

AUTISM SPECTRUM DISORDERS OUTCOME STUDY & TRAINING PROJECT

A STATEWIDE STUDY
OF STUDENT PROGRESS

FINAL PROJECT REPORT
Fall 1998 to Summer 2003

A COLLABORATIVE PROJECT BETWEEN
PORTLAND STATE UNIVERSITY
AND THE OREGON DEPARTMENT OF EDUCATION

Joel Arick, Ph.D. (Project Director)
Helen Young, M.S.
Ruth Falco, Ph.D.
Dave Krug, Ph.D.

Lauren Loos, M.A.
Marilyn Gense, M.A.
Steve Johnson, M.A.

Table of Contents

Executive Summary	ii
Summary of Results for Cohort #1.....	ii
Summary of Results for Cohort #2.....	iv
Training and On-site Consulting.....	vi
Observation Data.....	vii
Conclusion and Recommendations.....	viii
Introduction	1
Methods	3
Instruments.....	4
Procedures.....	5
Data Analysis.....	6
Description of Instructional Strategies.....	7
Cohort #1	8
Demographics	9
Services Received.....	10
Results.....	13
Assessment Results.....	13
Feedback from Parents.....	18
Cohort #2	39
Demographics	40
Services Received.....	41
Results.....	44
Assessment Results.....	44
Feedback from Parents.....	49
Teacher Survey Results on Student Progress.....	61
References	64

Executive Summary
Autism Spectrum Disorders Outcome Study & Training Project

Many special education service providers are responding to the challenge of providing the best services possible to young children with autism spectrum disorders. They are initiating programs of more intensive services with varied approaches that have demonstrated promising outcomes for young children with autism spectrum disorder. In order to develop and sustain these programs, service providers will need to demonstrate positive outcomes for children with autism spectrum disorder. Even for those school and home programs where parents and service providers have been satisfied, it is important to document results to determine the factors that have contributed to their success.

In 1998, the Oregon Department of Education realizing the importance of documenting outcome results, contracted with Portland State University to design a study to collect outcome data for young students with autism spectrum disorder in Oregon. The Autism Spectrum Disorder Outcome Study and Training Project was developed at that time. This document reports the results of this study.

The five-year study began in October 1998 and ended in August 2003. One-hundred twenty-three students participated in this study. Sixty-seven children began the study in 1998 and an additional 56 children joined the study in 2001. In this report, the children who began the study in 1998 are referred to as Cohort #1, and the children who joined the study in 2001 are referred to as Cohort #2.

Summary of Outcome Results for Cohort #1

Assessments Administered by Assessment Team to Cohort #1

Numerous standardized assessments were administered to the students in Cohort #1. In general, during their 52 months of participation in the study, the students made progress in all areas assessed.

Expressive Language Assessment. To measure the expressive language age of the students, they were administered the ASIEP-2 Sample of Vocal Behavior subtest (Krug, Arick, Almond, 1993) and the Expressive One-Word Picture Vocabulary test (Brownell, 2000). The average language age gain was 33 months in the 52 months that the students in Cohort #1 were involved in the study. Ninety-one percent of the students made gains in their expressive language abilities, and 21% of those students gained 52 or more months of expressive language age during their 52 months of participation in the study. In addition, 17% of the students, in spring 2003, had an expressive language age that was within 12 months of their chronological age.

Educational Assessments. The educational assessments administered to the students included: 1) the ASIEP-2 Educational Assessment subtest (Krug, et al., 1993), which assesses receptive language, expressive language, body concept, and speech imitation, and 2) portions of the Extended Basic Academic Skills Assessment System (Tindal, McDonald,

Crawford, & Tedesco, 2000), which measures academic skills. The students made significant ($<.01$) improvement on their educational assessments. From 1999 to 2003, the students' mean percent correct on their ASIEP-2 Educational Assessment increased from 48% to 79% and on their Basic Skills Academic assessment from 0% to 25%.

Social Interaction Assessment. To assess the students' spontaneous social interactions, the ASIEP-2 Interaction Assessment subtest was administered. During this assessment, the student was observed for a 12 minute period. Results show that appropriate social interactions with the adult present and constructive independent play by the child during the assessment increased from 51% of the observation time in 1999 to 81% of the observation time in 2003. After 52 months in the study, they engaged in significantly ($p \leq .01$) more social interactions with the adult present and more constructive independent play.

Cognitive Assessment. A Battelle Developmental Inventory: Cognitive Domain Screening test (Newborg, et al., 1984) was annually administered to the students. This standardized assessment was used to measure each participant's skills and abilities that were conceptual in nature. Paired t-tests showed that the mean age equivalent scores significantly ($p \leq .01$) increased from 27.43 months in winter 2000 to 43.92 months in spring 2003.

Assessments Completed by Teachers of Cohort #1

ASIEP-2 Autism Behavior Checklist. Each year, teachers completed an ASIEP-2 Autism Behavior Checklist, which provides a general picture of how an individual "looks" in comparison to others. There was a significant ($p \leq .05$) decrease found between the winter 1999 mean score and the spring 2002 mean score. Students were displaying significantly fewer behavior/attributes associated with autism spectrum disorder. In the last twelve months of the study, teachers did not report significant decreases in the behaviors/attributes displayed by their students. One possible explanation is that as the children aged, they could have been displaying behaviors that resulted in higher scores on the checklist.

Vineland Adaptive Behavior Scales. Teachers completed Vineland Adaptive Behavior Scales assessments each school year. This standardized test was used to provide a general assessment of the participants' adaptive behaviors. When examining a subgroup of 38 students, their mean age equivalent adaptive behavior scores significantly ($p \leq .01$) increased from 21.84 months in winter 2000 to 27.08 months in winter 2003.

Information Collected from Parents of Cohort #1

Parent Survey Results. At the end of each school year, parents were sent surveys to gather information about their children's progress in the areas of communication, social interaction, and behavior. In addition, parents had the opportunity to comment on their children's programs, report any special treatments they were using with their children, and describe any additional interventions they were paying for with their own family funds.

The majority of parents agreed that their children's skills and behaviors had increased each school year. Over the study period, parents agreed their children had the most significant improvements in: 1) using language or other means to communicate, 2) using spontaneous communication to request foods, toys, or activities, and 3) understanding and responding to directions.

The majority of parents were satisfied with their own involvement levels in their children's programs. Additionally, they were satisfied with the amount and quality of services their children received. At least 58% of the parents were satisfied with the amount of services their children received each year (range 58% to 71%), and at least 71% of the parents were satisfied with the quality of services their children received (range 71% to 84%).

When asked to specifically comment on what they liked about their children's services, they reported they were pleased with their children's service providers. They thought the teachers, paraprofessionals, and related service staff were "good," "caring," "patient," "knowledgeable," and "wonderful." The parents were also asked how they thought their children's services could be improved. Common responses included, "summer services," "more training for staff," "more funding," "more speech therapy," and "better communication."

Parents additionally reported interventions they were providing to their children that were not part of their school program. Common treatments listed by parents included gluten-free/casein free diets, vitamins, secretin, and supplements.

Summary of Outcome Results for Cohort #2

Assessments Administered by Assessment Team to Cohort #2

Numerous standardized assessments were administered to the students in Cohort #2. In general, students in Cohort #2 made progress in all areas assessed during their 18 months of participation in the study.

Expressive Language Assessment. To measure the expressive language age of the students, they were administered the ASIEP-2 Sample of Vocal Behavior subtest (Krug, et al., 1993) and the Expressive One-Word Picture Vocabulary test (Brownell, 2000). The average language age gain was 13 months in the 18 months the students in Cohort #2 were involved in the study. Seventy-nine percent of the students made gains in their expressive language abilities, and 40% of those students gained 18 or more months of expressive language age in their 18 months of participating in the study. In addition, 33% of the students, in spring 2003, had an expressive language age that was within 12 months of their chronological age.

Educational Assessments. The educational assessments administered to the students included, 1) the ASIEP-2 Educational Assessment subtest (Krug, et al.), which assesses receptive language, expressive language, body concept, and speech imitation, and 2) portions of the Extended Basic Academic Skills Assessment System (Tindal, et al., 2000), which measures academic skills. The students made significant ($p \leq .01$) improvement on their educational

assessments. From fall 2001 to spring 2003, the students' mean percent correct on their ASIEP-2 Educational Assessment increased from 35% to 65%, and their mean percent correct on their Basic Skills Academic Assessment increased from 0% to 4%.

Social Interaction Assessment. To assess the students' spontaneous social interactions, the ASIEP-2 Interaction Assessment was administered. During this assessment, the student was observed for a 12 minute period. Results show that appropriate social interactions with the adult present and constructive independent play by the child during the assessment increased from 52% of the assessment observation in 2001 to 81% of the observation time in 2003. After 18 months in the study, they engaged in significantly ($p \leq .01$) more social interactions with the adult present and more constructive independent play.

Cognitive Assessment. A Battelle Developmental Inventory: Cognitive Domain Screening test (Newborg, et al, 1984) was annually administered to the students. This standardized assessment was used to measure each participant's skills and abilities that were conceptual in nature. The mean age equivalent scores significantly ($p \leq .01$) increased from 21 months in winter 2000 to 31 months in spring 2003.

Assessments/Surveys Completed by Teachers of Cohort #2

ASIEP-2 Autism Behavior Checklist. Each year, teachers completed an ASIEP-2 Autism Behavior Checklist, which provides a general picture of how an individual "looks" in comparison with others. There was a significant ($p \leq .05$) decrease found between the fall 2001 mean score and the spring 2003 mean score. Students were displaying significantly fewer behavior/attributes associated with autism spectrum disorder.

Vineland Adaptive Behavior Scales. Teachers were asked to complete Vineland Adaptive Behavior Scales assessments each school year. This standardized assessment was used to provide a general assessment of the participants' adaptive behaviors. A paired t-test was used to examine the means of the students' scores. The students' mean age equivalent adaptive behavior score significantly ($p \leq .01$) increased from 16 months in winter 2001 to 23 months in winter 2003.

Teacher Survey Results. Teachers of Cohort #2 were sent surveys asking them to report on the skills and abilities of their students. Areas examined included receptive language, expressive language, routines, and pre-academic skills. These items were taken from the STAR Program (Arick, Loos, Falco, & Krug, 2004) curriculum and closely matched skills being taught. Teachers reported that students were more often verbalizing their wants and needs, responding to verbal cues, and independently participating in routines. Additionally the students' pre-academic skills (e.g., matching, rote counting, scissor use) substantially increased from fall 2001 to spring 2003.

Information Collected from Parents of Students in Cohort #2

Parent Survey Results. At the end of each school year, parents were sent surveys

to gather information about their children's progress in the areas of communication, social interaction, and behavior. In addition, parents had the opportunity to comment on their satisfaction with their children's programs, identify any special treatments they were using with their children, and describe any additional interventions they were paying for with their own family funds.

The majority of parents agreed that their children's skills and behaviors had increased each school year. Over the study period, the areas that parents agreed had the most significant improvement included: 1) using language or other means to communicate, 2) using spontaneous communication to request foods, toys, or activities, and 3) understanding and responding to directions.

The majority of parents were satisfied with their own involvement levels in their children's programs. Additionally, they were satisfied with the amount and quality of services their children received. Seventy-eight percent of the parents in the 2001/2002 school year and 55% of the parents in the 2002/2003 school year agreed or strongly agreed that they were satisfied with the amount of services their children received each year. Eighty-five percent of the parents in the 2001/2002 school year and 78% of the parents in the 2002/2003 school year agreed or strongly agreed that they were satisfied with the quality of services their children received.

When asked to specifically comment on what they liked about their children's services, they reported they were pleased with their children's service providers. They thought the teachers, paraprofessionals, and related service staff were "very caring," "loved their children," provided "individualized and personalized programs," and were "knowledgeable and dedicated."

The parents were also asked how they thought their children's services could be improved. Common responses included, "more hours in the classroom," "year round program," "more one-to-one," "more teacher training," and "more parent training."

Parents additionally reported interventions they were providing to their children that were not part of their school program. Common treatments listed by parents included gluten-free/casein free diets, vitamins, and supplements.

Summary of Training and On-Site Consulting Provided by the Project

Behavioral Instructional Strategy Workshops. In an effort to strive for fidelity of implementation, training workshops in behavioral instructional strategies for teaching children with autism spectrum disorder were conducted each school year. Topics covered included pivotal response training, discrete trial training, functional routines, and data collection strategies.

The workshops were attended by teachers, instructional assistants, administrators, related service providers, and parents. Hundreds of participants from around the state attended these workshops each year.

In the last two years of the study, participants were asked to complete evaluation forms at the end of each workshop. Ninety-nine percent of the participants who completed evaluations agreed that

the workshops had increased their knowledge on instructional strategies to use when teaching children with autism. When asked how they would rate the workshops using a scale of 1 = poor, 2 = fair, 3 = good, 4 = excellent, and 5 = outstanding, the participants rated the workshops between excellent and outstanding (4.4 mean in 2002 and 4.02 mean in 2003).

Observation Data Provided by Consultants. Special education professionals with expertise in behavioral instructional strategies and extensive knowledge in designing and implementing programs for children with autism spectrum disorders, visited each classroom or home site to observe and give individual consulting advice to teachers of students in the study. While in the classroom, the consultants observed the student and their program, and then completed a form rating the appropriateness of six areas: placement, written programs, one-to-one instruction, group instruction, social interaction, and communication instruction. The classroom observation form was given to the teacher after the visit.

There were correlations found when comparing data gathered during the observations with data collected from student assessments. For example, when examining the area of communication for Cohort #1, there was a significant relationship found between the 16 month language age gain for the students and the classroom communication instruction rating given by consultants $r(48) = .424 p \leq .05$.

Conclusion and Recommendations

The PSU Research Team recommends the following to appropriately provide services to Oregon children with autism:

- Children with autism should be enrolled in an early intervention program as soon as they are diagnosed
- Instruction for children with autism should include applied behavioral analysis techniques
- Students with autism should receive appropriate amounts of pull-out one-to-one discrete trial teaching, pivotal response training, and functional routines teaching per week
- Classrooms should maintain low student-teacher ratios
- Students' progress should be measured and assessed to provide independent feedback to the teacher
- Parents should be actively included in their children's education
- Service providers and parents should receive on-going training in research-based applied behavioral analysis techniques to use for effectively teaching children with autism
- Classrooms should be provided with research-based curriculum specifically designed for teaching children with autism
- Regional Autism Training Sites should continue to be developed and implemented around the State of Oregon
- A dissemination/development center should be developed in the State of Oregon to provide research-based literature on best practice, disseminate project information, coordinate training for service providers, and evaluate the Regional Autism Training Sites being implemented in the state

Following is a more thorough description of the P.S.U. Research Team's recommendations:

Services to Children

Experts in the field autism recommend that as soon as a child is diagnosed with autism, he or she should immediately be enrolled in an early intervention program (Green, Brennan & Fein, 2002; Hurth, Shaw, Izeman, Whaley & Rogers, 1999; Maurice, Harris & Handleman, 2002; National Research Council, 2001). **The P.S.U. research team and results from this study support the**

recommendation that a child with autism should be enrolled in an early intervention program as soon as he or she is diagnosed.

Table I shows a comparison of the two cohorts of students during their first 16 to 18 months of participating in the study. A majority of students in both cohorts (over 80%) received approximately 6 hours of pull-out one-to-one instruction per week during their first 17 (average) months participating in the study. Even though they received similar hours of one-to-one instruction, they made different progress during their first 17 months (average) of participation in the study.

Cohort #1 was approximately 12 months older and had higher Battelle cognitive age equivalent scores, but Cohort #2 made greater gains in the areas assessed during approximately the same amount of time participating in the study. The younger baseline mean age of the children in Cohort #2 could account for at least part of their greater gains.

Table I		
	Cohort #1 (Began participating in 1998/1999)	Cohort #2 (Began participating in 2001)
Average Chronological Age at Baseline	51 months	39 months
Battelle Developmental Inventory Assessment (Cognitive Domain)	28 months (collected during 1999/ 2000 school year)	21 months (collected during 2001/2002 school year)
Gains in assessment scores during their first 17 (average) months in the study		
Assessment Area	Average gain scores for Cohort #1 (approximately 16 months)	Average gain scores for Cohort #2 (approximately 18 months)
Expressive Language Age (as measured by ASIEP-2 and Expressive One-Word)	10 months	13 months
Educational Assessment (as measured by ASIEP-2)	20% increase in number correct	30% increase in number correct
Social Interaction Assessment (as measured by ASIEP-2)	18% increase in appropriate social interactions with adults and constructive independent play	30% increase in appropriate social interactions with adults and constructive independent play

Most of the students in both cohorts received pull-out one-to-one instruction during their participation in the study. The majority of the pull-out one-to-one instruction consisted of discrete trial teaching and pivotal response training. Research has shown that these strategies, based on a behavioral model, have the broadest empirical validation for effectiveness to help children with autism learn (Schreibman, 2000; Smith, 2001). **The Portland State University (P.S.U.) research team and the results of this study, support the claims that applied**

behavioral analysis techniques are effective for teaching children with autism. Service providers in Oregon should continue to teach children with autism using applied behavioral analysis instructional techniques.

Additionally, experts in the field of autism recommend that children with autism should be enrolled in programs that: 1) include low student/teacher ratios of no more than two young children per adult (Hurth, et al., 1999; National Research Council, 2001), 2) include repeated, planned teaching opportunities generally organized around relatively brief periods of time (National Research Council, 2001), and 3) provide on-going program evaluation and assessments of individual children's progress, and adjustments made if necessary (National Research Council, 2001).

The P.S.U. research team recommends: 1) that classrooms maintain low student teacher ratios, 2) the students with autism receive *appropriate amounts (see the following examples) of discrete trial teaching, pivotal response training, and functional routines teaching per week, and 3) the students' progress be measured and assessed to provide independent feedback to the teacher.

*Examples of appropriate hours: Discrete Trial (DT) and Pivotal Response Training (PRT) sessions should be carried out during one-to-one teaching rotations. The number of DT and PRT rotations may vary, based on each child's individual needs. Factors such as the child's age, functioning levels, and behavior can influence the amount of 1:1 instruction appropriate for each child. The work by PSU researchers suggests that one-to-one instruction should occur four to five days per week. The length of each DT rotation varies between 5 and 30 minutes, depending on the child. It is best to carry out at least two discrete trial rotations per day and at least one pivotal response session per day. Many children will receive more discrete trial or pivotal response training sessions than this, but it is the experience of the research team, that this minimum amount of 1:1 instruction is needed for ensuring continued student progress. In addition to the time spent in 1:1 programs, students should be instructed in functional routines throughout their school day. Instruction in functional routines can occur during a pre-school time for young children and during classroom instruction for a school age student. Routines include activities such as transitions, restroom use, snack, lunch, circle, independent seatwork, group instruction, and recess.

Family Involvement

The Autism Spectrum Disorders Outcome Study and Training Project had no difficulty in obtaining participants. Families were eager to allow their children to participate in this project. During the study period, they provided valuable information about the progress of their children. Many commented in writing and verbally how much they appreciated the opportunity to provide feedback.

Researchers agree that family involvement is a key component in effectively educating children with autism (e.g., Division TEACCH, 2003; Hurth, et al., 1999, National Research Council, 2001). Not only do many researchers agree it is important, the federal government also believes

parent involvement is necessary, as reflected in the Individuals with Disabilities Education Act (IDEA) (1997), which mandates a partnership between school districts and the parents of students with autism (Newcomer & Zirkel, 1999). Additionally, the Autism Spectrum Disorder Task Force recommended that opportunities should be enhanced for parents to design and implement services for individuals with autism (ODE, 2000).

The PSU researchers also highly recommend that parents be actively included in their children's education. The results of this study show that parents have valuable information to provide about their children, and they want to be involved in their children's education.

Training of Service Providers and Parents

Training workshops in research-based instructional strategies were conducted each school year. The workshops were attended by teachers, instructional assistants, administrators, related service providers, and parents. Hundreds of participants from around the state attended these workshops each year and found them to be valuable. Written evaluations showed that 99% percent of the participants who completed evaluations agreed that the workshops had increased their knowledge on instructional strategies to use when teaching children with autism.

The PSU research team recommends that service providers and parents continue to receive on-going training in research-based applied behavioral analysis techniques to use for effectively teaching children with autism. This recommendation was also supported by the Autism Spectrum Disorder Task Force (O.D.E, 2000). This training could be provided by outside consultants and autism specialists in each regional program areas.

Curriculum

In addition to training, curriculum designed using strategies supported by research for teaching children with autism was distributed to participants at workshops conducted during the five-year study period. Participants appreciated receiving the curriculum that they could implement in their classrooms. One participant stated that she “almost started crying when she saw the curriculum,” because she knew she would “finally know what to do when she got back into her classroom.” She thought that just learning about the techniques was not enough, but instead it was mandatory that teachers have curriculum and training. **The PSU research team recommends that classrooms are provided with research-based curriculum designed specifically for teaching children with autism.**

The children in Cohort #2 made greater gains than Cohort #1 in all areas assessed during approximately the same amount of time (their first 17 months) participating in the study (see Table I). In the last two years of the study, the service providers received research-based curriculum and were given training in how to use the curriculum. This could account for at least part of their greater gains.

Regional Autism Training Sites

Regional Autism Training Sites are currently being implemented. These sites which were recommended by The Autism Spectrum Disorder Task Force (ODE, 2000, pg. 2) to “...provide intensive training and model educational sites” are currently being implemented across the state. **The P.S.U. research team has seen first hand how these sites have improved services for children in Oregon and highly recommends the continued development and implementation of Regional Autism Training Sites continue in the future.**

Dissemination Center

The Autism Spectrum Disorder Task Force recommended that the state implement an Oregon Autism Spectrum Development Center “...to conduct and review research, disseminate information, and evaluate and develop programs for improved effectiveness” (ODE, 2000, pg. 2). **The PSU research team strongly agrees that a dissemination/development center be implemented. It is imperative that a center be developed in the State of Oregon to provide research-based literature on best practice, disseminate project information, coordinate training for service providers, and evaluate the Regional Autism Training Sites being implemented in the state.**

Introduction

No area of early intervention and early childhood special education (EI/ECSE) has sparked as much controversy in recent years, as the provision of services for young children with autism spectrum disorder. Service providers and parents are often confused about the effectiveness of various intervention practices (Hurth, et al., 1999). This confusion has led to an increase in complaints, due process hearings, and legal proceedings that sometimes result in highly stressful relations between service providers and parents.

While families, their advocates, and professionals have engaged in extensive debates over the last decade about the efficacy of various treatments and educational strategies, documentation has emerged indicating that intensive early intervention can have significant, positive outcomes for young children with autism spectrum disorder. These positive effects include acceleration of their own development rates, significant language gains, improved social behavior, and a decrease in the symptoms of autism (Rogers, 1996).

Even though there is some disagreement on the best teaching methods, there has been some agreement among nationally known and validated educational programs for young children with autism spectrum disorder. They agree that in addition to early intervention, services should include specialized curriculum, individualization, intensity of engagement, systematic instruction, and family involvement (Hurth et al., 1999). Furthermore, it is now widely accepted that programs based on a behavioral model have shown to have the broadest empirical validation for effectively teaching children with autism spectrum disorder (Schreibman, 2000).

Many special education service providers are responding to the challenge of providing the best services possible to young children with autism spectrum disorders. They are initiating programs of more intensive services with varied approaches that have demonstrated promising outcomes for young children with autism spectrum disorder. In order to develop and sustain these programs, service providers will need to demonstrate positive outcomes for children with autism spectrum disorder. Even for those school and home programs where parents and service providers have been satisfied, it is important to document results to determine the factors that have contributed to their success.

In 1998, the Oregon Department of Education, realizing the importance of documenting outcome results, contracted with Portland State University to design a study to collect outcome data for young students with autism spectrum disorder in Oregon. The Autism Spectrum Disorder Outcome Study and Training Project was developed at that time.

Purpose of the Study

During the initial planning phase of the project, the research team determined the purpose of collecting the student outcome data would be to provide the following:

- Objective individual student outcome data for participating programs and parents
- Information to assist service providers in planning student programs
- A description of the various instructional strategies being used by programs serving students with autism spectrum disorder
- A comparison of outcome data results between various school and home-based programs
- Information on the effectiveness of specific instructional strategies on student outcomes
- A framework for a statewide database of student characteristics, student assessment data, and program implementation strategies, that would allow for longitudinal tracking of students and program performance

Methods

Participants

The five-year study began in October 1998 and ended in August 2003. One-hundred twenty-three students participated in the study. Sixty-seven students began the study in 1998 and an additional 56 students joined the study in 2001. In this report, the children who began the study in 1998 are referred to as Cohort #1 and the children who joined the study in 2001 are referred to as Cohort #2. During the five year study period, some children moved out of Oregon and no longer participated in the study. When the project ended in August 2003, 109 students were still participating in the study.

Sixty-seven preschool students, between the ages of 2-6, whose primary diagnosis for services was autism spectrum disorder, began participating in this study in the fall of 1998. These 67 students in Cohort #1 represented approximately 10% of all the children ages 2-6 in Oregon whose primary diagnosis for services was autism. The majority of the students in the first cohort were 3 and 4 years of age at the beginning of the study.

In the fall of 2001, 56 additional students between 2-4 years old were added to the study. This new group of student in Cohort #2 represented approximately 16% of all the 2-4 year olds in Oregon whose primary diagnosis for services was autism.

Table 1 - Ages of Students in the Study Compared to All Oregon Students

Age Group (2-6)	Cohort #1 - Began study in 1998 Number of students in each age group	1998 Oregon Census of children whose primary disabling condition was autism	Age Group (2-4)	Cohort #2 (Began the study in 2001) Number of students in each age group	2001 Oregon Census of children whose primary disabling condition was autism
2	9	18	2	12	34
3	23	86	3	37	130
4	22	126	4	7	192
5	10	196			
6	3	217			
Total	67 Total students beginning study in 1998	643 Total students ages 2 -6 in 1998 Oregon Census	Total	56 Total students beginning study in 2001	356 Total students ages 2-4 in 2001 Oregon Census

Instruments

In order to monitor the educational progress of the students, numerous standardized tests were administered by the assessment team. In addition, information was collected from their teachers, specialists, parents, and consultants. The following table lists the instruments used to collect information regarding the students' progress and the frequency of administration of each instrument.

Table 2 - Study Assessments and Program Measures

Instrument	Frequency of Administration (X = assessment administered to Cohort #1) (O = assessment administered to Cohort #2)			
	Baseline (beginning of study)	Quarterly (three times during the school year)	Bi-Annual (twice a year)	Annually (once a year)
ASIEP-2 Subtests:				
Autism Behavior Checklist	X O		O	X
Social Interaction Assessment	X O	X	O	
Sample of Vocal Behavior	X O	X	O	
Educational Assessment	X O	X	O	
Expressive One Word Picture Vocabulary Test	O	X	O	
Extended Basic Academic Skills System	O	X	O	
Battelle Developmental Inventory (cognitive domain)	X O			X O
Vineland Adaptive Behavior Scales (survey form)	O			X O
Student Learning Profile (curriculum based assessment)	X O			X O
Program Implementation Checklist (hours & types of services provided)	X O		XO	
Program Observation Data	X			X O
Parent Survey				X O

Procedures

Standardized Assessments Completed by the Assessment Team

The assessment visits were completed by special education professionals who were well-trained in administering standardized assessments. The assessments included: 1) the ASIEP-2 Sample of Vocal Behavior, Educational Assessment, and Interaction Assessment subtests (Krug, et al., 1993), 2) the Battelle Developmental Inventory: Cognitive Domain Screening test (Newborg, Stock, J., Wnek, L., Guidubaldi, & Svinicki, 1984), 3) the Expressive One Word Picture Vocabulary test (Brownell, 2000), and 4) portions of the State of Oregon Basic Academic Skills Assessment System (Tindal, et al., 2000).

Information Collected from Teachers

Each school year, every teacher was asked to complete a program implementation checklist describing the total hours per week that each participant received services, how the services were provided (e.g., group, pull out, one-to-one), the type of one-to-one, pull-out teaching the students were receiving (e.g., pivotal response training, discrete trial), and who provided the services (e.g., teacher, educational assistant, related services staff). At the end of the school year, the information was again reviewed and verified with the teacher by a consultant during a classroom observation visit.

Additionally, each year an ASIEP-2 (Krug et al., 1993) Autism Behavior Checklist, a Vineland Adaptive Behavior Scales: Interview Edition (Sparrow S., Ball, D., & Cicchetti, D., 1984), and a survey were completed by the teacher.

Information Collected From Parents

At the end of each school year, parents were sent surveys that gave them an opportunity to provide input on their child's communication skills, social interaction skills, and behavior. In addition, they could rate and comment on their child's program, report any special therapies they were using with their child, and describe any additional services they were paying for with their own family funds.

Observation Data Provided by Consultants

Special education professionals with expertise in behavioral instructional strategies and extensive knowledge in designing and implementing programs for children with autism spectrum disorders, visited each classroom or home site to observe and give individual consulting advice to teachers of students in the study. The classroom observation form was completed during the visit and then a comment sheet was given to the teacher.

Data Analysis

Data collected from the standardized assessments, the teachers, and the parents were entered into the SPSS computer software data file (SPSS, Inc., 1999). The results were analyzed and are reported in tables, graphs, and charts in this report.

Behavioral Instructional Strategies Training

In an effort to strive for fidelity of implementation, training workshops in behavioral instructional strategies for teaching children with autism spectrum disorder were conducted each school year. These workshops were conducted by special educational professionals with extensive experience in teaching instructional behavioral techniques used for instructing children with autism spectrum disorder. Topics covered included pivotal response training, discrete trial, and functional routines. Instruction in data collection strategies were also included in the training workshops.

The workshops were attended by teachers, instructional assistants, administrators, related service providers, and parents. Hundreds of participants from around the state attended these workshops each year.

In the last two years of the study, participants were asked to complete evaluation forms at the end of each workshop. Table 3 shows that 99% of the participants who completed evaluations agreed that the workshops had increased their knowledge on instructional strategies to use when teaching children with autism. When asked how they would rate the workshops using a scale of 1 = poor, 2 = fair, 3 = good, 4 = excellent, and 5 = outstanding, the participants rated the workshops between excellent and outstanding (4.4 mean in 2002 and 4.02 mean in 2003).

Table 3 – Participant Ratings of Behavioral Instructional Strategies Workshops		
Question Asked	2001/2002 School year	2002/2003 School Year
Did the information presented in this workshop increase your knowledge of the topic presented?	Yes 99%	Yes 99%
How would you rate this workshop? 1 = poor, 2 = fair, 3 = good, 4 = excellent, 5 = outstanding	Mean 4.40	Mean 4.02

Description of Instructional Strategies

The behavioral teaching strategies taught by the project included discrete trial training, pivotal response training and teaching functional routines. These strategies have been identified by the literature to be effective in teaching with children with autism (National Research Council, 2001; Green, 2001; Koegel, 1999; Lovaas, 1981; Lovaas, 1987; Arick, Young, Falco, Loos, Krug, Gense, & Johnson, 2002; Krug, Rosenblum, Almond & Arick, 1981; Marcus, Schopler & Lord, 2000). Following is a description of each of these instructional strategies:

Discrete Trial Training (DT): Discrete trial training is used to teach receptive language concepts, pre-academic concepts, and some mid and advanced level expressive language concepts. Skills are taught in a logical sequence building on previously learned skills. Concepts to be taught are identified and then broken down into specific program elements for instruction. Each instructional session consists of a series of discrete trials. A discrete trial consists of a four-step sequence: 1) instructional cue, 2) child response, 3) consequence (generally a positive reinforcer), and 4) pause. Data is collected to monitor the child's progress and to help determine when a pre-set criteria has been reached.

Pivotal Response Training (PRT): Pivotal response training is primarily used to teach and generalize expressive language, play, and socialization skills. PRT is also based on the 4 step sequence: cue, child response, consequence, and pause. However, "trials" within PRT are incorporated into the environment in a functional context. During PRT, the child chooses the activity or object, and the reinforcer is a natural consequence to the behavior being rewarded. The nature of this strategy makes it possible to engage the child throughout all activities and locations throughout the day.

Teaching Functional Routines (FR): Functional routines are predictable events that involve a chain of behaviors. Routines are generally associated with a functional outcome for the child. Some common examples that all children engage in include: restroom, arrival, and snack routines. The functional outcome of a routine usually serves as the reinforcer for typically developing children. Training in FR gives the teacher skills to systematically teach children to independently participate in most common school and self-care routines.

**COHORT #1
STUDENTS WHO
BEGAN
PARTICIPATING
IN THE
STUDY IN 1998**

Demographics of Cohort #1

Table 4 shows that Cohort #1 consisted of 67 students who began participating in the study in 1998. The children were located in seven geographic areas of the state in approximate proportion to the population. Eastern Oregon Regional Program did not nominate students for Cohort #1.

Table 4
Students Participating from each Regional Program
(Baseline Data) - Cohort #1 - Began study in 1998

Regional Program	Cohort #1
	Number of Students
Region I - Eastern Oregon Regional Program	0
Region II – High Desert Regional Program	5
Region III - Southern Oregon Regional Program	10
Region IV - Cascade Regional Program	8
Region V - Mid-Oregon Regional Program	7
Region VI - Columbia Regional Program	10
Region VII - Lane Regional Program	7
Region VIII - Northwest Regional Program	20
Students Participating in Each Cohort	67

Table 5 shows additional demographic information for each student in the study. Seventy-three percent of the participants in Cohort #1 were male and 27% were female. At baseline, their average age was 51 months. Teachers reported that the students received approximately 18.5 hours (range 6 – 40 hours) of services per week, and that 34% of the students were non-verbal.

Table 5
Baseline Information Reported By Teachers

	Cohort #1
Gender	73% Male 27% Female
Average Age	51 months
Average total hours per week of instruction at home and school as reported by teachers	18.5 hours
Range of Instructional hours per week (home and school) as reported by teachers	6 - 40 hours
Percent of students listed as non-verbal by teachers (uses no words to communicate)	34%

Services Received by Cohort #1 Students

Cohort #1 - Services Reported by Teachers

Each school year, teachers reported the number of hours and the types of services their students received in their programs. Tables 6 through 8 display the information reported by the students' service providers for the children in Cohort #1.

Table 6 shows that on average, the total number of hours of instruction per week increased as they got older and moved to elementary school settings. At baseline (1998/99) the teachers reported the students were receiving approximately 18.5 hours of services per week. By the second year (1999/2000) of the study that number had increased to 20 hours per week and in the final year of the study (2002/2003), the students' average number of hours of services was 30 hours a week.

Table 6 – Cohort #1
Services Provided to all Students During the Regular School Year

Number of Hours	1999/2000 School Year (N=67)		2000/2001 School Year (N=65)		2001/2002 School Year (N=62)		2002/2003 School Year (N = 54)	
	Average (hours)	Range of hours	Average (hours)	Range of hours	Average (hours)	Range of hours	Average (hours)	Range of hours
Average number of hours of all services students received per week	20	9.5 to 40	22	7 to 35	29.5	12 to 39	30.3	10.5 to 45
Average number of hours of services received of one-to-one pull-out instruction with teacher or assistant	6	0 to 33	7.5	0 to 30	7.7	0 to 31	5.9	0 to 45
Average number of hours of services received in a large group (4 or more children to 1 adult)	5.6	0 to 17	5.9	0 to 30	7.7	0 to 35	8.9	0 to 32
Average number of hours of services received in a small group (2-3 children to 1 adult)	4.1	0 to 21.3	3.6	0 to 24	4.6	0 to 32	11.2	0 to 29.6
Average number of hours of services received in a one-to-one instruction in a group	3.9	0 to 25	4	0 to 22	8.6	0 to 35	3.2	0 to 32.8
Average number of hours of services received in pullout with a related services provider	.6	0 to 5	1	0 to 5	1	0 to 5.5	1	0 to 3

Table 7 shows where the students' received their services. Approximately 70% of the children spent at least part of their day in a self-contained classroom each year. In the final year of the study, 48% of the students also spent at least part of their day in a typical elementary school classroom. Twenty-six percent of those students spent all day in a typical classroom. The majority had some paraprofessional assistance, but 23% of the students who spent time in a typical classroom had no paraprofessional help while they were in the typical classroom.

Table 7 – Cohort #1
Settings Where Services Were Received During Regular School Year
(Some students may receive services in more than one setting during a school day)

Setting	Percent of Students Receiving Service in this Setting			
	1999/2000 School Year	2000/2001 School Year	2001/2002 School Year	2002/2003 School Year
	Percent served in this setting:	Percent served in this setting:	Percent served in this setting:	Percent served in this setting:
Self-contained classroom	73%	69%	68%	70%
Elementary school classroom	28%	53%	61%	48%
Special classroom integrated w/typical peers	24%	9%	3%	0%
Home	18%	5%	5%	6%
Community preschool	12%	5%	3%	0%
Other setting	3%	13%	7%	0%

Table 8 shows that the majority of the students received pull-out one-to-one instruction. As the children got older and transitioned to elementary school, the number of children receiving pull-out one-to one instruction decreased from 84% to 52%. However, the amount of hours for the children who did receive one-to-one instruction increased from 7.1 to 12.4 hours.

In the 1999/2000 school year, the one-to-one pull-out strategy that was used most often was discrete trial training (3.93 mean hours). In the 2002/2003 school year, discrete trial training decreased to 2.6 hours, and the majority of one-to-one instruction (6 mean hours) focused on academics.

Table 8 Students who Received One-to-One Instruction During Regular School Year Students from Cohort #1								
	1999/2000 School Year		2000/2001 School Year		2001/2002 School Year		2002/2003 School Year	
Percent of all students in Cohort #1 receiving pull-out one-to-one instruction	84%		81%		63%		52%	
	Average	Range	Average	Range	Average	Range	Average	Range
Average number of hours per week of one-to-one instruction received by the students who were given one-to-one instruction	7.1 hours	1 to 33 hours	9.1 hours	1 to 30 hours	11.9 hours	1 to 31 hours	12.4 hours	.33 to 45 hours
Type of pull-out one-to-one teaching received per week:	Average	Range	Average	Range	Average	Range	Average	Range
Discrete Trial	3.93 hours	1 to 32 hours	2.5 hours	0 to 21 hours	3.5 hours	0 to 13 hours	2.6 hours	0 to 10.4 hours
Pivotal Response	1.71 hours	1 to 7.5 hours	1.18 hours	0 to 9 hours	1.9 hours	0 to 7.5 hours	1.14 hours	0 to 7.5 hours
Other Strategies (functional routines, incidental teaching, structured teaching, floor time, sensory integration, academics, and/or pecs)	1.58 hours	1 to 15 hours	3.81 hours	0 to 13 hours	6.46 hours	1 to 25 hours	8.66 hours (6 hours academics)	0 to 28.9 hours

Results for Cohort #1

Summary of Student Assessment Results

Students in Cohort #1 began the study in the fall of 1998. For the majority of the children, the first standardized tests were administered by the P.S.U. assessment team beginning in January of 1999.

In general, during the study, the students made progress in all areas assessed. Ninety-one percent of the students made gains in their expressive language abilities, and 21% of those students gained 52 or more months of expressive language age in the first 52 months of the study. In addition, the students made significant ($p \leq .05$) gains on the educational assessment, social interaction assessment, and on the Battelle Developmental Inventory Cognitive Assessment. For a more thorough description of the assessment results, refer to Tables 9 - 13

Vocal Behavior/Language Assessment

Expressive Language Age

To measure the expressive language age of students in the study, the children were administered the ASIEP-2 Sample of Vocal Behavior subtest and the Expressive One-Word Picture Vocabulary test. Table 9 shows the average language age gain for all students was 33 months from winter 1999 to spring 2003. Ninety-one percent of the students made some language gain. Approximately 21% of the students gained 52 or more months in the first 52 months. In addition, 17% of the students, in spring 2003, had an expressive language age that was within 12 months of their chronological age.

Winter 1999	Spring 1999	Spring 2000	Spring 2001	Spring 2002	Spring 2003	Signf Diff at Prob. $p \leq .01^{**}$ (N=47)
Baseline 0 months (N=60)	Approx. 4 months from baseline (N=59)	Approx. 16 months from baseline (N=64)	Approx. 28 months from baseline (N=60)	Approx. 40 months from baseline (N=61)	Approx. 52 months from baseline (N=54)	
23 months	27 months	33 months	43 months	47 months	56 months	Yes**

Educational Assessment

Students were given the ASIEP-2 Educational Assessment subtest (assesses receptive and expressive language, body concept, speech imitation), and portions of the Basic Academic Skills Assessment System (assesses academic skills). Table 10 shows that the students made significant ($p \leq .01$) improvement on these educational assessments when comparing their winter 1999 scores and their spring 2003 scores. From 1999 to 2003, the students' mean percent correct increased: 1) on the ASIEP-2 Educational Assessment from 48% to 79%, 2) on the Basic Skills Academic Assessment from 0% to 25%, and 3) on the composite (combination of both assessments) from 10% to 36%.

Table 10 - Cohort #1							
Educational Assessment - mean percent of correct answers							
	Winter 1999	Spring 1999	Spring 2000	Spring 2001	Spring 2002	Spring 2003	Signf Diff at Prob. $p \leq .01^{**}$ (N=48)
Assessment	Baseline 0 months (N=61)	Approx. 4 months from baseline (N=61)	Approx. 16 months from baseline (N=65)	Approx. 28 months from baseline (N=63)	Approx. 40 months from baseline (N=62)	Approx. 52 months from baseline (N=54)	
ASIEP-2 Educational Assessment	29/60 48%	32/60 53%	41/60 68%	44/60 73%	45/60 75%	47/60 79%	Yes**
Basic Skills Academic Assessment	0/234 0%	0/234 0%	6/234 3%	22/234 9%	35/234 15%	59/234 25%	Yes**
Educational Composite (ASIEP-2 Educational Assessment & Precademic Assessment)	29/294 10%	32/294 11%	47/294 16%	66/294 22%	80/294 27%	106/294 36%	Yes**

Social Interaction Assessment

On each assessment visit, students were given the ASIEP-2 Social Interaction Assessment subtest. Table 11 shows that there were statistically significant ($p \leq .01$) increases in appropriate social interactions found when comparing the assessments from winter 1999 and spring 2003. After 52 months, the students engaged in significantly, 1) more social interactions with the adult present, 2) more constructive independent play, 3) less self-stimulation/repetitive play behaviors, and 4) fewer aggressive negative reactions towards adult present. Results show that appropriate social interactions with the adult present and constructive independent play by the child during the assessment, increased from 52% of the observation time in 1999 to 81% of the observation time in 2003.

Table 11 - COHORT #1							
Appropriate & Inappropriate Social Interactions or Behaviors							
Area Assessed	Winter 1999	Spring 1999	Spring 2000	Fall 2001	Spring 2002	Spring 2003	Significant Difference
	Baseline 0 months (N=62)	Approx. 4 months from baseline (N=60)	Approx. 16 months from baseline (N=63)	Approx. 28 months from baseline (N=62)	Approx. 40 months from baseline (N=61)	Approx. 53 months from baseline (N=54)	Significant at Probability $p \leq .01^{**}$ (N=49)
Appropriate Social Interactions	13%	21%	19%	31%	31%	33%	Yes**
Appropriate Constructive Independent Play	39%	36%	41%	36%	47%	48%	Yes**
Self-Stimulation and Non-Responsive to Toys/Adult	46%	43%	37%	32%	22%	19%	Yes**
Aggressive Negative Towards Adult	2%	1%	3%	1%	0%	<1%	Yes**

Autism Behavior

ASIEP-2 Autism Behavior Checklist

Teachers were asked to complete an ASIEP-2 Autism Behavior Checklist for their students each school year. Table 12 shows that teachers reported the behaviors related to autism had decreased in their students during the first 40 months of the study period. When examining the total Autism Behavior Checklist score, there was a significant ($p \leq .05$) decrease found between the winter 1999 mean score and the spring 2002 mean score. Students were displaying significantly fewer behavior/attributes associated with autism spectrum disorder.

In the last twelve months of the study, teachers did not report significant decreases in the behaviors/attributes displayed by their students. One possible explanation for the variability in scores was that in 2003 all the children had transitioned to elementary school and they were in different classrooms each year (unlike in preschool where many of them had the same teachers for more than one year). Different people were completing the checklists. Additionally, as the students aged, he or she could be displaying different behaviors that resulted in higher scores on the checklist.

Areas Assessed	Winter 1999 Baseline 0 months (N=63)	Winter/Spring 2001 Approx. 24-28 months from baseline (N=60)	Spring 2002 Approx. 40 months from baseline (N=49)	Spring 2003 Approx. 52 months from baseline (N=45)	Significant Difference Significant at Probability $\leq .01^{**}$ $\leq .05^*$ (N=42)
Sensory	10.90	8.13	8.24	10.33	No
Relating	18.97	16.95	15.67	19.82	No
Body and Object Use	12.49	11.93	12.25	13.51	No
Language	14.08	12.22	11.50	14.84	No
Social and Self Help	15.37	14.25	11.88	14.02	No
Total (A score of 54 or higher is a typical score for a child with autism)	71.78	63.18	59.56	72.56	No

Vineland Adaptive Behavior Scales & Battelle Developmental Inventory Cognitive Screening Assessment

Age Equivalent Scores

The assessment team screened all students each school year using the Battelle Developmental Inventory Cognitive Assessment. In addition, teachers were asked to annually complete a Vineland Adaptive Behavior Scales (interview form) for each of their students. Table 13 shows the age equivalent scores for both these assessments significantly ($p \leq .01$) increased from 2000 to 2003.

The students' mean age equivalent score on the Battelle Developmental Inventory Cognitive Assessment increased from 27.89 months in winter 2000 to 43.93 months in winter 2003. In spring 2003, 38 teachers returned Vineland Adaptive Behavior Scales (interview form) assessments. When comparing this subgroup of students ($n = 38$), their mean age equivalent score increased from 21.84 in winter 2000 to 27.08 months in winter 2003.

Table 13 Battelle Assessment - Students in Cohort #1 Age Equivalent Scores										
Assessment	Winter 2000 Age Equiv. Score		Winter 2001 Age Equiv. Score		Winter 2002 Age Equiv. Score		Winter 2003 Age Equiv. Score		Paired t-tests Significant at Probability $\leq .01^{**}$	
	N	Mean	N	Mean	N	Mean	N	Mean	N	Sign. Dif.
Battelle Developmental Inventory (Cognitive Screening Assessment)	66	27.89	62	32.41	61	38.0	54	43.93	53	Yes**
Vineland Adaptive Behavior Scales (scores for assessments completed by teachers)	61	25.61	57	30.96	43	33.09	38	27.08	38	Yes**

Feedback from Parents of Cohort #1

At the end of each school year, parents were sent surveys to give them the opportunity to provide input on their children and their children's programs. For Cohort #1 (parents of students who began the study in 1998), over 50% returned their surveys at the end of each school year. Their responses can be found in Tables 14 to 32.

Changes in Skills and Behaviors

Each year parents were asked to advise us of changes in their children's skills and behaviors. Table 14 shows the percentage of parents who answered if their children's skills or behaviors decreased, stayed the same, or increased during the school year. In the majority of areas listed below, parents thought their children's skills or behaviors had increased in all three school years. The areas that parents consistently thought their children's skills or behaviors had increased the most each year were, 1) using language or other means to communicate, 2) using spontaneous communication to request foods, toys, or activities, and 3) understanding and responding to directions.

During the last year of the study, many parents additionally noticed that their children were increasing their imitation of other children and adults during play. Eighty-one percent of the parents noticed an increase in this behavior during the 2002/03 school year.

TABLE 14 (Parent Responses) Cohort #1 - Students who began study in 1998 Changes in Skills or Behaviors												
Question Asked: Please let us know whether these skills or behaviors have decreased, stayed the same, or increased for your child during the school year:												
Skill or Behavior	1999/2000 School Year (N=41)			2000/2001 School Year (N=39)			2001/2002 School Year (N =37)			2002/2003 School Year (N = 31)		
	Decrease	Same	Increase	Decrease	Same	Increase	Decrease	Same	Increase	Decrease	Same	Increase
Using language or other means to communicate	0%	7%	93%	0%	3%	97%	3%	19%	78%	0%	10%	90%
Using spontaneous communication to request foods, toys, or activities	0%	15%	85%	0%	10%	90%	3%	19%	78%	0%	16%	84%
Labeling items and pictures in response to questions	0%	27%	73%	3%	27%	70%	0%	42%	58%	0%	26%	74%
Understanding and responding to directions	0%	10%	90%	0%	5%	95%	3%	24%	73%	0%	13%	87%
Imitation of other children and adults during play	0%	34%	66%	3%	33%	64%	3%	39%	58%	0%	19%	81%
Playing with toys in ways that are appropriate to his/her age	0%	29%	71%	3%	38%	59%	0%	46%	54%	0%	36%	65%
Play with other children	3%	29%	68%	5%	36%	59%	3%	41%	56%	0%	35%	65%
Engagement in imaginative/pretext end play	0%	46%	54%	2%	58%	40%	2%	49%	49%	0%	42%	58%
Self-care/independence in areas such as eating, dressing, and toileting	3%	29%	68%	0%	38%	62%	3%	38%	59%	0%	29%	71%
Appropriate behavior	2%	25%	73%	8%	31%	61%	3%	40%	57%	0%	32%	68%

Description of Changes in Skills or Behaviors

Parents were asked to describe any changes they had seen in their children's skills or behaviors each year. Their responses can be found in Tables 15 through 18. Each year, common responses were given by the parents. They consistently listed skills or behaviors that had improved for their children as: 1) communication, 2) toilet training, 3) social interaction, 4) eye contact, and 5) academics.

TABLE 15 (Parent Responses)
Cohort #1 - Description Of Changes In Skills Or Behaviors - 1999/2000 School Year (N=41)

<p>Question Asked: Please describe any other changes in skills or behaviors you have seen in your child this past school year:</p> <p>Comments regarding communication/language: My child's communication skills have improved/increased (4) Expressive communication has greatly increased (2) My child's now uses peccs to request things (2) My child has a greater sense of the rhythm of language. Receptive communication is incredible. Responds better to directions. Babbles more.</p> <p>Comments regarding social interaction or play: My child is more aware of surroundings. (3) Likes to help others. My child no longer totally freaks when new people try to interact with him/her. More social. A general increase in desire and ability to interact with other people. My child now loves to play with other children. My child has become less tolerant of disabled peer interaction. More connected to other people.</p> <p>Comments regarding inappropriate/appropriate behaviors and emotions: Less tantruming/less volatile (2) My child has started screaming when he doesn't like something. Decrease in inappropriate behavior. He has been hitting, spitting, and generally being silly at inappropriate times. My child still needs work on regulating self. Can sometimes calm self. My child sings to her/himself.</p> <p>Comments regarding sensory issues: Has intense need to be squeezed.</p> <p>Comments regarding independence: Still has trouble transitioning, but it is getting better.</p> <p>Comments regarding motor skills: Gross motor skills have increased drastically. My child is able to ride a bike.</p> <p>Comment regarding generalization: My child has been able to generalize skills with others. Applies skills learned at school to home situations.</p> <p>Comments regarding learning/improvement/academics: My child is making amazing progress/doing very well. (2). This has been a positive year. Gains have been made in all areas. Learned structured teaching schedule helped with increased self-confidence. Learns very quickly after seeing things demonstrated. My child's complete attention is not needed to hear/understand a direction. Very little changes this past year. Attempting consonants.</p> <p>() = number of parents who gave similar response / No parentheses = 1 parent gave this comment</p>
--

TABLE 16 (Parent Responses - Cohort #1)
 Cohort #1 - Students who began study in 1998
 Description Of Changes In Skills Or Behaviors: 2000/2001 School Year (N=39)

<p>Question Asked: Please describe any other changes in skills or behaviors you have seen in your child this past school year.</p> <p>Comments regarding communication/language: My child's communication skills have improved. (4) My child is babbling more and making more sounds. (2) My child understands/responds to oral requests better. (2) My child is using picture board at home</p> <p>Comments regarding social interaction or play: My child has better eye contact. (3) My child wants to interact with other children now. (2) My child is more social. (2)</p> <p>Comments regarding inappropriate/appropriate behaviors and emotions: My child's behavior has become more aggressive. (2) My child has had a decrease in negative behaviors. (2) My child's anxiety level has increased. My child is showing more inappropriate behaviors. My child has less self-injurious behaviors. My child is more willing to negotiate and compromise. My child is displaying more appropriate behavior. My child tantrums more now if he doesn't get his way. My child is happier.</p> <p>Comments regarding sensory issues: My child has increased sensory needs. My child likes to be rubbed vigorously. My child's reading skills have greatly improved. (2) My child started writing</p> <p>Comments regarding learning/improvement/academics: My child is more aware of surroundings. (3) My child is doing great. (2) There have been small to moderate increases in my child's learning. When my child was mainstreamed into typical first grade, he digressed in many areas. My child has learned many new things. My child has made progress but still has not caught up to age level. My child has made amazing improvements. My child still has trouble with transitions.</p> <p>Comments regarding independence: My child is now using the bathroom/my child is toilet trained. (3) My child is become more independent - often says, "I do myself" if I try to help him. My child has had an increase in using utensils. My child is more temperamental, especially when it comes to protesting or asserting independence.</p> <p>() = Number of parents who gave similar response / No parentheses = 1 parent gave this comment</p>
--

Table 17 (Parent Responses Cohort #1 - Students Who Began Study In 1998)
 Description of Changes in Skills or Behaviors: 2001/2002 School Year (N=37)

<p>Question Asked: Please describe any other changes in skills or behaviors you have seen in your child this past school year.</p> <p>Comments regarding communication/language: Academic abilities have greatly improved. (3) Talking/babbling a lot more now (2) We understand what she wants better. We are pleased. Seen an increase in expressive communication. Answers phone with hello. More spontaneous language. Increased vocabulary. Still does not verbalize thoughts, ideas, wants or needs. Able to use and understand cue cards in schedule. Developing greater understanding of others point of view. My child now uses language to express needs or concerns instead of having a meltdown.</p> <p>Comments regarding inappropriate/appropriate behaviors and emotions: My child's behavior has gotten worse. (4) Less tantruming. (2) My child has more good days than bad/less mood swings (2) He is very independent (not always in the best interest of his safety) Behavior has improved. Home-schooling has improved my child's behavior. My child is taking the drug Risperdal and his outbursts have decreased dramatically. We see different forms of self-stimming behavior now. More frustration. My child is more flexible. More self-stimming. Happier outlook. He has become more emotional and emotionally needy.</p> <p>Comments regarding social interaction and play: Increase in social interaction . (4) Plays & interacts more now with other children in class. (3) My child has more eye contact. Starting to have an imagination.</p> <p>Comments regarding independence: Better toileting skills now. (2) Started riding regular bus and is doing well. My child eats better. My child has regressed in area of self-care.</p> <p>Comments regarding motor skills: Rides bike with training wheels.</p> <p>Comments regarding learning/improvement/academics: My child has increased in most areas. Participates more in class. My child matches a lot better. Learned to write numbers and letters. Reading skills have increased a lot!</p> <p>Other comments: My child can play the harmonica through his nose! () = Number of parents who gave similar response / No parentheses = 1 parent gave this comment</p>

TABLE 18 (Parent Responses - Cohort #1)
 Cohort #1 - Students who began study in 1998
 Description Of Changes In Skills Or Behaviors: 2002/2003 School Year (N=31)

<p>Question Asked: Please describe any other changes in skills or behaviors you have seen in your child this past school year.</p> <p>Comments regarding communication/language: Uses PECS more. My child is more verbal this school year. My child's vocabulary is amazing. Starting to hold phone conversations and converse with others his age (sometimes). Babbling a lot, talking in own language, and getting sounds out. Communicating more and more social. My child had parts in two programs that required him to speak in front of all parents and did great. Using VBA/errorless teaching at home, my child has learned to speak and expressively request, label, comment, and describe.</p> <p>Comments regarding inappropriate/appropriate behaviors: Doesn't throw as many fits. My child was very happy this year, due to a much better classroom placement, unlike the year before. Has more fixative or obsessed behaviors. Behavior problems made it so my child did not go to school most of the 2002/03 school year. Has had perfect appropriateness. Can get naughty when bored, and will urinate in strange places. Doesn't run away as much. My child has more obsessive ness and anxiety.</p> <p>Comments regarding emotions: Seems to get depressed or sad more and feels different from other kids. Is concerned about getting older, and is afraid of death, and thinking of this causes sadness.</p> <p>Comments regarding social interaction and play: More eye contact. (2) After starting meds, his socially inappropriate behaviors have decreased. Has a lot more pretend play. Talking to toys. As my child becomes more aware and interacts, she is becoming more anxious.</p> <p>Comments regarding independence: My child is not potty trained.</p> <p>Comments regarding motor skills: My child has improved in fine motor cutting and writing skills.</p> <p>Comments regarding learning/improvement/academics: Understands directions more. My child can calculate and see patterns. My child has an increased acquisition rate in math skills and a greater interest in books and songs due to VBA/errorless teaching. Math and writing skills have increased. My child has a greater willingness to learn. Continually adds new songs - she can whistle on key. Increase in logical thought and ability to adapt to change. My child has made tremendous leaps in academics (math, writing, reading and spelling).</p> <p>Other comments: Tries new foods more. Continues to improve in all areas.</p> <p>() = Number of parents who gave similar response / No parentheses = 1 parent gave this comment</p>
--

Parent Involvement

Parents were asked to rate their involvement levels and their satisfaction with their involvement levels in their children’s early childhood or school-age programs. Table 19 shows that parents rated their involvement levels between 7.54 and 7.66 (means) during all four years (10 = intensely involved.....1 = not involved at all). When rating how satisfied they were with their levels of involvement, the mean rating during the study period ranged from 6.41 to 7.21 (10 = extremely satisfied.....1 = not at all satisfied).

TABLE 19 - (Parent Responses) Cohort #1 - Students who began study in 1998 Involvement Level in Child's Early Childhood or School-Age Program				
Question Asked	Mean 1999/2000 School Year (N=41)	Mean 2000/2001 School Year (N=39)	Mean 2001/2002 School Year (N= 37)	Mean 2002/2003 School Year (N =31)
Please rate your level of involvement with your child's early childhood or school-age program. (Scale: 10 = intensely involved / 1 = not involved at all)	7.66	7.59	7.54	7.65
Please rate how satisfied you are with your involvement with your child's early childhood or school age program. (Scale: 10 = extremely satisfied / 1 = not at all satisfied)	6.95	7.21	6.41	7.03

Services Received

Satisfaction with Services Received

Parents were asked whether or not they were satisfied with the amount of services their children received and the quality of services their children received. During the study period, the majority of parents reported that they were satisfied with the amount and quality of services their children received. Table 20 shows that 69% of the parents in the 1999/2000 school year, 71% in 2000/2001 school year, 58% in the 2001/2002 school year, and 67% in the 2002/2003 school year either agreed or strongly agreed with the amount of services their child received.

When asked about the quality of their children’s services, 81% of the parents in the 1999/2000 school year, 71% in the 2000/2001 school year, 75% in the 2001/2002 school year, and 84% in the 2002/2003 school year agreed or strongly agreed that they were satisfied with the quality of services their child received.

TABLE 20 - (Parent Responses) Cohort #1 - Students who began study in 1998 Amount and Quality of Services								
	I am satisfied with the amount of services my child received				I am satisfied with the quality of services my child received			
	Strongly Disagree	Disagree	Agree	Strongly Agree	Strongly Disagree	Disagree	Agree	Strongly Agree
1999/2000 School Year (N=41)	2%	29%	59%	10%	7%	12%	39%	42%
2000/2001 School Year (N=39)	5%	24%	55%	16%	8%	21%	45%	26%
2001/2002 School Year (N=37)	14%	28%	41%	17%	8%	17%	53%	22%
2002/2003 School Year (N=31)	10%	23%	50%	17%	10%	6%	47%	37%

What Parents Liked About the Services Their Children Received

Parents were asked what they liked about the services their children received during each school year. Tables 21 through 24 show their comments. The most common responses given by the parents on why they liked about their children's services, centered on the teaching staff. They thought the teachers and instructional assistants were "good," "caring," "patient," "knowledgeable," and "wonderful."

TABLE 21 - (Parent Responses)
 Cohort #1 - Students who began study in 1998
 What Parents Liked About Their Children's Services 1999/2000 School Year (N=41)

<p>Question Asked: What do you like about the services your child received?</p> <p>Good instructional assistants. (5) Good teachers. (4) Caring teachers and/or instructional assistants. (4) Communication is very good with the staff. (3) Knowledgeable/well trained teachers and/or staff. (3) Emphasis placed on one-to-one instruction. (3) Highly skilled staff. (2) Staff is very receptive to parent input. The teachers are very patient with my child. I really like the staff. I like the teaching style. Parent involvement is encouraged. We have developed good relationship with the teacher and therapists. Staff is very cooperative. Staff are very committed. Close and detailed association with instructors - we do a lot of planning together. I love my child's program. Home services. The number of school hours. Full day service was great - he made remarkable improvements. Related services staff is very competent and knowledgeable. The school age program works with me respectfully and honestly. Involvement with typically developing peers. My child has really been helped a great deal. Great interventions. Structured teaching. Services are focused and specialized. My child has come a long way since being in the program. The district provided psychologist visiting our home. There is a good balance between one-to-one and enticing him to work in a group. The services really helped. The effort made to develop a child's full spectrum of skills. The "Teach Me Language" Program. My child got to be part of studies that count for something. My child gets speech therapy when needed. My child learned critical skills to ask for help and recognize a need for a break. My child learned to use a schedule for daily activities & work.</p> <p>() = Number of parents who gave similar response / No parentheses = 1 parent gave this comment</p>

TABLE 22 - (Parent Responses)
 Cohort #1 - Students who began study in 1998
 What Parents Liked About Their Children's Services
 2000/2001 School Year (N=37)

<p>Question Asked: What do you like about the services your child received?</p> <p>Caring/helpful/patient teachers and/or instructional assistants. (13) Services were customized/specialized to my child's needs. (6) Good teachers/instructional assistants. (6) Emphasis placed on one-to-one instruction. (3) Highly skilled staff. (3) Knowledgeable/well-trained teachers and/or staff. (2) Communication is very good with the staff. (2) My child has really been helped a great deal. (1) Classroom structure was excellent. A variety of services were offered. My child's program has served my children very well. The fact that my child has had some services at all. My child enjoys going to school. They have been consistent and provide a routine. He is expected to perform to the level of his peers. They are making an effort to keep up with current teaching trends in autism. We have received services in our home.</p> <p>() = Number of parents who gave similar response No parentheses = 1 parent gave this comment</p>
--

TABLE 23 - (Parent Responses)
 Cohort #1 - Students who began study in 1998
 What Parents Liked About Their Children's Services
 2001/2002 School Year (N=37)

<p>Question Asked: What do you like about the services your child received?</p> <p>Staff communicates very well. (6)</p> <p>Staff willingness to accommodate or adapt to my child's needs. (5)</p> <p>Qualified/knowledgeable staff. (4)</p> <p>Staff is very caring. (3)</p> <p>There aren't enough services in our small town, but we are happy with what is available. (2)</p> <p>One-to-one teaching. (2)</p> <p>Staff knows my child very well. (2)</p> <p>Nothing. (2)</p> <p>I love the staff.</p> <p>Consistent, persistent programming.</p> <p>The staff is somewhat agreeable to his needs.</p> <p>The staff who work with my child.</p> <p>The staff are advocates for my child.</p> <p>IEP.</p> <p>Small classroom.</p> <p>Staff is great.</p> <p>My child has made giant leaps so that speaks for itself.</p> <p>My child attends a Christian school and we are very happy with it.</p> <p>I think they are doing a great job.</p> <p>Consistency.</p> <p>My child is learning life skills, such as cooking.</p> <p>Intensive services.</p> <p>Gets appropriate structure.</p> <p>Gets appropriate amount of time in his typical kindergarten class.</p> <p>() = Number of parents who gave similar response / No parentheses = 1 parent gave this comment</p>
--

TABLE 24- (Parent Responses)
 Cohort #1 - Students who began study in 1998
 What Parents Liked About Their Child's Services
 2002/2003 School Year (N=31)

<p>Question Asked: What do you like about the services your child received?</p> <p>The staff is great/terrific/wonderful/very good. (10) Caring/loving staff (5) Everyone seems to care about my child's success. (2) The staff are very knowledgeable. Staff really follows through with frequent updates and to progress. The specialist never gives up. The specialists are great. The one to one aide this year was great. The keep my child interacting. Instructional assistant received training. Team coordination. Most important: my child is happy and enjoys school. My child's 1:1 time. The ERC classroom is perfect for my child, with the right amount of staff and structure. He has his own "cubicle". Excellent support - had 2 aides in classroom with visual cues. My child has a lot more small group learning. I loved my child's teacher and aides. Current providers are effective and facilitate assimilation of substantive curriculum. Wonderful program that helped my child make big academic strides this year. I am happy with the skills level and problem solving abilities of the specialists administering program. My child has structure and a schedule.</p> <p>() = Number of parents who gave similar response / No parentheses = 1 parent gave this comment</p>
--

How Services Could be Improved

In addition to asking the parents what they liked about the services their child received, parents were also asked to give input on how services could be improved. Tables 25 through 28 show their responses during the study period. Common improvements parents listed included, "summer services," "more training for staff," "more funding," "more speech therapy," and "better communication."

Table 25- (Parent Responses)
Cohort #1 - Students who began study in 1998
How Parents Thought Services Could Be Improved
1999/2000 School Year (N = 41)

Questions Asked: How could services be improved?
Summer school schedule should be the same as the school year - my child needs services all year. (4) My child need more hours. (3) My child's sensory issues need to be dealt with. (2) More services to support the entire family. (2) My child's teacher needs to care about the kids and get training and learn communication skills. Generalizing discrete trial tasks into other environments. Need day-to-day communication with the staff. Keeping up on how quickly my child masters a task More guidance and support. More information on options available. More one-to-one. More one-to-one speech therapy. Monthly meetings are needed to keep parents up to date. Give teachers more support from their superiors to do what they need to do. Better play area. Home visits. More parent involvement. Put more priority on learning things useful. The teacher needs more knowledge. The bus drivers are a problem - they refuse to let parents help their children on and off the bus. Services my child is receiving in early intervention, should also be given in elementary school. Need more emphasis on speech therapy. Need more help from an autism specialist. Better communication between staff and parents. More money to provide services. Smaller mainstream classes to better provide placement options. Help the parents be more resourceful. Individual staff should introduce themselves to the parents. No suggestions - my child's program needs to stay as it is. Mandatory courses for staff to focus on autism awareness, effective approaches, and strategies. A certification test should be given to staff to work with individuals with autism.
() = Number of parents who gave similar response / No parentheses = 1 parent gave this comment

Table 26 (Parent Responses)
 Cohort #1 - Students who began study in 1998
 How Parents Thought Services Could Be Improved
 2000/2001 School Year (N = 39)

<p>Question Asked: How could services be improved?</p> <p>Staff needs more training in how to specifically work/teach children with autism. (8) My child need more one-to-one. (5) More funding. (4) Summer school schedule should be the same as the school year-my child needs services all year. (3) Need more emphasis on speech therapy. (3) Nothing - I am a satisfied with my child's services. (2) Better communication between staff and parents. (2) My child's sensory issues need to be dealt with. (2) More services to support the entire family. (2) Better communication between our intensive services program and the school district. My child is thrown into one room with students with mixed disabilities. My child need more hours. My child needs an assistant to help him with writing. More training for parents. Competency of leadership. I would like my child to be in a class with 10 kids - 2 with autism and the rest typical. There needs to be more of an emphasis into functionalizing skills learned in one-to-one. More instructional assistants. I need to be more involved. I assist everyday at recess and lunch - my child needs an assistant to help with behavior issues. More help with how to respond with the right responses in social situations. There needs to be a better tool for teaching my child communication. My child need more direct instruction. The bus services in my district have been very poor - they border on abuse! Teachers need to be better trained-my child spends all his time with an educational assistant. My child needs more services. They need to follow through on things we discussed they are needed for my child. Instructional assistant could have been more involved. Kids should be tested on learned information in different environment to see if they generalize.</p> <p>() = Number of parents who gave similar response / No parentheses = 1 parent gave this comment</p>

Table 27- (Parent Responses)
 Cohort #1 - Students who began study in 1998
 How Parents Thought Services Could be Improved
 2001/2002 school year (n =37)

<p>Questions Asked: How could services be improved?</p> <p>Summer services/ESY. (4) Better services for small towns. (2) More services/time. (3) More one-to-one services.(3) Staff needs more training. More of a "team", including parents. There needs to be more consistency. Staff needs to know how to take my child to the next level of education. Allow toddler sibling into class to visit. Need more funding to pay for needed assistants and teachers. Schedule should be the same daily. Autism specialist needs to work with my child more. Need more communication and feedback from school. More outside classroom peers interaction. More money and resources need to be available to the school district. Staff needs training, training, training. IEP needs to be more specific. Staff needs to understand and support the bio-medical portion of the child's therapy Allow for more social time and interaction. More communication needed between staff and parents. More attention by teachers. Speech sessions are a joke. Need more options for younger kids (e.g., day camps, role playing, socialization skills) More understanding on how differently autism can affect each child. Staff needs to look for other strategies when one is not working. Very dissatisfied with the school-age program and believe it caused inappropriate behaviors to spike. My child and I could have used some kind of advice for ongoing challenging behavior. Only her regular classroom teacher would help us. I could get no other services for my child.</p> <p>() = Number of parents who gave similar response / No parentheses = 1 parent gave this comment</p>
--

TABLE 28- (Parent Responses)
 Cohort #1 - Students who began study in 1998
 How Parents Thought Services Could Be Improved
 2002/2003 School Year (N =31)

<p>Questions Asked: How could services be improved?</p> <p>Extended school year/more summer services. (3) More training for the staff. (3) More 1:1 speech therapy (3) Better and more speech therapy (2) Better funding. (2) More services (2) More respect for parents views. More help. Better communication between teachers (classroom, music, theater) and parents. Music lessons should be offered - you might be surprised at outcome. More occupational therapy for fine motor skills. Staff needs to know how to work with higher functioning children with autism. Pay more attention to individual student and adapt teaching style. Need staff that highly skilled to deal with aggressive behaviors. Nothing - they are doing just fine. Services have greatly improved this year with the hiring of a new teacher. Better computers My child is in a private school. We had to get a second mortgage. I wish we could get public help. More resources for staff. More behavioral services like social skills, communication, appropriate behavior, & safety. Better "non-combative" communication between district and IEP team members and parents. More involvement from autism consultant. More small classes/reverse mainstream groups available for permanent placement. More 1:1 time and less time left alone. More visits from the autism specialist (they have been very helpful). I wish my child could have an autism specialist with him everyday. Whole experience was unsatisfactory - removed child from public school and now home school. The quality of behavioral intervention in school district inadequate.</p> <p>() = Number of parents who gave similar response / No parentheses = 1 parent gave this comment</p>

Treatments or Services Provided by Parents

In order to determine if other factors were affecting their children’s educational progress, parents were asked to report any treatments their children were receiving or had received during each school year. Tables 29 through 32 show the parent responses. Common treatments listed by parents included gluten-free/casein free diets, vitamins, secretin, and supplements.

Table 29- (Parent Responses)
 Cohort #1 - Students who began study in 1998
 Treatments or Services Provided by Parents During the 1999/2000 School Year (N=41)

Gluten-free/casein free diet (8)	Swim therapy Psychologist
Secretin (7)	Music therapy
Vitamins (6)	Melatonin
DMG (5)	Violin
ABA programs (4)	Naturopathy physician's care
Magnesium (3)	Floor time therapy
B-6 (3)	Private therapy
Swimming (3)	Home program to teach independent tasks
Dairy free diet (3)	Tutoring for academic skills
Speech therapy (3)	Therapeutic horseback riding
Private preschool (3)	Less sugar
Gluten free diet (3)	Autism Research Project at OHSU
Yeast-free diet (2)	Autism Research Institute
Audio sensory training (2)	TMG
Respite care (2)	Zinc
In-home aide to assist with functional skills (2)	Calcium
Occupational therapy (2)	Naturopath her regimen
Fungal probiotics therapy	Prozac
() = number of parents who gave similar response / No parentheses = 1 parent gave this comment	

Table 30- (Parent Responses) Cohort #1
 Students who began study in 1998
 Treatments or Services Provided by Parents during the 2000/01 School Year (N=39)

Treatment Reported	Comments (not all parents gave comments)
Gluten-Free/Casein-Free Diet (13)	We tried it but quit (2) Been on it for 1 ½ years On it for 9 months - it has improved everything Tried it for 7 months - no notable changes Tried it for 1 ½ years It was hard to follow - didn't see any great positive changes - so we quit Tried it for 10 months, but stopped because no improvement was noticed Has improved drooling and involuntary body movement was reduced Been off & on diet - When she's off, we notice gut problems It didn't work so we quit Saw immediate positive behavior changes & is progressing quicker than before
Dimethyl glycine-DMG (11)	Stopped because he was self-abusing more. She takes this (4 times a day) - without it she's totally different One month trial - no improvement This has helped with attention and speech No noticeable difference Works very well
Vitamin B-6 (9)	Used for 2 years, but stopped on doctor's advice On & off for 4 years - I think it helps but has a nasty taste Helps keep him calm & he have improved eye contact Tried it, but he hated the taste so we quite Works very well
Secretin (9)	One injection in 1999 (3) No improvement noticed (2) Four shots in 1999 On and off over the last few years Three months - no change good or bad Works very well
Super Nu-Thera (6)	We have observed a decrease in stimming Eye contact, overall sensory issues have been helped
Melatonin (5)	Daily sleep-aid (3)
Magnesium (2)	Has helped to increase bowel movements
Phytobears	Helps keep him in good health
Alpha-Lipoic-acid	For detoxification for 3 months
Homeopathy treatment	Still trying - not sure if it is working
Xanax	Xanax is used to attend church
Glconutrients:Ambr otose & PhytAloe	No behavior changes noted thus far

Table 30 – Continued (Parent Responses) Cohort #1 Students who began study in 1998 Treatments or Services Provided by Parents during the 2000/01 School Year (N=39)	
Neurontin	Was prescribed to help with anxiety - Did not work
Tegretol	It's working for us
Kava Kava	Lowers stress
Chemet	Taking to decrease levels of toxic substances in body
"Dan Protocol"	Taking for detoxification
Risperidol	Working well to help her manage self & process information
I give my child no treatments	It's bunk
Other treatments listed with no comments: Daily multi-vitamin (5), Fish oil (2), Dairy-Free Diet (2) Topamax (1), Paxi (1), Low sugar diet (1), Omega 3 (1), Hypo-sorbate Calcium (1), Rice protein (1), Zinc (1), Iron (1) , and Vitamin C (1)	
() = number of parents who gave similar response	

Table 31 - (Parent Responses)
 Cohort #1 - Students who began study in 1998
 Treatments or Services Provided by Parents during the 2001/02 School Year (N=37)

Treatment Reported	Comments (not all parents gave comments)
Casein-Free Diet (16)	<p>Got sick so we stopped. Beneficial Tried it, but quit because saw no effect. Good for weight control. Does seem to help some but not to the degree we hoped. Tried it but quit. We've seen a big change in cognitive & academics, but my child is still hyper. Tried for 2 years, but are now stopping. Tried it for 1 month, but stopped due to extreme negative reaction to changes My child has been on it for 2 years.</p>
Gluten-Free Diet (15)	<p>Got sick, so we stopped Tried it, but quit because saw no effect. Good for weight control. Does seem to help some but not to the degree we hoped. We tried it but quit. We've seen a big change in cognitive & academics, but my child is still hyper. Tried for 2 years, but are now stopping. Tried it for 1 month, but stopped due to extreme negative reaction to changes.</p>
Vitamin B-6 (13)	<p>Tried it but stopped (3). It helped, but we quit because it was too hard to get my child to take it. Did it for a year, and then we stopped. Tried it but quit because child would not take without fight. We've seen a big change in cognitive & academics, but my child is still hyper. I only give when hyper. Tried it for one year but quit because we saw no change.</p>
Dimethyl glycine DMG (10)	<p>Focuses better so can learn better. Tried it but stopped. No apparent effect. Tried it but quit because child would not take without fight We've seen a big change in cognitive & academics, but my child is still hyper.</p>
Secretin (11)	<p>Tried for 3 months (2) Tried it - no effect Tried - no effect. Had 2 injections in 2000, but stopped. One infusion only as part of study at OHSU. Two trials only. Was involved in OHSU study.</p>
Melatonin (10)	<p>Used to help with sleep. (2) Give to help with season change. Used for 5 years, but quit because we found out it delays puberty.</p>
Multi-vitamin (5)	<p>Been giving it to my child for 5 years. Been giving to my child since infancy.</p>

Table 31 - Continued (Parent Responses) Cohort #1 - Students who began study in 1998 Treatments or Services Provided by Parents during the 2001/02 School Year (N=37)	
Super Nu-thera (3)	Tried it but stopped.
Paxil (2)	We have been trying for about 9 months and it seems to show improvement.
Mannatech dietary supplement (2)	Takes for immune system
Risperdal (2)	For ADHD and has helped control level of frustration. This has helped enormously. "Hears" us better and is able to control tantrums.
Chelation (1)	On this regime for heavy metal poisoning.
Homeopathic (1)	Trial and error - still working on it.
Pepcid (1)	For reflux problem
Reglan (1)	For reflux problem
Robinul (1)	For reflux problem
Flonase (1)	For nasal discharge
Topamax (1)	Give for seizures
Tegretol (1)	Give for seizures
Ditropan (1)	For bladder control.
DPRIV enzyme (1)	Takes with meals and we have seen no diarrhea and no increase in stimming & screeching.
Zyrtec (1)	Takes for allergies.
Other treatments listed with no comments: I give my child no treatments (9), Cod Liver Oil (3), Iron (2), Protein Supplement (2), Probiotics (2), Magnesium (2), Calcium (2), Zinc (2), Colostrum (2), Zinc (1), V-IG (1), IV-glutathiomine (1), Amino Acids (1), Yeast Free (1), Acidopholys (1), Taurine (1), Guanfacine (generic Tenex) (1), and Trace Minerals (1)	
() = number of parents who gave similar response	

Table 32 - (Parent Responses)
 Cohort #1 - Students who began study in 1998
 Treatments or Services Provided by Parents during the 2002/03 School Year (N=31)

Treatment Reported	Comments (not all parents gave comments)
Multi-vitamin (11)	Since age of 2. Since age of 4. Started 3 years ago. Took vitamins for a while, but saw no improvement and quit. Since 6 months of age. Give it to my child when we can afford.
Casein-Free Diet (9)	Tried for 7 months - quit because no change. Just started this past month. Helps with overweight problem, but not much effect on autism. Tried it but stopped.
Vitamin B-6 (7)	Tried it but quit. (2) Tried for 6 months, but quit because we and doctor thought it wasn't helping. Tried it and quit, because she refused to take it.
Gluten-Free Diet (6)	Tried for 9 months - quit because no change. Helps with overweight problem, but not much effect on autism Tried it but quit
Dimethyl glycine DMG (5)	Tried it but quit. (2) Tried it and quit, because she refused to take it.
Secretin (5)	Had 2 injections - saw no change. Tried it, but quit. One infusion only (OHSU study). Moved from cream to injections 6 months ago.
No treatments (5)	No comments given.
Melatonin (3)	Tried it, but quit. Use it occasionally - my child sleeps much better. Tried it - no marked change.
Risperdone (2)	Started 3 years ago - in the process of reassessing use
Risperdol	Stopped taking in June 2003, but medication was highly successful.
Benafiber	My child tends to eat a lot of dirt and rocks.
Ditropan	For potty training
Chemet	Used it a couple of years ago until his mercury levels dropped to normal
Paxil (1)	No comment given.
DMPS/DMSA (1)	No comment given.
Lo Carb Diet (1)	No comment given.
Cod Liver Oil (1)	No comment given.
Magnesium (1)	No comment given.
Zinc (1)	No comment given.
Super Nu-thera (1)	No comment given.
Concerta (1)	No comment given.
() = number of parents who gave similar response	

**COHORT #2
STUDENTS WHO
BEGAN
PARTICIPATING
IN THE
STUDY IN 2001**

Demographic Information – Cohort #2

Table 33 shows that Cohort #2 consisted of 56 students who began participating in the study in 2001. The participants were located in eight geographic areas of the state in approximate proportion to the population.

Table 33
Students Participating from each Regional Program
(Baseline Data) - Cohort #2 - Began Study in 2001

Regional Program	Cohort #2
	Number of Students
Region I - Eastern Oregon Regional Program	4
Region II – High Desert Oregon Regional Program	6
Region III - Southern Oregon Regional Program	3
Region IV - Cascade Regional Program	2
Region V - Mid-Oregon Regional Program	10
Region VI - Columbia Regional Program	12
Region VII - Lane Regional Program	10
Region VIII - Northwest Regional Program	9
Students Participating in Each Cohort	56

Table 34 shows baseline demographic information reported by teachers for Cohort #2. Seventy-one percent of the participants were male and 29% were female. At baseline, their average age was 39 months. Teachers reported that the students received approximately 11 hours (range 0 – 25 hours) of services per week, and 56% of the students were non-verbal.

Table 34
Baseline Information Reported By Teachers

Gender	71% Male 29% Female
Average Age	39 months
Average total hours per week of instruction at home and school as reported by teachers	11 hours
Range of Instructional hours per week (home and school) as reported by teachers	0 - 25 hours
Percent of students listed as non-verbal by teachers. *Please Note: definition changed for cohort #2	56% * (can not use 5 or more words to communicate)

Services Received by Cohort #2 Students

Services Reported by Teachers

Cohort #2 included 56 students who began the study in 2001. Each school year, teachers reported the number of hours and the type of services their students received in their programs. Tables 35 through 37 show the information reported by the students' service providers.

Table 35 shows that on average, children received approximately 11.8 hours of instruction in the 2001/02 school year. In the 2002/2003 school year, the average hours of instruction increased to 13.1 hours. Approximately half of the services received each week were spent in one-to-one instruction.

Table 35 One to One Instruction During Regular School Year Students from Cohort #2				
Number of Hours	2001/2002 School Year		2002/2003 School Year	
	Average (hours)	Range (of hours)	Average (hours)	Range (of hours)
Average number of hours of all services students received per week	11.8 hours	1 to 22.5 hours	13.1 hours	3 to 33.5 hours
Average number of hours of services received of one-to-one pull-out instruction with teacher or assistant	5.8 hours	0 to 18 hours	6.8 hours	0 to 21 hours
Average number of hours of services received in a large group (4 or more children to 1 adult)	1.2 hours	0 to 15 hours	2.2 hours	0 to 19 hours
Average number of hours of services received in a small group (2-3 children to 1 adult)	1.3 hours	0 to 10 hours	2.6 hours	0 to 14 hours
Average number of hours of services received in a one-to-one instruction in a group	3 hours	0 to 10 hours	1 hour	0 to 12 hours
Average number of hours of services received in pullout with a related services provider	1 hour	0 to 8 hours	.50 (½ hour)	0 to 2 hours

Table 36 shows that the majority of the children in Cohort #2 spent most of their time in self-contained classrooms: 78% in 2001/02 school year and 75% in the 2002/03 school year. Other placements included special classrooms integrated with typical peers, home, and community preschools. In the 2001/2002 school year, 16% spent time in a special classroom integrated with typical peers, 15% received services in their home, and 4% spent some time in a community preschool. The amount of time spent in classrooms with typical peers and in community preschools increased in the 2002/2003 school year. During the second year of the study, 22% of the children spent time in special classrooms integrated with typical peers and 21% of the children spent time in community preschools with typical peers.

Table 36 Settings Where Services Received During Regular School Year (Some students may receive services in more than one setting during a school day)		
Setting	Percent of Students Receiving Service in this Setting	
	Percent served in this setting:	
	2001/2002 School Year (N=56)	2002/2003 School Year (N=48)
Self-contained classroom	78%	75%
Special classroom integrated w/typical peers	16%	22%
Home	15%	8%
Community preschool	4%	21%
Elementary school classroom	0%	0%
Other setting	0%	0%

Table 37 shows that the majority (88% in 2001/2002 and 79% in 2002/2003) of children received some pull-out one-to-one instruction. The students who were given pull-out one-to-one instruction, received approximately 7 to 8 hours each school year. The specific techniques that teachers reported as most commonly used in these sessions were discrete trial training and pivotal response training. Other teaching strategies included functional routines, incidental teaching, structured teaching, floor time, sensory integration, academics, and peccs.

Table 37
One to One Instruction During Regular School Year
Students from Cohort #2 who received one-to-one instruction

	2001/2002 School Year (N=56)		2002/2003 School Year (N=48)	
Percent of all students in Cohort #2 receiving pull-out one-to-one instruction	88%		79%	
Average number of hours per week of one-to-one instruction received by the students who were given one-to-one instruction	<i>Average</i> 6.9 hours	<i>Range</i> 1 to 18 hours	<i>Average</i> 7.9	<i>Range</i> .33 to 21 hours
Type of pull-out one-to-one teaching received per week:	<i>Average</i>	<i>Range</i>	<i>Average</i>	<i>Range</i>
Discrete Trial	2.37 hours	0 to 8 hours	2.58 hours	0 to 10 hours
Pivotal Response	2.07 hours	0 to 8 hours	1.49 hours	0 to 5 hours
Other Strategies (functional routines, incidental teaching, structured teaching, floor time, sensory integration, academics, and/or peccs)	2.46 hours	0 to 10 hours	3.85 hours	0 to 15 hours

Results For Cohort #2

Summary Of Results

Students in Cohort #2 began the study in the fall of 2001. Standardized assessments were administered to the students in the fall and spring of each school year.

In general, students in Cohort #2 made progress in all areas assessed. The average language age gain for all students was 13 months in the 18 month period they were involved in the study. Seventy-nine percent of the students made gains in their expressive language abilities, and 40% of those students gained 18 or more months of expressive language age in their 18 months of participation in the study. In addition, the students made significant ($p \leq .05$) gains on the educational assessment, social interaction assessment, and on the Battelle Developmental Inventory Cognitive assessment.

Teachers also completed standardized assessments for their students. Results from the ASIEP-2 Autism Behavior Checklist show that students were displaying significantly ($p \leq .05$) fewer behaviors/attributes associated with autism spectrum disorder. Additionally, they reported on the Vineland Behavior Scales that students were displaying significantly ($p \leq .01$) more adaptive behaviors. For a more thorough description of the assessment results, please refer to Tables 38 – 42.

Vocal Behavior/Language Assessment

Expressive Language Age

To measure the expressive language age of students in the study, the children were administered the ASIEP-2 Sample of Vocal Behavior subtest and the Expressive One-Word Picture Vocabulary test. Table 38 shows the average language age gain for all students was 13 months in the 18 month period they were involved in the study. Seventy-nine percent of the students made some language gain. Approximately 40% of the students gained 18 or more months in 18 months they participated in the study.

Table 38 - Cohort #2 Expressive Language Age in Months (means)				
Fall 2001/Winter 2002	Spring 2002	Fall 2002	Spring 2003	Signf Diff at Prob. $p \leq .01^{**}$
Baseline 0 months (N=55)	Approx. 6 months from baseline (N=52)	Approx. 12 months from baseline (N=47)	Approx. 18 months from baseline (N=47)	(N=47)
21 months	27 months	29 months	34 months	Yes**

Educational Assessment

Students were given the ASIEP-2 Educational Assessment subtest (assesses receptive and expressive language, body concept, speech imitation), and portions of the Basic Academic Skills Assessment System (assesses academic skills). Table 39 shows that the students made significant ($p \leq .01$) improvement on these educational assessments when comparing their fall 2001 scores and their spring 2003 scores. The students' mean percent correct increased: 1) on the ASIEP-2 Educational Assessment from 35% correct to 65% correct, 2) on the Basic Skills Academic Assessment from 0% to 4%, and 3) on the composite (combination of both assessments) from 7% to 16%.

Table 39 - Cohort #2					
Educational Assessment - mean percent of correct answers					
Assessment	Fall 2001	Spring 2002	Fall 2002	Spring 2003	Signf. Diff.at Prob. $p \leq .01$ (N=48)
	Baseline 0 months (N=54)	Approx. 6 months from baseline (N=48)	Approx. 12 months from baseline (N=48)	Approx. 18 months from baseline (N=48)	
ASIEP-2 Educational Assessment	21/60 35%	30/60 50%	36/60 60%	39/60 65%	Yes**
Basic Skills Academic Assessment	2/234 0%	3/234 1%	4/234 2%	9/234 4%	Yes**
Educational Composite (ASIEP-2 Educational Assessment & Preacademic Assessment)	22/294 7%	33/294 11%	40/294 14%	48/294 16%	Yes**

Social Interaction Assessment

On each assessment visit, students were given the ASIEP-2 Social Interaction Assessment. Table 40 shows that there were statistically significant ($p \leq .01$) increases in appropriate social interactions found when comparing the assessments from fall 2001 and spring 2003. After approximately 18 months, the students engaged in significantly, 1) more social interaction with the adult present, 2) more constructive independent play, and 3) less self-stimulation/repetitive play behavior. Results show that appropriate social interactions with the adult present and constructive independent play by the child during the assessment increased from 51% of the assessment observation in 2001 to 81% of the observation time in 2003. After 18 months in the study, they engaged in significantly ($p \leq .01$) more social interactions with the adult present and more constructive independent play.

Table 40 - Cohort #2 Appropriate & Inappropriate Social Interaction Behavior					
Area Assessed	Fall 2001	Spring 2002	Fall 2002	Spring 2003	Significant Difference
	Baseline 0 months (N=55)	Approx. 6 months from baseline (N=52)	Approx. 12 months from baseline (N=47)	Approx. 18 months from baseline (N=46)	Significant at Probability $p \leq .01^{**}$ (N=46)
Appropriate Social Interactions	15%	24%	30%	36%	Yes**
Appropriate Constructive Independent Play	36%	49%	47%	45%	Yes**
Self-Stimulation and Non-Responsive to Toys/Adult	47%	26%	22%	18%	Yes**
Aggressive Negative Towards Adult	2%	1%	1%	<1%	No

Autism Behavior

The majority of the teachers completed an ASIEP-2 Autism Behavior Checklist for their students each school year. Table 41 shows that teachers reported the behaviors related to autism had decreased in their students during the first 18 months of participation in the study. When examining the total Autism Behavior Checklist score, there was a significant ($p \leq .05$) decrease found between the fall 2001 mean score and the spring 2003 mean score. Students were displaying significantly fewer behaviors/attributes associated with autism spectrum disorder.

Table 41 Autism Behavior Checklist Students In Cohort #2 Behavior/Attributes Associated with ASD			
Areas Assessed	Fall 2001 Baseline 0 months (N=36)	Spring 2003 Approximately 18 months from baseline (N=45)	Significant Difference Significant at Probability $p \leq .01^{**}$ (N=27)
Sensory	8.89	8.29	No
Relating	20.06	16.51	Yes**
Body and Object Use	10.58	9.18	No
Language	12.28	9.51	Yes**
Social and Self Help	13.19	12.38	No
Total (A score of 54 or higher is a typical score for a child with autism)	64.94	55.07	Yes**

Vineland Adaptive Behavior Scales & Battelle Developmental Inventory Cognitive Screening Assessment

Age Equivalent Scores

The assessment team screened all students each school year using the Battelle Developmental Inventory Cognitive assessment. In addition, teachers were asked to complete a Vineland Adaptive Behavior Scales (interview edition) on each student. Table 42 shows there was a significant increase ($p \leq .01$) in the age equivalent mean scores for both assessments when comparing the scores between winter 2001 and spring 2003. Over the study period, the students' mean age equivalent scores on the Battelle Developmental Inventory increased from 21 months to 31 months and on the Vineland Adaptive Behavior Scales from 16 months to 23 months.

Table 42
Battelle Developmental Inventory Cognitive Assessment & Battelle Developmental Inventory Cognitive Assessment (Screening) - Cohort #2

Assessment	Baseline* 2001/02 School Year Age Equivalency Scores		2002/03 School Year Age Equivalency Scores		Paired t-tests Significant at Probability $p \leq$.01**	
	N	Mean	N	Mean	N	Sign. Dif
Battelle Developmental Inventory Cognitive Assessment *baseline was administered by assessment team between 12/01 to 2/02	53	21 months	47	31 months	45	Yes**
Vineland Adaptive Behavior Scales (interview edition) *baseline reported by teachers between 12/01 to 8/02	46	16 months	44	23 months	35	Yes**

Feedback from Parents of Cohort #2

At the end of each school year, parents of Cohort 2 were sent surveys to give them the opportunity to provide input on their children and their children's program. Approximately 60% returned their surveys during the summers of 2002 and 2003. Their responses can be found in Tables 43 to 53.

Changes in Skills and Behaviors

Parents were asked to report any changes in their children's skills and behaviors. Table 43 shows the percentage of parents who answered that their children's skills or behaviors decreased, stayed the same, or increased during each school year. In the majority of areas listed below, parents overwhelmingly thought their children's skills or behaviors had increased each school year. The areas that parents consistently thought their children's skills or behaviors had increased the most each year were: 1) using language or other means to communicate, 2) using spontaneous communication to request foods, toys, or activities, and 3) understanding and responding to directions.

One area that parents thought increased a notable amount in the 2002/2003 school year was self-care and independence in areas such as eating, dressing, and toileting. In their first year of participation in the study, only 39% of the parents thought their children had an increase in this area, but in the 2002/03 school year, 70% of the parents thought their children had increased their skills in these self-care and independence areas.

Table 43 (Parent Responses)
Cohort #2 - Students who Began Study In 2001
Changes in Skills or Behaviors

Question Asked: Please let us know whether these skills or behaviors have decreased, stayed the same, or increased for your child during the school year:

Skill or Behavior	2001/2002 School Year (N = 33)			2002/2003 School Year (N = 31)		
	Decreased	Stayed the Same	Increased	Decreased	Stayed the Same	Increased
Using language or other means to communicate	0%	15%	85%	4%	7%	89%
Using spontaneous communication to request foods, toys, or activities	0%	12%	88%	4%	7%	89%
Labeling items and pictures in response to questions	0%	39%	61%	0%	33%	67%
Understanding and responding to directions	0%	24%	76%	0%	4%	96%
Imitation of other children and adults during play	0%	27%	73%	0%	33%	67%
Playing with toys in ways that are appropriate to his/her age	0%	27%	73%	4%	29%	67%
Play with other children	0%	36%	64%	0%	44%	56%
Engagement in imaginative or pretend play	0%	28%	72%	0%	41%	59%
Self-care and independence in areas such as eating, dressing, and toileting	0%	61%	39%	0%	30%	70%
Appropriate behavior	3%	36%	61%	4%	31%	65%

Description of Changes in Skills or Behaviors

Each year, parents were asked to describe any changes they had seen in their children's skills or behaviors. All of their responses can be found in Tables 44 and 45. Improved skills or behaviors that parents consistently listed that they had seen in their children included: 1) increases in receptive and expressive language, 2) progress in toilet training, and, 3) more eye contact.

Table 44 (Parent Responses) - Cohort #2 - Students who began study in 2001 Description Of Changes in Skills or Behaviors 2001/02 School Year (N=33)	
Question Asked: Please describe any other changes in skills or behaviors you have seen in your child this past school year:	
<p>Comments regarding communication/language: More talking. (5) More involved in conversation with adults and children (2) Follows directions better. (2) My child's ability to understand has increased. (2) He requests/asks for things better now (2) Language and comprehension has increased dramatically. My child's speech has improved. Learning to express feelings verbally. Increase in receptive communication skills. Ability to verbally request items to play with or eat. Tries to address people by name now. Uses PECS & some limited words to communicate. My child's vocabulary has increased. Responds to "no" better. Echoing phrases.</p> <p>Comments regarding social interaction or play: More eye contact. (4) More social now. (3) Much better at tolerating new people and places (2) Tolerates close contact with others better. He's less frustrated with us on home. Plays with lots more toys. Walks hand and hand with me without pulling away. More social, although my child's social anxiety takes over at times. Notices adults more in our home and wants attention from them.</p>	<p>Comments regarding inappropriate/appropriate behaviors and emotions: Has intense tantrums. (3) Less head banging. I have seen an increase in self-stimulating behaviors. Fewer temper tantrums. Doesn't like being told to wait. Happier. More active. Has developed a sense of humor.</p> <p>Comments regarding independence: Succeeded at toilet training/Progress in toileting training. (3) More independent. (2) Uses computer by self.</p> <p>Comments regarding learning/ improvement/academics: Enjoys going to school. (2) My child is better able to attend to activities. (2) My child has learned many new skills. All around improvement. My child has improved intensely. My child is much more aware of his environment. She's interested in things. There is no question that my child has improved since attending school</p> <p>Comments regarding motor skills: Greater physical-motor skills</p>
() = number of parents who gave similar response No parentheses = 1 parent gave this comment	

Table 45 (Parent Responses) - Cohort #2 - Students Who Began Study in 2001
Description of Changes in Skills or Behaviors 2002/03 School Year (N=33)

<p>Question Asked: Please describe any other changes in skills or behaviors you have seen in your child this past school year:</p>	
<p>Comments regarding communication/language: Increase in receptive language. (2) Language just continues to improve all the time. Starting to use words to communicate wants. Use of language has really increased. He is excited about going to school. Communicating wants regarding toys & activities better. Great increase in vocabulary. Repeating one word after we say it (not consistent). Asserts personality. Tolerates and enjoys going to new places and meeting new people. Improvement in communication with the introduction to visual strips.</p> <p>Comments regarding social interaction or play: He plays Nintendo & computer with his brother. She is more responsive to strangers. She acknowledges other children more. Seeking out certain people for needs and playing. More eye contact. Plays with siblings more. Overcoming intense fear of animals. Says he loves parents on a regular unprompted basis. He is more affectionate and loving with his family and wants to constantly be around us.</p> <p>Comments regarding independence: My child is now toilet trained. (2) More independent and helpful.</p> <p>Comments regarding motor skills: Can scoot along on trike. Better coordination. Jumping off of couch, chairs, and stairs.</p>	<p>Comments regarding inappropriate/appropriate behaviors and emotions: Fewer tantrums. (2). More confidence as well as feelings for others. Knows more meanings like sad & mad and uses them appropriately. Child's behavior has become more challenging at home. Has frequent/intense tantrums and increased stimming. He had increased self abuse and aggression, but we treated it with ABA & medication and improvements have been seen. Is now being able to feel what another party might be feeling in a situation. Negative aggressive behaviors are still present, depending on stress level. We stopped her medication and she has gone from very aggressive behavior back to being withdrawn When hurt or upset, takes my hand and leads me to rocking chair so I can comfort him by rocking & singing to him.</p> <p>Comments and diet/food: Eating more variety of foods. More curious about food, but still eats poorly. My child is now self-feeding and helping self to things in refrigerator</p> <p>Comments regarding learning/ improvement/academics: Reading has increased.</p> <p>General comments: Has improved in every area possible and now most people do not even know my child has autism.</p>
<p>() = number of parents who gave similar response / No parentheses = 1 parent gave this comment</p>	

Parent Involvement

At the end of the 2001/2002 school year, parents of students in Cohort #2 were asked to rate their involvement levels and their satisfaction with their involvement levels in their children's early childhood or school-age program. Most parents appeared to be satisfied with the amount of time spent and their involvement levels in their children's programs. Table 46 shows the mean rating

for all parents was 7.45 in the 2001/02 school year and 7.51 in the 2002/03 school year (10 = intensely involved.....1 = not involved at all) when rating their involvement level. When rating how satisfied they were with their level of involvement, the mean rating for parents was 7.88 in the 2001/02 school year and 6.81 in the 2002/03 school year (10 = extremely satisfied.....1 = not at all satisfied).

Question Asked	Mean 2001/02 School Year (N=33)	Mean 2002/03 School Year (N=31)
Please rate your level of involvement with your child's early childhood or school-age program. (Scale: 10 = intensely involved / 1 = not involved at all)	7.45	7.51
Please rate how satisfied you are with your involvement with your child's early childhood or school-age program. (Scale: 10 = extremely satisfied / 1 = not at all satisfied)	7.88	6.81

Satisfaction with Services Received

At the end of the 2001/2002 and 2002/2003 school years, parents of students in Cohort #2 were asked whether or not they were satisfied with the amount of services their own children received and the quality of services their children received. The majority of parents reported they were satisfied with the amount and quality of services their children received. Table 47 shows that 78% of the parents in the 2001/2002 school year and 55% of the parents in the 2002/2003 school year either agreed or strongly agreed that they were satisfied with the amount of services their child received.

When asked about their satisfaction with the quality of their child's services, 85% of the parents in the 2001/2002 school year and 78% of the parents in the 2002/2003 school year agreed or strongly agreed that they were satisfied with the quality of services their child received.

Statement	Agreement Level 2001/2002 (N=33)				Agreement Level 2002/2003 (N=31)			
	Strongly Disagree	Disagree	Agree	Strongly Agree	Strongly Disagree	Disagree	Agree	Strongly Agree
I am satisfied with the <i>amount</i> of services my child received	9%	12%	42%	36%	19%	26%	33%	22%
I am satisfied with the <i>quality</i> of services my child received	0%	15%	46%	39%	11%	11%	30%	48%

What Parents Liked about the Services Their Children Received

Parents were asked each year what they liked about the services their children received. Table 48 shows that most of the parents liked their children's services, because they were impressed with the quality of the service providers. Common responses about the teaching staff included they “provided individualized and personalized programs,” and were “knowledgeable,” “dedicated,” “caring,” and qualified.”

TABLE 48 - (Parent Responses)
 Cohort #2 - Students who began study in 2001
 What Parents Liked about Their Children’s Services - 2001/2002 School Year (N=33)

Question Asked: What do you like about the services your child received?
Individual and personalized programs for my child. (4)
Teacher and staff very knowledgeable and dedicated. (4)
Teaching by people who know and love my child. (2)
Home visits. (2)
Intense autism program.
Intensity of our home program.
Involvement of his teachers.
The services provided by both a private preschool and Easter Seals were excellent.
The staff makes my child feel very special.
The quality of services is sometimes better than what is offered privately.
The teachers are kind & considerate.
They make my child feel more normal.
The teacher is always thinking of new ways to help my child.
It has helped my child make huge gains in speech & understanding.
Staff really cares - They are encouraging, complimentary, & so helpful to all our family.
The teaching staff gives my child teaching and skills that I can't give.
One-to-one in autism class.
My child's communication is getting better thanks to school!
Teachers are always available, enthusiastic, empathetic, and never give up on our child.
Supportive staff.
I like the teachers.
Flexibility of staff.
Staff is Fantastic.
I have a large say in the curriculum we use with my child.
Parents are involved with program.
Everything.
Consistency.
Communication with caseworker.
Daily notebooks that let me know what my child was doing at school.
Teachers have helped tremendously with social skills.
() = Number of parents who gave similar response / No parentheses = 1 parent gave this comment

Table 49- (Parent Responses)
 Cohort #2 - Students Who Began Study in 2001
 What Parents Liked about Their Children's Services - 2002/2003 School Year (N=31)

<p>Question Asked: What do you like about the services your child received?</p> <p>The staff is very caring/kind/concerned. (5)</p> <p>The staff are competent/qualified/knowledgeable. (4)</p> <p>The staff are very good/great. (2)</p> <p>The staff are dependable/dedicated. (2)</p> <p>The staff and I work well together. (2)</p> <p>Communication is good.</p> <p>The staff really knows my child.</p> <p>There have been improvements in my child's functional abilities.</p> <p>I like the structure, peer interaction, and weekly progress reports.</p> <p>The staff is totally concerned about progress.</p> <p>Personal attention from teacher.</p> <p>The services have been beneficial to our entire family.</p> <p>Nothing, except that they were free.</p> <p>The preschool is very good for her social skills.</p> <p>Quality of services.</p> <p>His teachers are wonderful.</p> <p>The staff adjusts my child's program to meet needs.</p> <p>Excellent STAR curriculum.</p> <p>Use of PECS.</p> <p>Good ratio of teachers to students.</p> <p>Staff really cares.</p> <p>Extended day with one to one attention.</p> <p>The social skills class and integrative preschool was a good combination.</p> <p>I child did very well in EI class and seemed to enjoy going to preschool.</p> <p>All.</p> <p>Child to teacher ratio is good.</p> <p>Staff get down on a personal basis with each child and family.</p> <p>His goals were met and when he could exceed goals, teachers helped with excess progress.</p> <p>Federal government should help fund services during state budget crisis.</p> <p>The services are outstanding.</p> <p>() = Number of parents who gave similar response / No parentheses = 1 parent gave this comment</p>

How Services Could be Improved

In addition to asking the parents what they liked about the services their children received, parents were also asked to give input on how services could be improved. Table 50 shows their suggestions for each school year. Common improvements parents thought were needed included, "more hours in the classroom," "year round program," "more one to one," "more teacher training," and "more parent training."

TABLE 50 - (Parent Responses) Cohort #2 - Students who began study in 2001 HOW PARENTS THOUGHT SERVICES COULD BE IMPROVED 2001/2002 SCHOOL YEAR (N =33)
Questions Asked: How could services be improved?
<p>More hours in the classroom. (5) Program should be year round. (3) More one to one with the kids. (2) More parent training. (2) No suggestions - I am satisfied with services. (3) No improvement needed. (2) Less harried teachers. More one to one speech therapy. Need better communication from teacher. More work with peers as a group. The services provided by the regional program were of inferior quality. The staff from the regional program spent almost all their hours on paperwork, meetings, & evaluations. More frequent services. More meetings with parents. Pay at least 1/2 of the services my child gets. I now pay 75%. More support during breaks. More structure in the classroom. State funded/free preschool for siblings of same family. More staff. Better follow-through by staff. More services. Less time in a parent/toddler class and more class time in a structured directed environment. More home visits. Information (articles) available to give to parents. O.T. time More parent support. Too many in-service days.</p> <p>() = Number of parents who gave similar response / No parentheses = 1 parent gave this comment</p>

Table 51 (Parent Responses)
 Cohort #2 - Students who began study in 2001
 How Parents Thought Services Could Be Improved
 2002/2003 School Year (N =31)

<p>Questions Asked: How could services be improved?</p> <p>More hours/more time. (10)</p> <p>More funding. (4)</p> <p>More training for staff. (3)</p> <p>Don't know/can't think of anything/nothing (3)</p> <p>Better communication.</p> <p>Faster pick-up on behavior.</p> <p>Listen to parents and respect their wishes.</p> <p>Better placement at kindergarten.</p> <p>Kindergarten staff are completely unprepared for his special needs.</p> <p>Staff needs to follow the program that is working.</p> <p>Students should be grouped more closely by abilities.</p> <p>More stability in student and teacher population.</p> <p>Best practice is a minimum of 25 hours per week, but my child only get 15 hours.</p> <p>It would be beneficial to have an observation area for parents to watch children without them knowing.</p> <p>() = Number of parents who gave similar response No parentheses = 1 parent gave this comment</p>

Treatments or Services Provided by Parents

In order to determine if other factors were affecting their children's educational progress, parents of students in Cohort #2 were asked to report any treatments their children were receiving or had received during each school year. Tables 52 and 53 show their responses. Common treatments listed by parents included casein free diets, gluten-free diets, vitamins, and supplements.

Table 52 - (Parent Responses)
 Cohort #2 - Students who began study in 2001
 Treatments or Services Provided by Parents
 during the 2001/02 School Year (N=33)

Treatment Reported	Comments (not all parents gave comments)
Casein-Free Diet (11)	<p>Been on it for 2 months Been on it for 7 months. Small Change When off diet, undesirable behaviors increase dramatically. Eye contact worsens, child is in own world when not on diet. Stimming increases when my child is not on diet. Tried it for 4 months and then stopped. Tried it a couple of years ago and then stopped Tried it for 3 months, then quit and noticed no difference. Tried it for 2 months a last year, but quit.</p>
Dimethyl glycine-DMG (10)	<p>Tried it, but quit because no noticeable improvement. (2) Tried for 10 months, but quit. Just started trying it. Tried it for 2 months a last year, but quit.</p>
Vitamin B-6 (10)	<p>Tried Kirkman, but quit because there was no improvement. (2) Tried but quit because it upset my child's stomach. Tried it but quit - it disrupted sleep. Tried it but quit - caused diarrhea Tried it for 2 months last year, but quit. If we miss this, we really see behavior variations.</p>
Gluten-Free Diet (9)	<p>Been on it for 2 months. Been on it for 7 months. Small change. When off diet, undesirable behaviors increase dramatically. Eye contact worsens, child is in own world when not on diet. Stimming increases when my child is not on diet. Tried it for 5 months and then stopped. Tried it a couple of years ago and then stopped. Tried it for 3 months, then quit and noticed no difference. Tried it for 2 months a last year, but quit. My child is not on a gluten-free diet, instead eats only gluten products.</p>
Multi-vitamin (7)	<p>Chewable kind. Multi-vitamin with fluoride and iron Since infancy.</p>
Melatonin (7)	<p>Tried but stopped - my child sleeps better after we quit it. (2) My child likes the chewable kind. Tried it but quit, because it was ineffective for sleep. Use for sleep. Use as a p.r.n.</p>

Table 52 Continued - (Parent Responses)
 Cohort #2 - Students who began study in 2001
 Treatments or Services Provided by Parents
 during the 2001/02 School Year (N=33)

Super Nu-Thera (6)	Tried but quit because it disrupted sleep. Been using for one month. Tried it for 3 months, but quit because it made no difference.
Secretin (2)	Good results.
Qi Gong Massage (1)	Last 7 months my child is participating in study - we have seen fairly dramatic positive effects. It is the most important intervention we have tried.
Massage (1)	Ongoing
Chelation (1)	Tried for 1 year, but did not like day after effect
Ketoconazole (1)	Been on it for 4 months.
Nystatin (1)	Been on it for 4 months.
Probiotics (1)	Been on it for 4 months.
Risperidol (1)	Much calmer now
<p>Other treatments listed with no comments: I give my child no treatments (10), Cod Liver Oil (4), Zinc (2), Salicylate free diet (1), Phenol free diet (1), Soy Free Diet (1), Mercury Detox (1), Acetyl L-Carnitine (1), Amino Support (1), Ambrotose (1), Mediclear (1), Re L Glutathione (lotion) (1), Pro bio gold (1), Epsom Salt Cream (1), Enzymes (2), DDPIV (1), Yeast control (1), Colostrom gold (1), Biocidin (1), Nystatin (1), S. Boulardii (1), Milk Thistle (1), Nutricidal (1), Glutathione (1), Formula Soy (1), Flaxseed Oil (1), Amino Full (1), Calcium (1), MSM (1), Liver cleanse tea (1), Homeopattarics (1), Everyday Companion (1), Folirinse (1), Vitamin C (2)B-Complex #1 (1), Ribo 5 Phosphate (1), DMPS (1), Co-Enzyme Q-10 (1)</p> <p>() = number of parents who gave similar response</p>	

Table 53- (Parent Responses)
 Cohort #2 - Students who began study in 2001
 Treatments or Services Provided by Parents during the 2002/03 School Year (N=31)

Casein-Free Diet (12)	Tried it but stopped (5) Tried it, but stopped, because we saw no change. (2) Sleeps Better Major improvements in all areas: physical & mental. No more stomach aches.
Gluten Free Diet (11)	Tried it, but stopped. (5) Stopped - saw no effect (3) Feeding problems - no change My child does not have allergies, so I don't use diets. We noticed immediate improvement in behavior: better cognitive abilities, sleep, and understanding/ less tantrums and head banging
Multi-vitamin (10)	Provide because I am concerned about limited food intake
Melatonin (10)	Sleeps 7 -8 hours a night Don't use anymore - instead use other meds Tried it, but stopped. We use as need to keep on regular 10 p.m. to 6 a.m. sleep. Tried it, but it didn't work. Helped my child sleep well. We use occasionally for sleeping.
Dimethylglcine (DMG) (10)	Tried it, but stopped. (2)
Vitamin B-6 (7)	Diarrhea
Secretin - (3)	Agitation Some improvement - but why?
Risperdal (3)	Placed on due to behavior issues
Ritalin (2)	Tried, but stopped (2)
Zirteck (1)	Food Allergies
Benedryl (1)	Helps with sleeping
Iniprunine (1)	Placed on due to behavior issues
Adderal (1)	Tried, but did not do well at all.
L-Carnosine (1)	We started this and within 2 weeks he went from not words to never shutting up. It was like a miracle. Social skills improved right away too.
B K. Injections HMP (1)	Growth hormone
Carn-Aware (1)	Noticeable increase in eye contact & more mental awareness.
GLA Plus (1)	Firmer bowel movements, more mentally aware, more eye contact.
Soy Plus (1)	Main source of food.
<p>Other treatment listed with no comments: I give my child not treatments (6), Heavy metal chelation (2), Cod liver oil (2), Corn soy diet (1), SCD diet (1) , no sugar diet (1) , Prozac (1) , Chinese massage (1) Homeopathics (1) , Herbal liver cleanse (1) , Carnetine (1) ,Acidophilus (1) , Paxil, (1) Zinc (1) , Super-NuThera (1) , Amino acids (1) , enzymes (1) , clatheration (1) , Omega 3 (1) , Lethacin (1) . () = number of parents who gave similar response</p>	

Student Progress Information Reported By Teachers

Service providers (e.g., teachers, instructional assistants, related services staff, and administrators) were an important part of the project. They provided valuable information about the progress of each student. Beginning in the 2001/2002 school year, teaching teams for students in Cohort #2 (students who began study in 2001) were sent surveys asking them to report on the skills and abilities of their students. Areas examined included receptive language, expressive language, routines, and pre-academic skills. These items were taken from the STAR Program curriculum and closely matched skills being taught.

Teachers reported that their students made significant improvements in their skills and abilities from fall 2001 and spring 2003. To see complete results from the teacher surveys, please refer to the tables 54 to 57.

Table 54 shows that the teachers responses to questions about the students' expressive language skills. Their responses show that the students' expressive language skills increased over the 18 months they were participating in the study. They were more often verbalizing their wants and needs.

For the children who could not communicate their wants and needs verbally, the teachers responded that they most often used picture systems, gestures, or sounds to ask for needs or wants.

Table 54 - Expressive Language - Cohort #2

Question #1: Can the student ask (verbalize) for wants using at least one word?						
Survey Date	No	Yes, for 1 item	Yes, for 2-4 items	Yes, for 5+ items		
Fall 2001	49%	17%	8%	26%		
Spring 2003	2%	2%	67%	29%		
Question #2: Can the student ask (verbalize) for wants using the phrase: "I want x" (x is any item wanted), or use his/her own name (e.g., John wants X)?						
Survey Date	No	Yes, for 1 item	Yes, for 2-4 items	Yes, for 5+ items		
Fall 2001	80%	3%	9%	8%		
Spring 2003	0%	2%	67%	31%		
Question #3: Can the student say "No" (verbalize) to reject unwanted items?						
Survey Date	No	Yes, uses the word no for 1 item	Yes, uses the word no for 2-4 items	Yes, uses the word no for 5+ items		
Fall 2001	73%	3%	6%	18%		
Spring 2003	0%	9%	60%	31%		
Question #4: If the student cannot verbalize his wants/needs, how does he ask for his wants/needs?						
Survey Date	Sounds	Picture System	Voice Aug. system	Sign language	Gestures	Other
Fall 2001	62%	59%	3%	0%	79%	28%
Spring 2003	39%	65%	30%	13%	44%	22%

Teachers were asked to report if their students responded to verbal cues. Table 55 shows that the students had a significant increase in their responses. The requests that had the most increases in student responses included: Check you schedule (53% increase), Give me five (47% increase), Point to X (45% increase), Give me X (44% increase), and Touch X (43% increase).

Table 55 - Receptive Language - Cohort #2

Question Asked: Can the student independently complete requests when giving them one verbal cue?			
Request	Percent of students who can complete this request with one verbal cue		
	Fall 2001	Spring 2003	% increase
Check Your Schedule	14%	67%	53%
Give Me Five	37%	84%	47%
Point to "X"	12%	57%	45%
Give Me "X"	29%	73%	44%
Touch "X"	18%	61%	43%
Stop	9%	46%	37%
Time For Play	29%	65%	36%
Wait	6%	41%	35%
Hands Down	27%	61%	34%
Stand Up	43%	73%	30%
My Turn	43%	71%	28%
Look At Me	37%	64%	27%
Sit Down	49%	73%	24%
Sit Up	17%	42%	25%
Come Here	29%	50%	21%

Teachers were asked if the students could independently participate in routines. Table 56 shows they had substantial improvement in their abilities to independently complete routines. The routines that had the most increases included: Transition between in-class activities (38% increase), Going on a walk (31% increase), and Transition between locations (31% increase).

Table 56 - Routines - Cohort #2

Question Asked: Which of the following routines can the student do independently at least 4/5 times?			
Routine	Percent of students who can independently complete this routine		
	Fall 2001	Spring 2003	% increase
Transition Between In-Class Activities	6%	44%	38%
Going on a Walk	6%	37%	31%
Transition Between Locations	3%	34%	31%
Snack	27%	53%	26%
Departure	3%	29%	26%
Arrival	11%	31%	20%
Independent Seatwork	3%	21%	18%
Hand washing	9%	24%	15%
Bathroom Use	6%	21%	15%

Table 57 shows that the students' pre-academic skills increased over the study period. The students matching skills showed the most increases: colors (52% increase), objects (51% increase), pictures (46% increase), and shapes (40% increase). Additionally, students had substantial increases in scissor use (31% increase), rote counting (29% increase), and identifying letters and numbers (27% increase).

Table 57 - Pre-Academics – Cohort #2

Question Asked: Which of the pre-academic task can the student do?			
Pre-Academic Task	Percent of students who can do this task when asked by teacher		
	Fall 2001	Spring 2003	% increase
Match At Least 4 Colors	32%	84%	52%
Match At Least 5 Objects	37%	88%	51%
Match At Least 4 Pictures	38%	84%	46%
Match At Least 4 Shapes	44%	84%	40%
Use A Scissors	9%	40%	31%
Rote Count To 10	18%	47%	29%
Identify Upper/Lower Case Letters A-Z	9%	36%	27%
Read At Least 5 Sight Words	3%	27%	24%
Count Sets of 2-10 Objects	6%	21%	15%
Sit And Do Independent Seatwork For At least 15 Minutes	6%	20%	14%
Color Within 1/4 Inch Of Picture Lines	3%	14%	11%

References

- Arick, J., Loos, L., Falco, R., & Krug, D. (2004). *The star program: Strategies for teaching based on autism research*. Austin, TX: Pro-ed, Inc.
- Arick, J., Young, H., Falco, R., Loos, L., Krug, D., Gense, M., & Johnson, S. (2003). Designing an outcome study to monitor the progress of students with autism spectrum disorder. *Focus on Autism and Other Developmental Disabilities, 18*, (2), 75-87.
- Brownell, R. (2000). *Expressive one-word picture vocabulary test*. Novato, CA: Academic Therapy Publications.
- Division TEACCH, Autism Society of North Carolina. *Structured teaching*. Retrieved November 27, 2002, from <http://www.teacch.com>.
- Green, G. (2001). Behavior analytic instruction for learners with autism: Advances in stimulus control technology. *Focus on autism and Other Developmental Disabilities, 16*, 72-85.
- Green, G., Brennan, L. & Fein, D. (2002). Intensive behavioral treatment for a toddler at high risk for autism. *Behavior Modification, 26*(1), 69-102.
- Green, G. (1996). Early behavioral intervention for autism: What does the research tell us? In C. Maurice, G. Green, & S.C. Luce (Eds.) *Behavioral intervention for young children with autism: A manual for parents and professionals*, 15-27. Austin, TX: PRO-ED, Inc.
- Hurth, J., Shaw, E., Izeman, S., Whaley, K. & Rogers, S. (1999). Areas of agreement about effective practices among programs serving young children with autism spectrum disorders. *Infants & Young Children, 12*(2) 17-26.
- Individuals with Disabilities Education Act of 1990, 20 U.S.C. § 1400 *et seq.*
- Koegel, L.K., Koegel, R.L., Shosan, Y., & McNerney, E. (1999). Pivotal response intervention II: Preliminary long-term outcome data. *Journal of The Association for the Severely Handicapped, 24*, 186-198.
- Krug, D., Arick, J., Almond, P. (1993). *Autism screening instrument for educational planning, second edition*. Austin, TX: PRO-ED, Inc.
- Krug, D.A., Rosenblum, J.F., Almond, P.J., & Arick, J.R. (1981). *Autistic and severely handicapped in the classroom: Assessment, behavior management, and communication training*. Portland, OR: ASIEP Education Co.
- Lovaas, O.I., (1981). *Teaching developmentally disabled children: The me book*. Austin, TX: PRO-Ed

- Lovaas, O.I. (1987). Behavioral treatment and normal educational and intellectual functioning of young autistic children. *Journal of Consulting and Clinical Psychology*, 55, 3-9.
- Marcus, L., Schopler, E., & Lord, C. (2000). TEACCH services for preschool children. In J.S. Handleman & S.L. Harris (Eds.), *Preschool education programs for children with autism*. Austin, TX: PRO-ED, Inc.
- Maurice, C., Green, G., & Luce, S.C. (Eds.) (1996). *Behavioral intervention for young children with autism: A manual for parents and professionals*. Austin, TX: PRO-ED, Inc.
- National Research Council. (2001). *Educating children with autism*. Committee on Educational Interventions for Children with Autism, Division of Behavioral and Social Sciences and Education. Washington, DC: National Academy Press.
- Newborg, J., Stock, J., Wnek, L., Guidubaldi, J., & Svinicki. (1984). *Battelle developmental inventory* Itasca, IL: Riverside Publishing.
- Oregon Department of Education (O.D.E.), (2000), Report of the Caring for Oregon's Children with Autism Spectrum Disorder Task Force . Retrieved June 8, 2004 from www.ode.state.or.us/sped/spedareas/autism/autismtaskforce.htm.
- Rogers, S. (1996). Brief report: Early intervention in autism. *Journal of Autism and Developmental Disabilities*, 26, 243-246.
- S.P.S.S., Inc. (1999) *SPSS*. Chicago, IL: SPSS
- Sparrow, S., Balla, D., & Cicchetti, D. (1984). *Vineland adaptive behavior scales: Interview edition*. Circle Pines, MN: American Guidance Service.
- Schreibman, L. (2000). Intensive behavioral/psychoeducational treatments for autism: Research needs and future directions. *Journal of Autism and Developmental Disorders*, 30(5), 373-378.
- Smith, T. (2001). Discrete trial training in the treatment of autism. *Focus on Autism and Other Developmental Disabilities*, 16(2), 86-92.
- Tindal, G., McDonald, M., Crawford, L., & Tedesco, M. (2000). *Extended basic academic skills assessment system*. Salem, OR: Oregon Department of Education.