

We must do a better job of tracking the number of ASD children in our state if they are to receive appropriate, disability-specific services and LEAs are to receive funding appropriate to this type of disability. Suggestions for improving tracking include 1) finding ways to broaden the language of the definition of Autism for the state SPED census that adhere to federal guidelines while allowing for inclusion of PDD and Asperger' youngsters under the ASD category, 2) work with LEAs to educate SPED directors and MDTs about these changes, 3) encourage LEAs to use the Autism census category where appropriate for children with ASD instead of the categories of Developmentally Delayed, Behaviorally Disordered, Mentally Retarded, Other Health Impaired, Learning Disabled, Speech or Language Disordered and Multi-Handicapped and 4) encourage LEAs to change census categories when children are switched to an ASD diagnosis.

Uses of Diagnostic Tests and Measures

Currently ASD professionals use a huge variety of tests and scales for assessing children with ASD. Some of these are outdated and/or of questionable value. Without standardization of the use of diagnostic tests it is difficult to compare program effectiveness and progress of children with ASD across LEAs. It is recommended that RIDE, in consultation with ASD experts in the different disciplines, issue guidelines on effective diagnostic tests for ASD in each discipline.

Inservice Training Recommendations and

Recommendations to Improve Consistency in ASD programming

The amount of inservicing and the quality of inservicing needs to be increased in our state. It is recommended that RIDE issue inservicing recommendations to LEAs that are specific to the needs of ASD children and that funding for inservicing be increased.

Additionally, we need to address inconsistency in ASD programs across districts. It may be helpful to organize ASD programs by collaboratives instead of LEAs. RIDE should also issue guidelines on appropriate ASD interventions and programs.

RIAP has begun to address inservicing issues through the development of a course on ASD that has already been offered twice in our state. In addition we also recommend training in TEACCH and implementation of TEACCH pilot classrooms for three reasons. First, TEACCH is a nationally recognized model for autism education with proven effectiveness (Dawson and Osterling 1996; Mesibov 1997; Ozonoff and Cathcart 1998). Second, it is a complete and comprehensive methodology which addresses all aspects of a

complete ASD program. Third, examples from case law [see Washoe County School District 27 IDELR 133 (SEA NEV 1997), In RE: Henderson County Public Schools 27 IDELR 435 (SEA NC 1997), Board of Education of the Greenwood Lake Union Free School District 23 IDELR 103 (1996)] demonstrate that TEACCH is consistently upheld by the courts as an effective and appropriate methodology for children with ASD. Implementing TEACCH inservicing and pilots will allow Rhode Island simultaneously to improve the quality of services for ASD children in LEAs and address inservicing needs.

Diagnostic Initiatives

The issue of delayed diagnosis emerged as problematic in several areas of the research. While there may be compelling reasons to delay an ASD diagnosis in some cases, we must also acknowledge that delayed diagnosis can lead to delay in receipt of appropriate services. We offer three suggestions for diagnostic initiatives.

It is recommended that the state and RIAP work with pediatricians to develop better screening procedures for ASD. It is also recommended that they work with diagnosticians to develop diagnostic labels that are accurate in describing each child's symptoms *and* are recognized under federal and state guidelines for ASD education and treatment services. Finally, the issue of purposefully delaying an ASD diagnosis must be addressed and explored with diagnosticians in order to ascertain ways to balance concerns about misdiagnosis with the need for a timely ASD diagnosis and related treatment.

Information/Knowledge Initiatives

The problem of lack of knowledge and information on ASD was universally reported by all seven research populations. We offer three policy recommendations in this area.

First, we recommend developing a clearinghouse and resource center of information on ASD that addresses the specific concerns of educators, parents, professionals and the community. Second, we suggest creating guidelines and procedures on ASD education and services for educators, parents, and professionals. Finally, we should disseminate data and share results of research with state agencies.

Parent and Family Initiatives

Parents identified many areas where they lacked information, support or access. We feel that several policy initiatives could alleviate some of these issues.

First, we recommend that flow charts of procedures for receiving various services be created and made available through the information clearinghouse. Second, we recommend that parents of children with ASD be told about the information

clearinghouse at the time of their child's diagnosis. Third, we recommend that existing respite care be made easier to access. We also recommend that RIDE find means for creating informal respite opportunities in the form of weekend or evening recreational activities in LEAs or collaboratives as a part of Extended School Year or Extended School Day programs. Finally, we recommend that the state find ways to assure that parents of newly diagnosed ASD children are informed of their legal rights at a time when they are able to process and absorb that information.

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Methodological Appendix

Appendix I-A Letter of Introduction to LEA Special Education Directors

October 30, 1997

Name
Address

Dear,

As you may recall, Joan Colwell recently shared with RIDE Special Education Directors exciting news of the recently funded Rhode Island Autism Project. The mission of this project is to develop a system of educational services for meeting the needs of children with Autism Spectrum Disorder (ASD) in the state of Rhode Island.

During the first phase of this project I will be conducting research to collect information about the diagnostic process, educational services and related service support systems currently available to children with ASD in Rhode Island. Data will be collected from special education administrators, teachers, service providers, the medical community and parents. This information will be analyzed and shared with you next Spring so that we can create programs and services which are more responsive to the needs of this population.

I would like to meet with you to talk about your school district. Our meeting will take no more than one hour and the questions I will ask will be made available to you ahead of time. At the interview I will also give you surveys to distribute to your staff. I will be calling you within the next week to schedule an appointment. If you have questions about the project in the meantime please feel free to call our office at 401-844-7956. Thank you for your contribution to this important project. I look forward to meeting you.

Sincerely,

Martha E. Lang
Project Manager
Research and Assessment Phase
Rhode Island Autism Project

Appendix I-B: Protocol for LEA SPED Directors' Interviews

SECTION I PERSONAL BACKGROUND

- 1) In what school district do you work?
- 2) How long have you been a Special Education Director for this school district?
- 3) How long have you worked in the field of special education?

SECTION II AUTISM PREVALENCE AND PROGRAM PLACEMENT

- 4) According to RIDE statistics, currently 1 boy or girl who have been diagnosed with autism is enrolled in your school district. Do you think this is an accurate count? Why or Why not?
- 5) Of the total number of children with Autism Spectrum Disorder in your district, do you know how many of them have severe autism, Pervasive Developmental Disorder, or Asperger's Syndrome? (Note, I will describe these in detail in the interview)
- 5a) What is the age distribution of children with ASD in your district?
- 5b) Do you know if children with ASD in your district who have other disabilities (for example, mental retardation) have been placed in other categories of primary disability in the RIDE census? If yes, please describe.
- 6) In your district, how many children with Autism Spectrum Disorder are serviced through:
 - _____ Inclusion in regular classrooms with aide support
 - _____ Inclusion in regular classrooms without aide support
 - _____ Self-contained classrooms in school district
 - _____ Combination placement (some time in regular classrooms and some in self-contained classrooms)
 - _____ Out of district placements (do you know if any of these are in private or parochial school?)
- 7) When reporting to the state, in what category do you place preschoolers with ASD?

SECTION III ASSESSMENT AND EDUCATION

- 8) In your district does your multidisciplinary team make the diagnosis of ASD? If yes,

who makes the diagnosis?

9) If you use other agencies or health groups to make the diagnosis, which do you use?

10) What are the procedural steps involved in having a student with ASD receive services in your district?

11) Once a child is identified as having ASD, how do you track his or her progress?

12) In your school district what techniques do you use to link assessment to instruction strategies chosen for the student with ASD?

13) What treatment models (for example Picture Exchange System, Applied Behavioral Analysis, TEACCH, Social Stories etc.), does your district use for students with ASD in:
Preschool

Elementary

Middle School

High School

14) In your school district how do you utilize sensory integration therapy for children with ASD?

15) In your school how do you utilize Occupational Therapy (OT) for children with ASD?

16) In your school district how do you utilize speech language therapists to work on social skills of students with ASD? What techniques do they use?

17) In your school district how do you utilize social workers to work with children with ASD or their families? What techniques do they use?

18) In your school district who designs the behavior plan for children with ASD?

PART IV NETWORKS AND STAFF TRAINING

19) Are families of students with ASD included in the process of diagnosis and developmental assessment? If yes, how does this work?

20) How is information about students shared among multidisciplinary team members involved with ASD students?

21) Are there opportunities for staff working with students with ASD to receive inservice training? If yes, how does this work?

22) In your school district what techniques do you use to promote carryover of skills and learning in the ASD student's home?

23) How are parents of students with ASD involved in the creation of their child's IEP?

24) How does your school system plan for transitions for a child with ASD, for example a new classroom or new teacher?

25) Do the general education teachers on your staff need more information about ASD in order to meet the needs of ASD students in their classes?

26) Do the special education teachers on your staff need training in techniques specific to autism (for example, PECS, Social Stories, TEACCH) in order to meet the needs of ASD students in their classes?

27) Are you interested in receiving training about specific nationally recognized models for autism education?

28) Are you interested in having a pilot ASD classroom in your district if the state were to provide training for a team of your staff? If yes, at what grade level?

PART V YOUR VIEWPOINTS

29) Please consider services and treatment currently available to children with ASD in Rhode Island. In what ways are we meeting their needs successfully in the state as a whole? In your district specifically?

30) Please consider services and treatment currently available to children with ASD in Rhode Island. In what ways are we not meeting their needs in the state as a whole? In your district specifically?

31) What do you think are the greatest barriers to services for students with ASD in the state as a whole? In your district specifically?

Appendix I-C: Letter Accompanying Preliminary District Report

Date

Dear «JobTitle» «LastName»,

As you may recall, I spoke with you some months ago about services available to children with Autism Spectrum Disorders in your district. Enclosed you will find a preliminary report and brief narrative description as well on services for children with ASD in your district. Please take a few moments to look over these items and ascertain that the information presented in them is accurate and complete. If changes or additions need to be made to any part of the report or narrative description please note your modifications directly on the sheets and mail them back to me in the enclosed self-addressed envelope. You may also contact me directly by telephone (884-7956) to present modifications or additions. I thank you for your care and attention to this detail.

In order to allow me to meet deadlines in a timely manner it is essential that you get any modifications or corrections to me no later than the end of the business day on Wednesday, June 17th (about 10 days from the time you should be receiving this). If I do not hear from you by then I will assume that my information for your district is complete and accurate and will present it as such in the final report.

Thank you for your continued involvement in the Rhode Island Autism Project. Please feel free to call me if you have any questions or concerns. Our final report will be sent to you as soon as it is available.

Sincerely,

Martha E. Lang, Ph.D.
Project Manager,
Research and Assessment Phase

Appendix I-D: Preliminary District Report Form

Preliminary District Report for

Director Name:

Years Special Ed Director for this district:

Years in the Field of Special Education:

ASD caseload:

- The number of cases of autism reported by SPED Director
- The number of cases of PDD-NOS reported by SPED Director
- The number of cases of Asperger's reported by SPED Director
- The grand total autism, PDD and Asperger's cases reported by SPED Director
- The total number of cases in the autism category reported in Table 5 of the 1995-96 RIDE Census for this district
- Difference: Numeric difference between Total cases reported by SPED director and cases on RIDE Census

Age distribution of students with ASD in district:

- Number of Preschool students w/ ASD
- Number of Elementary School students w/ ASD
- Number of Junior High School students w/ ASD
- Number of High School students w/ ASD
- Number of Post Graduate (18-21 years old) students w/ ASD

Number of students in different types of classrooms:

- Inclusion in regular classrooms with aide support
- Inclusion in regular classrooms without aide support
- Self contained classroom in school district
- Combination placement (some time in regular classroom or specials and some in self-contained)
- Out of district placements

Out of District Placements for Students with ASD:

- 1)
- 2)
- 3)

Diagnosis and Assessment:

- Multidisciplinary Team makes the diagnosis of ASD children in the district.
- Team makes ASD diagnosis but sometimes refers to outside diagnosticians for difficult cases or a second opinion.
- Team always goes to an outside diagnostician for an ASD diagnosis
- Outside Diagnosticians who are used by district for diagnosis:

Techniques for linking assessment to instructional strategies. Subcategories are as follows:

- Through the goals on the IEP
- Data gathered from ABA methodologies
- Data gathered from diagnostic tests, batteries and scales

Methods by which MDT shares information about students. Subcategories are as follows.

- MDT meets about once a week
- Informal communications in school setting
- Phone calls between MDT members

Who designs behavior plan?

- School Psychologist
- Child's classroom teacher
- Occupational therapist
- Social worker
- Entire MDT
- Comments

School District Use of Specific Treatment Models:

Preschool

Elementary School

Junior High

High

Utilization of OTs, Speech Language Pathologists and Social Workers:

OT Methods Used:

- Trampoline
- Brushing techniques
- Swings
- Noted Need for More OTs

Speech Language methods used:

- Social Skills Groups
- One on One Instruction
- OTHER
- Noted Need for More SLs Self-Explanatory

Use of Social Workers:

- Work with children with ASD
- Work with families of children with ASD

Plans for transitions to a new classroom or teacher:

- Child visits new school or classroom
- New teacher visits student in current classroom
- Student spends time in each classroom, making gradual transition to new classroom.
- In months, how long a transition plan usually takes to implement

Home Carryover Techniques:

- Phone calls between school and home
- Notebooks between school and home
- Parent teacher meetings at school
- Visits by school personnell to ASD student's home
- Home program designed for reinforcement of school skills

Staff inservicing:

- Reg Ed. Staff need more ASD Training
- SPED Staff need more ASD training
- Director wants info about ASD educational models
- Would like pilot ASD Classroom in District
- Grade level of proposed classroom
- Staff currently receive ASD inservice training
- District has outside specialists (consultants like Kathleen Quill or representatives from facilities like Groden) come to sites in the district to do training
- District uses own staff to do its own inservicing.
- District sends staff out for training
 1. Sends staff to conferences
 2. Sends staff to workshops
 3. Sends staff to facilities like Groden or Bradley
 4. Sends staff to course or classes
- District Pays for training
- District provides time off for training
- Staff must use professional days for training
- Staff must use own time for training

Appendix I-E: Letter of Introduction to Private Agency Directors

October 27, 1997

Dear

As a professional who works with children with Autism Spectrum Disorder (ASD), I'm sure you are concerned about the unique needs of this population. Your concern is shared by the Rhode Island Department of Education. Recently, RIDE funded a grant developed by the Autism Society of Rhode Island. The mission of this project is to develop a system of educational services for meeting the needs of children with ASD in the state of Rhode Island.

During the first phase of this project I will be conducting research to collect information about the diagnostic process, educational services and related service support systems currently available to children with ASD in Rhode Island. Data will be collected from special education administrators, teachers, service providers, the medical community and parents. This information will be analyzed and shared with you next Spring so that we can create programs and services which are more responsive to the needs of this population.

I would like to meet with you to talk about your facility. Our meeting will take no more than one hour and the questions I will ask will be made available to you ahead of time. At the interview I will also give you surveys to distribute to members of multidisciplinary teams who work directly with children with ASD. I will be calling you within the next week to schedule an appointment. If you have questions about the project in the meantime please feel free to call our office at 401-884-7956. Thank you for your contribution to this important project. I look forward to meeting you.

Sincerely,

Martha E. Lang
Project Manager
Research and Assessment Phase
Rhode Island Autism Project

Appendix I-F: Protocol for Private Agency Directors' Interviews

SECTION I PERSONAL BACKGROUND

- 1) In what agency do you work?
- 2) How long have you been a Director for this agency?
- 3) How long have you worked in the field of special education?

SECTION II AUTISM PREVALENCE AND PROGRAM PLACEMENT

- 4) How many boys and girls who have been diagnosed with Autism Spectrum Disorder (ASD) are serviced by your agency?
 - 4a) What percentage are children with ASD of your total caseload?
 - 5) Of the total number of children with Autism Spectrum Disorder in your agency, do you know how many of them have severe autism, Pervasive Developmental Disorder, or Asperger's Syndrome?
 - 5a) What is the age distribution of children with ASD in your agency?
 - 5b) Do you know if children with ASD in your agency who have other disabilities (for example, mental retardation) have been placed in other categories of primary disability? If yes, please describe.
- 6) In your agency, how are classrooms set up for children with Autism Spectrum Disorder
- 7) Do you provide an extended day program?

SECTION III ASSESSMENT AND EDUCATION

- 8) In your agency does your multidisciplinary team make the diagnosis of ASD? If yes, who makes the diagnosis?
- 9) What are the procedural steps involved in having a student with ASD receive services in your agency?

- 10) Once a child is identified as having ASD, how do you track his or her progress?
- 11) In your agency what techniques do you use to link assessment to instruction strategies chosen for the student with ASD?
- 12) What is your agency's general philosophy of care?
- 13) What treatment models (for example Picture Exchange System, Applied Behavioral Analysis, TEACCH, Social Stories etc.), does your agency use for students with ASD in:
- Preschool
 - Elementary
 - Middle School
 - High School
- 14) In your agency how do you utilize sensory integration therapy for children with ASD?
- 15) In your school how do you utilize Occupational Therapy (OT) for children with ASD?
- 16) In your agency how do you utilize speech language therapists to work on social skills of students with ASD? What techniques do they use?
- 17) In your agency how do you utilize social workers to work with children with ASD or their families? What techniques do they use?
- 18) In your agency who designs the behavior plan for children with ASD?
- 19) How do the public school systems utilize your agency for:
- Consults (in what specific areas do they ask for consultation?),
 - Placements
 - Evaluation

PART IV NETWORKS AND STAFF TRAINING

- 20) Are families of students with ASD included in the process of diagnosis and developmental assessment? If yes, how does this work?

- 21) How is information about students shared among multidisciplinary team members involved with ASD students?
- 22) Are there opportunities for staff working with students with ASD to receive inservice training? If yes, how does this work?
- 23) In your agency what techniques do you use to promote carryover of skills and learning in the ASD student's home?
- 24) How are parents of students with ASD involved in the creation of their child's IEP?
- 25) How does your school system plan for transitions for a child with ASD, for example a new classroom or new teacher?
- 26) Do the teachers on your staff need more information about ASD in order to meet the needs of ASD students in their classes?
- 27) Do the teachers on your staff need training in techniques specific to autism (for example, PECS, Social Stories, TEACCH) in order to meet the needs of ASD students in their classes?
- 28) Are you interested in receiving training about specific nationally recognized models for autism education?
- 29) Are you interested in having a pilot ASD classroom in your agency if the state were to provide training for a team of your staff? If yes, at what grade level?

PART V YOUR VIEWPOINTS

- 30) Please consider services and treatment currently available to children with ASD in Rhode Island. In what ways are we meeting their needs successfully in the state as a whole? In your agency specifically?
- 31) Please consider services and treatment currently available to children with ASD in Rhode Island. In what ways are we not meeting their needs in the state as a whole? In your agency specifically?
- 32) What do you think are the greatest barriers to services for students with ASD in the state as a whole? In your agency specifically?

Appendix I-G: Letter of Introduction to Early Intervention Directors

November 12, 1997

Dear «Title» «LastName»,

As a professional who works with children with Autism Spectrum Disorder (ASD), I'm sure you are concerned about the unique needs of this population. Your concern is shared by the Rhode Island Department of Education. Recently, RIDE funded a grant developed by the Autism Society of Rhode Island. The mission of this project is to develop a system of educational services for meeting the needs of children with ASD in the state of Rhode Island.

During the first phase of this project I will be conducting research to collect information about the diagnostic process, educational services and related service support systems currently available to children with ASD in Rhode Island. Data will be collected from special education administrators, teachers, service providers, the medical community and parents. This information will be analyzed and shared with you next Spring so that we can create programs and services which are more responsive to the needs of this population.

I would like to meet with you to talk about your Early Intervention program. Our meeting will take no more than one hour and the questions I will ask will be made available to you ahead of time. At the interview I will also give you surveys to distribute to your staff. I will be calling you within the next week to schedule an appointment. If you have questions about the project in the meantime please feel free to call our office at 401-884-7956. Thank you for your contribution to this important project. I look forward to meeting you.

Sincerely,

Martha E. Lang
Project Manager
Research and Assessment Phase
Rhode Island Autism Project

Appendix I-H: Protocol for EI Directors' Interviews

SECTION I PERSONAL BACKGROUND

- 1) In what EI program do you work?
- 2) How long have you been an EI Director for this region?
- 3) How long have you worked in the field of Early Intervention?

SECTION II AUTISM PREVALENCE AND PROGRAM PLACEMENT

- 4) About how many boys and girls who have been diagnosed with autism are enrolled in your program?
- 5) Of the total number of children with Autism Spectrum Disorder in your program, do you know how many of them have severe autism, Pervasive Developmental Disorder, or Asperger's Syndrome? (Note, I will describe these in detail in the interview)
- 5a) What is the age distribution of children with ASD in your program?
- 5b) Do you know if children with ASD in your program who have other disabilities (for example, mental retardation) have been placed in other categories of primary disability in the ROH-EI census? If yes, please describe.
- 6) In your program, how many children with Autism Spectrum Disorder receive their intervention primarily in the following settings:
 - _____ **Early Intervention Center/Classroom:** Center/classroom program refers to an organized program of at least one hour duration provided on a regular basis for a group of children. The program is usually directed toward the facilitation of several developmental areas.
 - _____ **Family Child Care:** Services are provided to the child in a home but the home is *not* the principal residence of the child's family.
 - _____ **Home:** Services are provided in the principal residence of the child's family or caregivers.
 - _____ **Hospital:** Hospital refers to a residential medical facility. Child must be receiving services on an inpatient basis.
 - _____ **Outpatient Service Facility:** Outpatient services are provided at a center, clinic, or hospital where the infant or toddler comes for short periods of time (e.g. 45 minutes) to receive services. These services may be provided individually or to a small group of children.
 - _____ **Regular Nursery School/Child Care Center:** Services are provided in a facility regularly attended by a group of children. Most of the children in this setting do not have disabilities.

- _____ **Residential Facility:** Residential Program refers to a treatment facility which is not primarily medical in nature where the infant or toddler currently resides in order to receive early intervention services.
- _____ **Other:** any service setting not described by the settings or programs listed above. For example, if the only component of the infant's early intervention services is parent counseling during which the child is not present and the child receives no direct service count as "other."

7) When reporting to the state, in what eligibility category do you place children birth to 3 with ASD: single established conditions, developmentally delayed, or multiple established conditions?

7a) What ICD-9 code(s) do you use when reporting these children?

SECTION III ASSESSMENT AND EDUCATION

8) In your program does your multidisciplinary team make the diagnosis of ASD? If yes, who makes the diagnosis?

9) If you use other agencies or health groups to make the diagnosis, which do you use?

10) What are the procedural steps involved in having a child with ASD receive services in your program?

11) Once a child is identified as having ASD, how do you measure his or her progress?

12) In your program what techniques do you use to link assessment to instruction strategies chosen for the child with ASD?

13) Does your program use any specific program models for teaching children with ASD? If so, which ones?

14) In your program how do you utilize sensory integration therapy for children with ASD? If so how?

15) In your program do you utilize Occupational Therapy (OT) for children with ASD? If so, how?

16) In your program do you utilize speech language therapists, psychologists, counselors social workers etc. to work on social skills of children with ASD? If so, what techniques do they use?

17) In your program do you utilize social workers to work with children with ASD or their families? What techniques do they use?

18) Are there behavior plans for children with ASD in your program? If yes, who designs them?

PART IV NETWORKS AND STAFF TRAINING

19) Are families of children with ASD included in the process of evaluation and assessment? If yes, how does this work?

20) How is information about children shared among multidisciplinary team members involved with children with ASD?

21) Are there opportunities for staff working with children with ASD to receive inservice training? If yes, how does this work?

22) In your program what techniques do you use to promote carryover of skills and learning in the child's home, if that isn't the primary setting where services are delivered?

23) How are parents of children with ASD involved in the creation of their child's IFSP?

24) How does your EI Program plan for transitions for a child with ASD to a school system?

25) Do the personnel on your staff need more information about ASD in order to meet the needs of ASD child's in their classes?

26) Do the personnel on your staff need training in techniques specific to autism in order to meet the needs of ASD child's in their classes?

27) Are you interested in receiving training about specific nationally recognized models for intervening with autism?

28) Are you interested in having a pilot ASD intervention program in your region if the state were to provide training for a team of your staff?

PART V YOUR VIEWPOINTS

29) Please consider services and treatment currently available to children with ASD in Rhode Island. In what ways are we meeting their needs successfully in the state as a whole? In your program specifically?

30) Please consider services and treatment currently available to children with ASD in Rhode Island. In what ways are we not meeting their needs in the state as a whole? In your program specifically?

31) What do you think are the greatest barriers to services for children with ASD in the state as a whole? In your program specifically?

Appendix I-I: Protocol for Diagnosticians' Interviews

- 1) What formal diagnostic criteria do you and/or your team use to make a diagnosis of Autism, Pervasive Developmental Disorder Not Otherwise Specified and Asperger's Syndrome?
- 2) Do you and/or your team ever suspect that a child has Autism, PDD-NOS, or Asperger's Syndrome but delay making a formal diagnosis?
 - 2a) If you answered yes, what would be the factors that would go into your choice?
 - 2b) What do you think are the pros and cons of delaying a diagnosis?
- 3) After you and/or your team assesses a child about how long does it take you to give to parents a written draft of your report?
- 4) When you and/or your team present a diagnosis of Autism, PDD-NOS, or Asperger's Syndrome to parents do you discuss with them resource or treatment options? For example:
 - a) Tell them about parent support groups or connect them with other parents?
 - b) Tell them about medical interventions?
 - c) Tell them about educational interventions?
 - d) Tell them about respite care?
 - e) Tell them about their legal rights as parents of a child with a disability?
- 5) How do you use information and/or input from parents in your diagnostic process?
- 6) To what extent are you able to customize your evaluations to parents' expectations and/or needs?
- 7) Please consider the services and treatment currently available to children with Autism/PDD-NOS/Asperger's Syndrome in Rhode Island. Based on your experience, in what ways do you feel their needs are being met successfully?
- 8) Please consider the services and treatment currently available to children with Autism/PDD-NOS/Asperger's Syndrome in Rhode Island. Based on your experience, in what ways do you feel their needs are not being met? (Please list up to four)
- 9) Based on your experience, what do you feel are the greatest barriers to services for children with Autism/PDD-NOS/Asperger's Syndrome in Rhode Island? (Please list up to four)

Appendix I-J: Cover Letter to Professional Survey

January 13, 1998

Dear Autism Professional,

As a person who works with children with Autism Spectrum Disorder (ASD, which includes autism, PDD-NOS and Asperger's Syndrome), I'm sure you are concerned about the unique needs of this population. Your concern is shared by the Rhode Island Department of Education. RIDE recently funded a grant developed by the Autism Society of Rhode Island. The mission of this project is to develop a system of educational services for meeting the needs of children with ASD in our state. As a first step in the process we are conducting research on the diagnostic processes, educational services and related service support systems currently available to this population.

You are one of a small number of professionals who have been selected to give their views and input on the current status of services and treatment for children with ASD in our state. In order to achieve results that provide a representative sample of each school district, Early Intervention region and educational agency it is important that each questionnaire be completed and returned as quickly as possible. Because the questionnaire is targeted to a wide variety of professionals, it includes a broad range of items, some of which may be unfamiliar to you. We do not expect you to be familiar with every item; what we are most interested in is your own direct experience with and knowledge of children with ASD. The questionnaire takes no more than 20 minutes to complete and we have provided a self-addressed stamped envelope for your convenience.

Your completed questionnaire will help us to assess the current needs of children with ASD in Rhode Island and the services available to them. Our research findings will be shared with each school district as well as state officials and will help all of us to create services that are more responsive to the needs of the ASD student population. It is for this reason that your participation in the project is so crucial.

It is important that only professionals who are currently involved in the evaluation, referral and/or provision of services for children with ASD in the state of Rhode Island participate in this study. If you do not work with this population you do not need to fill out this questionnaire. Please return it to the person who gave it to you.

We would be most happy to answer any questions you might have about the survey or the Rhode Island Autism Project. Please feel free to call us at our office (401-884-7956).

Thank you for your assistance with this important project.

Sincerely,

Martha E. Lang, Ph.D.
Project Manager
Rhode Island Autism Project

Appendix I-K: Survey of Autism Professionals

1. What educational agency and/or school district do you work for? _____

2. What age level do you work with most often (eg early intervention, preschool, elementary, junior high, high school etc.)? _____

3. Please check your position

Classroom Aide	
Early Childhood Special Educator	
Early Intervention Director	
Educational Diagnostician	
Occupational Therapist	
Physical Therapist	
Principal	

School Psychologist	
School Social Worker	
Special Education Aide	
Special Education Teacher	
Speech Language Pathologist	
Teacher in a Regular Classroom	
Other (please specify below)	

4. Please check the best estimate of children of children that you work with directly who are diagnosed with Autism Spectrum Disorder (ASD) or who you suspect of having ASD

0 children	
1-10 children	
11-20 children	
21-30 children	
more than 30 children	

5 Please check all the diagnostic tests that are used in your evaluation of children with Autism Spectrum Disorder

Bailey Scales of Infant Development	
Mullens	
WPPSI-R	
WISC-III-R	
WIAT	
Vineland	
Binet	
Social Skills Inventory	
Kaufman ABC	
Leiter	
Woodcock Johnson	
Brigance Comprehensive Inventory	
CARS	
PAB-R	

Peabody Developmental Motor Scales	
Miller Assessment Preschools (MAP)	
Pediatric Eval. of Disability Inventory (PEDI)	
Bruinks-Oserctsky (BOTMP)	
Sensory Integration and Praxis Test	
Rosetti	
CSPS	
OWLS	
CELF	
Preschool Language Scale	
TOPL	
Am unfamiliar with diagnostic tests	
Do not use diagnostic tests	

Please list any other evaluations that you use that have not been included above _____

6. Please check all settings in which you work with children with ASD.

Setting	Do Assessments	Provide Direct Services
Self-contained classroom		
Regular classroom		
Private facility (ie. Groden, Bradley),		
Your office or clinic		
Early care nursery school		
Day care center		
Child's Home		
Other (please specify _____)		

7. Please check all boxes that apply to your experience with each of the following instructional methods

Instructional Method	Use	Don't Use	Effective	Ineffective	Not familiar w/ method	No opinion
Sign/Gesture Communication						
Picture Exchange System						
Picture/Word Boards or Books						
Sensory Integration						
Auditory Integration Training						
ABA/Lovaas						
Miller						
TEACCH						
Greenspan						
Social Stories						
Comic Strip Conversations						
Social Skills Groups						

Please list any methods that you use that are not included above.

Of those you just listed, which do you find effective? _____

8) Please check all methods that you use to promote carryover of skills learned in school to the child's home **and/or** to implement a home program.

Method	Carryover of school skills	Implement a home program
Phone calls		
Home visits by school personnel		
Written notes between school and home		
Treatment in the home by school personnel		
Program designed for families to do at home		
No communication between school and home		

9) When you consider the services and treatment currently available to children with ASD in Rhode Island, in what ways do you feel their needs are being met successfully? (Please list up to four)

- A) _____
 B) _____
 C) _____
 D) _____

10) When you consider the services and treatment currently available to children with ASD in Rhode Island, in what ways do you feel their needs are not being met? (Please list up to four)

- A) _____
 B) _____
 C) _____
 D) _____

11) What do you feel are the greatest barriers to receiving services for children with ASD in Rhode Island? (Please list up to four)

- A) _____
 B) _____
 C) _____
 D) _____

12) Please check the item that best matches your opinion.

Statement:	Agree Strongly	Agree Some what	Neutr al	Disag ree Some what	Disag ree Stron gly	Don't Know	Not Appli cable
I feel I am well prepared to perform evaluations on children with ASD							
I feel I am well prepared to treat children with ASD							
I feel I am well prepared to teach children with ASD							
I feel that the present structure of education for the child with ASD in RI is appropriate							
I feel that I have adequate opportunities for continuing education in the field of ASD							

This is the end of the survey. Thank you for your time. If you would be willing to be interviewed further on this topic or participate in a focus group, please fill out the information below.

NAME: _____

ADDRESS: _____

TELEPHONE: _____

BEST TIMES TO REACH YOU: _____

Appendix I-L: Cover Letter to Parents' Survey

January 12, 1998

Dear Parent,

As the mother or father of a child with Autism, Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) or Asperger's Syndrome, I'm sure you are concerned about the unique needs of these children. Your concern is shared by the Rhode Island Department of Education (RIDE). RIDE recently funded a grant developed by the Autism Society of Rhode Island. The mission of this project is to develop a system of educational services for meeting the needs of children with Autism, PDD-NOS or Asperger's Syndrome in the state of Rhode Island. As a first step in the process we are researching the diagnostic, educational and support services currently available to this population.

We cannot assess the needs of children with autism without first understanding the experiences of their parents. Therefore, your input to this research is crucial. Our research findings will be shared with each school district, autism specialists and state officials and will help to improve services for children with Autism, PDD-NOS or Asperger's Syndrome. It is for this reason that your participation is so important.

Enclosed you will find a questionnaire about your experiences as a parent of a child with Autism, PDD-NOS or Asperger's Syndrome. Please take a moment to fill out this booklet so that we can include your perspectives in our report. Due to project deadlines, it is important that you complete and return the questionnaire as quickly as possible. A self-addressed stamped envelope is included for your convenience. If for some reason you receive more than one survey, please fill out and return only one.

The information that you are providing will be treated as confidential information in accordance with the provisions of the IDEA (Individuals with Disabilities Education Act) and GEPA (General Education Provision Act) which is Public Law 93568. The information will be used for the purposes of improving services for children with autism in the state of Rhode Island. The information shall be destroyed when no longer needed for the purposes for which this study is being conducted. The information you are providing is voluntary and if you should have any questions about this or the study being conducted, call Robert Pryhoda at the Rhode Island Department of Education at 401-222-4600 extension 2300.

If you have questions about the survey or know of other parents who would like to be included in the study but did not receive a booklet, please feel free to call the Rhode Island Autism Project office at 884-7956. Spanish and Portuguese translations of the survey are also available through our office.

I thank you personally for taking the time to participate in this important project.

Sincerely,

Martha E. Lang, Ph.D.
Project Manager
Rhode Island Autism Project

Appendix I-M: Survey of Parents

Please fill out this questionnaire as completely as possible. If you have any questions or need assistance, feel free to call our office at 884-7956.

Section 1 Child's Background and Diagnosis

This first series of questions will provide us with background about the diagnosis of your child with Autism/PDD-NOS/Asperger's Syndrome and about your experience in getting a diagnosis for your child

1) What is the age and sex of your child with Autism/PDD-NOS/Asperger's Syndrome? (Please fill in the blank below) (Note: if you have more than one child with Autism/PDD-NOS/Asperger's Syndrome, please base your answers for this survey on the experience of just one of your children.)

2) How old was your child with Autism/PDD-NOS/Asperger's Syndrome when he/she first started showing signs of the disorder? (Please fill in the blank below)

3) How old was your child with Autism/PDD-NOS/Asperger's Syndrome when a diagnosis was made? (Please fill in the blank)

4) What was the name of the doctor or autism specialist who made the diagnosis? (Please fill in the blank)

5) What exactly was the formal, written diagnosis ? (Please fill in the blank)

5a) If your child with Autism/PDD-NOS/Asperger's Syndrome has been diagnosed with one or more other health conditions and/or disabilities, please note them in the blanks below.

6) Please circle the number of the item that best describes your experience in getting a diagnosis of Autism/PDD-NOS/Asperger's Syndrome for your child.

- 1 EXTREMELY EASY TO GET A DIAGNOSIS
- 2 SOMEWHAT EASY TO GET A DIAGNOSIS
- 3 NEITHER EASY OR DIFFICULT TO GET A DIAGNOSIS (NEUTRAL)
- 4 SOMEWHAT DIFFICULT TO GET A DIAGNOSIS
- 5 EXTREMELY DIFFICULT TO GET A DIAGNOSIS

Section 2 Use of Government Programs

Your answers to the next series of questions will help us to understand how families of children with autism use certain national government programs designed to assist some people with disabilities.

7) Does your child with Autism/PDD-NOS/Asperger's Syndrome currently receive Medicaid? (Please circle the number of your answer)

- 1 YES, MY CHILD RECEIVES MEDICAID THROUGH SSI (SUPPLEMENTAL SECURITY INCOME)
- 2 YES, MY CHILD RECEIVES MEDICAID THROUGH KATIE BECKETT
- 3 YES, MY CHILD RECEIVES MEDICAID THROUGH RITECARE
- 4 NO, MY CHILD DOES NOT QUALIFY FOR THIS PROGRAM
- 5 NO, I CHOOSE NOT TO USE THIS PROGRAM
- 6 NO, I WAS NOT AWARE THAT THIS PROGRAM EXISTED
- 7 DON'T KNOW

7a) Did he or she ever receive it in the past? (Please circle the number of your answer)

- 1 YES
- 2 NO
- 3 DON'T KNOW

8) Does your child with Autism/PDD-NOS/Asperger's Syndrome currently receive EPSDT (Early and Periodic Screening, Diagnosis and Treatment) services (? (Please circle the number of your answer)

- 1 YES
- 2 NO, MY CHILD DOES NOT QUALIFY FOR THIS PROGRAM
- 3 NO, I CHOOSE NOT TO USE THIS PROGRAM
- 4 NO, I WAS NOT AWARE THAT THIS PROGRAM EXISTED
- 5 DON'T KNOW

8a) Did he or she ever receive it in the past? (Please circle the number of your answer)

- 1 YES
- 2 NO
- 3 DON'T KNOW

9) If your child with Autism/PDD-NOS/Asperger's Syndrome has received one or more of the programs described on the previous page, please circle the number of the item that best describes your experience in getting services for your child. If your child has received more than one program, please think of the one that was the hardest to get in choosing your answer.

- 1 EXTREMELY EASY TO GET PROGRAM
- 2 SOMEWHAT EASY TO GET PROGRAM
- 3 NEITHER EASY OR DIFFICULT TO GET PROGRAM (NEUTRAL)
- 4 SOMEWHAT DIFFICULT TO GET PROGRAM
- 5 EXTREMELY DIFFICULT TO GET PROGRAM

This is the end of the first two sections of the survey. Please feel free to use the space below for any additional comments or responses you may have.

Section 3 Education

Your answers to these questions will help us to assess the current education programs for children with Autism/PDD-NOS/Asperger's Syndrome in Rhode Island.

10) What is the school district of your child with Autism/PDD/ Asperger's Syndrome? (Please fill in the blank below.)

11) What is the current educational program if your child with Autism/PDD/ Asperger's Syndrome? (Please circle number and/or fill in the blank)

- 1 REGULAR CLASSROOM WITH AIDE SUPPORT IN A PUBLIC SCHOOL
- 2 REGULAR CLASSROOM WITHOUT AIDE SUPPORT IN A PUBLIC SCHOOL
- 3 SELF CONTAINED CLASSROOM WITH SOME REGULAR CLASS ROOM ACADEMIC TIME N A PUBLIC SCHOOL
- 4 SELF CONTAINED CLASSROOM BUT MAINSTREAMED FOR ART, GYM, MUSIC AND/OR LUNCH
- 5 COMPLETELY SELF CONTAINED CLASSROOM
- 6 PRIVATE FACILITY, FOR EXAMPLE, GRODEN OR BRADLEY (WHICH ONE? _____)
- 7 PRIVATE OR PAROCHIAL SCHOOL (WHICH ONE? _____)
- 8 OTHER (PLEASE SPECIFY _____)
- 9 DON'T KNOW

12) Does your child with Autism/PDD-NOS/ Asperger's Syndrome currently receive education (For example speech therapy or occupational therapy) and/or treatment (for example homeopathy, megavitamin therapy) at home?

- 1 YES
- 2 NO
- 3 DON'T KNOW

13) If you chose yes for the previous question, please note in the blanks below what forms of education and/or treatment your child is receiving at home. If any of these are funded by your child's school and or health insurance please circle them.

14) Does your child's school provide ways for you to teach or reinforce in your home the things that your child is learning in the classroom?

- 1 YES
- 2 YES, BUT, I CHOOSE NOT TO BE INVOLVED
- 3 NO, I WAS NOT AWARE THAT THIS WAS POSSIBLE
- 4 DON'T KNOW

15) If you chose Yes for the previous question, Please circle the number of all methods that you and your child's school use to communicate.

- 1 PHONE CALLS
- 2 HOME VISITS BY SCHOOL PERSONNEL
- 3 WRITTEN NOTES BETWEEN SCHOOL AND HOME
- 4 TREATMENT IN THE HOME BY SCHOOL PERSONNEL
- 5 PROGRAM DESIGNED FOR FAMILIES TO DO AT HOME

16) Are you and/or your spouse currently involved in the Multidisciplinary Team that creates and oversees your child's program?

- 1 YES
- 2 NO, WE CHOSE NOT TO DO THIS
- 3 NO, WE REQUESTED INVOLVEMENT, BUT SCHOOL HAS NOT YET INCLUDED US
- 4 NO, I WAS NOT AWARE THAT THIS PROGRAM EXISTED
- 5 DON'T KNOW

17) Were you and/or your spouse involved in making your child's Individualized Education Plan (IEP)?

- 1 YES
- 2 NO, WE CHOSE NOT TO DO THIS
- 3 NO, WE REQUESTED INVOLVEMENT, BUT SCHOOL DID NOT INCLUDE US
- 4 NO, WE DID NOT KNOW THIS CHOICE WAS AVAILABLE TO US
- 5 DON'T KNOW

18) Please circle the number of the item that best describes your feelings about your child's current educational program.

- 1 EXTREMELY SATISFIED
- 2 SOMEWHAT SATISFIED
- 3 NEITHER SATISFIED OR DISSATISFIED (NEUTRAL)
- 4 SOMEWHAT DISSATISFIED
- 5 EXTREMELY DISSATISFIED

Section 4 Social Supports

The next set of questions are about services designed to help families cope with raising a child with Autism/PDD-NOS/Asperger's Syndrome.

19) Do you use government sponsored respite care? Respite is a program that provides care for children with Autism/PDD/ Asperger's Syndrome so that their families can have some relaxation time. (Please circle the number of your answer)

- 1 YES
- 2 NO, MY CHILD DOES NOT QUALIFY FOR THIS PROGRAM
- 3 NO, WE HAVE APPLIED BUT ARE ON A WAITING LIST
- 4 NO, I CHOOSE NOT TO
- 5 NO, I WAS NOT AWARE THAT THIS PROGRAM EXISTED
- 6 DON'T KNOW

20) Are you or your spouse involved in a support or informational group for parents with children with Autism/PDD-NOS/Asperger's Syndrome? (Please circle the number of all answers that apply)

- 1 YES, I AM INVOLVED
- 2 YES, MY SPOUSE IS INVOLVED
- 3 NO BUT WE HAVE BEEN INVOLVED IN THE PAST.
- 4 NO, CHOOSE NOT TO
- 5 NO, WE WERE NOT AWARE THAT THESE PROGRAMS EXISTED
- 6 DON'T KNOW

21) If you have other children, are one or more of them in a support group or program for brothers and sisters of children with Autism/PDD-NOS/Asperger's Syndrome? (Please circle the number of your answer)

- 1 YES
- 2 NO, THEY CHOOSE NOT TO
- 3 NO, BUT THEY HAVE BEEN INVOLVED IN THE PAST
- 3 NO, I WAS NOT AWARE THAT THIS PROGRAM EXISTED
- 4 DON'T KNOW

22) In the space below, please list any people and/or organizations who provide you with social and/or emotional support in raising your child with Autism/PDD-NOS/Asperger's Syndrome, for example, relatives, church or synagogue, social clubs. Please be as specific as possible.

Section 5 Your Viewpoints

In this section we would like you to share your overall perceptions about the needs of children with Autism/PDD-NOS/Asperger's and the services available to them in the State of Rhode Island.

23) Please consider the services and treatment currently available to children with Autism/PDD-NOS/Asperger's Syndrome in Rhode Island. Based on your experience, in what ways do you feel their needs are being met successfully? (Please list up to four)

- A) _____
- B) _____
- C) _____
- D) _____

24) Please consider the services and treatment currently available to children with Autism/PDD-NOS/Asperger's Syndrome in Rhode Island. Based on your experience, in what ways do you feel their needs are not being met? (Please list up to four)

- A) _____
- B) _____
- C) _____
- D) _____

25) Based on your experience, what do you feel are the greatest barriers to services for children with Autism/PDD-NOS/Asperger's Syndrome in Rhode Island? (Please list up to four)

- A) _____
- B) _____
- C) _____
- D) _____

This is the end of this section of the survey. Please feel free to use the space below for any additional comments or responses you may have.

Section 6 Background Information

Your answers to this final set of questions will help us to understand any possible effect that social background may have on the services children with Autism/PDD-NOS/Asperger's Syndrome now receive. All questions in this section are optional.

26) Who filled out this survey? (Please circle number)

- 1) Mother of child with Autism/PDD-NOS/Asperger's Syndrome
- 2) Father of child with Autism/PDD-NOS/Asperger's Syndrome
- 3) Other (Please specify _____)

27) Current age of parents of child with Autism/PDD-NOS/Asperger's Syndrome: (Please fill in the blanks)

_____ Father
_____ Mother

28) What is the job or occupation of each parent of child Autism/PDD-NOS/Asperger's Syndrome ? Please be as specific as possible.

_____ (Mother's job)
_____ (Father's job)

29) What is the highest level of education achieved by each parent of child Autism/PDD-NOS/Asperger's Syndrome Please circle your answer for each parent

MOTHER	FATHER	LEVEL OF EDUCATION COMPLETED
1	1	LESS THAN HIGH SCHOOL GRADUATE
2	2	HIGH SCHOOL GRADUATE
3	3	SOME COLLEGE
4	4	COLLEGE GRADUATE
5	5	GRADUATE OR PROFESSIONAL DEGREE

30) If you have other children, what are their ages and sexes? (Please fill in the blanks below)

31) Do any of your other children have disabilities? (Please circle the number of your answer)

- 1 YES (If yes please note here which child/children has a disability and what kind of disability it is _____)
- 2 NO
- 3 DON'T KNOW

32) What is the current marital status of parents of child with Autism/PDD-NOS/Asperger's Syndrome? (Please circle number)

- 1 MARRIED
- 2 SEPARATED
- 3 DIVORCED
- 4 NEVER MARRIED
- 5 WIDOWED

33) How would you describe the race or ethnicity of your family? (Please circle the number of your answer)

- 1 AFRICAN AMERICAN
- 2 ASIAN/PACIFIC ISLANDER
- 3 HISPANIC/LATINO
- 4 NATIVE AMERICAN/ESKIMO/ALEUT
- 5 WHITE/CAUCASIAN
- 6 OTHER (PLEASE SPECIFY_____)

34) What language is spoken most often in your home? (Please circle the number of your answer)

- 1 ENGLISH
- 2 SPANISH
- 3 PORTUGUESE
- 4 ITALIAN
- 5 FRENCH
- 6 CAMBODIAN
- 7 LAOTIAN
- 8 HMONG
- 9 CREOLE/PATOIS (PLEASE SPECIFY_____)
- 10 OTHER (PLEASE SPECIFY_____)

This is the end of the survey. We thank you for the time and care you have taken in filling it out. Please put it in the enclosed self-addressed, stamped, envelope and drop it in the mail.

If you would you be willing to be interviewed in person or participate in a focus group about autism, please contact our office at 884-7956. Thank you!

***Appendix I-N: Cover Letter to Family Practitioners
Participating in Pediatrician Survey***

January 5, 1998

Dear Colleague,

As a family practice physician, I am sure you are concerned about the health and social issues presented by children with special needs. Children with Autism Spectrum Disorder (ASD, includes autism, PDD-NOS and Asperger's Syndrome), present particularly unique challenges to all professionals with whom they come in contact. These needs are recognized by the Rhode Island Department of Education (RIDE). RIDE recently funded a grant developed by the Autism Society of Rhode Island. The mission of this project is to develop a system of educational services for meeting the needs of children with ASD in the state of Rhode Island. As a first step in the process they are conducting research on the medical needs, diagnostic processes, educational services and related service support systems currently available to this population.

You are one of a small number of pediatricians who have been selected to give their views and input on the current status of services and treatment for children with ASD in our state. In order to achieve results that provide a representative sample it is important that each questionnaire be completed and returned as quickly as possible. The questionnaire takes no more than ten minutes to fill out. Your answers will help the Rhode Island Autism Project research team to assess the current needs of children with ASD in Rhode Island and the services available to them.

The American Academy of Family Medicine is serves as advocate for children's health issues. We support this project and urge you to participate by promptly completing and returning the enclosed questionnaire. If you have any questions about this survey or the Rhode Island Autism Project please feel free to call their office at 401-884-7956.

Thank you for your assistance with this important project.

Sincerely,

*Appendix I-O: Cover Letter to Pediatricians
Participating in Pediatrician Survey*

March 5, 1998

Dear Colleague,

As a pediatrician, I am sure you are concerned about the health and social issues presented by children with special needs. Children with Autism Spectrum Disorder (ASD, includes autism, PDD-NOS and Asperger's Syndrome), present particularly unique challenges to all professionals with whom they come in contact. These needs are recognized by the Rhode Island Department of Education (RIDE). RIDE recently funded a grant developed by the Autism Society of Rhode Island. The mission of this project is to develop a system of educational services for meeting the needs of children with ASD in the state of Rhode Island. As a first step in the process they are conducting research on the medical needs, diagnostic processes, educational services and related service support systems currently available to this population.

You are one of a small number of pediatricians who have been selected to give their views and input on the current status of services and treatment for children with ASD in our state. In order to achieve results that provide a representative sample it is important that each questionnaire be completed and returned as quickly as possible. The questionnaire takes no more than ten minutes to fill out. Your answers will help the Rhode Island Autism Project research team to assess the current needs of children with ASD in Rhode Island and the services available to them.

The American Academy of Pediatrics is at the forefront of advocating for children's health issues. We support this project and urge you to participate by promptly completing and returning the enclosed questionnaire. If you have any questions about this survey or the Rhode Island Autism Project please feel free to call their office at 401-884-7956.

Thank you for your assistance with this important project.

Sincerely,

David Chronley, M.D.
President
Rhode Island Chapter
American Academy of Pediatrics

Appendix I-P: Pediatrician Survey

***Rhode Island Autism Project
Survey of Pediatricians***

1) For how many years have you been a pediatrician? (Please fill in the blank below)

2) At what point in your experience as a medical student and a pediatrician did you receive most of your training on Autism Spectrum Disorder (ASD which includes Autism, Pervasive Developmental Disorder-Not Otherwise Specified and Asperger's Syndrome)? (Please circle the number of your answer)

- 1 MEDICAL SCHOOL
- 2 INTERNSHIP
- 3 RESIDENCY
- 4 IN PRACTICE AS A PEDIATRICIAN
- 5 HAVE NOT YET RECEIVED TRAINING ON ASD

comments _____

3) At what point in a pediatrician's medical career do you think it it would be most helpful for him/her to receive training on ASD?

- 1 MEDICAL SCHOOL
- 2 INTERNSHIP
- 3 RESIDENCY
- 4 IN PRACTICE AS A PEDIATRICIAN
- 5 DON'T KNOW/NOT SURE

comments _____

4) Approximately how many patients do you serve in your current general pediatric practice? (Please fill in the estimated number below)

5) Approximately how many children in your current general pediatric practice caseload exhibit some form of developmental delay? (Please fill in the estimated number below)

6) How many children in your current general pediatric practice caseload have some form of Autism Spectrum Disorder? (Please fill in the number below)

7) Of these children with Autism Spectrum Disorder, how many have you referred to outside specialists for further testing and/or assessment. (Please fill in the number below)

Please go to the next page

8) If you have used outside specialists or consultants for your patients with Autism, Spectrum Disorder, please list up to four who you have found to be particularly helpful.

- 1) _____
- 2) _____
- 3) _____
- 4) _____

9) Please consider the services and treatment currently available to children with ASD in Rhode Island. Based on your experience, in what ways do you feel their needs are being met successfully? (Please list up to four)

- A) _____
- B) _____
- C) _____
- D) _____

10) Please consider the services and treatment currently available to children with ASD in Rhode Island. Based on your experience, in what ways do you feel their needs are not being met? (Please list up to four)

- A) _____
- B) _____
- C) _____
- D) _____

11) Based on your experience, what do you feel are the greatest barriers to services for children with ASD in Rhode Island? (Please list up to four)

- A) _____
- B) _____
- C) _____
- D) _____

12) In the space below, please note briefly any ideas that you have for improving services for children with ASD in Rhode Island.

This is the end of the survey, if you would you be willing to be interviewed further or participate in a focus group on the issue of Autism Spectrum Disorder, please fill in the information below

NAME _____
ADDRESS _____

TELEPHONE _____

Thank you for taking the time to fill out this survey!

