



Published in final edited form as:

*Focus Autism Other Dev Disabl.* 2013 September 1; 28(3): 138–146. doi:10.1177/1088357612468028.

## Child and family characteristics influencing intervention choices in autism spectrum disorders

Elena Patten\*, Grace T. Baranek, Linda R. Watson, and Beth Schultz

University of North Carolina at Chapel Hill

### Abstract

A myriad of treatment options are available for children with autism, yet little is understood regarding characteristics of parents (e.g., education) and children (e.g., severity of autism symptoms) that influence types and amounts of therapy utilization. Interviews from 70 families were analyzed to determine potential influences on utilization (e.g., start of first services, use of traditional services). Descriptive findings regarding therapy types were similar to national studies. However, only three of the variables predicted utilization of specific therapies: severity of sensory processing problems was associated with earlier initiation of services in general, and higher maternal and paternal education was associated with the use of dietary and/or vitamin therapy as well as with more types of services. No other variables had predictive value; thus, the amount and type of therapies received may be more related to diagnostic practices and/or to the affordances/constraints of service delivery and reimbursement systems at particular ages.

### Keywords

autism; sensory; therapy; intervention; services

### Introduction

The annual societal cost for caring for and treating people with autism in the U.S. is currently estimated at \$35 billion. Direct costs such as physician and outpatient services, prescription medication, behavioral therapies, special education and child care average \$67,000 to \$72,000 per person per year (Ganz, 2006). Indeed, therapies addressing special needs in individuals with autism are widely varied and often costly. Parents are confronted with myriad decisions regarding the type and intensity of services their child should or is eligible to receive. Although hundreds of services have been implicated in the treatment of autism (Green, Pituch, Itchon, Choi, O'Reilly, & Sigafos, 1999), on average, each child receives approximately seven services at any given time. Services tend to fall roughly into categories such as educational, therapeutic and social support (Green et al., 1999; Kohler, 1999), yet little is understood about child or family characteristics influencing utilization of therapeutic interventions. Understanding relationships between service utilization and characteristics of families and children can help us discover potential differences that may or may not be beneficial for child and family outcomes. The growing body of evidence-based practices can be mapped onto service consumption to determine whether treatments that are recommended and selected match evidence-based recommendations. If a discrepancy exists, it is important to determine the reasons so that interventionists can guide families to services based on research efficacy, family values and clinical wisdom. Further, with government

\*Contact Information: Elena Patten, Department of Communication Sciences and Disorders, University of North Carolina, Greensboro, 300 Ferguson Building, 27412-6170, voice: 336-334-4657, fax: 336-334-4475, e\_patten@uncg.edu.

funding portions of services (e.g., through public schools) understanding how services are utilized may help inform better allocation of resources. Many factors could impact the type and intensity of therapies children with autism receive. Ideally, evidence from well controlled studies would strongly influence selection of therapies; however, many specific interventions have not been rigorously evaluated (Volkmar, Lord, Bailey, Schultz, & Klin, 2004). Recently, the National Standards Project (NAC, 2009) evaluated a total of 38 interventions of which only 11 were identified as having sufficient evidence to be considered effective. These 11 were: antecedent package, behavioral package, comprehensive behavioral treatment for young children, joint attention intervention, modeling, naturalistic teaching strategies, peer training package, pivotal response treatment, schedules, self-management and story-based intervention package. Other treatments were considered emerging (i.e., some support, but insufficient evidence to be confident of their effectiveness) or unestablished (i.e., having no sound evidence). See results of the National Standards Project (NAC, 2009) for detailed results. Thus, families rely on professionals' recommendations, availability of therapeutic interventions within health or educational service delivery systems, and/or word-of-mouth. There is also little evidence to show whether family (e.g., parent education, household income) or child (e.g., severity of autism, race) characteristics influence therapy selection/utilization. The purpose of this paper is to further describe the type and intensity of therapeutic interventions received by children with autism from initiation of first services to 7 years of age, as well as to examine child and family characteristics that may influence therapy utilization.

### **Therapeutic Interventions for the Children with Autism**

There is an immense array of services reported in the treatment of autism. Over 100 treatments were identified through MEDLINE and PsycINFO (Green et al., 2006). These interventions were broadly varied, ranging from self-contained preschool, to therapeutic horseback riding, to chelation therapy. Categorizing therapeutic interventions can be helpful in studying patterns of service utilization, but methods are not universal or consistent across studies, adding to the growing confusion for families and professionals considering utilization of these services. Three issues appeared to account for study differences: (1) specific vs. broad categorization of therapies (e.g., social stories specifically, or social stories embedded into the category of speech-language therapy), (2) lack of clear definitions (e.g., sensory integration versus sensory diet) and, (3) measurement differences in calculating intensity of therapies (e.g., frequency versus duration; individual versus group).

Even with the inherent ambiguity in research regarding interventions, a few trends have clearly emerged. The most commonly reported interventions are educational and therapeutic (Green et al., 2006; Kohler, 1999; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007; Thomas, Morrissey, & McLaurin, 2006). With regard to educational interventions, delineating utilization characteristics becomes more difficult. A national survey of 552 participants revealed applied behavioral analysis (ABA) as the most frequently used educational intervention, but a survey of 383 North Carolina families reported TEACCH as the most commonly used educational intervention (Green et al., 2006; Thomas et al., 2006), suggesting regional biases. Again, specific interventions such as the use of visual schedules were reported on the same frequency table and were reported as occurring more often than ABA (Green et al., 2006); however, visual schedules are commonly used across educational settings, reflecting further ambiguities in delineating consumption of specific services.

Of the traditional therapeutic interventions, speech-language therapy (SLT) is the most common intervention followed by occupational therapy (OT) and then physical therapy (PT) (Kohler, 1999; Thomas et al., 2007). Given that communication deficits comprise one of the core features of autism, high utilization of SLT is not surprising. Communication impairments are manifest in delayed or total lack of spoken language, the inability to sustain

conversation and idiosyncrasies of language such as echolalia. By adolescence and young adulthood, approximately 49% of individuals with autism do not exhibit functional language (i.e., language age below 30 months) (Sigman & McGovern, 2005). Regarding the use of SLT, one study reported 83% of children with autism 8 years and under received SLT in the school setting (Thomas et al., 2007). This same study reported that 64% of these children received OT in the school setting. PT is used in the treatment of autism less frequently than other therapies with estimates being approximately 10% of children receiving PT (Kohler, 1999; Thomas et al., 2007). This is likely because gross motor problems are less commonly identified as an area of need for children with autism.

OT services are often received by children with autism and these services may target a variety of functional problems in daily living and school performance, including impairments in fine motor or play skills (e.g., Kasari, Freeman & Paparella, 2006; Wakeford & Baranek, in press). While not a core feature of autism, sensory processing problems are present in approximately 69% of children with autism (Baranek, David, Poe, Stone, & Watson, 2006). Sensory-based therapies are the most common OT recommendation for children with autism (Hodgetts & Hodgetts, 2007). Some researchers have listed OT separate from sensory-based therapies with sensory-based therapies being endorsed for 21% of children under age 8 (Thomas et al., 2007) and 38% for children in the birth to 14 year range (Green et al., 2006). It should be noted however, that the Green et al. study inadvertently omitted the categories of OT and PT from their list of 108 therapeutic interventions.

Even within the category of sensory-based therapies aimed at normalizing responses to sensory stimuli, a multitude of approaches exists. Baranek (2002) published an efficacy review of sensory-motor therapeutic interventions that classified sensory-based therapies into classical sensory integration therapy (based on the work of Jean Ayers and requiring specialized equipment), sensory-based therapies (e.g., sensory diet, the Alert program), sensory stimulation techniques (e.g., hug machine, deep pressure) and acoustic interventions (e.g., auditory integration therapy, Tomatis).

The statistics provided earlier regarding utilization of sensory-based therapies are likely to be underestimates for several reasons. First, sensory-based therapies are often integrated into eclectic therapeutic approaches and may be used but not necessarily reported. Second, sensory-based therapies are often used in traditional therapies as a component of a broader intervention protocol by various service providers (e.g., occupational therapists, physical therapists, speech-language pathologists). Third, information regarding utilization of these interventions is often based on parent report and parents may not always be aware of all of the techniques used in treatment session and/or the purpose of various techniques used.

Other common therapeutic interventions are pharmacological or alternative in nature. Topping the list of pharmacological interventions are sleep aids, antipsychotic medications and antidepressants (Green et al., 2006) with approximately 40% of children 8 years or younger receiving medication (Thomas et al., 2007). Alternative interventions are typically vitamin supplements or dietary changes such as gluten-casein free diets.

### **Factors Affecting Therapy Utilization**

Clearly, some therapies are received by nearly all children with autism while other services are received by only a few children. Very little empirical evidence exists that might explain how therapies are recommended to or selected by families. Influences could relate to demographic features of the child or family. For example, culture plays a role in therapy decisions with Latino children being six times more likely than children of other ethnicities to use nontraditional therapeutic strategies. Furthermore, children of minority race and

ethnicity have been found to receive therapies at a later age than white children (Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003). The same study found that low levels of parental education, and living in non-metropolitan areas limited a child's access to care, while odds of receiving therapies increased with parental stress and the use of a major treatment approach (e.g., TEAACH or ABA). Increased therapy use was also associated with both higher family income and access to Medicaid. Although these findings help to illuminate some influences of service consumption, critical features such as the relationship of behavioral manifestations of autism and services has not been explored. This current research is aimed at determining if child characteristics or parent/family characteristics are related to features of service utilization.

In summary, children with autism receive on average seven interventions at any given time (Green et al., 2006; Kohler, 1999). The costs associated with these interventions are large, yet little empirical evidence exists regarding efficacy and there is no universal consensus concerning therapy recommendations. A better understanding of how certain therapies are recommended and selected as well as associated child/family factors that influence their utilization is needed. Furthermore, even though sensory-based therapies are the most commonly recommended therapy by occupational therapists and can be administered as a component of many traditional therapies, very little is known about how these interventions are selected. This paper seeks to describe specific family and child characteristics that may be associated with the type and intensity of interventions children with autism receive. Specifically, this study aims to answer the following research questions:

1. What is the frequency of utilization of specific educational, traditional and alternative therapies in this sample?
2. How are family (maternal and paternal education, income) and child (severity of autism, severity of sensory processing problems, mental age, gender, race) related to service utilization?

Specifically with regard to:

- a. Total number of different types of services
- b. Total hours of traditional therapies (OT, PT, SLT combined)
- c. Age at start of first services
- d. Use of sensory integration within traditional therapies
- e. Use of alternative interventions

## Methods

This descriptive study was part of a larger grant studying sensory features in young children with autism, and utilized analysis of extant interview data regarding services utilization. The Sensory Experiences Project was funded by the National Institute for Child Health and Human Development (#42168) to examine the development, functional impact, and cause of various sensory features in children with autism, developmental delay, and/or typical development, ages 2-12 years. The availability of this dataset provided a unique opportunity to evaluate the association of parent and child characteristics, including severity of sensory processing problems, with service utilization of traditional, alternative, and sensory-based interventions, above and beyond what is reported in the existing literature. All services data, including common educational services (e.g., ABA, TEACCH), were described in order to compare utilization of services in our local sample with other national studies. Subsequently, we focused our analyses on how parent and child variables were associated specifically with therapeutic services in three categories (i.e., traditional, alternative and sensory-based). We

chose not to focus on specific educational interventions because sufficient data exists with respect to the utilization and efficacy of these services (e.g., Green et al., 2006; Mesibov & Shea, 2010; National Research Council 2001; Thomas et al., 2007) and moreover, we were interested in variables potentially associated with the use of interventions specifically targeting sensory processing problems that were the focus of the larger funded grant project.

## Participants

Participants between 2 and 7 years of age were recruited through a university research registry, community agencies and developmental clinics, and email list serves in the state of North Carolina. The participants had a clinical diagnosis of autism spectrum disorder (i.e., Autistic Disorder, Asperger Disorder, or Pervasive Developmental Disorder, Not Otherwise Specified) from a licensed psychologist or physician, confirmed by results of the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994) and the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, Dilavore, & Risi, 1999). In addition, they had no known genetic/medical conditions (e.g., fragile X syndrome; tuberous sclerosis; seizure disorder/epilepsy) as confirmed by medical records/examination; hearing acuity and uncorrected or corrected visual acuity within normal limits, as verified by audiological and vision screenings; and they had no significant physical impairments.

## Instruments and Data Collection

The intervention interview data were collected by trained professionals whose backgrounds included: occupational therapy, speech-language pathology, early childhood intervention and psychology. All had substantial experience in working with families and children affected by autism. Caregivers were asked retrospectively about 18 specific types of therapeutic interventions their child had ever received within the five broad categories (educational, traditional therapy, other therapy, sensory-based and alternative interventions). See Table 1 for the list of therapeutic interventions by category. A detailed list of sensory-based therapies was included since the larger grant was particularly interested in characterizing severity of sensory processing problems and the relationship of those problems to services received. To encourage recall, each therapeutic category was listed along with several specific interventions, both common and less common, in a systematic manner. All of the seventy caregivers listed at least one service but it still should be noted that recall of therapies, amounts and dates is expected to be imperfect. However, given the caregivers were provided systematic lists to enhance recall by an experienced clinician, the data are likely a good representation of services consumed.

Once the caregiver endorsed a service as having been received, they reported the following information: (1) age at start of service, (2) session duration [how long each session lasted], (3) frequency [how often were services delivered], (4) treatment duration [total amount of time enrolled in that service], (5) setting location, (6) setting ratio [group vs. individual], (7) satisfaction, and (8) specific goals targeted. Intervention interview data were collected between March, 2004 and December, 2006.

Sensory processing symptom severity, autism severity, mental age, and demographic data were obtained from the larger project data set and all assessments were administered by trained research staff specific to the project. The Demographics Form was used to collect information such as child race and ethnicity, parent education levels, household income, parent occupation(s), marital status, living situation and number of adults in the household.

Severity of sensory processing problems was determined by the Sensory Profile (SP) (Dunn, 1999), which is a parent report measure of 125 questions designed to evaluate children's responses to commonly occurring sensory events. Completing the SP takes about 15



minutes. A five-point Likert scale ranging from “always” to “never” is used to assess the frequency with which a child exhibits eight categories of sensory processing problems: auditory, visual, activity level, taste/smell, body position, movement, touch, emotional/social. The SP has good psychometric properties and is able to discriminate children with autism from children without autism (Erner & Dunn, 1998; Kientz & Dunn, 1997). For these analyses, the total score of the SP was used.

Severity of autism symptoms was measured using the Childhood Autism Rating Scale (CARS) (Schopler, Reichler, & Renner, 1988) which is a 15-item behavioral rating scale used to identify autism. Items are rated on a scale of 1 (normal) to 4 (severely abnormal). The CARS was scored from videotaped structured play sessions.

A measure of mental age was obtained through the Visual Reception Scale of the Mullen Scales of Early Learning (MSEL) (Mullen, 1995). The MSEL is a comprehensive measure of development for infants and preschool children from birth to 68 months. It consists of five scales: visual reception, gross and fine motor, receptive and expressive language. The MSEL was standardized on a large, nationally representative sample. The visual reception scale is a valid measure of cognitive abilities that is not confounded by verbal or motoric demands. The visual reception scale has good psychometrics properties for internal consistency (.79), test-retest reliability (.85), and inter-rater reliability (.96-.99, varying by age).

### Coding of Service Utilization

After the number of interventions was determined and descriptive statistics were generated (see Table 1), these data were reorganized to reflect key variables of interest. Services were categorized as traditional therapies, sensory-based therapies, alternative biological therapies and alternative nonbiological therapies. Results for the entire sample of 70 participants are presented first and then the sample is divided into age categories that reflect different service delivery systems: 0-35 months,  $n=13$  (Cat 1: early intervention with infants/toddlers); 36-59 months,  $n=32$  (Cat 2: preschool); 60 months and older,  $n=25$  (Cat 3: school-age). The frequencies reported reflected the number of children who received a specific intervention in that particular age range. For example, services reported for a child who was 65 months at the time of interview may be counted in all three categories if he had ongoing speech services since he was 24 months, but a child who was 30 months at the time of the interview could only be counted in the 0-35 month age range. There were no missing data for any cases regarding presence of interventions.

To determine potential factors influencing intervention utilization, categories were further streamlined. Alternative interventions, which are occasionally provided for the treatment of sensory processing problems, included cranial sacral therapy, gluten/casein free diet, vitamin therapy, and hug therapy. Forty-four of the 64 endorsements for alternative interventions were for vitamin therapy and dietary alterations, with a total of 20 endorsements for other alternative interventions combined (e.g., chelation, aquatic, hippotherapy, cranial-sacral, music, hug). Therefore, only gluten/casein free diet and vitamin therapy were maintained for analyses. Sensory-based therapies were often reported as part of OT, PT or SLT services but rarely as independent interventions (only 12 reports). To address this, original interviews were reanalyzed to determine the presence of sensory-based therapies as part of OT, PT or SLT services. The total number of services was recoded to reflect the number of different types of services the child had received in their lifetime based on category (see Table 2). Each service was only counted once per therapy category such that a score of “1” was given if the child had received speech-language therapy in different settings at different times. All other variables of interest remained as previously described.

## Statistical Analyses

Initially, all of the intervention types were included to provide descriptive statistics (see Table 1) and allow comparisons with national averages. After the treatment variables were streamlined (i.e., traditional, alternative, and sensory-based), descriptive statistics were generated for all variables and regression analyses were used to determine the predictive value of family characteristics and child characteristics on service utilization. Using PAWS version 18.0, tests for normality were run. Natural log transformations were performed for *total number of services* and *amount of services* so that all outcome variables met distributional assumptions (i.e., approximate normality and homoscedasticity). Pairwise correlations were run between all variables using Spearman as a more conservative estimate of correlation than Pearson, as the distributions of some variables were mildly skewed. Linear regression was used to test continuous variables (i.e., total number of different types of services, total hours of traditional therapies [OT, PT, SLT combined] and age at start of first services) and logistic regression was used to test dichotomous variables (i.e., use of sensory integration within traditional therapies and use of alternative interventions). For empirical and theoretical reasons, models were adjusted for age at start of first intervention and/or age at interview for child and family predictors. Theoretically, starting first intervention at a younger age and being older at the services interview would allow for such things as more total service hours and more types of intervention. Empirically, correlations were found supporting these assumptions.

## Results

### Sample Characteristics

Child and family characteristics are presented in Table 3. Nationally, eighty percent of children with autism are male (Yeargin-Allsopp, Rice, Karapurkar, Doernbery, Boyle, & Murphy, 2003); males comprised 87% of the current sample. This sample was slightly less racially/ethnically diverse than the population from which it was drawn, with white participants comprising 80% while the North Carolina average is 74%. Furthermore, income level was slightly higher for this sample than the North Carolina annual median income of \$40,739 (United States Census, 2005). Maternal and paternal education for this sample was also higher than national averages with 56% and 51% of this sample having at least a bachelor's degree, while the national average is 27% and 29% respectively (United States Census, 2005).

### Therapeutic Intervention Utilization

To answer research question 1, the number of times parents endorsed utilization of services is reported in Table 1. The average number of services each child received in this sample of seventy children was 4.5 (sd = 2.1), ranging from 1 to a total of 11 different services. The median number of services obtained was 4. The mean age at start of first services was 27.0 months (sd = 10.5), ranging from 8 months to 54 months. It should be noted that some children started receiving early intervention prior to a formal diagnosis of autism.

Table 2 contains percentages of participants endorsing each service separately, by category, and by age group. Traditional therapies were by far the most frequently endorsed therapies with SLT identified as the most commonly obtained service (91.40%) followed by OT (71.4%) and then PT (22.9%) in our sample. Two-thirds of the sample reported having used some form of sensory-based therapies and almost one-third of the sample used either vitamin therapy or gluten/casein free diets.

## Utilization Trends

Based upon descriptive data presented in Table 2, a slight increase in SLT services as children aged appeared to occur while utilization of OT and PT services appeared relatively constant. The percentage of children having ever received sensory-based therapies was 67.1%, with fewer endorsements of sensory-based therapies as the children aged. As mentioned earlier, sensory-based therapies are often incorporated within the context of traditional therapies. Parents reported whether their child received sensory-based therapies during OT, PT and SLT with the following results: 88% (44/50) of children received sensory-based therapies during OT, 12.5% (2/16) of children received sensory-based therapies during PT and 26.6% (17/64) of children received sensory-based therapies during SLT. These findings should be interpreted with caution given results are limited by recall and whether or not the parent was informed of specific treatments within sessions.

Thirty-three percent of our total sample endorsed utilization of vitamin supplements to address symptoms of autism. Similar percentages were noted across age groups. However, endorsement of gluten/casein free diets appeared to decrease slightly as the children aged.

## Factors Potentially Influencing Interventions Utilized

To answer research question 2, linear and logistic regressions were run to determine parent and child characteristics that may influence service utilization. Three factors were significantly associated with service utilization: higher maternal education and higher paternal education were associated with the use of gluten/casein free diets and/or vitamin therapy ( $p = .014$  and  $p = .042$  respectively) and were also associated with more types of services obtained ( $r^2 = .248$ ,  $p = .004$  and  $r^2 = .223$ ,  $p = .028$ , respectively), and higher severity of sensory processing problems was associated with earlier initiation of first service ( $r^2 = .189$ ,  $p = .039$ ). No other factors yielded significant associations.

Although maternal and paternal education and severity of sensory processing problems were the only three predictor variables of statistical significance, two other factors indicated a noteworthy trend. The data trended toward white children receiving more types of services ( $r^2 = .151$ ),  $p = .067$  and higher severity of sensory processing problems also being associated with receiving more types of services ( $r^2 = .335$ ,  $p = .099$ ).

## Discussion

With regard to specific services parents endorsed, our results are partially consistent with other study findings. In our initial descriptive analysis, we included all services (see Table 1). Educational and therapeutic interventions top the list with SLT being the most frequently obtained therapeutic intervention, which is similar to national studies (Kohler, 1999; Thomas et al., 2007). Our data reflect a lower utilization of behavioral interventions (i.e., discrete trial learning and ABA) compared to national averages (Green et al., 1999). This may be due to a regional difference or possibly that caregivers may not have reported use of these techniques within preschool or other early intervention programs as specific techniques within broader educational setting were not explicitly queried.

After initial analyses, we narrowed our scope of intervention types to include only traditional, alternative, and sensory-based therapies. Our figures regarding utilization of sensory-based therapies were strikingly higher than other studies have reported (67.1% vs. 21%-38%). The interview from which our data were taken was from a study aimed at sensory differences in children with autism so there may have been a selection bias where parents who are aware of sensory differences in their children were more interested in study participation. Also, more parents in this study may have reported sensory-based therapies because the interview specifically asked questions about these types of therapies, which may



have served to improve parent recall of such services. Based on the report that sensory-based therapies are the most commonly recommended treatment type by occupational therapists for children with autism, and that approximately 69% of children with autism present with sensory processing problems, it seems plausible that utilization of sensory-based therapies is more prevalent than reported in other studies.

Thirty-three percent of our total sample received vitamin supplements, which is higher than Thomas et al.'s 2007 finding that 18% of their sample received vitamin supplements. This could be related to our finding that higher maternal and paternal education was associated with use of alternative (i.e., vitamin use and gluten/casein free diet) and our sample had a much higher than average level of education. Green et al., found 26.8% of their sample was currently using a casein-free diet and 23.1% of their sample was using a gluten-free diet. Similarly, 30% of our sample was currently using or had used a gluten/casein free diet. Similar percentages were noted across age groups for vitamin utilization but endorsement of gluten/casein free diets appeared to decrease slightly as the child ages. These results may reflect the relative ease and economy associated with utilization of vitamin supplements compared to the labor intensity and higher cost associated with maintaining a gluten/casein free diet.

An important caveat in this study is that we sought to understand variables influencing service utilization, not efficacy of services utilized. Our data suggest that the use of sensory-based interventions, gluten/casein free diets, and vitamin therapy are associated with specific child and family characteristics; however, these results have no further ramifications for understanding the efficacy of any of the interventions surveyed in this study. It is important to note that although sensory processing problems are common in autism, and often targeted through the use of sensory-based and alternative therapies, there exists limited empirical validation for many of these treatments (NAC, 2009) and further research is needed.

There is a complexity of issues inherent in defining specific intervention components within the context of broader therapeutic services, and soliciting this information from families in reliable and meaningful ways. Since sensory-based therapies are nearly always delivered by a therapist, sensory-based therapies were viewed only in the context of OT, PT, or SLT services in this study. To illustrate how confusion could easily arise by viewing sensory-based treatments as an independent intervention as opposed to a component of a broader therapeutic approach, we take the example of "hippotherapy". A few parents in this sample endorsed use of hippotherapy for their child with autism, yet only one of these parents indicated sensory processing problems were targeted as part of the treatment protocol of hippotherapy. Thus, it is unclear whether only one child's hippotherapy focused on sensory processing issues, or whether all children receiving hippotherapy had similar sensory-based intervention protocols, but only one parent was aware of this treatment component. This leaves an important caveat to consider for data interpretation and future research on service utilization.

### **Factors Affecting Receipt of Services**

Our findings indicated that higher maternal and paternal education increased the likelihood of the child having received a gluten/casein free diet or vitamin therapy. A possible interpretation of this finding is that learning about such interventions requires the ability to seek out non-standard treatment options on the part of the caregiver. Such interventions are not considered part of standard intervention protocols and are less likely to be discussed in pediatricians' offices and educational settings compared to more traditional interventions. Therefore, parents who are more able to independently use research tools, even through social networks, are probably more likely to learn about and possibly have the financial

means to support dietary changes and vitamin therapies that are often not covered by insurance.

Higher maternal and paternal educations were also found to be predictive of more types of services obtained. Again, parents with higher education may be better able to learn about and financially support a wider variety of treatment options. Interestingly, higher education was not predictive of the actual amount (total number of hours) of service received. This may mean that children of parents with higher education may be trying more types of services but only for short periods.

Our third finding of statistical significance was that severity of sensory processing problems, as reported by parents, was related to initiation of first services. Thus, the more severe the child's sensory processing problems, the earlier first services were initiated. This finding may point to the level of distress families may experience when their child presents with strong sensory processing problems such that parents are motivated to seek outside help earlier. One limitation to consider is the cross-sectional design of this study. Specifically, the caregiver completed the sensory measure at the time of interview, which was usually after initiation of first services, so some participants might have changed in their sensory profiles over time. However, based upon data indicating that sensory processing problems tend to improve with increasing chronological and/or mental age (e.g., Baranek, Boyd, Poe, David, & Watson, 2007; Kern, et al., 2006), it is unlikely that children would have been less severe at start of services and more severe at the time of the interview; therefore, we feel our findings accurately reflect that higher levels of sensory processing problems are linked with earlier ages of first services. Future studies could use longitudinal designs to more definitively answer sequential predictions.

### **Service Trends by Chronological Age**

Trends based upon an analysis of the descriptive statistics in Table 2 provided additional insight into service delivery and service selection as children age. A trend towards increases in SLT services appeared as the children aged. This may be because communication difficulties become more evident and challenging as children age and more sophisticated communication is required, such as understanding nuances of language. Increased SLT utilization as children age also may be a result of ease of access to therapy in the school setting. On the other hand, the number of children receiving sensory-based therapies appeared to decrease as children age. This may be a function of the transition from early intervention service delivery models to school-based service delivery models emphasizing inclusive services within the context of the classroom. Public schools tend to limit special services to those that are educationally necessary and enable the child to function in the least restrictive placement. Some sensory-based therapies (i.e., those requiring specialized equipment) may be less likely to fit that criterion and have been controversial with respect to evidence-based practice.

We sought to determine family characteristics (maternal and education, income) and child characteristics (sensory processing severity, autism severity, mental age, race and gender) related to the number and intensity of interventions, age at initiation of first intervention as well as utilization of traditional, alternative, and sensory-based therapies. Surprisingly, we found only three of the variables predicted utilization of specific therapies (i.e., severity of sensory processing problems was associated with earlier initiation of services in general, and higher maternal and paternal education was associated with the use of dietary and/or vitamin therapy as well as with more types of services). A larger sample with a more sensitive measure may have afforded different results. Parents were asked to recall all services including type and amount as well as specific goals targeted within interventions. Totally accurate recall would have been difficult. Furthermore, with cross-sectional data it is not

possible to determine if the absence of effects are due to cohort effects. Still, absence of findings suggests perhaps some uncertainty of practice patterns in the treatment of autism. The marked heterogeneity of autism cannot be disregarded when studying interventions.

Another potential factor worthy of mention is the influence of diagnostic practices and insurance reimbursement on therapy utilization. Diagnoses tend to drive reimbursement regardless of severity of symptoms. In other words, third party payers set a cap on reimbursable services, often by discipline, based on the diagnostic code rather than severity of symptoms or other unique child related factors. Data were not collected on insurance reimbursement for our sample so the influence of that factor is impossible to judge, but further studies may wish to pursue this hypothesis.

In conclusion, the purpose of this paper was to identify potential family and child characteristics that influenced therapy utilization. We found that specific child characteristics (i.e., sensory processing symptom severity) may be associated with earlier initiation of services and family characteristics (i.e., maternal and paternal education) may be associated with greater utilization of specific alternative therapies. However, given the limited significant findings, it seems that service utilization is a complex issue for families with children with autism, and likely influenced by a multitude of factors that may include diagnostic practices, affordances/constraints of service delivery systems at particular ages, and insurance reimbursement issues to name a few. Likewise, little is known about how the perceived efficacy of services received actually impacts upon families' decisions to utilize those services, and/or how evidence-based practice parameters may alter therapy practices. Understanding the influences upon the type and amount of services received by children with autism in this study may provide additional insights that eventually help to inform evidence-based practice. By coupling what clinicians and families are choosing to do, alongside scientific studies that rigorously test the efficacy and effectiveness of commonly used therapies in their naturalistic contexts, the development of best practices for children with autism may be further enhanced. Future longitudinal studies are needed to address the limitations in this study and more definitively predict variables influencing service utilization in families of children with autism over time.

## References

- Baranek GT. Efficacy of sensory and motor interventions for children with autism. *Journal of Autism and Developmental Disorders*. 2002; 32(5):397–422. [PubMed: 12463517]
- Baranek GT, Boyd BA, Poe MD, David FJ, Watson LR. Hyperresponsive sensory patterns in young children with autism, developmental delay, and typical development. *American Journal on Mental Retardation*. 2007; 112(4):233–245. [PubMed: 17559291]
- Baranek GT, David FJ, Poe MD, Stone WL, Watson LR. Sensory Experiences Questionnaire: discriminating sensory features in young children with autism, developmental delays, and typical development. *Journal of Child Psychology and Psychiatry*. 2006; 47(6):591–601. [PubMed: 16712636]
- Dunn, W. *Sensory Profile*. The Psychological Corporation; San Antonio, TX: 1999.
- Ermer J, Dunn W. The Sensory Profile: A discriminant analysis of children with and without disabilities. *American Journal of Occupational Therapy*. 1998; 52(4):283–290. [PubMed: 9544354]
- Ganz, ML.; Moldin, SO.; Rubenstein, JLR. The Costs of Autism. In *Understanding autism: From basic neuroscience to treatment*. CRC Press; Boca Raton, FL, US: 2006. p. 475-502.
- Green VA, Pituch KA, Itchon J, Choi A, O'Reilly M, Sigafos J. Internet survey of treatments used by parents of children with autism. *Research in Developmental Disabilities*. 2006; 27(1):70–84. [PubMed: 15919178]
- Hodgetts S, Hodgetts W. Somatosensory stimulation interventions for children with autism: Literature review and clinical considerations. *Canadian Journal of Occupational Therapy*. 2007; 74(5):393–400.

- Kasari C, Freeman S, Paparella T. Joint attention and symbolic play in young children with autism: a randomized controlled intervention study. *Journal of Child Psychology and Psychiatry*. 2006; 47(6): 611–620. [PubMed: 16712638]
- Kern JK, Trivedi MH, Garver CR, Grannemann BD, Andrews AA, Savla JS, et al. The pattern of sensory processing abnormalities in autism. *Autism*. 2006; 10(5):480–494. [PubMed: 16940314]
- Kientz MA, Dunn W. A comparison of the performance of children with and without autism on the Sensory Profile. *American Journal of Occupational Therapy*. 1997; 51(7):530–537. [PubMed: 9242859]
- Kohler FW. Examining the services received by young children with autism and their families: A survey of parent responses. *Focus on Autism and Other Developmental Disabilities*. 1999; 14(3): 150–158.
- Levy SE, Mandell DS, Merhar S, Ittenbach RF, Pinto-Martin JA. Use of complementary and alternative medicine among children recently diagnosed with autistic spectrum disorder. *Journal of Developmental and Behavioral Pediatrics*. 2003; 24(6):418–423. [PubMed: 14671475]
- Lord, C.; Rutter, M.; Dilavore, P.; Risi, S. *The Autism Diagnostic Observation Schedule (ADOS)*. Western Psychological Corporation; Los Angeles: 1999.
- Lord C, Rutter M, Le Couteur A. Autism Diagnostic Interview-Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorder. *Journal of Autism and Developmental Disorders*. 1994; 24(5):659–685. [PubMed: 7814313]
- Mesibov GB, Shea V. The TEACCH Program in the Era of Evidence-Based Practice. *Journal of Autism and Developmental Disorders*. 2010; 40(5):570–579. [PubMed: 19937103]
- Mullen, EM. *Mullen Scales of Early Learning (AGS Edition)*. Western Psychological; Los Angeles: 1995.
- National Autism Center. *National Standards Report – Addressing the need for evidence-based practice guidelines for Autism Spectrum Disorders*. National Autism Center; Massachusetts: 2009.
- National Research Council. *Educating children with autism*. National Academy Press; Washington, DC: 2001.
- Schopler, E.; Reichler, RJ.; Renner, BR. *The Childhood Autism Rating Scale*. Western Psychological Services; Los Angeles, CA: 1988.
- Sigman M, McGovern CW. Improvement in Cognitive and Language Skills from Preschool to Adolescence in Autism. *Journal of Autism and Developmental Disorders*. 2005; 35(1):15–23. [PubMed: 15796118]
- Thomas K, Morrissey J, McLaurin C. Use of autism-related services by families and children. *Journal of Autism and Developmental Disorders*. 2006 forthcoming.
- Thomas KC, Ellis AR, McLaurin C, Daniels J, Morrissey JP. Access to care for autism-related services. *Journal of Autism and Developmental Disorders*. 2007; 37(10):1902–1912. [PubMed: 17372817]
- Volkmar FR, Lord C, Bailey A, Schultz RT, Klin A. Autism and pervasive developmental disorders. *Journal of Child Psychology and Psychiatry*. 2004; 45(1):135–170. [PubMed: 14959806]
- Wakeford, L.; Baranek, GT. Occupational therapy. In: Amaral, DG.; Dawson, G.; Geschwind, DH., editors. *Autism Spectrum Disorders*. Oxford University Press; New York: in press
- Yeargin-Allsopp M, Rice C, Karapurkar T, Doernberg N, Boyle C, Murphy C. Prevalence of autism in a US metropolitan area. *JAMA: Journal of the American Medical Association*. 2003; 289(1):49–55.

**Table 1**  
**Therapeutic Interventions, Endorsements by Category**

Service	Frequency n=70 children	Percent of children in sample
<b>Educational</b>		
Floortime	3	4.3%
Lovaas Discrete Trial Learning	0	0
Other ABA	6	8.6%
TEACCH	20	28.6%
Inclusive EI	32	45.7%
Other educational program	44	62.9%
<b>Traditional Therapies</b>		
OT	50	71.4%
PT	16	22.9%
SLT	64	91.4%
<b>Other Therapies</b>		
Music Therapy	2	2.9%
Other Therapy	10	14.3%
<b>Sensory-Based Therapies</b>		
Alert Program	0	0
Auditory Integration Training	4	5.7%
Hug Machine (squeeze therapy)	0	0
Sensory Diet: Brushing, Joint compression	9	12.9%
Sensory Integration (e.g., swings)	4	5.7%
<b>Alternative Therapies</b>		
Cranial Sacral Therapy	3	4.3%
Gluten / Casein Free Diet	21	30.0%
Hug Therapy	1	1.4%
Vitamin Therapy	23	32.9%
Other Therapy	2	2.9%
Average number of services per family	4.5 (sd= 2.1)	



**Table 2**  
**Percent Having Received Service Based on Age at Interview**

Therapeutic Intervention	Total Sample 0-60+ mos n=70	Early Intervention 0-35 mos n=54	Preschool 36-59 mos n= 56	School-aged 60 + mos n=25
<b>n and % of category endorsing each therapeutic intervention</b>				
<b>Traditional therapies</b>				
Occupational Therapy	n=50 (71.4%)	n=41 (75.9%)	n=40 (71.4%)	n=18 (72.0%)
Physical Therapy	n=16 (22.9%)	n=14 (25.9%)	n=14 (25.0%)	n= 6 (24.0%)
Speech-language therapy	n=64 (91.4%)	n=48 (88.9%)	n=52 (92.9%)	n=25 (100.0%)
<b>Sensory-based therapies</b>				
Any SI (including SI in traditional therapies%)	n=47 (67.1%)	n=40 (74.1%)	n=35 (62.5%)	n=13 (52.0%)
Classic SI	n= 4 (5.7%)	n= 4 (7.4%)	n= 3 (5.4%)	n= 1 (4.0%)
Sensory Diet	n= 9 (12.9%)	n= 9 (16.7%)	n= 8 (14.3%)	n= 3 (12.0%)
Auditory Integration	n=4 (5.7%)	n= 4 (7.4%)	n= 3 (5.4%)	n= 2 (8.0%)
<b>Alternative: biological</b>				
Vitamins	n=23 (32.9%)	n=19 (35.2%)	n=20 (35.7%)	n= 8 (32.0%)
Gluten/Casein free	n=21 (30.0%)	n=18 (33.3%)	n=16 (28.6%)	n= 7 (28.0%)
Other biological *	n= 1 (1.4%)	n= 1 (1.9%)	n= 1 (1.8%)	n= 1 (4.0%)
<b>Alternative: non-biological</b>				
Aquatic	n= 2 (2.9%)	n= 2 (3.7%)	n= 1 (1.8%)	n= 1 (4.0%)
Hippotherapy	n= 7 (10.0%)	n=4 (7.4%)	n= 7 (12.5%)	n= 5 (20.0%)
Cranial-sacral	n= 3 (4.3%)	n= 3 (5.6%)	n= 3 (5.4%)	n= 2 (8.0%)
Music	n= 2 (2.9%)	n= 2 (3.7%)	n= 1 (1.8%)	n= 1 (4.0%)
Hug	n= 1 (1.4%)	n=1 (1.9%)	n= 1 (1.8%)	n= 0 (0.0%)
Other non-biological **	n=4 (5.7%)	n=3 (5.6%)	n= 4 (7.1%)	n= 1 (4.0%)

\* other biological = chelation,

\*\* other nonbiological= play therapy, social skills, aural polarization

Table 3

## Demographics

Child characteristics	Mean (s.d.)
Age in months at interview	50.89 (16.60)
Male	87.1%
Race	
White (56)	80.0%
Non-white (14)	20.0%
<b>Family Characteristics</b>	
Household income	
Less than \$20,000	4.3%
\$20,000 - \$39,999	24.3%
\$40,000 - \$59,999	22.9%
\$60,000 - \$79,999	24.3%
\$80,000 - \$99,999	11.4%
More than \$100,000	12.9%
Maternal education	
High school grad / GED	17%
Associate / tech / partial college	27%
Bachelor of arts / science	40%
Master of arts / science / doctorate	16%
Paternal education	
High school grad / GED	30%
Associate / tech / partial college	17%
Bachelor of arts / science	39%
Master of arts / science / doctorate	13%