

Service Delivery Innovations for Autism Spectrum Disorders in the State of Texas

A Consumer Report Prepared by

The Burkhart Center for Autism Education and Research

at

Texas Tech University

for the

Texas Council for Developmental Disabilities and

Texas Council on Autism and Pervasive Developmental
Disabilities

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May 2008



TEXAS TECH UNIVERSITY

Burkhart Center *for* Autism
Education and Research

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Acknowledgements

The Burkhart Center for Autism Education and Research would like to express gratitude to the following individuals who spent hours compiling resources for the purpose of writing this report.

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Service Delivery Innovations for Autism Spectrum Disorders Project

Executive Summary

The Burkhart Center for Autism Education and Research at Texas Tech University was selected by the Texas Council for Developmental Disabilities (TCDD) and the Texas Department of Aging and Disability Services (DADS) to survey parents, caregivers, and professionals about their familiarity with and perceived helpfulness of interventions for children and youth who have Autism Spectrum Disorders (ASD). TCDD also asked The Burkhart Center to conduct a comprehensive review of the ASD literature and (1) create a directory of interventions for ASD and (2) identify a strategy to categorize interventions for ASD. The Burkhart Center undertook several major activities to accomplish these goals.

First, the Center conducted a comprehensive review of research articles related to treatment and intervention strategies for ASD. We found and reviewed 399 research articles and created a directory which lists all of these interventions for ASD. Among those articles was a scheme which organized interventions and treatments for ASD into a hierarchical classification system. The article was published in the journal, *Focus on Autism and Other Developmental Disabilities* in 2005 and was authored by Richard L. Simpson. The classification scheme itself was adapted by Simpson and his colleagues in 2005 and is the basis of organizing interventions for ASD as described in this report.

Next, the Center developed a survey which was used to collect information from parents, caregivers, and professionals in the community regarding their knowledge of interventions for ASD for children in Texas. The Project Advisory Committee which was created for this project helped recruit volunteers to complete the survey. More than 7,500 surveys were distributed. The return rate was 15% (or 1,141 participants). The parents, caregivers, and professionals who completed the survey were not representative of the general population in Texas because they were more likely to be Non-Hispanic White/Caucasian and were more likely to be in higher socioeconomic status groups (e.g., highly educated, higher median incomes, and married). More women than men participated in the project (e.g., completed a survey). Most of the women were the biological mother of the child participants reported on.

Most of the children participants reported on were diagnosed with Autism (39%), Pervasive Developmental Disability – Not Otherwise Specified (24%), Asperger's Syndrome (16%), High-functioning Autism (13%), or another diagnosis (7%). Nearly half of the children were reported as having a co-existing/co-occurring condition. Nearly all of the children had been diagnosed between ages 13 months and 5 years old.

Finally, The Burkhart Center analyzed the data collected from participants who completed the surveys. In summary, the quantitative and qualitative data both suggest that there is a disparity in overall knowledge of interventions for ASD between parents and caregivers, and professionals. Professionals appear to be much more familiar with interventions for ASD than parents and caregivers are. Moreover, professionals are more familiar than parents and caregivers with interventions which have empirical

evidence and efficacy for individuals who have ASD (e.g., Scientifically-based and Promising Practice interventions for children and youth who have ASD). Parents and caregivers were more likely than professionals were to be familiar with interventions which had limited supporting information for practice and interventions which were not classified by Simpson et al. (2005). Moreover, parents and caregivers were not sure whether interventions which were potentially harmful for children with ASD were helpful for children or not. Furthermore, upon closer inspection, it appears that parents and caregivers were more knowledgeable (e.g., were more familiar with and more likely to agree that particular interventions were helpful) than professionals about interventions which are relatively more accessible to parents and caregivers than other interventions are.

Implications and recommendations based on the findings of this report are included at the end of this report. For complete details regarding this project, readers are invited to contact the Burkhart Center or access the report using this hyperlink (www.burkhartcenter.org).

Service Delivery Innovations for Autism Spectrum Disorders Project

Introduction

In the spring of 2007, the TCDD contracted with The Burkhart Center for Autism Education and Research at Texas Tech University to survey parents, caregivers, and professionals across the state to determine what they knew about interventions for individuals with Autism Spectrum Disorders (ASD) and to find out if they thought those interventions were helpful for children. The Center was also to create a resource directory that would be housed on the Texas Department of Aging and Disability Services (DADS) website to help families find resources in their area.

The Service Delivery Innovations for ASD in the State of Texas Project had the following objectives:

- Create a project advisory committee to ensure that all stakeholders including parents who were interested in the project had the opportunity to help guide the direction of project;
- Conduct a literature review of current interventions for individuals with ASD that were described in research journals;
- During the literature review, find a method for categorizing or evaluating the quality of specific interventions to help an individual understand if research studies supported the use of particular interventions;
- Carry out a statewide survey to determine which interventions parents, caregivers and professionals were familiar with and learn how these stakeholder groups perceived the helpfulness of interventions for children who have ASD;
- Produce a comprehensive directory of existing services and supports for persons with ASD in Texas so that parents and families could find out what services and supports were available in their area; and
- Prepare a report that described what we did and what we found.

Project Advisory Committee

The Project Advisory Committee (PAC) was created by asking for nominations from the TCDD, the Texas Council for Autism and Pervasive Developmental Disorders (TCAPDD), DADS, and the Burkhart Center for Autism Education and Research and by inviting volunteers who expressed an interest in being on the PAC. Potential PAC members had to be nominated; Self-nominations were accepted. TCDD approved PAC members. The PAC first met in Austin, Texas in March 2007. Additional meetings were held in Lubbock, Texas or by telephone over the course of the year.

Literature Review

The literature review actually began in June 2006 and was completed in February 2007. The project team searched for peer-reviewed research articles which reported on interventions for individuals with ASD. The team found and reviewed a total 399 research articles. Only interventions published in peer-reviewed journals were included in the project's comprehensive list of interventions for ASD. In addition to finding interventions for ASD, TCDD also wanted the literature search to include information about the definition of ASD, identification of key terms, facts about ASD, trends, and the history of ASD. During the literature review, to fulfill one of the Project's objectives, Burkhart Center's research team also looked for articles which included a way of categorizing or classifying interventions for ASD.

Describing ASD

ASDs are described by three main differences in the way an individual functions including deficits in the areas of 1) communication, 2) socialization, and 3) intense interests and compulsivity (Heflin & Alaimo, 2007). These characteristics affect a person's ability to function in every environment and continue throughout a person's lifetime. However, not every person with ASD experiences difficulties in every area and an individual may change how they function over time (Lord, Cook, Leventhal, & Amaral, 2000).

Communication varies greatly from person to person and ranges from a complete lack of spoken language or communication to well developed spoken language with problems understanding gestures like body language (Lord & Paul, 1997). Social problems involving communication sometimes appear as an inability to understand verbal and nonverbal signals between people. It may also include issues such as social reciprocity or the ability to engage in turn taking in a conversation. Individuals with ASD also often have a preference for objects, the parts of objects, and/or an insistence on routine. They also have a need for sensory stimulation or control over the amount of sensory stimulation they receive.

Classifying Interventions for ASD

The project team searched hardcopy and electronic sources to find research articles which categorized interventions for ASD by the efficacy of each intervention (i.e., the ability of an intervention to produce a desired effect). The team focused on finding Evidence-based research which means that only research studies reported in peer-reviewed journals which used scientific, objective research methods and unbiased interpretation of the data were included in this project. The literature review confirmed that many interventions for ASD exist. However, the efficacy of many of these interventions remains unproven. Every intervention for ASD which was identified in the team's literature review was included in the survey we developed for this project.

Since parents often express frustration in not knowing what interventions are available

for their child, how well an intervention might work for their child, or whether an intervention will be worth the family's time, effort, and money, one of the goals of this project was to find a classification scheme which categorized interventions for ASD and was based on sound research methods. After searching through many research articles, the research team found an article by Richard L. Simpson that was reported in the journal, *Focus on Autism and Other Developmental Disabilities* in the Fall of 2005 (Simpson, 2005,) which can also be accessed at <http://foa.sagepub.com/content/vol20/issue3/>. The article, "Evidence-Based Practices and Students with Autism Spectrum Disorders" discussed issues and factors which related to identifying and using effective practices with students with autism-related disorders and recommended effective practices for students with ASD. Obtaining this article helped the project team meet the goal of finding a method for categorizing specific interventions for ASD based on research reports so that parents and families would have some way of evaluating ASD interventions for their children.

Simpson's report is based on work which was undertaken by him and his colleagues in 2005. Simpson's team evaluated 33 commonly used interventions and treatments for children and youth with ASD. They organized these interventions into five categories:

1. **Skill-based Interventions** which involve direct instruction with the individual;
2. **Cognitive Interventions** which focus on practicing expected behavioral responses;
3. **Physiological/Biological/Neurological Strategies** which address physical aspects of ASD;
4. **Interpersonal Relationship Development Strategies** which emphasize relationships between people; and
5. **Other Interventions** which include a variety of different strategies for ASD.

In addition to describing each intervention and organizing them into the groups described above, Simpson and his team also took the following factors into consideration: (1) reported outcomes and effects of the intervention; (2) qualifications of persons implementing the intervention or treatment; (3) how, where, and when the intervention or treatment is best administered; (4) potential risks associated with the intervention or treatment; (5) costs associated with using the intervention or treatment; and (6) methods for evaluating the effectiveness of the intervention. Based on their evaluation of each of these factors, Simpson's group also sorted the 33 commonly used interventions for ASD into one of four categories: scientifically-based practices, promising practices, practices with limited supporting information, and practices which were not recommended. Simpson defined these categories as follows:

1. **Scientifically-based practices** were defined as methods which had "significant and convincing empirical (i.e., based on observation or experience, not on a

2. **Promising practices** were defined as methods which had “efficacy” and was useful for individuals with ASD but which needed additional objective (i.e., unbiased) evidence from research studies;
3. **Practices with limited supporting information** were defined as methods which lacked objective and convincing supporting evidence but had undecided, possible, or potential use and efficacy; and
4. **Not recommended** were defined as interventions and treatments that were perceived to lack efficacy and that might have the potential to be harmful.

Table 1 is taken from Simpson’s 2005 research article. It lists the 33 interventions described above and also includes 2 additional interventions classified as “Other” interventions for ASD.

Table 1. Evaluation of Interventions for Learners with Autism Spectrum Disorders (Simpson, et al., 2005) ([Click here for the table in HTML](#))

Classification	Skill-based	Cognitive	Physiological/ Biological/ Neurological	Interpersonal Relationship	Other
Scientificallly-based Practice	Applied Behavior Analysis	Learning Experiences: <i>An Alternative Program for Preschoolers and Parents</i>			
	Discrete Trial Training				
	Pivotal Response Training				
Promising Practice	Picture Exchange Communication System	Cognitive Behavioral Modification	Sensory Integration	Play-oriented Strategies	
	Incidental Teaching	Cognitive Learning Strategies			
	Structured Teaching (e.g. TEACCH)	Social Stories			
	Augmentative Alternative Communication	Social decision-making strategies			
	Assistive Technology				
	Joint Action Routines				
Limited Supporting Information	Van Dijk Curricular Approach	Cognitive Scripts	Scotopic Sensitivity Syndrome	Gentle Teaching	Music therapy
	Fast ForWord	Cartooning	Auditory Integration Training	Option Method (Son-Rise)	Art therapy
		Power cards	Megavitamin therapy	Floor Time	
			Feingold diet	Pet/animal therapy	
			Herb, mineral, & other supplements	Relationship Development Intervention	
Not Recommended	Facilitated Communication		Holding Therapy		

Survey Development

Another goal of this project was to design a survey and collect information from parents, caregivers and professionals to find out how familiar these groups were with interventions for ASD and whether they agreed or disagreed that the intervention was helpful for their children. To address this goal, we created two different surveys, one for parents and caregivers and another for professionals. Survey development occurred over a period of time and included several different stages.

Demographic questions – which asked survey participants about their age, gender, ethnicity, income, etc. – were developed first. Questions regarding the child with ASD were developed next. These questions asked about the child’s specific diagnosis, age at initial diagnosis, and any co-occurring conditions.

In the next stage, interventions from the team’s literature search were organized into the type of intervention according to Simpson’s categories: Skill-based interventions, Cognitive interventions, Physiological/biological/neurological strategies, Interpersonal relationship development strategies, and other interventions for ASD. For each intervention listed, survey participants were instructed to fill in the bubbles of all the interventions they were familiar with.

In the next part of the survey, participants were given the same list of interventions again and this time were instructed to fill in the bubble of the response that best indicated the extent to which they agreed or disagreed with the statement. As an example, if the survey statement read, “Applied Behavior Analysis Approaches are helpful,” parents and caregivers or professionals would respond by selecting only one of the following choices: “Strongly Disagree”, “Disagree”, “Neutral”, “Agree”, or “Strongly Agree”. If participants were not familiar with the intervention, they were asked to fill in “N/A” (i.e., “not applicable”).

In addition to questions where responders were asked to “fill in the bubbles,” parents, caregivers and professionals were asked to respond to open-ended questions. Among the open-ended questions, parents and caregivers were asked to respond to the following questions: (1) “Please describe what barriers or issues (e.g., travel time, cost of treatment, lack of information), if any, limit your ability to seek the best services for your child”; and (2) “Please describe what barriers or issues (e.g., time, information, training), if any, limit your ability to implement specific strategies and/or interventions at home”. Professionals were asked to respond to the following questions: (1) “In your opinion, what is needed to improve the lives of individuals and families living with Autism Spectrum Disorders?” and (2) “If you could change two things that would enhance your service delivery outcomes, what would they be?”

Both surveys – the parents’ version and the professionals’ version - were translated into Spanish and were made available in both electronic and hard copy. Project members and PAC members pre-tested the surveys – on the internet and using hard copies – to ensure quality assurance and address any potential problems with the survey.

Survey Distribution

PAC members and others provided names of potential survey participants. Researchers invited potential survey respondents through email, conference and mail flyers, and website links through professional and parent organizations such as Texas Autism Advocacy, FEAT-Houston, Partner's Resource Network, SPAN/TSHA (ASA Midland Chapter), the San Antonio Autism Chapter, Texas Educational Service Centers, Board Certified Behavior Analysts (BCBA®), and online ASD resource guides. Educational Service Centers and Independent School District Superintendents were sent a letter asking them to forward the web link for the survey to teachers, other autism professionals such as speech therapists, and parents. Parent support groups and other groups that work with individuals who have ASD were also asked to send the link to the survey) to potential survey participants. 7500 surveys were distributed to potential survey participants including anyone who received an introductory email.

Survey Responders

When we tallied information about how participants found out about the opportunity to participate in the study we found out that 47% heard about the survey through email contact, 21% through websites, 18% through professional or parent organizations, and 14% through other sources such as friends or flyers. 1,159 individuals completed the survey for a return rate of 15% (1,159/7,500). Eighteen surveys were discarded because of concerns regarding the validity of some of the responses. Of the total number of people who responded, 76% completed the survey the first time the web link invitation was sent to potential survey participants and 24% completed the survey the second time the link was sent.

More parents and caregivers participated than ASD professionals did: 62% of survey responders identified themselves as parents or caregivers (714 parents and caregivers) vs. 38% who indicated that they were ASD professionals (445 professionals). However, even though more parents and caregivers participated, more professionals who started answering the survey actually completed it - 61% of all professionals who started the survey went on to complete it vs. 58% of parents and caregivers who started the survey and went on to complete it.

One-hundred of the 254 counties across the State of Texas were represented in the project (39% of all counties). Harris County represented the highest concentration of survey respondents. Non-Hispanic Caucasians made up the majority of survey responders. However, the sample population (i.e., all survey participants combined) is not representative of the general population of the state because responders were more likely to be urban white females who were married, were highly educated, and had a higher socioeconomic status than the general population of the state. Also, the vast majority of individuals who participated in the project were women – parents, caregivers and professionals combined - (89% women vs. 11% men).

When asked the question, "In addition to being a parent, caregiver, or professional, are

you an individual living with an Autism Spectrum Disorder?” 90% responded “No” and 10% responded “Yes.” Therefore, this question indicates that 120 individuals who have ASD – 10% of the individuals who responded to the survey – participated in the project.

Specific Characteristics of Survey Responders

Race/Ethnicity by group of responders

Figure 1 shows the percentages of participants by race/ethnicity. The vast majority of survey participants were White/Caucasian (Non-Hispanic) (75.3% for parents and 86.0 for professionals). Hispanic/Latino (14.0% for parents and 6.2 for professionals), Black/African American (5.7% for parents and 4.1 for professionals), Asian/Pacific Islander (2.9% for parents and .9 for professionals), and Other ethnic groups (1.1% for parents and 1.1 for professionals) made up the remainder of individuals who responded to the survey.

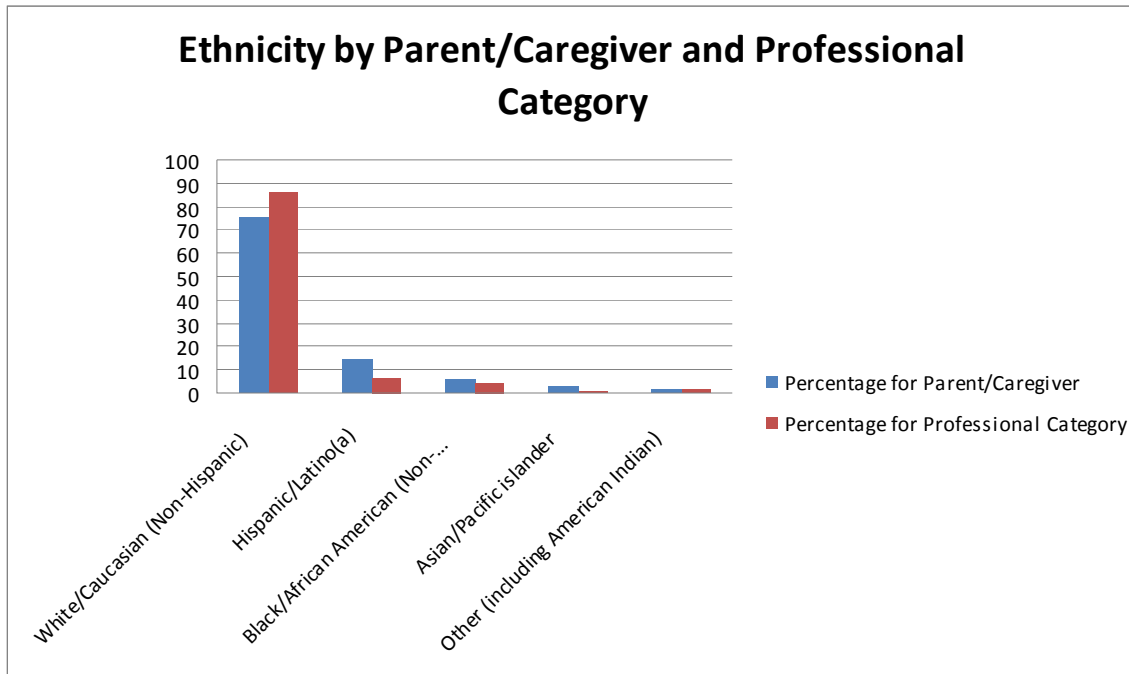


Figure 1: Ethnicity of Participants

Household income of parents/caregivers only

Participants were asked to provide their estimated annual household income. Figure 2 provides a summary of the estimated annual income of parents and caregivers. More than half of the participants were in the highest income group (51%). Participants earning \$60,000-\$74,999 were the next highest group (14%), followed by participants who earned \$45,000-\$59,999 and \$30,000-\$44,999 at 12% each. Individuals earning \$15,000-\$29,999 made up 7% of responders and responders earning less than \$15,000 made up the remaining 4% of parents and caregivers.

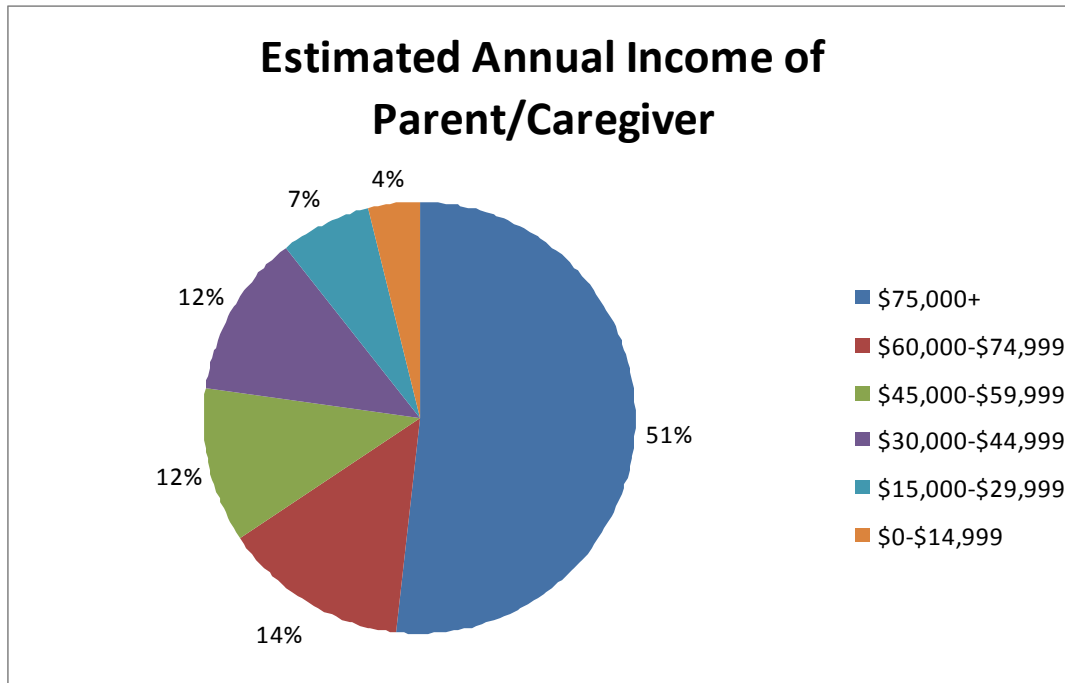


Figure 2: Estimated Annual Income of Parents/Caregivers

Education of parents/caregivers and professionals

Individuals who participated in this project were highly educated. Most of the individuals who participated in this project had at least some college.

The distribution of educational status among parents and caregivers is as follows:

- 23% obtained a graduate degree
- 49% obtained a college degree
- 28% had some college
- 3% reported other educational experiences including: vocational school, LVN training, cosmetology school, or trade school

The distribution of education among professionals is as follows:

- 70% obtained a graduate degree
- 22% obtained a college degree
- 2% had some college
- 21% reported other educational experiences including: vocational school, LVN training, cosmetology school, or trade school

Marital status of parents/caregivers

Parents and caregivers were asked to indicate their current relationship status. Most parents and caregivers reported being married (82%). Eight percent (8%) were divorced, 4% were single, 4% were never married, and 2% were separated.

Parent/caregiver relationship to child

Most of the parents and caregivers who responded to the survey reported being the child's biological mother (83%). The distribution of the parent or caregiver relationship to the child with ASD is as follows:

- 83% biological mother
- 9% biological father
- 7% "other" caregiver (e.g., adoptive mother, grandmother)
- 0.4% step-parent
- 0.3% foster-mother

Specific Characteristics of Children Participants Reported On

Child's education status

Parents and caregivers were asked to provide their child's grade level. Most of the respondents' children were in the Pre-K and Kindergarten (25%), followed by the 1st-3rd grade (23%), then by adults in post-secondary educational settings (17%), 6th-8th grade (16%), 11% in 4th or 5th grade, and finally high school (10%).

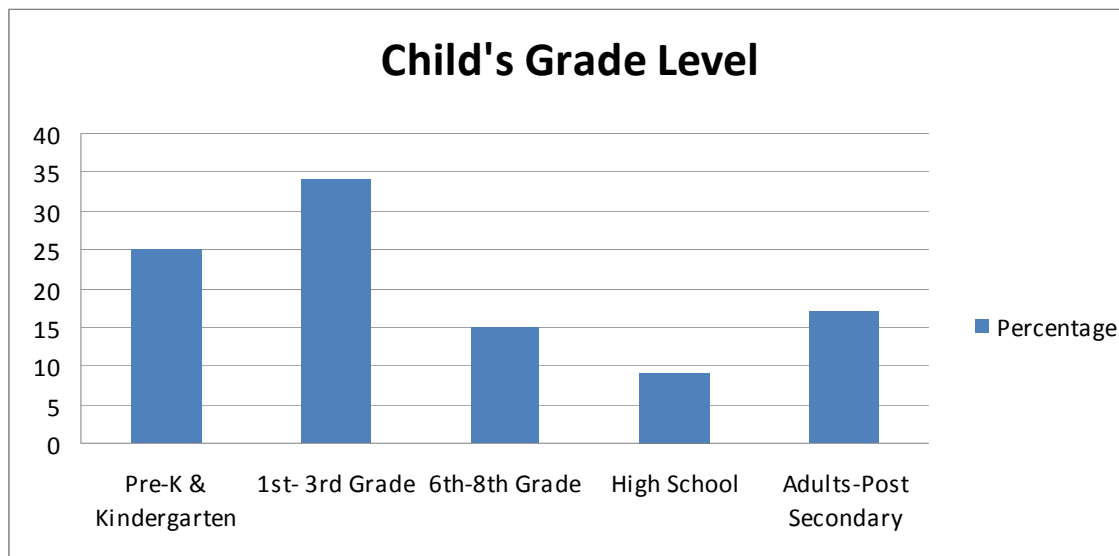


Figure 3: Percentage of Individuals by Grade Level

Child's Gender

Parents and caregivers were also asked if their child with ASD was male or female. Eighty-five percent (85%) reported that their child was a male and 15% reported that their child was female.

Number of children in the household

Parents and caregivers reported the number of children in the household as follows: 3% reported having no children, 28% had one child, 43% had two children, 19% had three children, 5% had four children, 1% had five children, and 0.1% (n=1) reported having six children living in the household.

Number of children in the household diagnosed with ASD

When asked to indicate the number of children with ASD who were living in the household, 89% reported having one child with ASD in the household. The remaining parents and caregivers reported the following: 8% reported having 2 children in the household with ASD, 3% reported having no children with ASD in the household, and 0.4% reported having 3 children with ASD in the household.

Child's diagnosis

When parents and caregivers were asked about the child's diagnosis, participants reported the following (Figure 4):

- 39% Autism
- 24% Pervasive Developmental Disability – Not Otherwise Specified
- 16% Asperger's Syndrome
- 13% High-functioning Autism
- 7% Other diagnosis
- 1% Not yet diagnosed

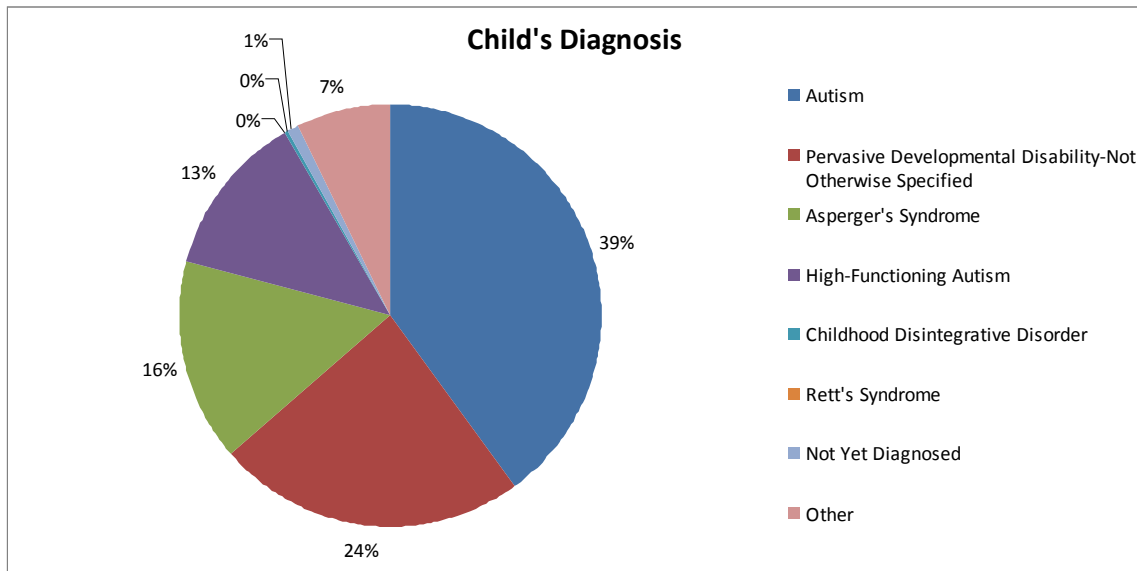


Figure 4: ASD Reported Diagnoses

Co-existing/Co-occurring conditions

When asked about co-existing or co-occurring conditions, 45% of parents and caregivers reported that the child with ASD had no co-existing or co-occurring conditions. Survey responders reported the following (Figure 5):

- 45% No co-existing/co-occurring conditions (n = 315)
- 25% "Other"* co-existing/co-occurring conditions (n = 179)
- 15% ASD and mental retardation (n = 108)
- 6% ASD and epilepsy (n = 41)
- 5% ASD and visual Impairment (n = 33)
- 3% ASD and hearing impairment (n = 19)
- 1% ASD and Fragile X (n = 10)

* "Other" includes depression, anxiety, obsessive-compulsive disorder or attention deficit hyperactivity disorder (ADHD)

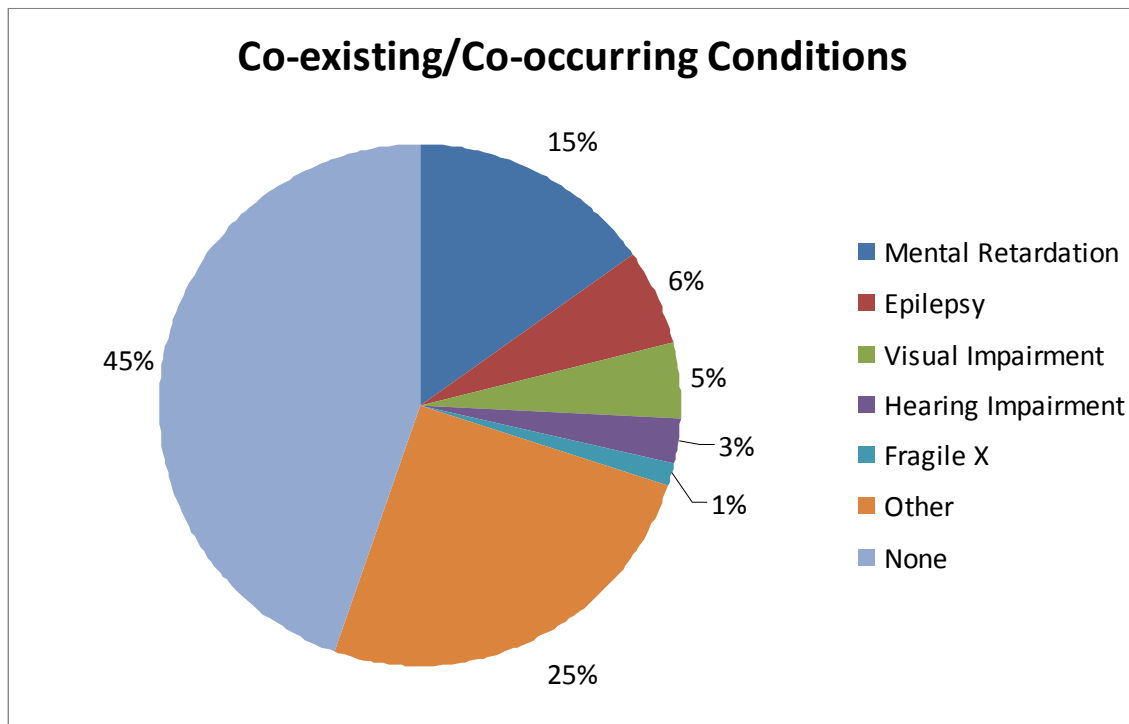


Figure 5: Co-existing/Co-occurring conditions reported by parents and caregivers

Child’s age at initial ASD diagnosis

Finally, parents and caregivers were asked to identify their child’s age at the time of initial ASD diagnosis. Figure 6 shows that 80% of children diagnosed with ASD were diagnosed between the ages of 13 months to 5 years old. Parents and caregivers reported the child’s age at initial diagnosis as follows: 49.6%, 3-5 years old

- 30.7%, 13-24 months old
- 10.4%, 6-8 years old
- 4.9%, 9-11 years old
- 2.3%, 12-14 years old
- 1%, Age 20 or older
- 0.4%, ≤ 1 year old
- 0.4%, 15-17 years old
- 0.1% 18-20 years old

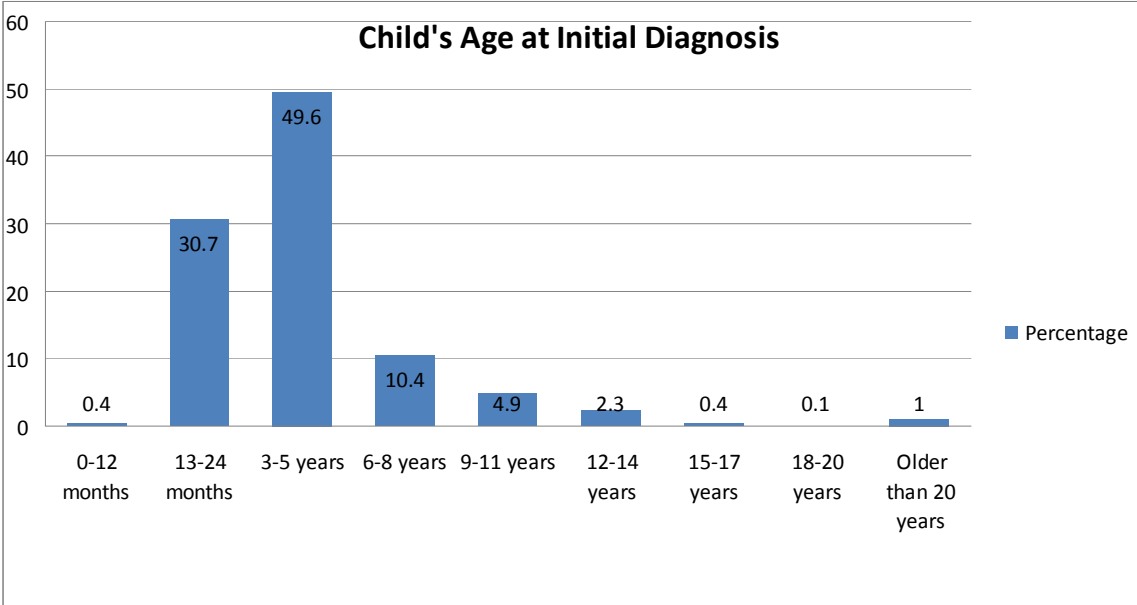


Figure 6: Initial Age of Diagnosis

Survey Findings

Participants’ responses to the surveys produced a great deal of information about how parents, caregivers, and professionals view interventions for children and youth with ASD. Information about familiarity with interventions and the perceived helpfulness of interventions for ASD will be presented first. Responses from open-ended questions will be presented second.

Research Question One: Which interventions are familiar to survey participants?

The first research question was “Which interventions are parents/caregivers and ASD professionals familiar with?” The term “familiar with” meant “having a knowledge/awareness of” versus the actual “use of” such interventions. Seven hundred and five parents/caregivers responded to this question. Four hundred and thirty six professionals responded to this question.

The survey listed the interventions for ASD grouped by categories Simpson identified

for evaluating the effectiveness of particular interventions: Scientifically-Based Practices, Promising Practices, Limited Supporting Information for Practice, and interventions which were Not Recommended (Table 1). Participants were instructed to fill in the bubbles of all the interventions they were familiar with.

Research Question Two: Do survey participants perceive the intervention as being helpful for children and youth with ASD?

The second research question was “How do parents/caregivers and ASD professionals perceive the helpfulness of specific ASD interventions?” Participants need not have tried any of the interventions to answer this set of questions. They only needed to be familiar with the intervention. The survey instructed participants to: “Fill in the bubble of the response that best indicates the extent to which you agree or disagree with each statement. If you are not familiar with an intervention, fill in the ‘N/A’ response.”

An example of questions regarding the perceived helpfulness of an intervention is as follows: “Applied Behavior Analysis Approaches are helpful”. Participants were asked to fill in the bubble of the response that best indicates the extent to which they agreed or disagreed with the statement. Response choices were: “Strongly Disagree”, “Disagree”, “Neutral”, “Agree”, “Strongly Agree”, and “N/A”. In order to calculate a mean score, these responses were assigned numerical values (i.e., Strongly Disagree=1, Disagree=2, Neutral=3, Agree=4, Strongly Agree=5). “N/A” responses were not included in the calculation of mean scores.

A total of 1141 participants responded to the set of questions related to the perceived helpfulness of each intervention. Seven hundred and five were parents/caregivers and 436 were professionals.

The data in Tables 2 through 6 informs the reader about:

- How familiar participants were with each intervention for ASD;
- The perceived helpfulness of the intervention for ASD;
- Differences in familiarity and perceived helpfulness of interventions for ASD between parents/caregivers and professionals;
- And, whether survey participants recognized Scientifically-Based or Promising Practices interventions for ASD more often than they recognized interventions with Limited Supporting Information for Practice and interventions Not Recommended for children and youth who have ASD.

Participants’ Familiarity with and Perceived Helpfulness of Interventions for ASD (Tables 2-6)

Familiarity with Skills-Based Strategies (Table 2)

Table 2 shows the percentage of parents/caregivers and professionals who were familiar with each Skills-Based Intervention for ASD and the percentage of individuals who found each specific intervention helpful. It also labels each intervention according

to the evaluation practice classification described by Simpson et al. – Scientifically-Based, Promising Practice, Limited Supporting Information for Practice, interventions Not Recommended - and interventions not classified by Simpson et al (2005).

A review of Table 2 reveals the following:

- *Familiar vs. Helpful Interventions*
 - The group which found Skills-Based interventions familiar (professionals) were also more likely to find the intervention helpful, except for Facilitated Communication (an intervention not recommended) and Fast ForWord (an intervention not classified by Simpson et al).
 - Parents, caregivers, and professionals agreed that the following 6 interventions were helpful for children who have ASD (Table 2, “All” column, mean score of 4.0 or higher) – listed in order of how strongly participants agreed that the intervention was helpful (a mean score of 5.0 indicates “strongly agree”; a mean score of 4.0 indicates “agree” that an intervention is helpful):
 - Applied Behavior Analysis (mean score = 4.28)
 - Assistive Technology (mean score = 4.24)
 - Picture Exchange Communication Systems (mean score = 4.20)
 - Incidental Teaching (mean score = 4.07)
 - Discrete Trial Training (mean score = 4.06)
 - Video Modeling (mean score = 4.02)
- *Parents/Caregivers vs. Professionals*
 - Professionals were more familiar with *every* intervention listed on Table 2 (Skills-based Strategy) than parents and caregivers were
 - Parents/caregivers and professional alike were *most* familiar with Applied Behavior Analysis (81%), a Scientifically-Based practice
 - Both parents/caregivers and professionals alike were *least* familiar with Van Dijk Curricular Approach (2.6%), an intervention with Limited Supporting Information for Practice
- *Scientifically-Based and Promising Practice vs. Limited Supporting Information for Practice and Interventions Not Recommended and Interventions Not Classified by Simpson et al.*
 - Parents, caregivers, and professionals alike agreed that only interventions which were Scientifically-based or interventions with Promising Practice were helpful for children with ASD (i.e., mean score for “All” was 4.0 or higher for at least one intervention in the group of Scientifically-based or Promising Practice interventions); This statement excludes Video Modeling which was not classified by Simpson et al.

- Of the Scientifically-based interventions, parents and caregivers were most familiar with ABA (76.4%), followed by Discrete Trail Training (30.7%), and Pivotal Response Training (8.2%). The same pattern of familiarity with Scientifically-based interventions was observed for professionals (88.3%, 62.9%, and 32.7% respectively)
 - However, more than twice as many professionals were familiar with 2 of the 3 scientifically-based interventions than parents and caregivers were
 - More than twice as many professionals were familiar with Discrete Trail Training than parents and caregivers were (62.9% vs. 30.7%)
 - More than 4 times as many professionals were familiar with Pivotal Response Training than parents and caregivers were (32.7% vs. 8.2%)
 - More professionals were familiar with Applied Behavior Analysis than parents and caregivers were (88.3% vs. 76.4%)
- Of the Promising Practice interventions, parents and caregivers were most familiar with PECS (65.9%), followed by TEACCH (41.6%), Assistive Technology (41.3%), Incidental Teaching (12.8%), and Joint Action Routine (3%). Professionals were most familiar with PECS (80.3%), followed by Assistive Technology (67%), TEACCH (59%), Incidental Teaching (47.4%), and Joint Action Routine (10.1%)
 - More than 4 times as many professionals were familiar with Incidental Teaching than parents and caregivers were (47.4% vs. 12.8%)
 - More than 3 times as many professionals were familiar with Joint Action Routine than parents and caregivers were (10.1% vs. 3%)
- Of the interventions with Limited Supporting Information:
 - Professionals were more familiar with Fast ForWord than parents and caregivers were (18.8% vs. 13.6%)
 - Six times as many professionals were familiar with Van Dijk Curricular Approach than parents and caregivers were (5.5% vs. 0.9%)
- Nearly 44% of all professionals were familiar with Facilitated Communication, an intervention which is Not Recommended for individuals with ASD; In contrast, only 26% of parents and caregivers were familiar with this intervention
 - Twice as many participants (parents/caregivers and professionals) were familiar with Facilitated Communication - an intervention Not Recommended for ASD - than they were with Pivotal Response Training - a Scientifically-Based intervention - (32.8% vs. 17.6%)

Table 2. Survey participant familiarity with and perceived helpfulness of **Skills-Based Interventions** for ASD as categorized by Simpson et al. (2005) ([Click here for the table in HTML](#))

	Parents/caregivers		Professionals		All	
	Familiar (%)	Helpful (mean score)	Familiar (%)	Helpful (mean score)	Familiar (%)	Helpful (mean score)
Scientifically-Based						
Applied Behavior Analysis	76.4	4.20	88.3	4.38	81.0	4.28
Discrete Trail Training	30.7	3.97	62.9	4.14	43.0	4.06
Pivotal Response Training	8.2	3.57	32.7	3.97	17.6	3.80
Promising Practice						
Picture Exchange Communication Systems	65.9	4.10	80.3	4.30	71.4	4.20
Assistive Technology	41.3	4.18	67.0	4.30	51.2	4.24
TEACCH/Structured Teaching	41.6	3.79	59.0	4.07	48.3	3.92
Incidental Teaching	12.8	3.81	47.4	4.29	26.0	4.07
Joint Action Routine	3.0	3.43	10.1	3.86	5.7	3.65
Limited Supporting Information for Practice						
Van Dijk Curricular Approach	0.9	3.11	5.5	3.32	2.6	3.21
Not Recommended						
Facilitated Communication	25.9	3.49	43.9	2.60	32.8	3.02
Not Classified by Simpson et al						
Video Modeling	20.2	3.99	38.7	4.05	27.3	4.02
Fast ForWord	13.6	3.45	18.8	3.25	15.6	3.36
SCERTS	5.0	3.35	20.8	3.65	11.0	3.52

Familiarity with Cognitive Intervention Strategies (Table 3)

Table 3 shows the percentage of parents/caregivers and professionals who were familiar with each Cognitive Intervention for ASD and the percentage of individuals who found each intervention helpful. It also labels each intervention according to the evaluation practice classification described by Simpson et al. – Scientifically-Based, Promising Practice, and Limited Supporting Information for Practice.

A review of Table 3 reveals the following:

- *Familiar vs. Helpful Interventions*
 - Professionals were more familiar with every Cognitive Intervention than parents and caregivers were and also perceived every Cognitive Intervention more helpful than parents/caregivers did
 - Parents, caregivers, and professionals agreed that the following 4 interventions were helpful for children who have ASD (Table 3, “All” column, mean score of 4.0 or higher) – listed in order of perceived helpfulness (a mean score of 5.0 indicates “strongly agree”; a mean score of 4.0 indicates “agree” that an intervention is helpful):
 - Social Stories (mean score = 4.19)
 - Social Decision-Making Strategies (mean score = 4.10)
 - Cognitive Behavioral Modification (mean score = 4.09)
 - Cognitive Learning Strategies (mean score = 4.05)

- *Parents/Caregivers vs. Professionals*
 - Professionals were more familiar with every intervention listed on Table 3 (Cognitive Interventions) than parents/caregivers were
 - Parents/caregivers and professionals alike were *most* familiar with Social Story (69.5%), a Promising Practice
 - Parents and caregivers were *least* familiar with Power Cards (7.7%), an intervention not classified by Simpson
 - Professionals were *least* familiar with LEAP (18.8%), a Scientifically-based intervention

- *Scientifically-Based and Promising Practice vs. Limited Supporting Information for Practice*
 - LEAP was the only Scientifically-based Cognitive Intervention and only 13% of all participants were familiar with this intervention (Table 3, “All” column):
 - Twice as many professionals were familiar with LEAP than parents and caregivers were (18.8% vs. 9.4%)
 - Professionals were only slightly more familiar with Power Cards, an intervention with limited supporting information for practice,

than they were with LEAP (21.1% vs. 18.8%)

- Parents, caregivers, and professionals were in agreement that *only* the interventions with Promising Practice were helpful for children with ASD (Table 3, “All” column, mean score of 4.0 or higher)
 - Of the Promising Practice interventions, parents and caregivers were most familiar with Social Story (63.6%), followed by Cognitive Behavior Modification (34.8%), Social-Decision-Making Strategies (19.9%), and Cognitive Learning Strategies (17.8%). Professionals were most familiar with Social Story (78.9%), followed by Cognitive Behavior Modification (57%), Cognitive Learning Strategies (42.1%), and Social Decision-Making Strategies (35%)

- Professionals were more familiar with the group of interventions with Limited Support than parents and caregivers were
 - More professionals were familiar with Cartooning than parents and caregivers were (25.9% vs. 15.6%)
 - Nearly three times as many professionals were familiar with Cognitive Scripts than parents and caregivers were (28.8/% vs. 10.4%)

Table 3. Survey participant familiarity with and perceived helpfulness of **Cognitive Interventions** for ASD as categorized by Simpson et al (2005) ([Click here for the table in HTML](#))

	Parents/caregivers		Professionals		All	
	Familiar (%)	Helpful (mean score)	Familiar (%)	Helpful (mean score)	Familiar (%)	Helpful (mean score)
Scientifically-Based						
Learning Experiences: An Alternative Program for Preschoolers and Parents	9.4	3.75	18.8	3.88	13.0	3.81
Promising Practice						
Social Stories	63.6	4.11	78.9	4.31	69.5	4.19
Cognitive Behavioral Modification	34.8	4.07	57.0	4.12	43.3	4.09
Cognitive Learning Strategies	17.8	4.02	42.1	4.09	27.1	4.05
Social Decision-Making Strategies	19.9	4.07	35.0	4.14	25.7	4.10
Limited Supporting Information for Practice						
Cartooning	15.6	3.67	25.9	3.69	19.5	3.68
Cognitive Scripts	10.4	3.70	28.8	3.90	17.4	3.80
Power Cards	7.7	3.51	21.1	3.68	12.8	3.60

Familiarity with Physiological/Biological/Neurological Interventions (Table 4)

Table 4 shows the percentage of parents/caregivers and professionals who were familiar with each Physiological/Biological/Neurological Intervention for ASD and the percentage of individuals who found each intervention helpful.

A review of Table 4 reveals the following:

- *Familiar vs. Helpful Interventions*
 - Parents, caregivers, and professionals alike were *most* familiar with Sensory Integration - 74.4% were familiar with the intervention (Table 4, “All” column)
 - Parents, caregivers and professionals alike were *least* familiar with Scotopic Sensitivity Training – 9.9% were familiar with the intervention (Table 4, “All column)

- Parents, caregivers, and professionals all agreed that *only one* Physiological/Biological/Neurological Intervention was helpful for children and youth with ASD – Sensory Integration (mean score = 4.21; Table 4, “All” column)
- Parents/Caregivers vs. Professionals
 - Parents/caregivers and professionals appear to be almost equally familiar with Sensory Integration Therapy - 73.2% of parents/caregivers vs. 76.4% of professionals
 - With the exception of Sensory Integration and Scotopic Sensitivity Training, parents and caregivers were *equally or more* familiar with the category of Physiological/Biological/Neurological Interventions than professionals were
- Promising Practice vs. Limited Supporting Information for Practice and Interventions Not classified by Simpson et al.
 - Only Sensory Integration – the only Promising Practice intervention – was scored as being helpful for children with ASD (mean score = 4.21)
 - Of the interventions with Limited Supporting Information:
 - Parents and caregivers were most familiar with Diet Therapy (60.1%), followed by herbs, minerals, and other supplements (49.6%), Megavitamin Therapy (33.8%), and Scotopic Sensitivity Training (5.7%). This pattern was also observed for professionals (53.1%, 38.7%, 27.2%, and 16.7% respectively)
 - Three times as many professionals were familiar with Scotopic Sensitivity Training than parents and caregivers were (16.7% vs. 5.7%)
 - Only about half of all parents/caregivers and professionals were familiar with medications as an intervention not classified by Simpson (55.8% of parents/caregivers and 48.7% of professionals); Both groups were only slightly more familiar with Diet Therapy (60.1% of parents/caregivers and 53.1% of professionals)

Table 4. Survey participant familiarity with and perceived helpfulness of **Physiological/Biological/Neurological Interventions** for ASD as categorized by Simpson et al (2005) ([Click here for the table in HTML](#))

Promising Practice	Parents/caregivers		Professionals		All	
	Familiar (%)	Helpful (mean score)	Familiar (%)	Helpful (mean score)	Familiar (%)	Helpful (mean score)
Sensory Integration	73.2	4.36	76.4	3.99	74.4	4.21
Limited Supporting Information for Practice						
Herb, Mineral, and Other Supplements	49.6	3.83	38.7	2.99	45.4	3.51
Megavitamin Therapy	33.8	3.50	27.2	2.74	31.3	3.20
Scotopic Sensitivity Training	5.7	3.35	16.7	2.90	9.9	3.10
Not Classified by Simpson et al						
Diet Therapy	60.1	3.73	53.1	3.24	57.4	3.53
Medications	55.8	3.60	48.7	3.55	53.1	3.58

Familiarity with Interpersonal Relationship Interventions (Table 5)

Table 5 shows the percentage of parents/caregivers and professionals who were familiar with each Interpersonal Relationship Interventions for ASD and the percentage of individuals who found each intervention helpful.

A review of Table 5 reveals the following:

- *Familiar vs. Helpful Interventions*
 - In general only half of everyone who responded to either the parent/caregiver or professional survey were familiar with the entire category of Interpersonal Relationship Interventions for ASD - the highest percentage for all participants was 49.4% who were familiar with Floor Time (Table 5, “All” column)
 - Parents, caregivers and professionals alike were *most* familiar with Floor Time (49.4%)
 - Parents, caregivers and professionals alike were *least* familiar with Gentle Teaching (11%; Table 5, “All” column), an intervention with Limited Supporting Information for Practice
 - Parents, caregivers, and professionals agreed on only one intervention as being helpful for children and youth with ASD – Play-oriented strategies, a Promising Practice (mean score = 4.12; Table 5, “All” column)

- Parents/Caregivers vs. Professionals
 - Professionals were more familiar with nearly every Interpersonal Relationship Intervention than parents and caregivers were; Parents, caregivers and professionals were equally familiar with Pet/Animal Therapy - 35.4% of parents and caregivers and 35.2% of professionals were familiar with this intervention
 - Even though professionals were more familiar with nearly every Interpersonal Relationship Intervention (e.g., excluding pet/animal therapy) than parents and caregivers were, parents and caregivers consistently reported every intervention as being helpful when compared to professionals

- Promising Practice vs. Limited Supporting Information for Practice and Interventions Not Recommended
 - More professionals were familiar with Play-oriented Strategies - the only Promising Practice - than parents/caregivers were (54.5% vs. 34.1%). However, parents, caregivers, and professionals almost equally ranked this intervention as being helpful (mean score = 4.14 vs. mean score = 4.11, respectively)
 - Of the interventions for ASD with Limited Supporting Information, Floor Time was *most* widely recognized by parents, caregivers and professionals (49.4%; Table 5, "All" column)
 - However, professionals were nearly *equally* as familiar with Floor Time (an intervention with Limited Supporting Information) as they were with Play-oriented Strategies (a Promising Practice) (55.1% vs. 54.5%)
 - Parents, caregivers and professionals were nearly *equally* familiar with Pet/Animal Therapy (35.4% and 35.2% respectively) and The Son-rise Program (20% and 23.1% respectively)
 - Professionals were more familiar than parents and caregivers were with Relationship Development Intervention (39.8% of professionals vs. 23.2% of parents and caregivers) and Gentle Teaching (18.5% of professionals vs. 6.4% of parents and caregivers)
 - Nearly 1 in every 5 parents/caregivers (19%) and 1 in every 4 professionals (24.5%) reported familiarity with Holding Therapy, an intervention which is Not Recommended for children and youth with ASD, according to Simpson's evaluation of interventions and treatments for ASD

Table 5. Survey participant familiarity with and perceived helpfulness of **Interpersonal Relationship Interventions** for ASD as categorized by Simpson et al (2005) ([Click here for the table in HTML](#))

Promising Practice	Parents/caregivers		Professionals		All	
	Familiar (%)	Helpful (mean score)	Familiar (%)	Helpful (mean score)	Familiar (%)	Helpful (mean score)
Play-oriented Strategies	34.1	4.14	54.5	4.11	41.9	4.12
Limited Supporting Information for Practice						
Floor Time	45.9	3.98	55.1	3.68	49.4	3.84
Pet/Animal Therapy	35.4	4.03	35.2	3.95	35.3	3.84
Relationship Development Intervention	23.2	3.94	39.8	3.70	29.5	3.83
Son-Rise Program	20.0	3.10	23.1	2.74	21.2	2.94
Gentle Teaching	6.4	3.55	18.5	3.16	11.0	3.36
Not Recommended						
Holding Therapy	19.0	3.17	24.5	2.39	21.1	2.78

Familiarity with Other Interventions for ASD (Table 6)

Table 6 shows the percentage of parents/caregivers and professionals who were familiar with each of the Other Interventions for ASD as categorized by Simpson et al and interventions not classified by Simpson et al.

A review of Table 6 reveals the following:

- *Familiar vs. Helpful Interventions*
 - Parents, caregivers, and professionals alike were *most* familiar with speech/language therapy as an intervention for children and youth with ASD - 81% were familiar with this therapy (Table 6, “All” column)
 - Parents, caregivers, and professionals were *least* familiar with Residential Facilities as an intervention for children who have ASD - 24% (Table 6, “All” column); In terms of therapies, parents, caregivers, and professionals alike were *least* familiar with Vocational Skills Training – an intervention not classified by Simpson - (31.5%) and Art Therapy – an intervention with limited supporting information for practice (31.6%)

- Parents, caregivers, and professionals agreed that the following interventions were helpful for children who have ASD (e.g., mean score of 4.0 indicates “agree” and 5.0 indicates “strongly agree” that the intervention is helpful):
 - Speech/Language Therapy (mean score = 4.52)
 - Social Support and Training (mean score = 4.50)
 - In-Home Therapy (mean score = 4.46)
 - Occupational Therapy (mean score = 4.45)
 - Diagnostic Evaluation (mean score = 4.38)
 - Vocational Skills Training (mean score = 4.30)
 - Physical Therapy (mean score = 4.24)

- Parents/caregivers vs. Professionals
 - Professionals were more familiar than parents with every “Other” intervention and interventions not classified by Simpson except Speech/Language Therapy (86.1% of parents vs. 72.8% of professionals were familiar with this intervention) and Occupational Therapy (79.5% of parents vs. 65.9% of professionals were familiar with this intervention)
 - Parents, caregivers and professionals were equally likely to agree that Speech/Language Therapy was helpful for children and youth with ASD (mean score = 4.52 for both groups)
 - Parents and caregivers were only slightly more likely to agree that Occupational Therapy was helpful for children and youth with ASD (mean score = 4.49 for parents/caregivers vs. mean score = 4.39 of professionals)

 - Professionals were more familiar with Music Therapy, Art Therapy, and Physical Therapy than parents but parents were more likely to agree that these interventions were helpful for children with ASD

- Limited Supporting Information for Practice and Interventions not classified by Simpson et al.
 - Of the 2 interventions with Limited Supporting Information, more professionals were more familiar with Music and Art Therapy but parents were more likely to agree that these interventions were helpful for children with ASD

 - Familiarity of interventions not classified by Simpson et al varied by parents/caregivers and professionals:
 - Speech/Language Therapy, Occupational Therapy, In-home Therapy, and Physical Therapy were most widely recognized by more than half of all parents/caregivers and professionals (81%, 74.3%, 61%, and 52.5% respectively; Table 6, “All” column)

- Less than half of parents/caregivers and professionals were familiar with the remaining interventions not classified by Simpson (Table 6, “All” column). Of all participants surveyed:
 - 43.5% were familiar with Diagnostic Evaluation as an intervention for ASD
 - 37.7% were familiar with Social Support and Training as an intervention for ASD
 - 31.5% were familiar with Vocational Skill Training as an intervention for ASD
 - 24% were familiar with Residential Facilities as an intervention for ASD

Table 6. Survey participant familiarity with and perceived helpfulness of **Other Interventions** for ASD as categorized by Simpson et al (2005) ([Click here for the table in HTML](#))

	Parents/caregivers		Professionals		All	
	Familiar (%)	Helpful (mean score)	Familiar (%)	Helpful (mean score)	Familiar (%)	Helpful (mean score)
Limited Supporting Information for Practice						
Music Therapy	51.1	4.10	56.1	3.77	53.0	3.96
Art Therapy	25.9	3.89	40.7	3.54	31.6	3.73
Not Classified by Simpson et al						
Speech/Language Therapy	86.1	4.52	72.8	4.52	81.0	4.52
Occupational Therapy	79.5	4.49	65.9	4.39	74.3	4.45
In-Home Therapy	56.1	4.42	68.9	4.51	61.0	4.46
Physical Therapy	47.7	4.33	60.2	4.14	52.5	4.24
Diagnostic Evaluation	41.1	4.34	47.4	4.44	43.5	4.38
Social Support and Training	28.7	4.45	52.2	4.56	37.7	4.50
Vocational Skill Training	23.7	4.22	43.9	4.38	31.5	4.30
Residential Facilities	16.3	3.31	36.4	3.50	24.0	3.41

Responses to Open-ended Questions

Parents and Caregivers

Parents and caregivers were asked to respond to open-ended questions related to barriers or issues which limited their ability to seek the best services for their child and barriers or issues which limited their ability to implement specific strategies or interventions for ASD at home. Analysis of written responses revealed several themes including barriers related to: (1) cost of services (2) availability of services (3) quality of services provided (4) time required to access services (e.g., travel time) and (5) limited information regarding services and interventions for their children. Parents and caregivers said that not having enough information about the quality of interventions as well as what those interventions can be expected to do makes it difficult for them to know where to go, how to access needed services and determine which services and interventions are most appropriate for their children.

Cost, Access to Care, Lack of Information and Limited Number of Qualified Professionals are Barriers for Parents and Caregivers

Responses from parents and caregivers support the commonly held belief that families overwhelmingly struggle with issues of cost of services, availability of services, and the quality of services provided.

Parents and caregivers routinely said that they spent enormous amounts of money for private therapy and ASD interventions. Many parents seek additional treatment beyond what is supplied by the public school system and most describe the cost as being “very difficult” given the typical family budget. One family said they spent \$5,000 per month for Applied Behavioral Analysis, Speech Therapy, Occupational Therapy, and other therapies and interventions. Other families cited insurance as helpful but stated that high co-payments make treatment almost impossible to pay for.

“Cost of treatment is a huge barrier. Her speech therapy was not covered for a long time by our private insurances; it is now, but our co-pays are high. Another barrier is getting her to speech, as time away from work is needed and not being paid for the time away from work hurts our budget.” - Parent/Caregiver

“Services are too difficult to get...the paperwork, interviews, appointments, and waiting. Service providers need to remember that we have autistic children and the jumping through hoops is too hard (and)...services are not always available to all ages.” - Parent/Caregiver

In addition to the high cost of interventions, parents and caregivers indicated that the lack of available, quality services was tremendously frustrating. They described long drives to therapy sessions, overwhelming amounts of paperwork for registration, and a total lack of available intervention service providers in different areas of the state. Families also reported that services in their area often did not fit the needs of their child. Moreover, many parents and caregivers explained that even when services were accessible, the quality of the service was disappointing. They also said they had no way of evaluating the service other than through trial and error.

"Nothing would keep me from seeking the best services available for my child. What keeps me from finding the best services available is lack of generous information about the services available to ALL parents of autistic children. If I am getting any services it is because I found out about something and asked for it. I am still finding out about things that I should have been told about from day 1. It is very frustrating for parents... and for those parents who don't have the heart to fight and who trust the system to care...it is impossible. Those children will be swept under the rug and ignored." - Parent/caregiver

Responses to open-ended questions also suggested that parents and caregivers struggle with finding meaningful information they can use to find appropriate interventions for their children. Parents and caregivers also said it was hard to find qualified personnel to provide services for ASD. They said they often sought information concerning interventions from friends and acquaintances, the internet, or other

informal systems. Parents and caregivers reported feeling overwhelmed by the vast amounts of information available and by conflicting opinions concerning the usefulness of different interventions for ASD. They expressed feelings of isolation, confusion, and a sense that they were "left to do it alone." Overall, many families felt a sense of frustration in choosing an intervention for ASD for their child because they had no real way to measure the quality of the different interventions for ASD.

In-home training was mentioned by many families as a tremendous support in their effort to learn to assist their child with ASD. However, many expressed concern about the limited amount of training time they received and described the need for more. Other parents and caregivers indicated that they had abandoned interventions at home because of a lack of qualified In-home trainers, conflicts with their work schedule, or excessive costs of the intervention. They reported feeling desperate with regards to handling their child's day-to-day needs and anguished over the lack of progress they observed with In-home training.

"The fact that I have two children, a business to run, only so many hours in the day, a house to take care of, and no idea where to start or what to do...I honestly don't know what to do at home." - Parent/caregiver

Professionals

Lack of Time and Cost of Training are Barriers for Professionals to Obtain More Information about Interventions for ASD

Professionals also responded to open-ended questions. When asked what they would do to improve the service delivery system for individuals and families living with ASD, professionals suggested the following improvement strategies: (1) need for greater funding (2) smaller caseloads (3) better training (4) increased availability and use of Evidence-based Practices (5) increased availability of services (6) improved coordination between services delivery systems and (7) better pay and benefits for staff working with ASD.

Professionals also described the need for society to understand that children and youth

who have ASD are different from their peers who do not have ASD. They suggested that all facets of society - including the medical and mental health community, families, educators, and people in general - must learn more about ASD. Professionals also suggested that education of Evidence-based practices be at the forefront of ASD initiatives and cited the need for increased access to interventions for ASD for families. They further said that interventions - above and beyond what is offered in the public school system - should be offered to families at an affordable price and should be provided in every community. Finally, many professionals identified their own need for increased information and training concerning interventions for ASD but cited time and cost as barriers to obtaining them.

Discussion

Whereas Tables 2 through 6 sort interventions for ASD by practice (e.g., Skills-based, Cognitive, Physiological/Biological/Neurological, Interpersonal Relationship, or Other), Table 7 sorts interventions for ASD by evaluation of the therapy or strategy (e.g., Scientifically-based, Promising Practice, Limited Supporting Evidence for Practice, Not Recommended, or Not Classified by Simpson et al.). Tables 2 through 7 will be referenced in the discussion below to describe differences in familiarity and helpfulness of interventions for ASD observed between parents and professionals.

There is a disparity in overall knowledge of interventions for ASD between parents, caregivers, and professionals

Results from this project clearly reveal that there is great disparity in knowledge of interventions for ASD between parents, caregivers, and professionals (Table 7). Far more professionals were familiar with interventions for ASD than parents and caregivers were. Professionals were familiar with 37 of the 44 interventions observed in this project (84%). In contrast, parents and caregivers were more familiar with only 7 of the 44 interventions observed (e.g., 16% of all interventions listed in Table 7).

Professionals are much more familiar with Scientific-based and Promising Practice interventions for ASD than parents and caregivers are

Not only was there an overall disparity in familiarity with interventions for ASD observed between parents and professionals but there was also a disparity between the types of interventions parents and professionals were familiar with. Professionals were much more familiar with interventions which were defined as having significant and convincing empirical efficacy and support (e.g., Scientifically-based interventions) or methods which had some efficacy for individuals with ASD (e.g., Promising Practice interventions) than parents and caregivers were. Table 7 shows that more professionals were familiar with **every** Scientifically-based and Promising Practice intervention for ASD than parents and caregivers were.

Professionals were also far more likely than parents and caregivers to agree that these 15 interventions - 4 Scientifically-based and 11 Promising Practices - were helpful for children and youth with ASD. Of these 15 interventions, parents and caregivers were only more likely than professionals to agree on the helpfulness of 2 interventions: Play-

oriented Strategies and Sensory Integration. However, upon closer examination, with respect to Play-oriented Strategies, parents and caregivers “scored” only slightly higher than professionals did (parent/caregivers’ mean score = 4.14 vs. professionals’ mean score was 4.36 (e.g., parents and caregivers agreed to nearly strongly agreed that Sensory Integration was helpful for children) compared to professionals whose mean score was 3.99 (e.g., professionals very nearly agreed that Sensory Integration was helpful for children). Even though parents and caregivers perceived these 2 interventions as helpful as professionals did, overall, less parents and caregivers were familiar with Scientifically-based and Promising Practice interventions for ASD than professionals were and were less likely to perceive these interventions as being helpful for their children.

Parents and caregivers are more familiar with interventions which have limited supporting evidence for practice and with interventions not classified by Simpson et al.

More parents than professionals were familiar with the following interventions: (1) Herbs, minerals, and supplements (2) Megavitamin Therapy (3) Pet/Animal Therapy (4) Diet Therapy (5) Medications (6) Occupational Therapy and (7) Speech/Language Therapy. These interventions are categorized as either having Limited Supporting Evidence for Practice or were not classified by Simpson et al.

In addition to being more familiar with these interventions than professionals were, parents were also more likely than professionals were to agree that these interventions were helpful for children and youth with ASD. The question then is: Why were more parents familiar with these particular interventions than professionals were and why did parents perceive these interventions as being helpful more often did professionals did? Additional research may be needed to definitively answer this question but one possible answer may be that these particular interventions are more accessible to parents and caregivers than the other 37 interventions are (Table 7). One could reasonably guess that parents and caregivers are more knowledgeable about these particular interventions for ASD because these interventions are relatively easy to access in the community (e.g., these interventions are more affordable than other interventions, are available in the community, and parents and caregivers can travel relatively short distances to these intervention strategies for ASD). The question then is: Are parent and caregiver knowledge of interventions for ASD associated with access to care? It is not unreasonable to conclude that knowledge of interventions for ASD and access to care are associated.

Parents and caregivers are not sure if interventions which are not recommended for children and youth with ASD are helpful

Data in Table 7 further reveals one more interesting piece of information. Even though more professionals are familiar with Facilitated Communication and Holding Therapy, parents and caregivers were more likely to agree that these interventions were helpful for children with ASD. However, neither of these interventions are recommended for children with ASD according to Simpson's classification scheme (Table 7).

"Parents of children with autism are confronted with raising children who have been identified with a life-long pernicious disability for which there is neither a clear explanation nor a universally accepted course of treatment. When confronted with opportunities and options that purport to lead to significantly improved outcomes, even if the techniques that are being considered lack scientific validation, it is understandable that many parents, as well as numerous professionals who work with these children and youth, are willing to consider and even forcefully advocate for approaches that promise improved outcomes or to restore an individual to normal functioning (Simpson, 2005)."

Even though parents were only "neutral" about the helpfulness of these interventions (e.g., mean score = 3.17 for Holding Therapy and mean score = 3.49 for Facilitated Communication), they still "scored higher" than professionals did with respect to perceived helpfulness of these interventions. Professionals disagreed that either of these interventions were helpful for children with ASD (e.g., professionals' mean score for Holding Therapy was 2.39 and their mean score for Facilitated Communication was 2.60). Even though parent and caregiver scores were "neutral" (e.g., parents neither agreed nor disagreed), they did not disagree (as professionals disagreed) that these interventions lacked efficacy and could potentially be harmful for children with ASD (according to Simpson's classification scheme). This observation supports their responses to open-ended questions regarding confusion about which strongly agreed that Sensory Integration was helpful for children) compared to professionals interventions are helpful for their children.

If highly educated parents and caregivers with resources are confused about interventions for children with ASD, what are other parents doing?

Taken together, results from this project suggest that even families in high socioeconomic status groups (e.g., highly educated, higher median income, and more likely to be married) struggle with the lack of information regarding interventions for children and youth who have ASD. When compared to professionals, parents and caregivers were much less familiar with the range of interventions for ASD. However, given that these parents and caregivers were highly educated and had resources available to them, it was surprising to note the disparity in knowledge between parents and professionals.

Moreover, responses parents and caregivers gave to open-ended questions support the quantitative findings (e.g., Tables 2 through 6) that parents are either less knowledgeable or have less access to Scientific-based and Promising Practice interventions for ASD, or both. Results from this project suggest that knowledge of interventions for ASD may be associated with access to care. That is, the more accessible an intervention is (i.e., herbs, minerals, supplements, megavitamins, pets and animals, diet therapy, medications, occupational, and speech therapy), the more

likely parents and caregivers are to be knowledgeable about the intervention. A follow-up project to evaluate the knowledge and perception of parents of lower socioeconomic status groups may lend support to this idea.

Table 7. Familiarity and helpfulness of interventions by responders ([Click here for table in HTML](#))

	Familiarity		Helpful	
	Parents/caregivers	Professionals	Parents/caregivers	Professionals
Scientifically-Based Practices				
Applied Behavior Analysis		+		+
Discrete Trial Teaching		+		+
LEAP		+		+
Pivotal Response Training		+		+
Promising Practices				
Assistive Technology		+		+
Cognitive Behavioral Modification		+		+
Cognitive Learning Strategies		+		+
Incidental Teaching		+		+
Joint Action Routines		+		+
Picture Exchange Communication Systems		+		+
Play-oriented Strategies		+	+	
Sensory Integration		+	+	
Social Decision-Making Strategies		+		+
Social Stories		+		+
TEACCH/Structured Teaching		+		+
Limited Supporting Evidence for Practices				
Art Therapy		+	+	
Cartooning		+		+
Cognitive Scripts		+		+
Floor Time		+	+	
Gentle Teaching		+	+	
<i>Herbs, Minerals, & Supplements</i>	+		+	
<i>Megavitamin Therapy</i>	+		+	
Music Therapy		+	+	
Option Method (Son-Rise)		+	+	
<i>Pet/Animal Therapy</i>	+		+	
Power Cards		+		+
Relationship Development Intervention		+	+	
Scotopic Sensitivity Syndrome		+	+	
Van Dijk Curricular Approach		+		+
Not Recommended				
Facilitated Communication		+	+	
Holding Therapy		+	+	
Not Classified by Simpson et al				
Diagnostic Evaluation		+		+
<i>Diet Therapy</i>	+		+	
Fast ForWord		+	+	
In-Home Therapy		+		+
<i>Medications</i>	+		+	
<i>Occupational Therapy</i>	+		+	
Physical Therapy		+	+	
Residential Facilities		+		+
SCERTS		+		+
Social Support and Training		+		+
<i>Speech/Language Therapy</i>	+		=	=
Video Modeling		+		+
Vocational Skills Training		+		+
Total (44)	7	37	19	24

"+": Indicates the group with the higher response (%) or higher mean score; "=": Indicates equal mean score; not counted in Total

Summary

Using Simpson's classification of interventions for children and youth with ASD helped the project team clearly identify the types of interventions parents and caregivers in Texas are familiar with (e.g., Scientifically-based, Promising Practice, Limited Supporting Information for Practice, or interventions which were Not Recommended). It also helped define which group was more likely to agree that an intervention was helpful, parents and caregivers or professionals.

"Children and youth with ASD have noticeably poor prognoses compared to other groups of students with disabilities. They also have the dubious distinction of regularly and commonly being exposed to intervention and treatment programs and strategies that lack efficacy and demonstrating relatively poor responses to intervention and treatment efforts (Simpson, 2005)."

Parents and caregivers did not fare as well as professionals did with respect to knowledge about interventions for ASD (e.g., familiarity and perceived helpfulness of interventions for ASD) – an observation which is not very surprising given the parent and caregiver responses to the open-ended questions. However, even though professionals were consistently more knowledgeable than parents and caregivers were, they also expressed a desire for education and training opportunities. Like parents and caregivers, professionals also cited limited time and money as barriers to accessing education and training opportunities for ASD.

In summary, results of this project support parents and caregivers who feel that they are "left to do it alone" because they have no real way to measure the quality of different interventions for ASD. Perhaps this report will help parents, caregivers, and professionals organize the information they have so that they can better prioritize their time, energy, and resources and achieve their goal to help children and youth with ASD realize successful outcomes.

Implications

The findings of this study reveal several critical issues concerning interventions for individuals with ASD in the State of Texas. What do all of these implications mean? The results of this study imply three major themes:

1. Knowledge is needed to accurately evaluate the quality of ASD interventions.
2. Access to the highest quality ASD interventions for all citizens continues to be critical.
3. Attention to the state's ASD Service Delivery System to address the disconnect between Simpson's classifications, professional awareness and parent/caregiver awareness and experiences is imperative.

Knowledge

- The literature does provide an effective method for analyzing the quality of ASD interventions.
 - Simpson's system (2005) for assessing the quality of ASD interventions was selected as it evaluated interventions for two characteristics: the quality of research done and the practical results of the studies.
 - Simpson's research classified many current ASD interventions into four practice categories that describe their effectiveness based on research and practical implications. (Scientifically-based Practices, Promising Practices, Limited Supporting Evidence for Practice, and Not Recommended Practices)
- Responses to the survey suggest that professionals are more familiar with the variety of interventions for ASD but parents/caregivers and professionals were nearly equally likely to perceive ASD interventions as being helpful. However, professionals were more likely than parents and caregivers to perceive scientifically-based and promising practices as being helpful.
 - Both parents/caregivers and professionals need to be able to evaluate the potential quality of an intervention before they spend money on it.
 - Parents/caregivers and professionals should spend their time and money on the highest quality interventions.

Access

- The survey results also indicated that many parents/caregivers and professionals lack access to a variety of the ASD interventions and were unable to respond to questions about their helpfulness.
 - This lack of access and information impacts awareness and acceptance of a variety of interventions as viable strategies for working with students with ASD.
 - Supplying information concerning a wide variety of acceptable, evidence-based interventions will encourage the use many more of these quality strategies.

Service Delivery

- Parents/caregivers and professionals suggested five additional barriers to obtaining quality ASD interventions in the current service delivery system in Texas.
 - Cost of care/lack of insurance coverage
 - Availability of quality interventions and services
 - Access to information about quality interventions and services
 - Lack of qualified professionals
 - Time to access ASD interventions

RECOMMENDATIONS

Recommendation #1

The literature review identified a specific classification system for evaluating the efficacy of many common ASD interventions. Meanwhile, the survey results for parents, caregivers, and professionals indicated that many people are familiar with a variety of these ASD interventions, but lack a mechanism for judging the quality or effectiveness of these interventions. Parents, caregivers, and professionals could utilize the findings of Simpson's (2005) study to guide their decision making but a more formal process that includes stakeholders along with experts to produce a systematic procedure for guiding families, schools, and other agencies in selecting and providing appropriate interventions to individuals with ASD would address uncertainty and disparity in intervention and "service and support resources" provision. Therefore, the researchers recommend that TCDD, TCAPDD, and state agencies involve consumers, families, and professionals in fully orienting the ASD care system toward the use of evidence-based interventions by establishing a published standard of care plan for all children with ASD in Texas.

1. Institute a consortium to bring the consumers and major providers together to establish appropriate interventions and/or "service and support resources" for individuals with ASD.
2. Develop a standard of care plan manual to delineate best practice intervention for individuals with ASD to ensure that assessment, diagnosis, and intervention utilize evidence-based practices to provide the best opportunities for successful outcomes.
3. Utilize the standard of care plan to determine the gaps in interventions and/or "service and support resources" and establish a method for closing these gaps.
4. Align relevant state programs to improve access and accountability for ASD interventions and/or "service and support resources."

Recommendation #2

The survey results indicated that some consumers, parents, caregivers, and professionals expressed frustration concerning the shortage of ASD interventions in their particular area. The urban areas with well-developed autism networks identified a number of options. However, people in suburbs and rural areas highlighted the need for interventions and/or "service and support resources" in their area. The researchers recommend to the TCDD, TCAPDD, and state agencies that the State of Texas attempt to eliminate disparities in ASD interventions and/or "service and support resources" by improving access to quality care in all areas of the state including rural and geographically remote areas.

1. Identify the needs of individuals not accessed by the online survey approach by conducting a person-to-person survey in under-represented areas of the state to directly establish gaps in supports.
2. Improve access to quality care that is culturally competent.
3. Promote the use of evidence-based practices for all individuals with ASD.
4. Improve and expand all school ASD programs to utilize evidence-based practices.

Recommendation #3

The survey results underscored the need for professionals to move from familiarity with common ASD interventions to more specific training for implementation of these interventions. Professionals cited the need for more preparation in order to provide effective and efficient therapies for individuals with ASD. Parents also emphasized the need to be informed about the qualifications of various intervention and/or “service and support resource” providers. They expressed their desire for increased availability of a variety of interventions. The researchers recommend to the TCDD, TCAPDD, and state agencies to engage in the State of Texas in improving and expanding the workforce providing evidence-based ASD interventions by creating outcome-based standards training for all professionals.

1. Develop a listing of outcome-based standards specific to assessment, diagnosis, and intervention for individuals with ASD.
2. Utilize outcome-based standards to raise the level of care throughout the state by providing a method for analyzing the knowledge base professionals including health care, mental health care, education, and assessment personnel.
3. Employ a data-driven feedback system for determining the highest quality of care and allow individuals to assess their need for additional training and improvement of their ASD interventions.
4. Advance outcome-based training by using dissemination and demonstration projects created through public-private partnerships across the state to speed their implementation.

Recommendation #4

Many of the survey respondents indicated that access to quality ASD had a tremendous impact on the lives of individuals with ASD. They explained that barriers such as travel time, lack of programming, and the overload of trying to determine appropriate interventions reduced their child’s opportunity for the best possible outcome. They

clarified that they felt they have been left to “do it on their own” and described the need for easier and clearer resources to handling their child’s ASD. The researchers recommend to the TCDD, TCAPDD, and state agencies to encourage the State of Texas to use technology and telehealth to improve access and coordination of ASD care, especially for Texans in remote areas or in underserved populations.

1. Determine needs for particular groups of individuals with ASD including adults, and adolescents.
2. Create a technology link to improve information about interventions for these and other subgroups.
3. Establish a seamless network for people with ASD and their families through the life span.

Recommendation #5

Simpson’s (2005) classification system for evaluating the effectiveness of common ASD interventions remains dependent upon quality research done in a manner that can be replicated and verified. Currently, the State of Texas does not have a Center for Excellence which might help to coordinate and facilitate research efforts at universities across the state. The State of Texas needs to move forward with steps to attain a Center for Excellence. The researchers recommend that TCDD, TCAPDD, and state agencies promote the acceleration of research specifically for the development of a census in the State of Texas to determine the numbers of individuals with ASD in the state in order to carefully plan for their needs now and in the future.

1. Establish the numbers of individuals with ASD in the state as well as a method to continue the count.
2. Use the census data to guide decision making for all areas including service provision, assessment and diagnosis, and long-term care.
3. Employ the census data to establish trends, fill intervention and support intervention and “service and support resource” gaps, and repair breakdowns in service delivery systems.
4. Apply the results of the statewide census to make informed decisions about the needs of consumers, their families, and the professionals who work with them.

NEXT STEPS

Finally, certain next steps for TCDD, TCAPDD, and state agencies are outlined below in order to get the most of the ASD Service Delivery Innovations in Texas Project.

1. Determine the most effective method for disseminating the report from the Autism Spectrum Disorders Service Innovations Project particularly the information concerning how to rate interventions.
2. Establish a method for circulating the Online Resource Directory so that it becomes a useful document for consumers.
3. Create a funding mechanism that will ensure that updates of “service and support resources” submitted through the Online Resource Directory will be added to the resource guide in a timely and efficient manner.

The Service Delivery Innovations for Autism Spectrum Disorders in the State of Texas Project sought to discover both what people know about interventions for ASD and how helpful they felt these interventions are. It also provided information about the barriers people experience when trying to find the right services and supports for their children with ASD. By considering the recommendations of the report and engaging our leadership in addressing these problems, it is hoped that the State of Texas can supply services and supports for individuals with ASD and their families that will provide the best possible outcomes for adulthood for each child with ASD.

References

Heflin, L.J., & Alaimo, D.F. (2007). *Students with autism spectrum disorders. Effective instructional practices*. Upper Saddle River, NJ: Pearson/Merrill/Prentice Hall.

Lord, C., Cook, E.H., Leventhal, B., & Amaral, D.G. (2000). Autism spectrum disorders. *Neuron*, 28, 355-363.

Lord, C., & Paul, R. (1997). Language and communication in autism. In D. Cohen & R. Volkmar (Eds.), *Handbook of autism and pervasive developmental disorders* (2nd ed., pp. 195-225). New York: Wiley.

Simpson, R.L. (2005). Evidence-based practices and students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 20(3), 140-149.

Appendix A. Description of interventions for children, adolescents, and adults with ASD categorized by Simpson’s hierarchy of interventions.

Scientifically-based Practices

- 1) **Applied Behavior Analysis (ABA) Therapy** – A method of teaching designed to analyze and change behavior in a precisely measurable and accountable manner. Also called behavior modification. A systematic process of studying and modifying observable behavior through a manipulation of the environment. (Skill-based intervention)
- 2) **Discrete Trial Teaching** – A part of ABA therapy. “Discrete trials” refer to the steps that are conducted in an ABA program. The activities or “trials” are conducted with the individual in order to elicit a proper response. These trials are used to teach smaller pieces of a larger activity or task. DDT involves breaking a behavior into the most functional units and presenting the units in a series. (Skill-based intervention)
- 3) **Pivotal Response Training (PRT)** – A type of behavioral intervention therapy emphasizing a naturalistic/inclusive approach in providing children with ASD a broad opportunity to participate and lead a meaningful life. (Skill-based intervention)
- 4) **LEAP (Learning Experiences: An Alternative Program for Preschoolers & Parents)** - This approach consists of two components comprising a typical preschool curriculum and the other specifically designed for children with autism. (Cognitive intervention)

Promising Practices

- 1) **Picture Exchange Communication System** – This system teaches children and adults to communicate by pointing to a picture of desired items in order to bridge the communication gap between nonverbal and verbal individuals. (Skill-based intervention)
- 2) **Incidental Teaching** – uses a student’s natural environment that has been organized around the student’s area of interest in order to create a cycle for learning that includes watching and listening for the student’s initiation of language, engaging the student in continued interaction, waiting for a second response, supporting the interaction and providing reinforcement. (Skill-based intervention)
- 3) **Structured Teaching** – also know as TEACCH – (Treatment and Education of Autistic Children and related communication Handicapped Children). TEACCH is a teaching method that focuses on a structured environment that provides social cues as to what is going to take place within certain areas of the classroom providing clear and established boundaries for students with ASD. (Skill-based intervention)
- 4) **Augmentative and Alternative Communication (AAC)** – AAC strategies assist individuals with severe communication disabilities. AAC may include the use of

devices that are used in combination with residual speech skills in order to enhance, aid, or supplement natural speech. (Skill-based intervention)

- 5) **Assistive Technology** – The Individuals with Disabilities Act defines AT as “any item, piece of equipment, or product system... that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.” AT devices are used in the educational setting to provide a variety of accommodations or adaptations for people with disabilities. (Skill-based intervention)
- 6) **Joint Action Routine** – A joint action routine (JAR) is a typical interaction between two or more people that is predictable, logical and repeatable over time using a specific strategy to encourage communication skills. The goal of a JAR is to develop spontaneous conversation and increased social understanding through frequent repetition and rehearsal of target language while using a functional or motivating activity. (Skill-based intervention)
- 7) **Cognitive Behavioral Therapy or Cognitive Behavioral Modification** - Seeks to change unproductive thought patterns of the individual by focusing on changing individual thought (cognitive patterns) in order to change behavior or emotional state. (Cognitive intervention)
- 8) **Cognitive Learning Strategies** - These are learning strategies that are explicitly taught to help individuals in the acquisition and mastery of skills. (Cognitive intervention)
- 9) **Social Story** – A short story that describes a situation, concept or social skill using a format meaningful for people with ASD. A process that results in a product for a person with an ASD. (Cognitive intervention)
- 10) **Social Decision-making Strategies** – Social Decision-making strategies are designed to help students analyze and understand social communication and social interactions through a problem-solving and decision-making technique that allows a student to reflect on a problem or situation, offer alternative options and strategies, identify consequences and choose an appropriate course of action. (Cognitive intervention)
- 11) **Sensory Integration Therapy** – Based on the notion that individuals with ASD and other developmental disabilities have abnormal responses to sensory stimuli, sensory integration therapy helps to stimulate development in the deficient sensory areas or realms. The treatment uses a controlled increase or decreased input of sensory stimulation to help the child with the organization of sensory information for on-going use. (Physiological/biological/neurological intervention)
- 12) **Play oriented Strategies** – Play-oriented strategies facilitate play behavior in the three types of play: symbolic, functional, and sociodramatic through adult-mediated instruction and intervention to encourage growth in developmental of socialization and social competence. (Interpersonal Relationship intervention)

Limited Supporting Information for Practice

- 1) **Van Dijk Curricular Approach** – This is an approach based on the goals of developing attachment, senses in relation to the world, skills for structuring the world, & natural communication. (Skill-based intervention)

- 2) **Fast ForWord** - computer software that digitally enhances speech and sounds for struggling readers. (Skill-based intervention)
- 3) **Cartooning – Comic Strip Conversation** – Incorporates the use of simple drawings to illustrate an ongoing conversation. Helps individuals with communication deficits practice and understand the quick exchange of information. Emphasizes what people may say or do and what they may be thinking. Provides insight into perspectives.
- 4) **Cognitive Scripts** - These are the themes that flow habitually through our thoughts that can influence both our emotions and our behavior. They are those things we tell ourselves over and over again, often without conscious awareness. (Cognitive intervention)
- 5) **Power Cards** - This is a visually oriented approach that is designed to support development of appropriate behavior or skill by linking it to an individual's special interest. (Cognitive intervention)
- 6) **Scotopic Sensitivity Syndrome** - Also known as Meares-Irlen syndrome or Irlen syndrome, it is a highly controversial visual perceptual disorder affecting primarily reading and writing based activities. Its existence is not recognized by major medical organizations including the American Academy of Pediatrics, the American Academy of Ophthalmology, and the American Association of Optometry. (Physiological/biological/neurological intervention)
- 7) **Auditory Integration Training** - Also known as AIT. It is based on the assumption that some children with autism may be sensitive to specific sounds or tones. The aim is to readjust the child's auditory processing system. (Physiological/biological/neurological intervention)
- 8) **Megavitamin Therapy** – The therapeutic use of large amount of vitamins (dimethylglycine (DMG) a naturally occurring substance similar to vitamin B, including the eight B vitamins. (Physiological/biological/neurological intervention)
- 9) **Feingold Diet** – The Feingold Diet is a food elimination program initially developed by Ben F. Feingold, MD to treat the symptoms of Attention Deficit Hyperactivity Disorder (ADHD). By eliminating certain artificial colors, flavors substances, preservatives and other items, Feingold reports changes in the behaviors of individual with ADHD and, more recently, autism. The Feingold Diet represents one of several different diets proposing to impact the symptoms of ASD. (Physiological/biological/neurological intervention)
- 10) **Herb, Mineral and Other Supplements** –Herb, Mineral and Other Supplements – Vitamin and mineral supplements may improve the symptoms of autism in a natural way. While not all researchers agree about whether these therapies are scientifically proven, many parents and an increasing number of physicians report improvement in people with ASD when using individual or combined nutritional supplements to improve mal-absorption problems and nutritional deficiencies, intestinal disorders and chronic gastrointestinal inflammation and disruptions in immune and general metabolic functions. (Physiological/biological/neurological intervention)

- 11) **Gentle Teaching** – This is an intervention based on the principle that children with autism need to be unconditionally accepted by the adults around them. (Interpersonal relationship intervention)
- 12) **Option Method: Son-Rise Program** - It is a relationship-focused intervention developed and implemented by the Autism Treatment Center of America. (Interpersonal relationship intervention)
- 13) **Floor Time** – Referred to as a developmental approach to therapy; Floor time therapy essentially begins working with the child one-on-one through the beginning of the developmental process in order to work on skills the child may have missed during development. (Interpersonal relationship intervention)
- 14) **Pet/Animal Therapy** - involves therapeutic use of pets/animals to provide emotional comfort and positive state of mind. (Interpersonal relationship intervention)
- 15) **Relationship Development Intervention** - It is a parent-based clinical treatment that addresses the core problems faced by all individuals with ASD. Developmental & systematic: a step-by-step program that focuses first on building the motivation so that skills will be used & generalized; followed by carefully and systematically building the skills for competence and fulfillment in a complex world (Interpersonal relationship intervention)
- 16) **Art Therapy** – Art Therapy offers a non-verbal avenue of communication that the child can use to overcome verbal difficulties through gently engaging and developing the child's interest in healthy interpersonal relationships. (Other interventions)
- 17) **Music Therapy** - This approach is based on the belief that music can help decrease stress, provide relief from pain, serve as a focus of attention, and improve interpersonal relationships. (Other intervention)

Not Recommended Practices

- 1) **Facilitated Communication** – A controversial method intended to help people with neurological impairments to use communication aids with their hands. FC is most often used with individuals with developmental disabilities, most commonly autism and Down syndrome. It is also known as the Hand Over Hand method. (Skill-based intervention)
- 2) **Holding Therapy** - This is an approach based on holding a distressed child with the aim of comforting the child. (Interpersonal relationship intervention)

Additional Interventions Not Found in the Simpson's Classification System

- 1) **Video modeling** A teaching technique that uses taped sequences as examples of behavior to assist in the acquisition of verbal and motor responses to enable the child to put long chains of behavior together. (Skill-based)
- 2) **SCERTS** – The SCERTS® model focuses on functional skills in every day activities across settings, and is informed by research on the unique learning style of children with ASD. It is based on research and practice that indicates that educational programming should focus on 1) developing spontaneous, functional communication and secure, trusting relationships with children and adults (Social

Communication), 2) enhancing the ability to maintain a well-regulated emotional state for learning and interacting (Emotional Regulation), and 3) supporting children, their families, and professionals to maximize positive social experiences across home, school and community settings (Transactional Support). (Skilled-based)

- 3) **Medications** –Medications are often used to treat behavioral problems, such as aggression, self-injurious behavior, and severe tantrums that keep the person with ASD from functioning more effectively at home or school. The medications used are those that have been developed to treat similar symptoms in other disorders. Many of these medications are prescribed "off-label." This means they have not been officially approved by the FDA for use in children, but the doctor prescribes the medications if he or she feels they are appropriate for a child. (Physiological, Biological, Neurological)
- 4) **In-home Therapy** – A variety of interventions for ASD that are administered in the home setting and that also include parental training for the intervention as well. (Other)
- 5) **Vocational Skill Training** – Vocational Skills Training – Vocational skills training includes employment skills training, life skills training, educational and community opportunities, individual job counseling, job development and placement, on the job training, follow-up support in supported & competitive job placements. (Other)
- 6) **Speech Therapy** – Speech therapy for individuals with ASD focuses a variety of areas including non-verbal communication, speech pragmatics, conversation skills, and concept skills. Speech therapy occurs for children across the autism spectrum. (Other)
- 7) **Occupational Therapy** – Occupational therapy has developed techniques for working on appropriately responding to information coming through the senses, facilitating play activities that instruct as well as aid a child in interacting and communicating with others, devising strategies to help the individual transition from one setting to another, from one person to another, and from one life phase to another, and developing adaptive techniques and strategies to get around apparent disabilities. (Other)
- 8) **Physical Therapy** – Physical therapists may work with very young children on basic motor skills such as sitting, rolling, standing and playing. They may also work with parents to teach them some techniques for helping their child build muscle strength, coordination and skills. As children grow older, physical therapists may work on more sophisticated skills such as skipping, kicking, throwing and catching. These skills are not only important for physical development, but also for social engagement in sports, recess and general play as well as the social aspects of physical skills. (Other)