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The Use of Complementary and Alternative Medicine by Children and Adolescents with Autistic Spectrum Disorders

by

William Benton Gibbard

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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies for acceptance, a thesis entitled “The Use of Complementary and Alternative Medicine by Children and Adolescents with Autistic Spectrum Disorders” submitted by William Benton Gibbard in partial fulfilment of the requirements for the degree of Masters of Science.

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Supervisor, Marja Verhoef, Ph.D.,
Department of Community Health Sciences

_____

Margaret Clarke, M.D., FRCPC,
Department of Pediatrics

_____

Bonnie Kaplan, Ph.D.,
Departments of Pediatrics and Community Health Sciences

_____

Elaine McKiel, Ph.D.,
Faculty of Nursing

July 27, 2005

Abstract

Background: Little is known about the use of complementary and alternative medicine (CAM) in children and adolescents with autistic spectrum disorders (ASDs) in Canada.
Purpose: To describe CAM use in children and adolescents with ASDs in southern Alberta.
Methods: A cross-sectional survey of parents.
Results: The response rate was 50.3% (176/350). The majority of children were male (83.5%), and diagnosed with classic autism (52.8%). The mean age was 8.9 years. The majority of children (93.8%) had used CAM, most commonly vitamins and minerals (63.1%), mind-body therapies (51.7%), and dietary-nutritional therapies (45.5%). The mean number of types of CAM used was 9.6. The main reason parents used CAM was to improve autistic symptoms in their children. The mean amount spent on CAM was almost $3,000. Most physicians were felt by parents to know about their use of CAM, but the majority of parents felt that they volunteered this information. Roughly one third of both family physicians and pediatricians were perceived to be encouraging of CAM use.
Conclusion: The use of CAM in children and adolescents with ASDs is very common, and highlights the need for further research with respect to efficacy, side effects and health policy for these therapies.

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Dedication

To Marilyn, Katherine and Evan

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CHAPTER ONE: INTRODUCTION

Autistic spectrum disorders (ASDs) are chronic neurodevelopmental conditions that are characterized by deficits in social reciprocity, communication, and cognitive skills, and by unusual restricted and repetitive behaviours.[1-4] Treatment for ASDs typically involves special educational and behavioral interventions, with the use of psychotropic medications for target symptoms, but there is no known cure.[5] In addition to conventional treatments, many parents of children and adolescents with ASDs use complementary and alternative medicine (CAM) for their children either in an attempt to cure their child's condition, or to ameliorate autistic symptoms.[6-12]

CAM encompasses a heterogeneous group of medical and health care systems, practices, and products that are not generally considered part of conventional medicine.[13-15] The use of CAM is increasing, with surveys indicating that 20-60% of the general population in industrialized nations use CAM.[16-23] However, CAM use in children and adolescents has been poorly studied. In particular, there have been few studies in the medical literature investigating the use of CAM in children and adolescents with ASDs.[7-12,24-27]

The primary aim of this study was to explore the use of CAM by children and adolescents with ASDs in southern Alberta. To date, there has been no research conducted with respect to the use of CAM by children and adolescents with ASDs in Canada. Specific goals included determining the proportion of children and adolescents who have ever used CAM, the specific types of CAM that are being used, the types of CAM practitioners that have been seen, and determinants of CAM use such as medical characteristics, socio-demographic factors, information sources, financial costs, and parent-physician communication regarding CAM use.

Investigating the use of CAM in children and adolescents with ASDs is important for a number of reasons. Information derived from this survey will: (1) provide a description of

the types of CAM that parents are using for this population; (2) increase the knowledge of conventional medical practitioners about the use of CAM in children and adolescents with ASDs, which in turn may facilitate an integrated approach to patient care; (3) help conventional practitioners monitor patients who use CAM in terms of possible benefits, side effects, and potential negative interactions of these therapies; and, (4) provide a starting point for the evaluation of CAM in the treatment of ASD, and in setting priorities for evidence-based clinical research for CAM in this area.

In this thesis, Chapter Two summarises the literature related to this study, including information about both ASDs and CAM in general, and specifically with respect to the use of CAM in pediatrics and in children with ASDs. The methods for this study are presented in Chapter Three. The study results are presented in Chapter Four. The evaluation, interpretation, and discussion of study findings are provided in Chapter Five.

CHAPTER TWO: BACKGROUND

This chapter reviews the literature pertinent to this study. First, information with respect to ASDs is presented, including definitions, epidemiology, associated medical and genetic conditions, and the use of conventional medicine for ASDs. Second, information with respect to CAM use is provided, including definitions, and the use of CAM by children and adolescents both in the general public and in populations of ASDs. Third, information regarding parent - physician communication about the use of CAM is summarized. Finally, this chapter concludes with a description of the study's rationale, purpose, and specific objectives.

A number of strategies were employed to identify literature pertinent to this investigation. Published articles were identified using a variety of computer-based search programs, including PubMed, OVID, MEDLINE, EMBASE, and PsycINFO. Books and other manuscripts were identified using the University of Calgary Library catalogue. Additional titles were obtained via review of the bibliographies of previously acquired references, and via consultation with content experts.

2.1 Autistic Spectrum Disorders

2.1.1 Definition of Autistic Spectrum Disorders

Autistic spectrum disorders are chronic neurodevelopmental conditions of unknown etiology that affect social, communicative, and cognitive skills, and are characterised by unusual restricted and repetitive behaviors.[1-4] Autistic spectrum disorders usually present during infancy or at the latest within the first three years of life. Classic autism is the most severe phenotype of this group of disorders that are conceptualised as "autistic spectrum disorders." Other disorders that fall within this spectrum include Asperger's Syndrome, pervasive developmental disorder - not otherwise specified (PDD-NOS), childhood disintegrative disorder, and Rett syndrome.[3] These disorders share with autism the common features of deficits in social skills and communication, but to varying

degrees of pervasiveness and onset.[1] Asperger's Syndrome involves the presence of social skills deficits and repetitive, circumscribed interests in individuals who are verbally fluent and who do not have cognitive or adaptive delays.[1,3] Childhood disintegrative disorder describes children who have apparently normal development for at least the first two years after birth, but who then exhibit clinically significant loss of previously acquired skills, and display the functional abnormalities associated with ASDs.[3] Rett syndrome, which primarily affects females, is characterized by a progressive loss of cognitive ability as well as both fine and gross motor skills, deceleration of head growth, and the development of stereotypic hand movements occurring after a period of normal development.[1,3,28,29] Children with Rett syndrome also display autistic behaviours, and some classifications, therefore, place Rett syndrome within the autistic spectrum of disorders.[3] Recently Rett syndrome has been linked to mutations of the methyl-CpG-binding protein 2 (MeCP2) gene on chromosome Xq28, and Rett syndrome itself may have a wider behavioural phenotype than previously thought.[30,31] As yet, ASDs are defined only by behavioural criteria, and no specific underlying causes have been identified for these disorders. It is likely that the ASD behavioral phenotype is the final result of a number of different etiologies, each pathway being multifactorial in nature. Possible factors that may contribute to the development of an ASD include genetic, prenatal, and postnatal factors.[1,2,4,32]

2.1.2 Epidemiology of Autistic Spectrum Disorders

A number of epidemiologic studies have been undertaken since the year 2000, predominantly in the United States and Europe, to assess the prevalence of ASDs.[33-45] Only one study has been conducted in Canada, and was published in 1988.[45] This study was carried out in Nova Scotia, and reported a prevalence for autism of 10 per 10,000, with a male to female gender ratio of 2.5:1. A review and meta-analysis of existing epidemiological surveys worldwide to assess the prevalence of ASDs was recently carried-out by Fombonne in 2003.[44] While this review was used as a primary information source, it does not provide information with respect to geographic variation with respect

to type of ASD diagnosis. Fombonne concluded that the overall prevalence for all ASDs combined was at least 27.5 per 10,000.[44] The estimated prevalence rates for each specific ASD diagnosis were as follows: for autism it was 10 per 10,000; for pervasive developmental disorder - not otherwise specified it was 15 per 10,000; for Asperger Syndrome it was 2.5 per 10,000; and, for childhood disintegrative disorder it was 0.2 per 10,000.[44] Fombonne cautioned that the calculated ASD prevalence estimates were likely underestimates due to inconsistencies between studies with respect to imperfect sensitivity of both the screening procedure used and subsequent case ascertainment.[44] Fombonne did not report on the prevalence of Rett syndrome, but this is reported elsewhere as ranging between 0.5 and 1 per 10,000 females, and this also likely represents an underestimate.[46-49] It has been postulated that at least 1 in 10 females with profound intellectual and physical disability may be affected by Rett syndrome.[50] Fombonne concluded that there was evidence that changing case definition and improved awareness of ASDs explained the upward trend of ASD rates in recent decades.[44] However, he cautioned that available epidemiological surveys do not provide a sufficient test of the hypothesis that the incidence of ASDs is increasing. Gender repartition among subjects with autism was also reviewed by Fombonne, with a male:female ratio that varied from 1.33 to 16.0, with a mean gender ratio of 4.3.[44]

The prognosis for adults and adolescents with ASDs is varied, but factors that are felt to be the most influential on functional outcome include the level of cognitive delay, and the level of language attained by 5 - 6 years of age.[51-54] Other factors negatively impacting prognosis are the presence of medical comorbid conditions such as a genetic syndrome, seizure disorder, or other neuropsychiatric condition.[51] Conversely, early and intensive developmental, behavioural, and educational intervention may positively impact functional outcomes in children and adolescents with ASDs. [51,53,55] However, previous studies surveying groups of adolescents and adults with ASDs have shown that the majority continue to live dependently with their parents, and that only a minority were engaged in regular employment.[51,54,56-58]

2.1.3 Genetic and Medical Conditions Associated with Autistic Spectrum Disorders

It is hypothesized that idiopathic autism is caused by interactions between multiple genes, epigenetic factors, and exposure to environmental modifiers that together may contribute to the variable expression of autistic traits.[59] Genetic conditions associated with ASDs include both cytogenetic abnormalities and single-gene defects, but together these account for less than ten percent of cases.[44,59-63] The review by Fombonne concluded that the percentage of cases of autism that could be potentially etiologically linked to a known genetic or medical condition ranged from 0% to 16.7%, with a median rate of 6.4%.[44] From this meta-analysis, median rates of common genetic and medical conditions associated with ASDs were also provided, and included: cerebral palsy in 2.0%, Down syndrome in 1.3%, tuberous sclerosis in 1.2%, and fragile X in 0.3%.[44] Elsewhere in the medical literature, the most common genetic conditions cited to be associated with ASDs include Down Syndrome, tuberous sclerosis complex, and fragile-X syndrome.[2] As many as 25% of patients with tuberous sclerosis complex have an ASD,[64,65] but this condition accounts for less than 3% of individuals with an ASD.[64] Similarly, 30% of individuals with fragile-X syndrome have an ASD.[66,67] A chromosomal abnormality involving chromosome 15q11-q13 is reported in between 1% to 4% of autistic individuals, and includes the genetic disorders of Angelman syndrome and Prader Willi syndrome.[59] Autistic spectrum disorders are also associated with the genetic conditions of neurofibromatosis, Duchene muscular dystrophy, Sotos syndrome, Williams syndrome, hypomelanosis of Ito, Cowden syndrome and Moebius syndrome.[59] An inborn error of metabolism is associated with ASDs in less than 5% of cases, most commonly untreated phenoketonuria.[59,68]

Seizure disorders are present in up to 30% of children and adolescents with an ASD.[2,59,69-73] In the meta-analysis by Fombonne, epilepsy was found to occur in individuals with ASDs with a median rate of 16.8% (range 0% - 26.4%).[44] Seizure occurrence in children and adolescents with ASDs typically follows a bimodal distribution, with the incidence peaking first in infancy to 5-years of age, and peaking

second in adolescence after age 10-years.[69] The risk for developing epilepsy is different for different types of ASDs. For classic autism, the risk of developing epilepsy by adolescence is likely more than 30%.[69] For Asperger's syndrome, the risk for developing epilepsy is 5% to 10% in early childhood.[69] The risk for developing epilepsy is as high as 70% in those with childhood disintegrative disorder, and for those with Rett syndrome, the risk for epilepsy is more than 90%.[69] The risk for developing epilepsy also increases with increased age, in individuals with moderate to severe cognitive delay, in those with motor deficits, and in those with severe receptive language deficits.[69] All types of seizures can be found in association with ASDs, and reports in the literature vary with the population studied.[69-73]

2.1.4 Conventional Therapy Use for Autistic Spectrum Disorders

The main treatment modality for children and adolescents with ASDs is early intensive behavioural intervention, as this has been shown to improve long-term outcomes.[55,74-76] Treatment often changes with the individual's age and development,[5] and typically involves special education and behavioural interventions, with pharmacotherapy for target symptoms.[4,5] Currently, intensive structured education forms the core of most treatment approaches, combined with positive behaviour management strategies, family support, and an emphasis on functional communication.[1,5] Occupational therapy and physiotherapy are used to target deficits in gross and fine motor skills.[4] Vocational programs, group living situations, and respite care are also important considerations for children and adolescents and their families.[2] While the focus of this research is on the use of CAM by children and adolescents, this group will also likely use conventional therapies and medications. As a result, the literature with respect to conventional medication use in children and adolescents with ASDs will be briefly summarized, including the use of psychotropic medications, anticonvulsants, and behavioural interventions.

There are a few studies in the literature reporting the frequency of use of psychotropic medications and anticonvulsants in populations of children and adolescents with ASDs, and these studies have all been undertaken in the United States (Table 1). Of note, there is no literature on the prevalence of use of conventional therapy for children and adolescents with ASDs in Canada.

Table 1: Psychotropic and Anticonvulsant Use in Populations with Autistic Spectrum Disorders in the United States

Study	**Aman et al, 1995[24]** **N = 838**	**Martin et al, 1999[77]** **N = 109**	**Aman et al, 2003[26]** **N = 417**	**Langwothy-Lam et al, 2002[25]** **N = 1,538**
Survey Date	**1992-1993**	**1997**	**1998-1999**	**2001**
Psychotropic Medication - Lifetime		68.8%		
Any Medication - Current[†]	53.3%		65%	63.7%
Psychotropic Medication - Current	30.5%	55.0%	45.6%	45.7%
Anticonvulsants - Current	13.2%		11.5%	12.4%
Antidepressants - Current	6.1%	32.1%	21.6%	21.7%
Antipsychotics - Current	12.2%	16.5%	14.9%	16.8%
Stimulants - Current	6.6%	20.2%	11.3%	13.9%
Mood Stabilizers - Current	3.9%	9.2%	4.5%	5.1%
Anxiolytics / Hypnotics - Current	6.3%	6.4%	8.7%	7.3%
Antihypertensives - Current	4.4%	6.4%	12.5%	9.5%

[†] Includes Psychotropics, Anticonvulsants, Vitamins, and Over the Counter Medications

Three studies in the literature used the same survey tool, and assessed the use of psychotropic medications, anticonvulsants, and over-the-counter preparations in individuals with ASDs (Table 1).[24-26] The data from these surveys were reported for all children, adolescents and adults with ASDs combined, and therefore information specifically with respect to psychotropic medication use in children and adolescents with ASDs is not given. The studies by Aman et al (1995) and Langworthy-Lam et al investigated the use of psychotropic medications in a population of individuals with ASDs in North Carolina in 1992/1993 and 2001 respectively.[24,25] The first study (Aman et al, 1995) found that 53.3% of the subjects reported using any "agent" including psychotropic medications, anticonvulsants, vitamins, or other over the counter preparations.[24] In addition, 30.5% of individuals surveyed were currently taking a psychotropic medication, and 13.2% reported using an anticonvulsant.[24] The follow-up study by Langworthy-Lam et al found that 63.7% of subjects reported using any "agent," including psychotropic medications, anticonvulsants, vitamins, or other over the counter preparations.[25] Furthermore, 45.7% of the population surveyed were taking a psychotropic medication, and 12.4% of respondents were taking an anticonvulsant.[25] In comparing these two sequential studies in the same geographic area, temporal changes in medication use were observed. The overall rate of psychotropic medication use increased by 50% over the eight years between the two surveys.[24,25,27] In addition, the rate of antidepressant use increased by 250%, with a shift toward the use of SSRIs over tricyclic antidepressants.[24,25,27] Moreover, the use of newer antipsychotic agents replaced the older generation of neuroleptics in the interval between the two studies, with atypical antipsychotics representing approximately 85% of all antipsychotics used in the second study.[24,25,27] A third study, by Aman et al, 2003, administered the same survey tool to a group of individuals with ASDs in Ohio, and was thus able to comment on regional differences in medication use.[26] The overall utilization patterns of both psychotropic medications and anticonvulsants by individuals with ASDs in this survey was not appreciably different than previous studies, with no regional differences noted over all categories of psychotropic medications.[26,27] All three studies found that the prevalence of

psychotropic or anticonvulsant medication use was associated with increased age, more severe cognitive delay, severity of autism, and with more restrictive residential placements.

Martin et al carried out another study which surveyed the use of psychotropic drug use in a group of children, adolescents and adults with high functioning autism who attended the Yale Child Study Centre in 1997 (Table 1).[77] Overall, 55% were found to be currently taking any psychotropic medication, with 29.3% reporting current use of two or more medications simultaneously.

A final study was carried out by Smith and Antolovich in 1995, who investigated the use of treatments supplemental to an applied behaviour analytic (ABA) intervention program for young children with autism in the states of Washington, California, and New Jersey.[12] This survey included basic information regarding the use of conventional medications in this population. In this study, all treatments that were not part of the intensive ABA program were defined as supplemental, including treatments that would be classified as conventional and those that would be considered CAM. The authors further categorize these so called supplemental treatments into four groups: (1) speech therapy; (2) sensorimotor treatment; (3) psychotherapy; and, (4) biomedical treatments which included conventional medications, vitamins, and elimination diets.[12] With respect to psychotropic medications, out of 121 respondents, 19.8% had at some point used an antidepressant, 9.1% had used a psychostimulant medication, and 3.3% had used an antipsychotic medication.

Finally, there is little literature documenting the types of behavioral interventions used by children and adolescents with ASDs, such as the use of intensive behavioral intervention programs, speech-language therapy, or occupational therapy. The study by Smith and Antolovich found that 85.1% of children had used speech therapy, 4.1% had used occupational therapy, and 1.7% had used physical therapy.[12]

In summary, literature available from United States populations indicates that the use of psychotropic medications in individuals with ASDs may be as high as 50%, with a noted trend towards increased psychotropic medication use between the years 1992 and 2001. The use of anticonvulsants is much lower, and mirrors the prevalence of epilepsy in this population. Little is known about the use of psychotropic medications by age group within this population, specifically in children and adolescents with ASDs as opposed to adult populations. Similarly, very little is known about the use of conventional multidisciplinary treatment modalities such as speech language therapy, occupational therapy, or physical therapy. Likewise, there is no literature documenting the prevalence of intensive behavioural interventions in populations of children with ASDs. Overall, there is no information with respect to the use of either conventional medication or multidisciplinary intervention for children and adolescents with ASDs in Canada.

2.2 Complementary and Alternative Medicine

2.2.1 Definition of Complementary and Alternative Medicine

The current health care system is witnessing an increasing use of CAM, which has been well documented in the United States,[17,21-23] Canada,[18,78-83] and Europe.[19] Surveys indicate that 20-60% of the general population in industrialized nations use CAM.[17,19-23,78-83] CAM has been described in both the medical and lay press as synonymous with the following terms: holistic, unorthodox, unconventional, non-western, unproven, non-medical and natural. CAM has been characterized as a catch-all term that "represents a heterogeneous population promoting disparate beliefs and practices that vary considerably from one movement or tradition to another and form no consistent . . . body of knowledge."[14] Further to the point, as Kaptchuk and Eisenberg point out, "an accurate definition of alternative medicine is further confounded because the boundary demarcating conventional and alternative medicine has always been porous and flexible."[15] By this, they mean that therapies have in the past moved from one camp into the other, often starting in the realm of CAM to then find acceptance within the realm of conventional medicine. Another definition of CAM is that it represents a "broad domain

of healing resources that encompasses all health systems, modalities and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system of a particular society or culture in a given historical period."[84] While this last definition is broad in scope, it is difficult to operationalize because it could be taken to include virtually any practice that an individual believes promotes health. New perspectives on defining or conceptualizing CAM have focused on establishing a taxonomy of these practices,[15] or on classifying them according to their underlying assumptions.[85] A more practical definition of CAM has been articulated by the National Center for Complementary and Alternative Medicine (NCCAM), who define CAM as "a group of diverse medical and health care systems, practices, and products that are not presently considered to be part of conventional medicine."[13] In addition, NCCAM further classifies CAM therapies into five categories or domains, including: (1) alternative medical systems; (2) mind-body interventions; (3) biologically-based therapies; (4) manipulative and body-based methods; and, (5) energy therapies.[13] Differences between conventional medicine and CAM have also been described in terms of their underlying philosophies. Conventional medicine, has been described as mechanistic or reductionist in philosophy, viewing illness and disease as related to specific, locally defined changes in organs, tissues, or physiologic processes.[86] Alternately, CAM is described as embracing a holistic mindset that views illness and disease as indicative of disruptive forces or processes at work in the body as a whole.[86]

2.2.2 Reasons Why Patients Use Complementary and Alternative Medicine

There are many reasons why patients use CAM, largely based on experience with adult populations. Therefore, these explanations may not be directly transferable to parent decision-making for children and adolescents with ASDs. These reasons include the dissatisfaction of patients with conventional treatments in terms of the effectiveness of the treatments,[87-89] the side effects of conventional therapies,[89-91] or the perception that conventional practitioners communicate and interact less effectively than their complementary counterparts.[89] Other reasons given by users of CAM are the need for a

sense of control,[92,93] a personal identification with the philosophical underpinnings of CAM,[16] the perception that CAM is natural and therefore safe,[80,94] and a belief that CAM is effective.[89,95] Regarding severe or chronic illnesses, there is also a strong desire to exhaust every therapeutic possibility, including the use of CAM.[96,97] It has also been suggested that complementary and alternative approaches to medicine "offer patients a participatory experience of empowerment, authenticity, and enlarged self-identity when illness threatens their sense of intactness and connection to the world."[98] It is postulated, then, that many types of CAM provide an alternate way for a patient to reorder and organize their disease experience to one of empowerment and perception of benefit.[98]

2.2.3 Complementary and Alternative Medicine Use by Children and Adolescents

While the use of CAM in adult populations has been well studied, information regarding CAM use in children and adolescents is limited.[91,99,100] Furthermore, overall estimates of the prevalence of CAM use in pediatric populations is dependant upon where the survey was conducted, with different estimates depending on whether the sample was drawn from primary care versus population-based settings. A review of prevalence surveys of CAM use in pediatrics conducted prior to 1998 was carried out by Ernst. This review included surveys drawn from disease specific pediatric populations, primary care pediatrics clinics, and one survey of a specific geographic area. Overall, Ernst concluded that a large proportion of children use some form of CAM, but that there was considerable variability in the prevalence figures between studies, ranging from 9% to 70%.[100] There have been a number of studies since 1998, that have surveyed the prevalence of CAM use in primary pediatric medical settings in the United States, which have found a range of CAM use of between 7% to 21%.[101-103] In contrast, it has been suggested in the literature that previous CAM prevalence estimates may be artificially high due to a focus on surveying CAM use in children who have chronic medical conditions, or who were sampled at health care facilities.[104] Population-based prevalence measures of CAM use in pediatric populations have been carried out with reported use of 1.8% in a study carried out in the United States,[104] and of 17.9% in a sample from south west England.[105]

There is some data regarding the use of CAM in Canadian pediatric populations. The largest survey of pediatric CAM use was carried out in a general outpatient clinic of a Canadian urban hospital in 1992.[91] This study found that 11% of the children seen through their clinic had previously consulted one or more alternative medical practitioners and of these, chiropractic, homeopathy, naturopathy, and acupuncture together accounted for 84% of the reported use.[91] Another study by Verhoef et al surveyed individuals in rural west-central Alberta in 1992 with respect to their use of alternative practitioners, and found that 24.4% of those aged 12 to 17-years had seen a CAM practitioner, and 12.7% of those aged 0 to 11-years had seen a CAM practitioner.[106] This study also found that children and adolescents were more likely to have seen a chiropractor within the preceding six months if their parents had also seen a chiropractor, suggesting that the use of alternative practitioners by children and adolescents may be affected by their parents.[106]

There are many factors associated with increased use of CAM in pediatric populations. Socio-demographic variables associated with CAM use in children include increased age, advanced maternal education, and parental use of CAM.[91,101,107,108] Children with chronic medical conditions not curable by conventional treatments have been noted to have a particularly high prevalence of CAM use.[100] In contrast, there is also recent report of increased use of CAM use for acute illnesses, such as respiratory problems or otitis media, in pediatric populations.[101,105]

In his review paper, Ernst raised a number of valid concerns with respect to interpreting the epidemiologic research of CAM use in pediatric populations.[100] First, there is a lack of a uniform, generally accepted definition of CAM across the different studies surveyed, which could result in different surveys covering different types of therapies. Second, it is difficult to compare significantly different populations of patients surveyed - from populations of children with specific problems such as cancer, to general pediatric inpatients. In addition, the sample populations from different surveys also varied in terms

of size and the country in which they were carried out. Third, the prevalence measures used differed between studies, ranging from one year prevalence to lifetime prevalence. Lastly, there are significant methodological differences between surveys, with some surveys being interview-based and others consisting of questionnaires. In addition, some surveys were conducted with parents and others with children, making it difficult to compare studies. The response rate was also different between studies, and in some studies the response rate was not reported.

There is also a growing body of literature on the use of CAM for specific medical diagnoses in pediatric populations. These include pediatric oncology,[109-112] cystic fibrosis,[113] juvenile arthritis,[114,115] asthma,[116-118] atopic dermatitis and psoriasis,[119] attention deficit hyperactivity disorder,[120-127] cerebral palsy,[128-143] Down syndrome,[144-147] as well as for other developmental disorders and neurologic conditions.[11,148-152] These studies employ varying methodologies including personal interviews, patient diaries, and self-administered questionnaires.

2.3 Complementary and Alternative Medicine Use for Children and Adolescents with Autistic Spectrum Disorders

There are few studies in the literature investigating the use of CAM in children and adolescents with ASDs. Much of the information on types of CAM used in ASD populations is derived from studies whose primary aim was to survey the use of psychotropic medications in this population. There is no information regarding the use of CAM in populations of children and adolescents with ASDs in Canada. This section will begin with a summary of studies that have either directly or indirectly surveyed the use of CAM in populations with ASDs, and will conclude with a review of the literature on specific types of CAM that have been used for the treatment of ASDs.

2.3.1 Prevalence of Complementary and Alternative Medicine Use for Children and Adolescents with Autistic Spectrum Disorders

The first study of CAM use in children and adolescents with ASDs was carried out by Nickel, who surveyed parents of children with autism in Oregon.[11] This study found that 50% of respondents used at least one nonstandard therapy, and of those surveyed 32% had tried two or more non-standard therapies.[11] This study equated "non-standard" treatments with "alternative" or "controversial" therapies. Nickel further operationalized the term "controversial" treatments as those treatments that were: (1) based on overly simplified scientific theories; (2) purported to be effective for a variety of conditions; (3) claimed that most children would respond dramatically; (4) were not supported by carefully designed research studies; (5) paid little attention to treatment objectives; and, (6) which have no or unremarkable side effects.[11,150] Nickel categorized controversial therapies into one of three categories: (1) medicines, vitamin and mineral supplements, and dietary treatments; (2) behavioural therapies; and, (3) surgeries.[11] Although only grouped data is reported for this survey, it is likely that the author's over-simplified operational definition for controversial therapies may have resulted in an under-representation of the actual use of CAM, as many CAM treatments would not fall within the narrow definition used.

The two studies carried out in North Carolina by Aman et al, described previously with respect to the prevalence of psychotropic and anticonvulsant medication, also reported on the use of vitamins in children, adolescents and adults with ASDs in 1992/1993 and 2001 respectively.[24,25] Results from these surveys found that the use of vitamins in general in this population increased from 19.2% to 25.0% in the time interval between the two studies. The use of vitamins specifically advocated for the treatment of autism increased marginally from 5.0% to 5.7% in the same time period.[24,25] The types of vitamins advocated for the treatment of autism in the first study included dimethylglycine, and vitamin B_6 and/or magnesium.[24] However, the percentage of individuals using each individual vitamin was not reported.[24] The prevalence of the use of vitamins advocated for the treatment of autism in the second study included dimethylglycine (2.7%), Super

NuThera (2.4%), and vitamin B_6 (1.0%).[25] There were no instances of the use of secretin reported in the second study.[25] A third study was carried out by Langworthy-Lam et al, and used the same survey tool as Aman et al,[24,25] but in a population of individuals with ASDs in Ohio.[26] This survey found that the use of vitamins in general in this population was 17.5%, and the use of vitamins advocated for the treatment of autism was found to be 10.3%, and included dimethylglycine, dimethylaminoethanol, and vitamin B_6.[26] However, the percentage of respondents using each individual vitamin were not reported. The use of vitamins advocated for the treatment of autism was higher in Ohio than in North Carolina (10.3% versus 5.7%).[27] The study authors postulated that these differences might reflect differences in local consumer interest at the time of each study.[27]

As described previously, Smith and Antolovich investigated the use of supplemental interventions received by young children with autism who started an intensive applied behavioural analysis (ABA) treatment program.[12] However, because the purpose of this study was to survey what therapies were being used in addition to the ABA treatment program, the supplemental treatments surveyed are a heterogeneous group of therapies that include both conventional approaches and CAM. Due to this broader focus, therefore, this study did not specifically assess CAM use in their survey population. As a result, the information with respect to the use of CAM available from this study is limited, and was extracted from the list of supplemental interventions provided. This study found that participants had received an average of seven supplemental interventions (range 1-15).[12] The most commonly used supplemental treatments that are types of CAM included: megadose B_6 and magnesium supplements (61.2%); sensory integration therapies (56.2%); elimination diets (49.6%), including dairy-free diets (27.3%), gluten/wheat-free diets (19.8%), casein-free diets (6.6%), sucrose-free diets (5.0%), the Feingold diet (5.0%), yeast-free diets (4.1%), and chocolate-free diets (3.3%); and, auditory integration therapy at 29.8%.[12] Parents responding to this survey were also asked to comment on whether they felt that each particular treatment was helpful or harmful to

their child. For those treatments that would be considered CAM, parents found elimination diets as a group (65.0%), sensory integration therapy (55.9%), and auditory integration therapy (50.0%) to be the most helpful.[12]

Smith and Antolovich also undertook a qualitative telephone interview of 24 caregivers of children with autism using standardized questions related to the use of the most common types of supplemental interventions, including types of CAM such as megavitamins, sensory integration therapy, and elimination diets.[12] The telephone interview included questions related to how parents learned about the interventions, what factors influenced the parents' decision to utilize these interventions, and what behavioural changes were noted with the use of these treatments. This study found that the use of supplemental therapies increased after the onset of the ABA treatment. Parents reported that they started the supplemental interventions after ABA treatment mainly because they did not know about the interventions until after they had started ABA for their child. It was also found that parents tended to report the positive effects rather than the negative effects of the supplemental interventions used for their child's behaviour. However, the positive effects were almost always reported as small and isolated to a few behaviours. Factors that influenced parental decisions to use supplemental interventions for their children with ASDs varied substantially, and depended on the type of intervention. Professional recommendation was identified as influential in parental decisions to use sensory integrative therapies, but never for the use of megavitamins or dietary interventions. The decision to use megavitamin or dietary interventions was supported by recommendations from other parents, research evidence, or advice given by writers on autism. Parents reported that disruptive behaviour was the motive for initiating megavitamin therapies, sensory integrative therapies, and dietary interventions. Irrespective of the particular intervention, parents also reported that the problems they sought to alleviate with supplemental interventions were longstanding concerns rather than acute issues for their child. Finally, parents in this study often reported that they

continued interventions for their children, despite having concluded that the interventions were unhelpful, because they received funding to do so.[12]

A recent study carried out by Levy et al reported on the use of CAM among children recently diagnosed with an ASD at a regional diagnostic centre in Philadelphia.[9] However, because this study was based on a retrospective chart review, the information with respect to the specific types of CAM used was limited. This study found that 31.7% of these children were using CAM.[9] The rates of use for some types of CAM were also reported, including vitamins (12%), a gluten-free or casein-free diet (16%), secretin (6%), melatonin (3%), cod liver oil (3%), "GI medications" (2%), "anti-infectives" (2%), and chelation (1%).[9] In addition, this study found that 20.8% had tried only one type of CAM, 5.3% had tried two, and 5.6% had tried three or more types of CAM. A limitation of this study is that the authors base their conceptual framework for CAM on four treatment categories,[7,8,9] which have limited heuristic utility. These treatment categories include: (1) unproven benign biological treatments that are commonly used but which have no theoretic basis; (2) unproven biological treatments that have some theoretic basis; (3) unproven, potentially harmful biologic treatments; and, (4) nonbiological treatments. Another shortcoming of this study is the limited number of types of specific CAM therapies for which information was collected, and the use of indistinct CAM categories such as "GI medications." This study found two significant correlates of CAM utilization in this population. Latino children had 6.5 the odds of using CAM compared to European-American children, and children with additional diagnoses were found to be 70% less likely to use CAM than children with no diagnosis other than autism.[9]

In summary, there are few studies that have surveyed the use of CAM by children and adolescents with ASDs. Large scale population-based studies have been conducted on the use of psychotropic medications in individuals of all ages with ASDs, which have also anecdotally reported on the use of some types of CAM. However, because these studies include adults with ASDs in their survey populations, the usefulness of the data for

pediatric populations is limited. Other surveys combine both conventional therapies and CAM in their investigations, making it difficult to parse out those treatments that are truly CAM for review and subsequent analysis. In addition, studies to date have not used definitions and categories of CAM that are widely accepted by the research community. Only one study, carried out by Levy et al, focused solely on retrospectively examining the use of CAM in children recently diagnosed with an ASD.[9] However, this study was limited by its theoretic definition of CAM, and the small number of CAM therapies that could be extracted via chart review. None of the studies systematically assessed the wide range of specific types of CAM that have been used for children and adolescents with ASDs. In addition, there is no research to date surveying the use of CAM in pediatric populations of individuals with ASDs in Canada.

2.3.2 Types of Complementary and Alternative Medicine Used for Children and Adolescents with Autistic Spectrum Disorders

There are many different types of CAM that have been proposed for treating children and adolescents with ASDs. These treatments are often based on single case reports, and most have not been systematically assessed. It has been argued that the increase in the use of CAM for children with ASDs may be due in part to the paucity of effective medications or other treatments for this group of disorders, and the frequency of adverse reactions to the medications that are currently used.[6] Many types of CAM reported to be beneficial in the treatment of ASDs have an underlying philosophical, neurological or physiological framework. In addition, many CAM treatments for ASDs focus on theories related to genetic causes, central nervous system, gastrointestinal, and immune system dysfunction, toxic exposures, or metabolic abnormalities.[153-156] Furthermore, the etiologic or treatment frameworks proposed for many types of CAM are not supported by scientific principles or evidence. Systematized or multi-step CAM approaches to treatment for ASDs are proposed by organizations such as “Defeat Autism Now!,”[153,154] and by private laboratories and companies offering CAM diagnostic tests and treatments. [155,156]

Based on review of the literature, many types of CAM used for children and adolescents with ASDs fall within specific categories, while some are not categorizable. The use of vitamins and nutritional supplements have been cited for use in treating ASDs,[157-161] including the use of megadose vitamin B_6 and magnesium,[6,158,162-172] vitamin C,[173] vitamin A,[174] dimethylglycine,[175] omega fatty acids,[176,177] phytochemicals and glyconutients,[178] and carnosine.[179] A number of dietary interventions have also been proposed for treating ASDs based on the belief that these children have gastrointestinal abnormalities,[180-191] the most common of which are gluten or casein free diets.[192-205] Another therapy advocated for children and adolescents with ASDs consists of supplemental gastrointestinal enzymes.[206] A number of complementary and alternative therapies focus on the removal of a hypothesized gastrointestinal yeast infection, and include dietary interventions and anti-yeast medications, while others focus on the correction of a presumed bacterial gastrointestinal overgrowth with probiotics or with antibiotics.[207-209] The use of secretin, a gastrointestinal hormone, has also been advocated for the treatment of ASDs, and has received intense public awareness and corresponding scientific scrutiny.[210-231] Numerous studies have focused on immunologic abnormalities in children with ASDs, and subsequent treatment with intravenous immunoglobulin has been reported.[232-238] Other complementary and alternative treatments proposed for ASDs include chelation of heavy metals,[239] auditory integration therapies,[240-247] music therapy,[248,249] relaxation training,[250] massage therapy,[251] Touch Therapy,[252] natural play therapy,[253] chiropractic manipulation,[254,255] and craniosacral therapy.[8] However, the overall number of specific types of CAM used for ASDs is much larger than that described in the medical literature. Review of CAM use for children and adolescents with ASDs from internet sites, discussions with parents, as well as the medical literature indicate that over 166 different types of treatments were being used at the time that this survey was conducted. Except for secretin, there have been few systematic evaluations of the efficacy of specific types of CAM for children and adolescents with ASDs. Those studies that exist are limited by small sample sizes, have methodological shortcomings, or have not been replicated.

2.4 Parent Communication with Physicians Regarding the Use of Complementary and Alternative Medicine

There is little information regarding parent communication with their pediatrician about the use of CAM for their children, and the existing literature is from studies conducted only in the United States. No studies were found that focused on parent-physician communication regarding CAM use for children and adolescents with ASDs.

One survey of CAM use in children seen in primary pediatrics clinics in the Washington, DC area found that 21% of parents surveyed had used CAM for their child over the preceding year.[101,256] Of the total sample of parents, including those who used CAM for their child and those who did not, 53% expressed a desire to discuss CAM with their pediatrician.[256] Of those parents who used CAM for their child, 81% reported that they would have liked to discuss it with their pediatrician, and 36% of these parents felt that they disclosed their use of CAM for their child to their pediatrician.[101,256] Factors associated with an increased likelihood of parental disclosure of CAM use included parental non-use of CAM, child age less than 6-years, and the type of CAM used - with bioenergetic therapies being more likely to be disclosed that biochemical, biomechanical, or mind-body therapies.[256] A minority of parents (16%) who used CAM for their child thought that their pediatrician would object to their use of CAM.[101,254] Pediatricians were felt to have asked about CAM use in 16% of respondents who reported using CAM for their child, in 11% of respondents who themselves as parents used CAM, and in 6% of the total population surveyed.[256] Other studies have found that between 40% to 50% percent of parents who use CAM for their children tell their physicians about their use.[100,102, 109]

With respect to physicians themselves, a survey of pediatricians in Michigan in 1997 found that 76.1% of respondents believed that their patients or the parents of their patients would tell them if they were using CAM.[257] While 53.5% of pediatricians reported that they talk to their patients or parents about CAM use, 84.7% felt that the discussion was initiated by the patient or parent.[257] In this study, 50.3% of pediatricians

would refer their patients to other practitioners for CAM therapies, and this was more often for chronic problems for which traditional therapies had failed.[257]

In summary, there is evidence in the literature that parents who use CAM for their children wish to discuss this use with their child's pediatrician. Furthermore, other research has shown that while most pediatricians feel that they talk to their patients or parents about CAM use, the majority do not initiate these discussions themselves. Therefore, to better meet the needs of parents with respect to their use of CAM for their children, many citations in the medical literature and evolving practice guidelines now advocate that physicians enquire directly about CAM use, and that physicians should provide unbiased advice to families regarding the use of CAM for their children.[9,11,100,102,108,258]

2.5 Study Rationale

It is apparent from studies describing CAM use in general pediatrics, and specifically in children and adolescents with chronic medical conditions, that the use of CAM in these populations is substantial. While there has been initial research with respect to CAM use in children and adolescents with ASDs, this literature is preliminary and lacking in detail. Often these studies employ definitions of CAM that do not conform to current generally accepted CAM descriptions. Therefore, it is important to study the patterns of CAM use in children and adolescents with ASDs in a systematic manner and in a way that employs presently accepted theoretic frameworks for CAM. Information from this study will: (1) characterize the types of CAM that parents are using for their children and adolescents with ASDs; (2) potentially increase the awareness of practitioners of conventional medicine about the use of CAM in this population, which in turn may facilitate integrated patient care; (3) help conventional practitioners monitor patients who use CAM in terms of both affects, side effects, and possible negative interactions of these therapies; and, (4) help set priorities for evidence-based clinical research for CAM in this area.

2.6 Study Purpose

The purpose of this study was to describe CAM use by children and adolescents with ASDs in southern Alberta.

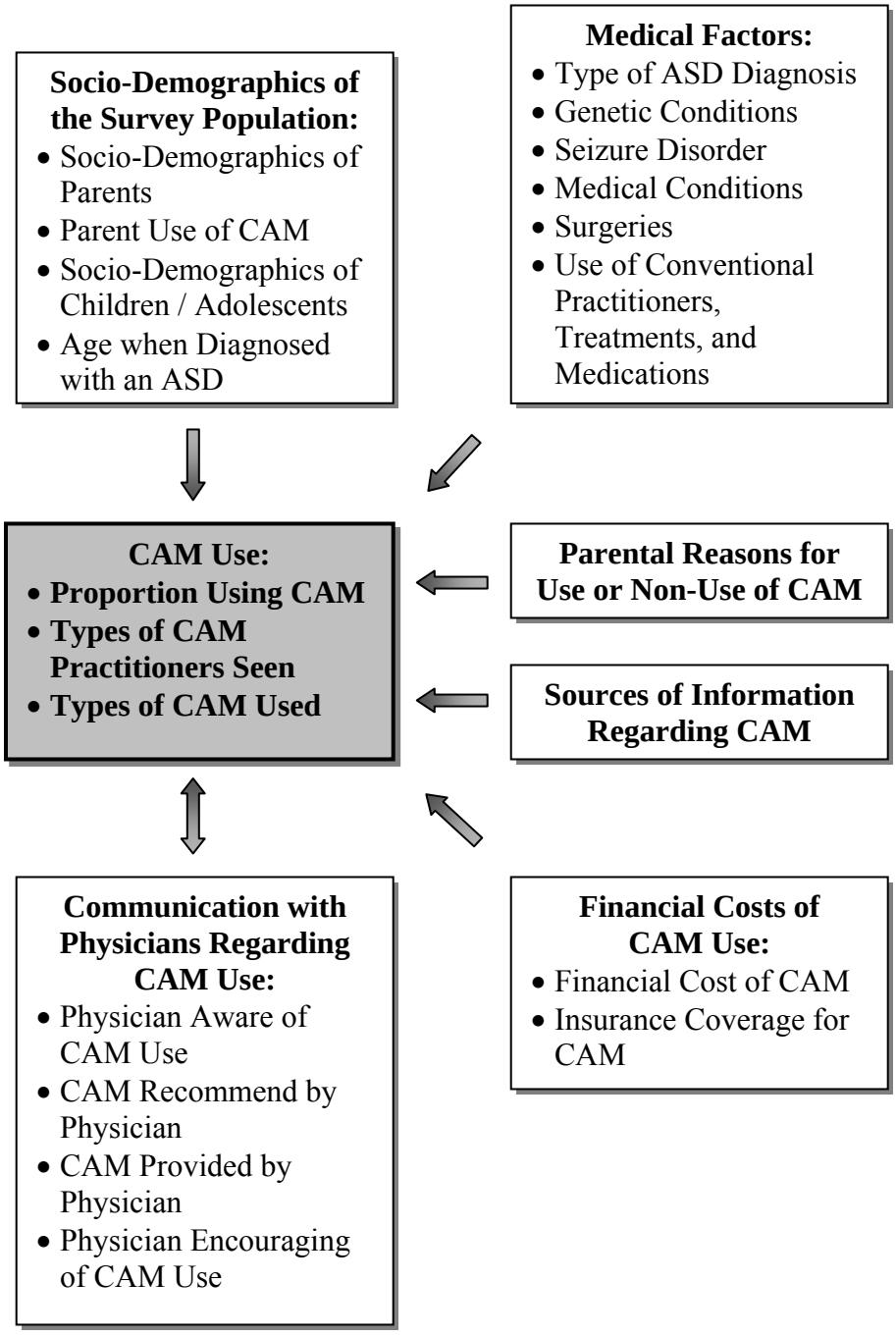
2.7 Study Objectives

The specific objectives for this study were to describe:

1. The proportion of children and adolescents with ASDs in southern Alberta who have ever used CAM.
2. The types of CAM that have ever been used by both general CAM category and by specific types of CAM.
3. The types of CAM practitioners that have been consulted.
4. The reasons why parents have used or not used CAM for their children or adolescents.
5. The information sources regarding CAM that parents have used.
6. The financial costs of CAM use in the preceding year.
7. Patient-physician communication with respect to CAM use.
8. The socio-demographic variables related to CAM use.
9. The medical characteristics of those who use CAM, including types of ASD diagnosis, and associated medical and genetic conditions.
10. The types of conventional medicine used by those responding to the survey questionnaire, including psychotropic medications, anticonvulsants, and multidisciplinary therapies.

A graphic representation of the interrelationship of the variables that are examined in this study is given in Figure 1. This diagram shows how the study variables may interact with variables in the shaded box, but is not intended to describe actual causal relationships with respect to patterns of CAM use overall.

Figure 1: Interrelationship of Study Variables



CHAPTER THREE: METHODS

This chapter reviews the methodology used for this study, including a description of the study design, study population, data collection instrument, and data collection procedure. How the data were analyzed is then outlined. Finally, ethical considerations pertinent to this study are reviewed.

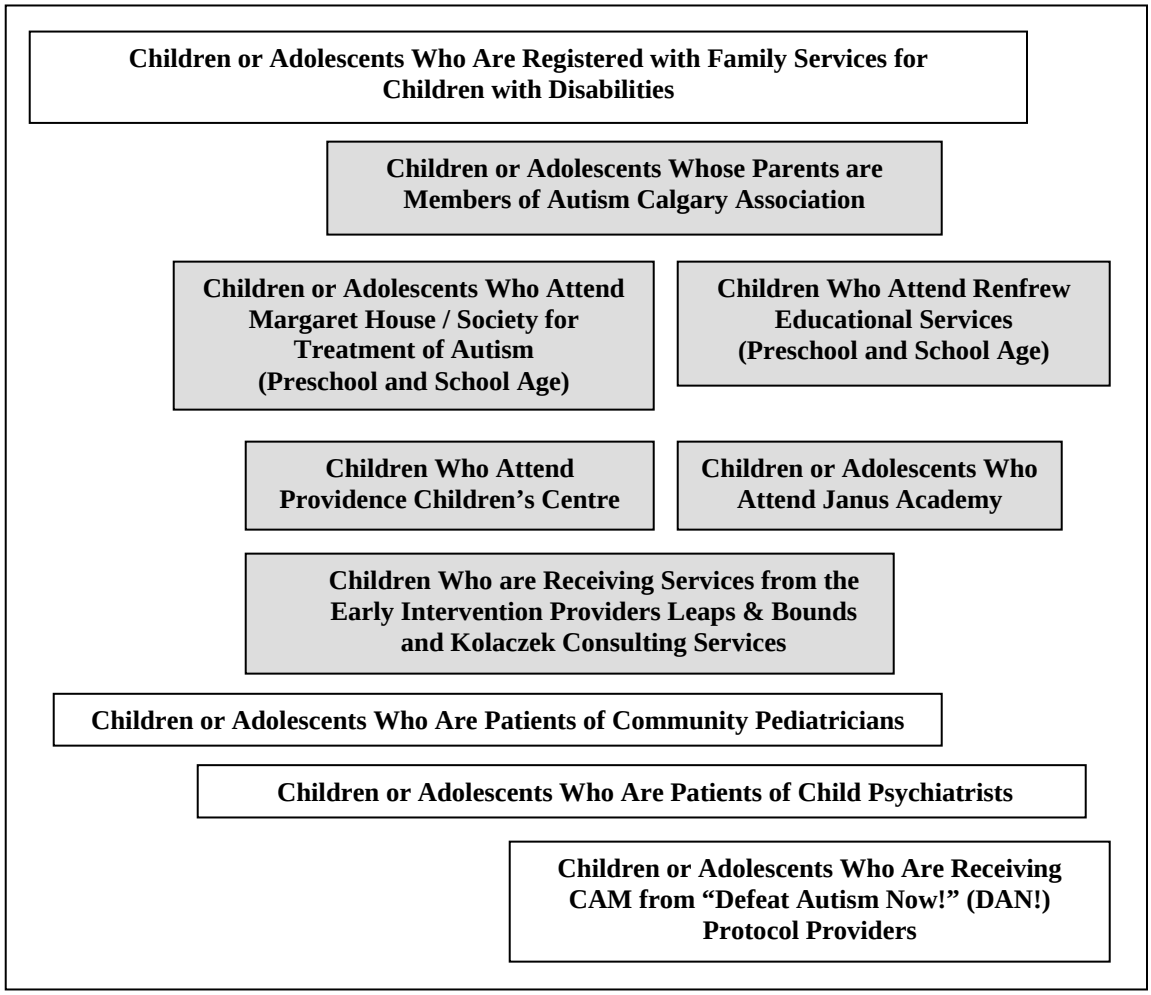
3.1 Design Type

The study design was a cross-sectional postal survey, which collected data on the use of CAM in children and adolescents with ASDs. The advantage of surveys include economy of design, minimal financial commitment, and rapid turn-around in data collection.[259] Limitations of surveys include potentially low response rates, which may limit generalizability.[260] However, other studies have indicated that the effects of non-response bias on mailed surveys are minimal.[261-263]

3.2 Study Population

As ASDs are relatively rare conditions, the study attempted to identify the majority of children and adolescents in southern Alberta who have been diagnosed with an ASD, including the primary diagnoses of autism, Asperger's syndrome, pervasive developmental disorder - not otherwise specified, childhood disintegrative disorder, and Rett syndrome. The actual study participants were the parents of children and adolescents with an ASD that were identified through this survey, and the data collected from parents was about each child or adolescent and their families. Identification of study participants was accomplished through a number of overlapping strategies, which are summarized in Figure 2 below. Organizations depicted in grey shading in Figure 2 served as primary sources for participant recruitment. Organizations depicted in Figure 2 in unshaded boxes, represented recruitment sources that were possible, but eventually not feasible due to organizational restrictions on research, or impracticality with respect to study efficiency and time constraints.

Figure 2: Diagrammatic Schema of Patient Identification Sources



One of the primary patient identification sources was the membership registration of the Autism Calgary Association. The majority of patients from southern Alberta should have been identified through this organization, as many parents make use of the membership services of this organization. Study participants were also identified using enrolment records from private schools that provide education to children and adolescents with ASDs, including Renfrew Educational Services, the Society for Treatment of Autism (including Margaret House, a residential facility for children and adolescents with ASDs), Janus Academy, and Providence Children's Centre. Two organizations providing early intervention to children with ASDs were also included as patient identification sources, to ensure that a sample of younger children with ASDs was represented in the

survey. The inclusion criteria for this study were that children or adolescents have an ASD diagnosis, and an age of 19-years or less. The age criteria for children and adolescents established for this study was based on the World Health Organization, and was defined as ranging from birth to 19-years-of-age.[264,265] Based on enrolment record numbers from organizations involved in this study, a total of 500 questionnaires were mailed out each on two separate occasions. It was anticipated that a proportion of individuals would be identified from multiple sources, and as a result the expected number of study participants was felt to be approximately 350.[A] A sample size calculation was not necessary because this was a population-based study, and the aim was to identify the maximum number of patients in southern Alberta that was feasible in the context of this research project.

3.3 Data Collection Instrument

Data were collected through the use of a self-report questionnaire developed for the purpose of this study (Appendix A). Questionnaire development was guided by other questionnaires that have been used in the area of CAM use. No validated questionnaire regarding CAM use in children and adolescents with ASDs exists. Because there is little information with respect to the patterns of use of both conventional medicine and CAM in populations of children and adolescents with ASDs, this questionnaire was constructed to provide detailed data regarding the utilization of these therapies. In the questionnaire introduction, CAM was defined as those therapies or remedies that are not generally provided or prescribed by physicians. In addition, different CAM treatments were described as falling within specific categories, and specific examples for each category of treatments were provided. It was also noted that many types of CAM do not fall within a specific category. The questionnaire introduction also stated that mainstream treatments

[A] The number of questionnaires sent to members of each organization in the patient identification strategy on each occasion included the following: Autism Calgary Association (300); Society for Treatment of Autism/Margaret House (70); Renfrew Educational Services (88); Providence Children's Centre (6); Janus Academy (15); and, Leaps & Bounds and Kolaczek Consulting Services (21). Based on informed estimates of the overlap between patient identification organizations, the total survey population was felt to be approximately 350

such as intensive behavioral intervention (IBI) were not generally considered to be CAM.

The response format contained a combination of closed-ended and short answer questions. The questionnaire contained information on types of CAM used, types of CAM diagnostic testing that had been done, determinants of CAM use, financial costs of CAM use, sources of information regarding CAM, reasons for using or not using CAM for their child or adolescent, communication between physicians and parents concerning CAM use for their child or adolescent, types of conventional treatments used, medical information about the child or adolescent with an ASD, and socio-demographic information about the family. Specifically, in reference to their child or adolescent, parents were asked to complete a number of tables that listed different types of both conventional treatments and CAM. For each treatment, respondents were asked to rate the degree to which they perceived a particular treatment helped the identified target symptom (autistic behaviors or epilepsy).

Development of the questionnaire was a staged process. Initial drafts of the questionnaire were reviewed for clarity and content by health professionals familiar with ASDs, CAM, and survey methodology. The revised questionnaire was pilot-tested on a small sample of parents from the target population (n = 3), who were recruited from the Autism Calgary Association. Participants were then contacted by the study investigator for a detailed review of each item on the questionnaire regarding clarity, content, and length. The questionnaire was then modified based on experience with the pilot, with some questions added, deleted, or changed (Appendix A). A total of 166 different types of CAM were identified for inclusion in the questionnaire from previous studies on CAM use in ASDs, the medical literature, internet searches, and feedback from parents themselves. The types of CAM identified were classified into twelve different categories based on common treatment groupings identified in the literature. The groups used included: body therapies, mind-body therapies, spiritual therapies, energy therapies, traditional or cultural practices, natural therapies, immune therapies, live cell and stem cell therapies, secretin

therapies, anti-yeast therapies, dietary or nutritional therapies, and vitamins and minerals. A final category entitled "other" was used for those therapies that did not fit within the previous twelve groupings.

3.4 Data Collection Procedure

Data were collected using a mailed survey. The questionnaires were addressed and mailed-out either by the principal investigator, or through a contact person within each organization responsible for their membership database, depending on the preference of each organization. Using this patient identification process, parents may have received more than one questionnaire. Parents were, therefore, instructed to expect to be identified from more than one source, and to fill in and return only one questionnaire per child. Likewise, if a family had more than one child with an ASD, the parents were instructed to fill in and return only one questionnaire per child, and were asked to select the child whose birthday was coming next in the year as the child for which the questionnaire was to be completed. No identifying information was placed on the surveys by either the investigators or the respondents, ensuring anonymity in data collection. The questionnaires were returned directly to the principal investigators at the Department of Community Health Sciences, the University of Calgary.

A cover letter containing the requisite components for informed consent (Appendix B), the questionnaire and a postage-paid return envelope were sent to all parents identified. Informed consent was assumed upon respondent participation as indicated by return of the completed questionnaire. The first questionnaire mail-out took place in December, 2002. To maximize response rates, a second questionnaire package was sent out in January, 2003 to all individuals that were sent the first mail-out survey. A cover letter for this second mail-out appealed for the participation of those who had not as yet responded (Appendix C). The remainder of this second cover letter was identical to the initial mail-out cover letter.

3.5 Data Analysis

A database was constructed in Microsoft Access 1997.[266] Microsoft Access 1997 was chosen as a database program because its use would create fewer data entry errors due to the limitations that the programmer can place on the type of data entered. All data were double entered into the Access database to optimize accuracy of data entry. Data tables were then exported into Microsoft Excel,[267] which in turn were imported into Intercooled Stata Version 8[268] in a step wise fashion to form a master data table with all variables. Data in the Stata 8 database were cleaned by running descriptive statistics, and unusual data points were checked against the raw questionnaire data and recoded if a discrepancy was found.

Descriptive statistics, including means, standard deviations, and frequencies, were used to summarize response variables with respect to CAM use, and other response variables. Data are reported as both raw scores and percentiles. In addition, 95% confidence intervals were calculated for key variables including overall CAM use, the use of each group of CAM, and the use of complementary practitioners. Because the vast majority of children and adolescents in the survey population used CAM, further data analysis with respect to cross-tabulations and logistic regression analysis could not be performed. Generally both the raw score and percentage is provided for all outcome variables. Of note, when there are fewer than 50 respondents in a particular cell, the use of a decimal does not connote increased precision, but is used for consistency in the reporting of data in all tables for this survey. In addition, for the purpose of reporting in tables, treatments were arbitrarily defined as “common” if 5% or more of respondents reported its use. The analysis of treatment helpfulness was based on the likert scale provided in the questionnaire, which included a finding of “no help,” “a little help,” “a lot of help,” “unsure,” and “made worse.” However, to simplify the reporting of results, the categories of “a little help,” and “a lot of help” were condensed into a single category entitled “helped.” In addition, for subsequent data reporting, therapies were arbitrarily defined to be helpful if greater than 60% of respondents reported that a particular therapy was

helpful, and if at least twenty individuals had reported using the treatment. Given the numbers and types of therapies that qualified as helpful based on this arbitrary definition, this decision rule for analysis appeared to be reasonable on a practical level. In addition, the questionnaire required that respondents check whether they had used a particular treatment either in the past or currently. Again, due to the large amount of data generated by this survey, and to simplify data analysis, the variables "used in the past" and "currently using" were condensed into a single category "ever used" for each treatment listed. To ensure that it was reasonable to group past CAM users with those who used CAM in the past and continued to use CAM, these two groups were compared using Fisher's exact tests for categorical variables and t-tests for continuous variables with respect to the top three groups of CAM used, type of ASD diagnosis, gender, age, education level of the parent completing the questionnaire, and for all CAM therapies that met criteria for "helpfulness."

To determine if the survey respondents were representative of the whole population of children and adolescents with ASD, the variables gender, type of ASD diagnosis, presence of an identifiable genetic syndrome, and presence of a seizure disorder in the survey population were compared to available population-based data in the literature. The representativeness of the survey population was also assessed by comparing early and late responders.[269] Early versus late responders were compared using the variables of overall CAM use, the top three groups of CAM used, type of ASD diagnosis, age, gender, and the education level of the parent completing the questionnaire using Fisher's exact tests and t-tests as appropriate.

3.6 Ethical Considerations

This investigation was undertaken in compliance with the guidelines set out in the Tricouncil Policy Statement,[270] which focuses on the ethical principles concerning human subject research of autonomy, beneficence, nonmaleficence and justice.[271] This research

project was approved by the Conjoint Health Research Ethics Board of the University of Calgary.

Respect for autonomy is founded on the premise of voluntary and informed consent.[271] This means that a person's decision to participate in the study is based upon sufficient knowledge of the harms and benefits of participation. As a result, all participants voluntarily chose to participate in the study, based on an antecedent full disclosure of the harms and benefits of the study to them. These harms and benefits were outlined in a covering letter that accompanied the questionnaire (Appendices B and C).

The principle of autonomy also involves self-determination and competency to make medical decisions for one's own self.[271] The competency of children and adolescents to make decisions about their medical treatment follows a gradation from not competent to competent, depending on a particular child's developmental stage. The issue of competency for medical decision-making is more problematic in some children and adolescents with ASDs, as a proportion of these children or adolescents will be cognitively delayed. Therefore, children and adolescents with ASDs are often not competent to make their own medical decisions, and their parents or guardians are usually responsible for this.

Associated with the principle of autonomy is the participant's right to privacy.[271] The right to privacy protects study participants with respect to the access, control and dissemination of personal information. Identifying patients through the Autism Calgary Association membership registry or through the enrolment lists of schools, or residential facilities may have been considered a violation of their privacy. There was, however, no other way to identify study participants. Consent to use the membership registry for each organization for the purposes of patient recruitment was obtained from those responsible for these information sources. In addition, study participants from each organization were identified by a representative from that organization, who also mailed out the

questionnaires to study participants. In this way, the investigators had no knowledge of the participants' identities, and questionnaire responses were strictly anonymous.

With respect to beneficence, it is unlikely that the study participants derived any direct benefit from participating in the study. Indirect benefits to the participants may result through the advancement of knowledge about CAM use for children and adolescents with ASDs as a result of this study. Regarding nonmaleficence, there were no substantive harms incurred for the study participants as a result of their involvement with this research. Minor harms such as the loss of time related to filling-out and returning the questionnaire can be expected with survey research. Participants were informed that declining to participate would in no way affect the current or future medical care that they or their family would receive.

CHAPTER FOUR: RESULTS

This chapter describes and summarizes the survey data. It includes an analysis of: (1) the survey response rate; (2) characteristics of both parents and of the children and adolescents with ASD in the study population; (3) type of ASD diagnosis and associated medical and genetic conditions of the children and adolescents; (4) the types of conventional medicine used; (4) the types of CAM used; (6) the reasons parents gave for using or not using CAM for their children; (7) sources of information that parents used with respect to the use of CAM for their children; (8) the costs of CAM in the preceding year; (9) parent communication with their conventional physicians regarding the use of CAM for their children; and, (10) the representativeness of the survey population. Responses to some survey questions were not analyzed as this was outside the scope of a master's research project, including the use of CAM diagnostic tests, and a qualitative analysis of respondents' comments to both open-ended questions and general comments provided at the end of the survey.

4.1 Response Rate

A total of 500 questionnaires were mailed out on two separate occasions. A number of questionnaires were returned from employees that were on the membership lists of organizations used for patient identification, and these questionnaires were not included in the analysis because they were not parents of a child with an ASD. One hundred and eighty three questionnaires were returned in total, two of which on further examination were identical, and the data from one of these questionnaire was deleted. A further seven questionnaires returned were excluded from the dataset because the reported ages of the individuals with an ASD were over 19-years, and were thus over the accepted age range defined for children and adolescents used for this survey. The individuals excluded from the analysis ranged in age from 20-years to 35-years. The final sample size used for analysis was 176. Given an estimated target population of approximately 350, the calculated response rate was 50.3% (176/350). The number of respondents completing

any one item on the questionnaire varied. Therefore, absolute numbers, percentages, and denominators are included in tables where appropriate.

4.2 Demographic Characteristics

4.2.1 Demographic Characteristics of Parents Completing the Survey

The majority of individuals completing the questionnaire for each child with an ASD were mothers (86.8%; 151/174), with 11.5% (20/174) of the questionnaires being completed by fathers. Only three individuals completing the survey indicated that they were guardians other than biologic parents: one respondent was a grandmother, and another two respondents were adoptive parents. As a result, all guardians are referred to as parents in the remainder of this thesis. The reported marital status for those completing the questionnaire included 85.1% married (149/175), 6.3% separated (11/175), 4.0% common law (7/175), and 2.9% divorced (5/175).

Employment status for the parent completing the questionnaire was diverse, and multiple responses were possible for this question. Almost half (44.6%; 78/175) categorized themselves as homemakers, 33.7% (59/175) worked part-time, and 24.0% (42/175) worked full-time. The majority of spousal employment status was identified as full-time work (81.6%; 137/168), with 10.1% (n=17/168) working part-time, and 7.7% (13/168) identified as homemakers. Further analysis revealed that both parents were engaged in paid work in 51.8% (87/168) of families, while in 46.4% (78/168) of families only one parent was engaged in paid work.

The reported highest education level completed by the parent who completed the survey was also varied. Of the 171 respondents to this question, 3.5% (6/171) had not completed high school, 19.9% (34/171) reported completing high school, 23.4% (40/171) reported completing technical training or diploma certification, 36.8% (63/171) completed an undergraduate or college degree, and 16.4% (28/171) had completed a graduate degree. The reported highest spousal education level achieved was similar to that reported for the survey respondents themselves.

About three quarters of the parents who completed the questionnaire (72.8%; 83/114) reported the use of CAM for themselves. Further details regarding parental use of CAM were not collected.

4.2.2 Demographic Characteristics of Children and Adolescents

The majority of the children were male (83.5%; 147/176), with a male:female gender ratio of 4.9:1. The mean age of the sample was 8.9 years, (range from 3-years to 18-years). The mean age at ASD diagnosis was 50-months (4-years-2-months). Parents first suspected an ASD diagnosis for their child at a mean age of 34-months. This means that there was an average 16-month time span between when parents first suspected something was wrong with their child's development, and the provision of an ASD diagnosis.

With respect to the child's place of residence, 97.1% (169/174) of children resided with their parents, with 2.9% (5/174) not residing with their parents. The five individuals not residing with their parents were reported to live in dependent residential situations outside of their parent's home. The age of those living independent of their parents ranged from between 11-years to 16-years.

4.3 Autistic Spectrum Disorder Diagnosis, Medical Factors and Associated Genetic Conditions

In terms of the primary ASD diagnosis, most were reported to have classic autism (52.8%; 93/176), with 29.0% (51/176) having pervasive developmental disorder - not otherwise specified, 16.5% (29/176) having Asperger's syndrome, 0.6% (1/176) having atypical autism, 0.6% (1/176) having Rett syndrome, and 0.6% (1/176) having childhood disintegrative disorder.

Most children and adolescents were diagnosed with an ASD by a developmental pediatrician (40.9%; 72/176), 16.5% (29/176) reported that a diagnosis came from a child psychiatrist, 13.1% (23/176) from a pediatrician, and 10.8% (19/176) from a

psychologist. Twenty three respondents (13.1%) reported that their child was diagnosed with an ASD by a multidisciplinary team.

The survey also collected information with respect to associated genetic conditions, epilepsy, medical conditions, or previous surgeries for each child or adolescent. An associated genetic condition was reported for only five children (2.8%). These included Down syndrome in two children, and one child each with Fragile-X syndrome, Elhers Danlos syndrome type 3, and osteopetrosis. Only eleven children (6.3%) were reported to have a seizure disorder. The types of seizure disorders reported were diverse, including generalized tonic clonic seizures, absence seizures, complex partial seizures, myoclonic seizures, and infantile spasms. The age of children and adolescents reported to have a seizure disorder ranged from 7-years to 18-years. No child under the age of 7-years was reported to have a seizure disorder. The age of onset of epilepsy could not be determined from the data collected. Eighty-two children and adolescents (46.6%) were reported to have at least one associated medical condition. The most common medical conditions reported were recurrent otitis media in 13.6% (24/176), some type of allergy (environmental, food, or drug allergy combined) in 10.2% (18/176), and asthma in 6.3% (11/176). Sixty five children and adolescents (36.9%) had one or more surgeries, the most common being tympanostomy tube placement in 12.5% (22/176), dental/oral surgery in 9.7% (17/176), adenoidectomy and/or tonsillectomy in 4.0% (7/176), followed by strabismus repair in 2.3% (4/176).

4.4 Use of Conventional Medicine

The survey collected data with respect to the use of conventional medicine by the study population, including the use of conventional medical practitioners - both allied health practitioners and physicians, the use of conventional multidisciplinary and behavioral interventions, and the use of conventional medications both for the treatment of the behaviors associated with ASDs and for seizures.

4.4.1 Use of Conventional Medical Practitioners

Respondents were surveyed regarding what types of conventional allied health professionals their child had seen in the past (Table 2). At least one allied health professional was seen by 99.4% of the survey population. The mean number of allied health care professional seen by all children and adolescents in the survey population was 5.0, and ranged from 0 to 8 different allied health care professionals.

Table 2: Types of Allied Health Professionals Seen by Children and Adolescents with an Autistic Spectrum Disorder

Allied Health Professionals	% Seen
Speech Language Pathologist	**95.5%** 168/176
Occupational Therapist	**92.1%** 162/176
Audiologist	**77.8%** 137/176
Psychologist	**72.7%** 128/176
Social Worker	**54.0%** 95/176
Optometrist	**53.4%** 94/176
Physical Therapist	**48.9%** 86/176
Family Councilor	**12.5%** 22/176

Similarly, parents were asked about what different types of conventional physicians their child had seen in the past (Table 3). At least one conventional physician was seen by 98.3% of the population**.** The mean number of different conventional physicians seen by

all children and adolescents in the survey population was 3.0, and the number ranged from 0 to 9 different physicians.

Table 3: Types of Conventional Physicians Seen by Children and Adolescents with an Autistic Spectrum Disorder

Physicians	% Seen
General Pediatrician	**72.7%** 128/176
Developmental Pediatrician	**70.5%** 124/176
Child Psychiatrist	**39.8%** 70/176
ENT Surgeon	**31.3%** 55/176
Neurologist	**26.1%** 46/176
Ophthalmologist	**21.0%** 37/176
Allergist/Immunologist	**18.8%** 33/176
Medical Geneticist	**17.6%** 31/176
Gastroenterologist	**7.4%** 13/176

4.4.2 Use of Conventional Treatments for Autistic Spectrum Disorders

Information regarding the use of conventional treatments other than medication for children and adolescents with ASDs was gathered, including treatments commonly recommended by physicians, or other allied health care providers (Table 4). Overall, 96.0% (169/176) of children or adolescents in the survey population had used one or

more of the conventional treatments listed in Table 4. The mean number of conventional treatments used was 4.0, and ranged from 0 to 7 treatments. The vast majority of children or adolescents had used speech-therapy (92.6%), and 30% to 50% of individuals had been engaged in some form of intensive behavioral intervention program (IBI). Therapies perceived to be helpful were also recorded for each therapy. Based on predetermined criteria, all treatment modalities presented were felt to be helpful, with over 80% of users for each therapy reporting that these therapies helped their child. It should be noted that the data reported in Table 4 differs from the data reported for each allied health practitioner listed in Table 2, because the numbers reported in Table 4 reflect the practice of a particular therapy, and not the practitioner themselves.

Table 4: Common Conventional Treatments Used for Children and Adolescents with an Autistic Spectrum Disorder

Treatment	% Used	Helped	Unsure	No Help	Made Worse
Speech-Language Therapy	**92.6%** (163/176)	90.2% (147/163)	4.3% (7/163)	2.5% (4/163)	3.1% (5/163)
Occupational Therapy*****	**86.4%** (152/176)	92.0% (138/150)	4.7% (7/150)	0.7% (1/150)	2.7% (4/150)
Picture Exchange Communication System	**61.4%** (108/176)	82.4% (89/108)	7.4% (8/108)	7.4% (8/108)	2.8% (3/108)
Physiotherapy	**43.8%** (77/176)	80.5% (62/77)	13.0% (10/77)	5.2% (4/77)	1.3% (1/77)
Intensive Behavioral Intervention (Home-Based)	**47.2%** (83/176)	89.2% (74/83)	2.4% (2/83)	2.4% (2/83)	6.0% (5/83)
Intensive Behavioral Intervention (Combined Home and Site-Based) †	**37.5%** (66/176)	87.7% (57/65)	3.1% (2/65)	3.1% (2/65)	6.2% (4/65)
Intensive Behavioral Intervention (Site/ School-Based) †	**34.1%** (60/176)	84.7% (50/59)	6.8% (4/59)	3.4% (2/59)	5.1% (3/59)

***** Two respondents did not report on helpfulness for the variable occupational therapy.
† One respondent did not report on helpfulness for the variables combined home and site-based IBI and site/school-based IBI.

4.4.3 Use of Conventional Medications for Autistic Spectrum Disorders

In the survey, parents were asked to identify the medications that their child or adolescent with an ASD had used. These medications were separated into two groups: (1) medications for seizure control, and: (2) medications for treating behaviors associated with ASDs. For the purpose of reporting in tables, medications were arbitrarily defined as "common" if 5% or more of respondents reported its use. Many other medications were reported as used by this population, but below the identified threshold for "common," and

are reported in Appendix D (seizure medications) and Appendix E (medications used for the behaviors associated with ASD).

As only a small minority of children or adolescents were identified as having a seizure disorder, a correspondingly small number in total had ever used seizure medications (4.5%; 8/176). The most common seizure medications used at some point were Carbamazepine at 3.4% (6/176), Phenobarbital and Clobazam each at 2.3 % (4/176), and Phenytoin at 1.7% (3/176). Due to the small numbers reporting use of seizure medications, the perceived helpfulness of these treatments for seizure control as reported by parents is not reported.

Seventy eight (44.3%) parents reported that their child or adolescent had ever used one or more conventional medications for treating autistic behavior, with 18.2% (32/176) reporting use of only one medication, and 26.1% (46/176) reporting the use of two or more medications. The mean number of conventional medications reported ever used by the survey population for treatment of autistic behavior was 1.2, and ranged from 0 to 10 different medications. The most common specific medications used for treating the behavioral manifestations of ASDs are listed in Table 5. Therapies perceived to be helpful for the treatment of autistic behaviors were recorded for each therapy. Based on predetermined criteria, medications perceived as helpful included only Risperidone, with 62.5% of individuals using this medication finding benefit by parent report.

Psychotropic medication use by class was determined for commonly used groups of medications by generating summary variables for each particular medication category. Stimulant medications were used by 18.8% (33/176) of the population surveyed, followed by antipsychotics (both typical and atypical) by 18.2% (32/176), and selective serotonin reuptake inhibitors (SSRI's) were used by 17.1% (30/176). Tricyclic antidepressants were only used by 1.7% (3/176) of children and adolescents in this survey.

Table 5: Common Conventional Medications Used for Behavioral Manifestations of Autistic Spectrum Disorders

Treatment	% Used	Helped	Unsure	No Help	Made Worse
Risperidone	**18.2%** (32/176)	62.5% (20/32)	6.3% (2/32)	9.4% (3/32)	21.9% (7/32)
Methylphenidate (Regular)	**13.6%** (24/176)	58.3% (14/24)	0%	12.5% (3/24)	29.2% (7/24)
Dexedrine (Regular)	**8.5%** (15/176)	60.0% (9/15)	6.7% (1/15)	0%	33.3% (5/15)
Paroxetine	**8.5%** (15/176)	66.7% (10/15)	20.0% (3/15)	6.7% (1/15)	6.7% (1/15)
Diphenhydramine	**8.5%** (15/176)	33.3% (5/15)	6.7% (1/15)	53.3% (8/15)	6.7% (1/15)
Methylphenidate (Sustained Release)	**6.8%** (12/176)	58.3% (7/12)	0%	0%	41.7% (5/12)
Melatonin†	**6.8%** (12/176)	90.9% (10/11)	0%	9.1% (1/11)	0%
Fluoxetine	**6.3%** (11/176)	36.4% (4/11)	27.3% (3/11)	36.4% (4/11)	0%
Clonidine	**6.3%** (11/176)	90.9% (10/11)	0%	9.1% (1/11)	0%
Carbamazepine	**5.7%** (10/176)	50.0% (5/10)	0%	40.0% (4/10)	10.0% (1/10)
Dexedrine Spansules	**5.1%** (9/176)	77.8% (7/9)	0%	0%	22.2% (2/9)

† One respondent did not report on helpfulness for the variable melatonin.

4.5 Use of Complementary and Alternative Medicine

The primary aim of this survey was to collect data with respect to the use of CAM by children and adolescents with ASDs. This included information about the use of both complementary and alternative practitioners and specific complementary and alternative therapies.

To determine whether it was reasonable to group together respondents who used any type of CAM in the past but stopped (n=23), and those who used any type of CAM in the past and continued (n=127), these two groups were compared using Fisher's exact tests or t-tests as appropriate with respect to the variables of: (1) the top three groups of CAM used (vitamins and minerals, mind-body therapies, and dietary-nutritional therapies); (2) type of ASD diagnosis; (3) age of the child or adolescent; (4) gender of the child or adolescent; (5) the education level of the parent completing the questionnaire; and, (6) for all CAM therapies that met criteria for the reporting of helpfulness.[B] This analysis found that the variable of "vitamins and minerals" as a group (p=0.006) discriminated between those who used CAM in the past and stopped and those who used CAM in the past and continued to use, with those who used CAM in the past and continued to use (as a group) being more likely to report using vitamins and minerals than those who used CAM in the past and stopped. However, the use of "vitamins and minerals" as a group was not significant in discriminating between past and present CAM users when the use of "multivitamins" was removed (p=0.173). Overall, none of the variables identified for inclusion in the analysis meaningfully discriminated between those who used CAM in the past and stopped, and those who used CAM in the past and continued to use. Therefore, these two groups are likely similar, and it is reasonable to combine them into a category "ever used" for analysis.

[B] Two other groups existed for possible temporal comparison, and included those who indicated that they had never used CAM (n=11), and those who indicated that they had only currently used CAM (n=15). Because these two groups were small, and because it was difficult to make meaningful temporal comparisons using these two groups, comparative analysis was not undertaken with these two groups of survey respondents.

4.5.1 Use of Complementary and Alternative Practitioners

Parents were surveyed with respect to the types of complementary and alternative medical practitioners that their child or adolescent with an ASD had seen (Table 6). Sixty five respondents (36.9%) reported that their child or adolescent had seen one or more CAM practitioners. The mean number of CAM practitioners seen by the survey population was 0, and ranged from 0 to 6 different CAM practitioners. It should be noted that the data reported in Table 6 refers to the number of respondents who reported seeing an alternative practitioner, rather a particular treatment modality.

Table 6: Types of Complementary and Alternative Medicine Practitioners Seen by Children and Adolescents with an Autistic Spectrum Disorder

CAM Practitioner	% Used	95% Confidence Interval
Chiropractor	**19.3%** (34/176)	13.4% - 25.2%
Naturopathic Doctor	**13.6%** (24/176)	8.5% - 18.8%
Homeopathic Doctor	**10.8%** (19/176)	6.2% - 15.4%
Craniosacral Therapist	**6.8%** (12/176)	3.1% - 10.6%
"Defeat Autism Now" Practitioner	**3.4%** (6/176)	0.7% - 6.1%

4.5.2 Use of Complementary and Alternative Therapies

One hundred and sixty five respondents (93.8%; 95% CI = 90.1% - 97.4%) indicated that they had used some form of CAM, either in the past or currently, for their child or adolescent with an ASD. When types of CAM that some researchers or clinicians do not believe fall within the limits of CAM were removed - specifically prayer, counseling, support groups, multivitamins, and sensory integration - the use of CAM in the past or currently dropped to 88.1% (95% CI = 83.2% - 92.9%). The mean number of different

CAM used by the survey population was 9.6. The range of different types of CAM used by those who used CAM both in the past or currently was from 1 to 79 different treatments. Because the number of different types of CAM used can accumulate over time, the range of CAM used only by those who used in the past was determined to be from 1 to 29, and for those who only endorsed using CAM presently, the range was from 1 to 13 different therapies. The total number of different CAM treatments used by any of the study participants was 173.

Table 7 lists the types of CAM used by category. Further analysis with respect to CAM use by category with types of therapies for which a designation of CAM is unclear removed are also provided for comparison purposes, and are depicted in light grey shading in Table 7. The most commonly used groups of CAM include vitamins and minerals (63.1%), mind-body therapies (51.7%), and dietary or nutritional therapies (45.5%). In addition, any special diet was employed for 37.5% of children or adolescents in this survey. Infrequently reported categories of therapies are not presented in tabular form. These include energy therapies, traditional or cultural practices, immune therapies, and secretin therapies. Generally these therapies were not widely used, often contrary to citations in the medical and popular literature. Amongst these groups of therapies, the only treatments that met the requirement for reporting as common (≥ 5% reporting use) were the energy therapy of Reiki at 6.3% (11/176), and the immune therapy of ambrotose at 6.8% (12/176). Secretin in any form (transdermal, oral, or intravenous) was used by only 4 individuals (2.3%). No respondents indicated that they had ever used live cell or stem cell therapies. The most common types of CAM used, irrespective of CAM category, were multivitamins (49.4%), sensory integration (44.3%), prayer by self or others (36.9%), music therapy (34.7%), massage (27.3%), play therapy (27.3%), a gluten-free diet (23.3%), and a casein-free diet (21.6%).

Table 7: CAM Treatments by Category Used for Children and Adolescents with an Autistic Spectrum Disorder

CAM Treatment Category	% Used	95% Confidence Interval	Mean	Range
Vitamins and Minerals	**63.1%** (111/176)	55.9% - 70.3%	3.2	1 - 20
Vitamins and Minerals without Multivitamins	**39.8%** (70/176)	32.5% - 47.1%	3.9	1 - 19
Mind-Body Therapies	**51.7%** (91/176)	44.2% - 59.2%	1.8	1 - 7
Mind-Body Therapies without Counseling or Support Groups	**42.1%** (74/176)	34.7% - 49.4%	1.4	1 - 5
Dietary or Nutritional Therapies	**45.5%** (80/176)	38.0% - 52.9%	5.2	1 - 28
Natural Therapies	**40.3%** (71/176)	33.0% - 47.7%	2.0	1 - 8
Body Therapies	**39.2%** (69/176)	31.9% - 46.5%	1.3	1 - 3
Spiritual Therapies	**36.9%** (65/176)	29.7% - 44.1%	1.3	1 - 4
Spiritual Therapies without Prayer	**6.8%** (12/176)	3.1% - 10.6%	1.5	1 - 3
Anti-Yeast Therapies	**31.3%** (55/176)	24.3% - 38.2%	2.2	1 - 8
Energy Therapies	**11.9%** (21/176)	7.1% - 16.8%	1.3	1 - 3
Immune Therapies	**8.5%** (15/176)	4.4% - 12.7%	1.3	1 - 2

Table 7: Continued

CAM Treatment Category	% Used	95% Confidence Interval	Mean	Range
Traditional or Cultural Practices	**6.3%** (11/176)	2.6% - 9.9%	1.1	1 - 2
Secretin Therapies	**2.3%** (4/176)	0.1% - 4.5%	1	N/A
Other Therapies	**67.1%** (118/176)	60.0% - 74.1%	2.1	1 - 10
Other Therapies without Sensory Integration	**55.7%** (98/176)	48.3% - 63.1%	1.7	1 - 9

Therapies perceived to be most helpful based on predetermined criteria for the treatment of autistic behaviors are reported in Table 8, with the mind-body therapies of relaxation (96.2%), and support groups (92.9%) receiving the highest ranking.

Table 8: Complementary and Alternative Therapies Perceived as Helpful by Parental Report

Type of CAM	% Reporting Therapy Helped
Relaxation	96.2%
Support groups	92.9%
Sensory integration	87.2%
Food free of additives and preservatives	84.2%
Counseling	83.3%
Music therapy	78.7%
Massage	77.1%
Play therapy	77.1%
Chocolate-free diet	71.4%
Herbal remedies	71.4%
Low sugar diet	66.7%
Auditory integration	64.7%
Omega-3 fatty acids	64.3%
Aromatherapy	64.0%
Lactobacillus acidophilus supplements	62.5%
Oral magnesium	61.5%
Gluten-free diet	61.0%
Casein-free diet	60.5%

Different specific types of CAM commonly used within each category are given in Tables 9 through 17. Each table also records the perceived helpfulness of each therapy. In addition, some tables contain summary variables, and these are depicted in light grey shading within the tables. For summary variables there is no corresponding helpfulness data. For the purpose of reporting in tables, types of CAM were arbitrarily defined as "common" if 5% or more of respondents reported its use. Many other types of CAM were

reported as used by this population, but below the identified threshold for "common," and are listed by category in Appendix F.

Table 9: Common Body Therapies Used for Children and Adolescents with an Autistic Spectrum Disorder

Treatment	% Used	Helped	Unsure	No Help	Made Worse
Massage	**27.3%** (48/176)	77.1% (37/48)	12.5% (6/48)	8.3% (4/48)	2.1% (1/48)
Chiropractic	**14.2%** (25/176)	28.0% (7/25)	40.0% (10/25)	28.0% (7/25)	0%
"Body Talk"	**5.7%** (10/176)	90.0% (9/10)	10.0% (1/10)	0%	0%

Table 10: Common Spiritual Therapies Used for Children and Adolescents with an Autistic Spectrum Disorder

Treatment	% Used	Helped	Unsure	No Help	Made Worse
Any Prayer	**36.9%** (65/176)	N/A	N/A	N/A	N/A
Prayer by Yourself	**35.2%** (62/176)	58.1% (36/62)	33.9% (21/62)	6.5% (4/62)	1.6% (1/62)
Prayer from Others	**27.3%** (48/176)	50.0% (24/48)	41.7% (20/48)	6.3% (3/48)	2.1% (1/48)
Laying on of Hands	**6.3%** (11/176)	72.7% (8/11)	9.1% (1/11)	18.2% (2/11)	0%

Table 11: Common Mind-Body Therapies Used for Children and Adolescents with an Autistic Spectrum Disorder

Treatment	% Used	Helped	Unsure	No Help	Made Worse
Music Therapy	**34.7%** (61/176)	78.7% (48/61)	13.1% (8/61)	8.2% (5/61)	0%
Counseling*****	**17.6%** (31/176)	83.3% (25/30)	6.7% (2/30)	10.0% (3/30)	0%
Support Groups	**15.9%** (28/176)	92.9% (26/28)	3.6% (1/28)	3.6% (1/28)	0%
Relaxation	**14.8%** (26/176)	96.2% (25/26)	0%	3.8% (1/26)	0%

***** One respondent did not report on helpfulness for the variable counseling.

Table 12: Common Anti-Yeast Therapies Used for Children and Adolescents with an Autistic Spectrum Disorder

Treatment	% Used	Helped	Unsure	No Help	Made Worse
Any Probiotic	**18.8%** (33/176)	N/A	N/A	N/A	N/A
Lactobacillus acidophilus	**18.2%** (32/176)	62.5% (20/32)	25.0% (8/32)	12.5% (4/32)	0%
Low Sugar Diet	**17.1%** (30/176)	66.7% (20/30)	10.0% (3/30)	23.3% (7/30)	0%
Yeast-Free Diet	**10.8%** (19/176)	47.4% (9/19)	15.8% (3/19)	36.8% (7/19)	0%
Antifungal Drugs	**6.3%** (11/176)	63.6% (7/11)	18.2% (2/11)	18.2% (2/11)	0%

Table 13: Common Natural Therapies Used for Children and Adolescents with an Autistic Spectrum Disorder

Treatment	% Used	Helped	Unsure	No Help	Made Worse
Aromatherapy	**14.2%** (25/176)	64.0% (16/25)	28.0% (7/25)	8.0% (2/25)	0%
Herbal Remedies	**11.9%** (21/176)	71.4% (15/21)	9.5% (2/21)	19.0% (4/21)	0%
Homeopathy	**10.2%** (18/176)	61.1% (11/18)	16.7% (3/18)	16.7% (3/18)	5.6% (1/18)
Evening Primrose Oil	**9.1%** (16/176)	31.3% (5/16)	37.5% (6/16)	25.0% (4/16)	6.3% (1/16)
Naturopathy	**7.4%** (13/176)	69.2% (9/13)	23.1% (3/13)	7.7% (1/13)	0%
Ginkgo biloba*****	**7.4%** (13/176)	41.7% (5/12)	41.7% (5/12)	8.3% (1/12)	8.3% (1/12)
Chamomile	**6.3%** (11/176)	72.7% (8/11)	9.1% (1/11)	9.1% (1/11)	0%

***** One respondent did not report on helpfulness for the variable ginkgo biloba.

Table 14: Common Nutritional Supplements Used for Children and Adolescents with an Autistic Spectrum Disorder

Treatment	% Used	Helped	Unsure	No Help	Made Worse
Any Omega Fatty Acid (Omega 3-6-9)	**17.1%** (30/176)	N/A	N/A	N/A	N/A
Omega-3 Fatty Acids	**15.9%** (28/176)	64.3% (18/28)	21.4% (6/28)	14.3% (4/28)	0%
Omega-6 Fatty Acids	**10.2%** (18/176)	61.1% (11/18)	27.8% (5/18)	11.1% (2/18)	0%
Omega-9 Fatty Acids	**10.2%** (18/176)	66.7% (12/18)	27.8% (5/18)	5.6% (1/18)	0%
Dimethylglycine	**12.5%** (22/176)	54.5% (12/22)	22.7% (5/22)	18.2% (4/22)	4.5% (1/22)
Eflax Oil	**6.3%** (11/176)	36.4% (4/11)	27.3% (3/11)	18.2% (2/11)	18.2% (2/11)

Table 15: Common Dietary Therapies Used for Children and Adolescents with an Autistic Spectrum Disorder

Treatment	% Used	Helped	Unsure	No Help	Made Worse
Any Special Diet	**37.5%** (66/176)	N/A	N/A	N/A	N/A
Gluten-Free Diet	**23.3%** (41/176)	61.0% (25/41)	17.1% (7/41)	22.0% (9/41)	0%
Casein-Free Diet	**21.6%** (38/176)	60.5% (23/38)	18.4% (7/38)	21.1% (8/38)	0%
Lactose-Free Diet	**17.6%** (31/176)	45.2% (14/31)	19.4% (6/31)	35.5% (11/31)	0%
Chocolate-Free Diet	**11.9%** (21/176)	71.4% (15/21)	19.0% (4/21)	9.5% (2/21)	0%
Food free of Additives and Preservatives†	**11.4%** (20/176)	84.2% (16/19)	0%	15.8% (3/19)	0%
Caffeine-Free Diet	**10.8%** (19/176)	68.4% (13/19)	21.1% (4/19)	10.5% (2/19)	0%
Refined Sugar-Free Diet	**8.5%** (15/176)	80.0% (12/15)	6.7% (1/15)	13.3% (2/15)	0%
Egg-Free Diet	**8.5%** (15/176)	60.0% (9/15)	20.0% (3/15)	20.0% (3/15)	0%
Organic Food Diet*	**7.4%** (13/176)	81.8% (9/11)	9.1% (1/11)	9.1% (1/11)	0%

† One respondent did not report on helpfulness for the variable foods free of additives and preservatives.

* Two respondents did not report on helpfulness for the variable organic food diet.

Table 16: Common Vitamin and Mineral Supplements Used for Children and Adolescents with an Autistic Spectrum Disorder

Treatment	% Used	No Help	Helped	Unsure	Made Worse
General Multivitamin	**49.4%** (87/176)	28.7% (25/87)	35.6% (31/87)	33.3% (29/87)	2.3% (2/87)
Any Magnesium and B_6 Combined	**17.1%** (30/176)	N/A	N/A	N/A	N/A
Oral Calcium	**16.5%** (29/176)	20.7% (6/29)	51.7% (15/29)	24.1% (7/29)	3.4% (1/29)
Any Magnesium	**16.5%** (29/176)	N/A	N/A	N/A	N/A
Oral Vitamin C	**14.8%** (26/176)	19.2% (5/26)	53.8% (14/26)	26.9% (7/26)	0%
Oral Magnesium	**14.8%** (26/176)	15.4% (4/26)	61.5% (16/26)	23.1% (6/26)	0%
Any B_6	**14.2%** (25/176)	N/A	N/A	N/A	N/A
Super Nu-Thera	**12.5%** (23/176)	30.4% (7/23)	30.4% (7/23)	26.1% (6/23)	13.0% (3/23)
Nu-Thera	**5.7%** (10/176)	10.0% (1/10)	30.0% (3/10)	50.0% (5/10)	10.0% (1/10)
Oral Vitamin B_6	**9.7%** (17/176)	35.3% (6/17)	41.2% (7/17)	23.5% (4/17)	0%
Epsom Salt Baths	**8.5%** (15/176)	33.3% (5/15)	53.3% (8/15)	13.3% (2/15)	0%
Cod Liver Oil	**8.5%** (15/176)	6.7% (1/15)	80.0% (12/15)	13.3% (2/15)	0%
Oral Zinc	**8.0%** (14/176)	7.1% (1/14)	64.3% (9/14)	28.6% (4/14)	0%

Table 17: Other Complementary and Alternative Treatments Commonly Used for Children and Adolescents with an Autistic Spectrum Disorder

Treatment	% Used	Helped	Unsure	No Help	Made Worse
Sensory Integration	**44.3%** (78/176)	87.2% (68/78)	7.7% (6/78)	2.6% (2/78)	2.6% (2/78)
Play therapy	**27.3%** (48/176)	77.1% (37/48)	6.3% (3/48)	12.5% (6/48)	4.2% (2/48)
Auditory Integration	**19.3%** (34/176)	64.7% (22/34)	11.8% (4/34)	23.5% (8/34)	0%
Hippotherapy	**9.1%** (16/176)	75.0% (12/16)	6.3% (1/16)	18.8% (3/16)	0%
Multisensory Stimulation	**8.0%** (14/176)	71.4% (10/14)	14.3% (2/14)	14.3% (2/14)	0%
Craniosacral Therapy	**6.8%** (12/176)	58.3% (7/12)	8.3% (1/12)	33.3% (4/12)	0%

4.6 Reasons for Use and Non-Use of Complementary and Alternative Medicine

Survey respondents were asked why they chose to use CAM for their child or adolescent with an ASD. Commonly endorsed reasons are provided in Table 18. The most commonly cited reason for using CAM was to improve the symptoms of autism in their child or adolescent. Other reasons for using CAM were provided by parents via textual comments. Common themes that emerged from these comments included a willingness to try anything, and a desire to avoid using too many types of conventional medication.

Table 18: Reasons That Parents Report for Using CAM for their Child or Adolescent with an Autistic Spectrum Disorder

Reason for Using CAM	Percentage
To improve the symptoms of autism in my child	**71.0%** (76/107)
To improve the mental and emotional well-being of my child	**63.6%** (68/107)
To improve the general health of my child	**58.9%** (63/107)
I believe that it couldn't hurt my child	**45.8%** (49/107)
Because conventional medicine did not have an answers or treatment options	**36.4%** (39/107)
I believe in a holistic approach to health	**33.6%** (36/107)
To take charge of the health of my child	**33.6%** (36/107)
To avoid the side effects of medications	**20.6%** (22/107)
Because I have used it in the past with improvement in my own health	**20.6%** (22/107)
To heal my child of their autistic spectrum disorder	**15.9%** (17/107)

Survey respondents were also asked why they did not use CAM for their child or adolescent with an ASD. Only 15 respondents (8.5%) indicated that they had not used CAM for their child or adolescent. Common reasons endorsed for not using CAM are provided in Table 19. The most frequently cited reason for not using CAM was that parents felt that they did not know enough about these treatments.

Table 19: Reasons That Parents Report for not Using CAM for their Child or Adolescent with an Autistic Spectrum Disorder

Reason for not Using CAM	Percentage
I do not know enough about these therapies	**53%** (8/15)
I do not believe these therapies work	**27%** (4/15)
I am satisfied with the therapy my doctors provide	**27%** (4/15)
There is not enough scientific evidence to support its use	**20%** (3/15)
The therapies are too expensive	**13%** (2/15)
I have never heard of any such therapies	**13%** (2/15)

4.7 Sources of Information About Complementary and Alternative Medicine Use for Children and Adolescents with Autistic Spectrum Disorders

Respondents were asked to identify the five most important sources of information about CAM use for treating ASDs that they had used (Table 20). The most commonly endorsed source of information regarding the use of CAM for ASDs was books about autism in over two thirds of respondents. Talking to another parent or guardian of a child with an ASD was an important information source regarding CAM for roughly two thirds of respondents, followed by autism support groups in half of the parents responding to the questionnaire.

Table 20: Important Sources of Information Endorsed by Parents Regarding the Use of Complementary and Alternative Medicine

Source of Information	Percentage
Books about autism	**68.8%** (77/112)
A parent or guardian who has a child with an autistic spectrum disorder	**60.7%** (68/112)
Autism Support groups	**50.0%** (56/112)
The internet	**43.8%** (49/112)
Stories or articles in magazines, newspapers or on television	**41.1%** (46/112)
Complementary practitioner	**27.7%** (31/112)
Books about complementary and alternative therapy	**26.8%** (30/112)
Friends	**21.4%** (24/112)
Physician	**20.5%** (23/112)
Scientific or medical journals	**20.5%** (23/112)
Self-help books on alternative therapies	**14.3%** (16/112)
Health food store personnel	**13.4%** (15/112)
Family members	**10.7%** (12/112)

4.8 Costs of Complementary and Alternative Medicine

Study participants were also asked to report on approximately how much money they had spent on CAM for their child or adolescent with an ASD in the previous twelve months, including both CAM diagnostic tests and therapies. There were a total of 101 respondents to this question, but only 76 reported spending money on CAM in the preceding year. Of these 76 respondents, the mean amount spent on CAM was $2,947 per year, and ranged from $10 to $70,000 per year. Study participants were also asked whether their private insurance - purchased privately or provided through their employer - covered any of the costs for the use of CAM for their child or adolescent with an ASD. Of one hundred respondents to this question, 2% indicated that the costs for CAM were completely covered by insurance, 8% reported that most of the costs were covered by insurance, 25% reported that a little bit of the costs were covered by insurance, and 65% reported that the costs of CAM were not covered by their insurance at all.

4.9 Parent - Physician Communication Regarding the Use of Complementary and Alternative Medicine for their Child or Adolescent with an Autistic Spectrum Disorder

The survey questionnaire contained a number of questions related to parent - physician communication regarding the use of CAM for their child or adolescent with an ASD. Survey participants were asked whether their physician (family physician, pediatrician, or developmental pediatrician) knew about their use of CAM for their child or adolescent. Eighty four percent (92/109) of parents felt that their physician knew about their use of CAM, with 88.8% (79/89) reporting that they volunteered this information to their physician, and 11.2% (10/89) reporting that their physician asked them directly about their use of CAM.[C] Fourteen percent (17/118) of parents indicated that their physicians recommended the use of CAM for ASDs. The types of therapies recommended by physicians were varied, and included various vitamins, magnesium, nutritional supplements, gluten and casein free diets, chiropractic, massage, music therapy,

[C] Three parents reported that they felt that their physician knew about their use of CAM for their child or adolescent, but did not subsequently provide information about whether this was due to their volunteering the information or due to their physician asking directly.

relaxation, play therapy, sensory integration, natural therapies including St. John's Wort, and secretin.[D]

Study participants were also asked to comment on whether they perceived their family physician or pediatrician to be encouraging of their use of CAM for their child or adolescent with an ASD (Table 21). Both family physicians and pediatricians were perceived to be more encouraging than discouraging of CAM use. The differences between family physicians and pediatricians for the variables of both encouraging of CAM use (p=0.41) and discouraging of CAM use (p=0.59) were not significant upon further statistical analysis.

Table 21: Parent Perception of Physician Encouragement of CAM Use

	Family Physician	Pediatrician
Discouraging	**12.1%** (10/83)	**14.9%** (14/94)
Neutral	**56.6%** (47/83)	**47.9%** (45/94)
Encouraging	**31.3%** (26/83)	**37.2%** (35/94)

4.10 Representativeness

4.10.1 Comparison of the Survey Population to Population-Based Data

To assess the representativeness of the survey population, the study population was compared to population-based data in the literature of individuals with ASDs with respect to the variables of gender, type of ASD diagnosis, presence of an identifiable genetic syndrome, and presence of a seizure disorder. A meta-analysis of epidemiological surveys of ASDs was recently carried-out by Fombonne, and synthesis data from this

[D] Only four parents reported that their physician "provided" CAM, including play therapy, auditory integration therapy, multivitamins, Naltrexone, and secretin. However, it is difficult to interpret what "provided" by a physician meant for many of the treatment options listed by study participants.

review for the identified variables was used for the purpose of comparison.[44] This review by Fombonne includes prevalence studies for ASDs that are primarily from Europe and North America.

A comparison of the rates of different ASD diagnoses between the survey and the medical literature is given in Table 22. Comparing data from this study to the existing literature with respect to the prevalence of different ASD diagnoses suggests that the diagnoses of autism and Asperger's syndrome are over-represented in the survey population, with an under-representation of individuals with a diagnosis of PDD-NOS.

Table 22: Comparison of Autistic Spectrum Disorder Diagnoses in the Survey Population with the Meta-Analysis by Fombonne[E]

ASD Diagnosis	Percentage in Survey Population	Estimated Percentage from the Medical Literature[44]
Autism	52.8%	36.1%
PDD-NOS	29.0%	54.2%
Asperger's Syndrome	16.5%	9.0%
Atypical Autism	0.6%	Not Available
Childhood Disintegrative Disorder	0.6%	0.7%
Rett Syndrome	0.6%	Not Applicable

The male:female gender ratio obtained from this survey was 4.9:1, and this value is similar to the mean gender ratio identified by Fombonne in the literature of 4.3:1.[44] A seizure disorder was reported in eleven children (6.3%), which is less than the median rate of 16.8% reported in Fombonne's meta-analysis.[44] Five children (2.8%) were found

[E] The percentage for each specific ASD diagnosis was obtained by deriving the ratio of the prevalence estimates for each specific ASD diagnosis compared to the overall prevalence estimates for all types of ASD combined.

to have an associated genetic condition which is also less than the 6.4% median rate identified in the literature review by Fombonne.[44]

4.10.2 Early Compared to Late Responders

An indirect method of evaluating representativeness of the data is to compare differences between early and late responders. It has been postulated that late responders closely resemble non-responders.[269] Thus, if there are significant differences between early and late responders, it is likely that non-responders are also different from responders, limiting generalizability of the data.

Early versus late responders were determined via plotting frequency of responders by week. Review of this frequency plot revealed that a large number of surveys were returned on the eleventh week following the first survey mail-out, and this followed a gradual decline in responses over the weeks prior to this. The increased survey return during the eleventh week is unexplained, and complicates the intended early versus late responder analysis. As a result, to fully explore early versus late responders, analysis was carried out using two groupings for early versus late. The first analysis categorized early responders as those who responded within weeks one to eleven inclusive (n=148), with late responders classified as those whose questionnaires were returned after the eleventh week (n=28). A second analysis was undertaken where early responders were classified as those who responded within weeks one to ten inclusive (n=120), with late responders classified as those whose questionnaires were returned after the tenth week (n=56). The relationship between the variables of overall CAM use, the top three groups of CAM used (vitamins and minerals, mind-body therapies, and dietary-nutritional therapies), type of ASD diagnosis, age, gender of the child, and the education level of the parent completing the questionnaire and the variable “early responders” versus “late responders” were assessed using Fisher’s exact tests or t-tests as appropriate. The results of this analysis indicate that the variable of ASD diagnoses of “autism” (p=0.036) discriminated between early and late responders, only when early responders were classified as those

who responded within weeks one to ten, with early responders being more likely to have a diagnosis of autism than another ASD diagnosis than those who were late responders. However, it is difficult to conceptualize that an actual difference exists between early and late responders based solely on the theoretic category of a diagnosis of autism versus all other ASDs combined. Overall, therefore, it is likely that early and late responders were similar with respect to all variables examined. This supports the assertion that the survey population is representative of the whole population of children and adolescents with ASDs in southern Alberta.

CHAPTER FIVE: DISCUSSION

This chapter begins with a brief summary of the key findings from this study. Following this, both the strengths and limitations of the study are outlined, including potential sources of bias. Next, the implications from this research for both clinical practice and future research are provided. Finally, the plan for how the findings from this study will be disseminated is given.

5.1 Description of Survey Population

The majority of children and adolescents with an ASD were male (83.5%), with a mean age of 8.9-years. Most of children and adolescents (97.1%) lived with their parents. Roughly half of the children and adolescents in this survey had classic autism (52.8%). The majority of parents completing the questionnaire were mothers (86.8%), and were married (85.1%). Over half (50.3%) had completed an undergraduate or graduate university degree. In roughly half of the families, both parents were engaged in paid work (51.8%), while in slightly fewer families (46.4%) only one parent was gainfully employed.

5.2 Use of Complementary and Alternative Medicine

Children or adolescents who used CAM also utilized conventional multidisciplinary or behavioral interventions. Almost all (99.4%) of the survey respondents indicated that they had seen at least one allied health professional, and at least one conventional physician (98.3%). Not surprisingly, this population was found to use multidisciplinary and behavioral therapies more frequently than conventional medications. The use of conventional multidisciplinary interventions were endorsed by 96.0% of survey respondents. One or more conventional medications were used by almost half of survey respondents (44.3%).

This survey assessed both the types of CAM therapies and the CAM practitioners utilized by children and adolescents in the survey population. The majority of children and

adolescents (93.8%) in the survey population had used some form of CAM either in the past or currently. The range of CAM used numbered from 1 to 79 different treatments by any one individual, and 173 different treatments were used in total. The most common types of CAM used included vitamins and minerals (63.1%), mind-body therapies (51.7%), and dietary or nutritional therapies (45.5%). Types of CAM used include treatments that are considered mainstream CAM such as chiropractic and massage, to unusual treatments such as bovine colostrum, and urine therapy. Common specific types of CAM used were wide ranging and fell within many different CAM categories. Because therapies such as prayer, counseling, support groups, multivitamins, and sensory integration therapies are aligned with conventional medicine or are not considered by many to be types of CAM, further analysis was performed regarding the overall rate of CAM use in this population with these therapies removed. When these therapies were removed from the analysis, the overall use of CAM in this population was still very high (88.1%). The rates of CAM use in this study are much higher than reported in previous studies. Early preliminary work in the United States suggested that the use of CAM in children and adolescents with ASDs was as high as 50%.[11] Levy et al found an overall rate of CAM use of 31.7% in a more comprehensive survey of CAM use in children with ASDs, but these were young children with a recent ASD diagnosis.[9] Because the survey by Levy et al used a limited definition for CAM and was based on a retrospective chart review, it is not surprising that the rates of CAM use reported are lower than found in this present study.

The use of CAM practitioners was assessed independent of CAM therapies, and roughly one third (36.9%) of children and adolescents in the survey population had seen one or more CAM practitioners. The most commonly seen CAM practitioners in the survey population were chiropractors (19.3%) and naturopathic doctors (13.6%). The rate of use of CAM practitioners is higher in this survey than reported elsewhere in general pediatric populations in Canada, where rates of approximately 11% to 16% have been reported.[91,106]

Possible explanations for the significant differences found between the rates of CAM use in this survey and in other surveys include variations in the survey population, and differences in the definition of CAM used in each study. The rate of CAM use may also be higher in this study because the questionnaire prompted participants to respond to a wide range of CAM therapies and practitioners that they may have used through the use of detailed lists, thereby increasing accurate reporting and decreasing the risk of parents forgetting what therapies they may have used. This strategy also increased the likelihood of capturing the complex use of CAM for children and adolescents with ASDs.

There is some literature concerning the use of specific types of CAM in populations of individuals with ASD, including vitamins and minerals, dietary interventions, sensory integration, and auditory integration.[9,12,24,25,26,27] The rates of use of these specific therapies are compared to our study findings below. These studies vary with respect to methodology, the age groups surveyed, and the definition of CAM used, making it difficult to compare the results from these studies to those found in our study. Studies in the United States have provided estimates of the prevalence of vitamin use for the treatment of autism in populations of children, adolescents and adults with ASDs of 5.7% and 10.3%.[25-27] In the study by Levy et al, vitamin use was reported at 12% in their survey population of young children with ASDs.[9] The results from our study found a much higher rate of vitamin and mineral use of 63.1%, but this rate dropped to 39.8% when multivitamins were removed from the analysis. Another study found that the use of megadose magnesium and B_6 in a population of young children with ASD was 61.2%.[12] In contrast, any type of combined magnesium and vitamin B_6 preparation, was used by 17.1% of our survey population. The use of sensory integration has been reported in a populations of young children with ASDs, with a rate of 56.2%,[12] which is comparable to the rate found in our study of 44.3%. The use of auditory integration has been reported in young children with ASD with a rate of 29.8%,[12] which is higher than the rate found in our study of 19.3%. Rates of use of any dietary intervention have also been reported in the literature at 49.6%,[12] which is higher than the findings of our survey of 37.5%. In

addition, rates of gluten-free or casein-free diets have been reported in the literature for young children with autism. In one study, the combined rates of use of gluten-free/casein-free diets use 16%,[9] while in another study gluten-free diets were used by 19.8%, and casein-free diet were used by 6.6% of the survey population. Our study found higher rates for gluten-free (23.3%) and casein-free (21.6%) diets than have been reported previously in the literature.

Some treatments that have a high profile within the ASD parent community such a chelation and secretin were found to be less commonly used in our survey with rates of use for chelation of 2.8%, and for secretin of 2.3%. This is comparable to the rates found in the study by Levy et al, where chelation was used by 1%, and secretin was used by relatively more individuals at 6%.[9] The reported use of secretin in particular is far less than one would expect given the attention given this treatment in the media and medical literature.

5.3 Parental Perception of Helpfulness of Complementary and Alternative Medicine

An exploratory component of this research was a survey of parental perception of the helpfulness of each type of CAM that they had used for their child or adolescent. In general, parents perceived many types of CAM to be helpful for their children or adolescents with an ASD. Overall, 18 different types of CAM met criteria for reporting with respect to parental perception of helpfulness for improving autistic behaviors. The most helpful treatments for improving autistic behaviors as perceived by parents included relaxation, support groups, sensory integration, food free of additives and preservatives, and counseling. Other types of CAM were also felt to be helpful by parents, but small numbers in total reported their use. There is some information in the medical literature on parental perception of how effective specific types of CAM were for their child or adolescent with an ASD, but these are limited to individual therapies such as glyconutrients, sensory integration, auditory integration, and supplements combining

magnesium and vitamin B_6, and the results from these studies are not compared to the data from our study.

However, for a number of reasons, the data concerning parental perception of CAM helpfulness must be interpreted with caution. First, there is debate about whether favorable ratings in survey questionnaires reflect actual improvement, as opposed to recall bias or response bias.[12,272] The use of a helpfulness rating in our survey only tapped into the subjective parental reporting of positive or negative changes in their child's symptoms, and as a result is subject to these biases. In addition, measurement of treatment effectiveness is a more complex concept than this survey was able to capture. Other researchers have suggested that the comprehensive assessment of treatment effectiveness should include measures of specific problem improvement, a measure of patient satisfaction with the treatment, and a measure of global improvement.[272] However, due to the number of treatments that were canvassed in this survey, this type of comprehensive ascertainment of effectiveness was outside the scope of this study. Future studies may want to include a more objective measure of symptom change with the use of specific types of CAM, which may more fully capture treatment effectiveness. Second, researchers in the area of CAM have found that patients generally do not perceive CAM to have deleterious effects, in contrast to conventional medications. [12,80,94] This may explain, in part, why parents tended to perceive CAM therapy as helpful rather than unhelpful ("made worse"), as well as a tendency for parents to more frequently rate CAM therapies as helpful than conventional medications. Third, it has also been suggested that the perception of benefit of CAM may be related to the need of CAM users to find benefit after investing money, time and effort into implementing a particular treatment, and this may have affected the accuracy of parental perception of CAM helpfulness for their child.[273] Fourth, the assessment of CAM helpfulness was also difficult due to the overlap that may exist for many children and adolescents in this study between their use of a number of different types of CAM, or between their use of CAM and conventional therapies. This may have made it difficult for parents to accurately ascribe positive or

negative changes to any one treatment. Finally, another reason to be cautious about the helpfulness data involves the use of the target outcome of improvement in "autistic behavior," as this poorly reflects the clinical reality of treating the behavioral manifestations of ASDs. Behavioral difficulties in children and adolescents with ASDs have an extensive differential diagnosis, and treatment with conventional therapies or medication is linked to identifiable symptom clusters. Likewise, we do not know what symptoms or behaviors that parents themselves were targeting with the use of CAM, such as sleep difficulties. It may have been more informative to have asked directly why each particular type of CAM or conventional therapy was used, or for what particular behavioral problem a treatment was initiated.

5.4 Reasons for Use and Non-Use of Complementary and Alternative Medicine

The most common reasons that parents reported for using CAM were to improve their child's autistic symptoms and to improve their child's emotional well-being and general health. Thus, the primary parental motive for using CAM for their children or adolescents was to positively change their child's emotional, behavioral or physical health. Roughly half of parents who used CAM for their child also reported that they did so because they felt that these therapies couldn't hurt, which is a commonly cited reason for use by people who use CAM.[80,94] A desire to take responsibility for the health of their child, dissatisfaction with conventional medicine, and a belief in holistic health are other reasons cited in the literature for using CAM, but these were endorsed only by roughly one-third of the parents responding to this question. Only a minority of parents (15.9%) identified that their motive for using CAM for their child or adolescent was to heal their child of their ASD.

A very small group of parents reported that they did not use CAM for their child, and the single most common reason endorsed by this group for not using these therapies was because they did not know enough about them. Other reasons cited for not using CAM were a belief that they did not work, satisfaction with the therapy provided by their

conventional physician, and a conviction that there was not enough scientific evidence to support their use. Very few parents identified cost as a barrier to the use of CAM.

5.5 Parental Use of Complementary and Alternative Medicine

Almost three quarters of parents responding to the questionnaire reported using CAM for themselves. Because the use of CAM among the children and adolescents in this study was so high, the association between parental use of CAM and the use of CAM by their children could not be determined. Previous studies have shown a strong relationship between parental utilization of CAM practitioners and use by their children.[274]

5.6 Sources of Information about Complementary and Alternative Medicine

Parents identified that the most important sources of information regarding CAM for treating children and adolescents with ASDs were books about autism, discussions with another parent or guardian of a child with an ASD, and autism support groups. The results from this study would suggest that parents find value in reading non-medical information and talking to other parents with respect to CAM. These findings may have implications for how health information regarding the safety and efficacy of CAM for ASDs is distributed to parents. How to best educate parents regarding CAM use for ASDs, including their own preferences for education and information, is an important question for future investigation.

5.7 Costs of Complementary and Alternative Medicine

About 40% of parents reported spending money on CAM in the preceding year for their child or adolescent, and the average amount spent by this group was almost $3,000, with considerable variation in the amount spent by each family from $10 to $70,000. The majority of parents reported that the costs of CAM were not covered by their insurance at all, while a minority reported that most or all of these costs were covered by private insurance. For many families, therefore, the use of CAM for their children or adolescents may entail a significant financial burden. Should future research provide evidence for the

efficacy of these treatments for individuals with ASDs, the argument could be made that they should be publicly funded. In the absence of evidence, however, families should be counseled to be cautious about their own personal expenditures on CAM.

5.8 Parent - Physician Communication Regarding Complementary and Alternative Medicine

Regarding parent-physician communication about the use of CAM for children and adolescents with ASDs, the majority of parents (84.0%) felt that their conventional physician was aware of their CAM use for their child. However, most of these parents (88.8%) felt that they told their physician about their use of CAM rather than their physician directly asking about it. Rates of parental disclosure about CAM use to their child's pediatrician was greater than that identified in the literature, where disclosure rates of 40% to 50% have been reported.[100-102,109,256] Similar to previous reports in the literature, parents also felt that they more often told their physician themselves about their use of CAM for their child, rather than their physician asking directly.[101,256] Parents in our survey indicated that few conventional physicians recommended the use of CAM for treating ASDs. Overall, roughly one third of family physicians and pediatricians were perceived by parents to be encouraging of their use of CAM. Only a minority of both physician groups were perceived to be discouraging of CAM use.

5.9 Response Rate

The response rate was 50.3%. A number of strategies were employed to promote participation in the survey. These included: (1) piloting the questionnaire with parents, which identified problems in the questionnaire and allowed for the reformatting of the survey tool to parent satisfaction; and, (2) the inclusion of a postage-paid return envelope, which has been shown to increase survey responsiveness.[275,276] Factors that may have negatively impacted the response rate include: (1) the length of the questionnaire; and (2) the timing of the first mail-out, which occurred in mid-December which is a busy time for most families. In addition, because one of the primary investigators was a conventional physician, and some of the individuals identified in this survey may have been one of his

patients, this may have resulted in some parents being less willing to disclose information about CAM use, despite the questionnaire being anonymous. This may also have resulted in the under-reporting of harmful treatments, or of negative treatment helpfulness. Other techniques or survey characteristics that have been shown to improve response rate, include the use of: advance notices; personalized letters or questionnaires and colored ink; monetary incentives; mail strategies such as the use of certified mail, stamped rather than metered return envelopes, or courier carriers; follow-up contact via telephone or written reminders; and the provision of additional questionnaires to non-respondents.[274-276] However, because this was an anonymous survey, personalized strategies to maximize questionnaire return could not be undertaken. Other techniques were outside the time and funding means of this graduate research project, and hence were not employed.

5.10 Representativeness

To assess whether the survey population was representative of the whole population of children and adolescents with ASDs in southern Alberta, the survey population was compared to a meta-analysis of population-based studies drawn primarily from Europe and the United States, with respect to gender, type of ASD diagnosis, and associated genetic syndromes or seizure disorders. Overall, no significant differences were found with respect to gender. Differences did exist with respect to type of ASD diagnoses between the survey population and aggregate rates reported in the medical literature. Specifically, the survey population was found to have an over-representation of the ASD diagnoses of autism and Asperger's syndrome, with an under-representation of PDD-NOS diagnoses. Similarly, the prevalence of both epilepsy and associated genetic conditions were lower in the survey population than the rates reported in the medical literature. As no Canadian data are available for direct comparison, it is difficult to determine whether these differences are reflective of true geographical differences, or whether these differences with respect to the variables are due to selection or non-response bias.

The representativeness of the survey population was also evaluated by comparing early and late responders. Early and late responders were found to be similar with respect to all variables examined, except possibly for the diagnostic variable of autism versus other ASDs. However, this difference is based on a theoretical construct and conceptually it is difficult to find meaning with respect to this comparison. Overall, it was felt that the survey respondents and the larger non-surveyed population are likely similar, and thus the results from this survey are likely representative of the population of children and adolescents with ASDs in southern Alberta.

5.11 Strengths of the Study

This study is the first comprehensive descriptive survey of CAM use in children and adolescents with ASDs in Canada. In addition, the survey utilized a broad identification strategy that aimed to capture all ages and types of ASD diagnosis. The survey tool was also based upon accepted CAM definitions, which strengthens its validity across both conventional and CAM research and clinical settings. In addition, by using a detailed survey, this study was able to capture the complexity of CAM use for children and adolescents with ASD. Likewise, this study differentiated between the use of both CAM practitioners and specific CAM therapies, which many previous studies have failed to do. This study not only provided detailed information with respect to the use of CAM, but also convention medicine use in this population for which there is little information. This study is also unique in being the first to report on other variables associated with CAM use for children and adolescents with ASDs, including reasons why parents choose to use or not use CAM, information sources, costs of CAM, insurance coverage, and communication patterns between parents and physicians regarding CAM use. Many parents also provided detailed narrative responses at the end of the survey questionnaire. These data will be analyzed in the future as they will provide an important source of qualitative information regarding the experiences and beliefs of parents who use CAM for their children. This research project also entailed working collaboratively with a number of organizations involved in providing support and intervention to children and

adolescents with ASDs, and this successful project will facilitate future collaborative research.

5.12 Limitations of the Study

5.12.1 General Limitations

This study has a number of limitations. First, although this is a descriptive study, the findings from this research project are limited by the response rate. The length and detail of the survey may have negatively impacted response rate. One option would have been to collect less data. However, it was decided to collect comprehensive and detailed information about the use of CAM in the survey population to guide future inquiry in this area. Second, this survey could not assess the systematic or sequential CAM treatment protocols that are proponed by ASD advocacy groups, as temporal relationships between different types of CAM used was not gathered. Third, this survey did not collect information related to the severity of each child or adolescent's ASD, such as level of cognition or speech-language skills, which could have been a possible determinant of CAM use. Finally, because the utilization of CAM in the survey population was so high, a number of research objectives could not be undertaken, such as exploring the association between socio-demographic variables or medical factors with CAM use.

5.12.2 Potential Sources of Bias

The results of this study may be impacted by three important sources of bias, including selection bias, non-response bias, and recall bias. However, it is difficult to determine whether the study results for any particular variable represent an underestimate or overestimate of the true population values because further information regarding how any of these variables may have influenced CAM use was not available. Because there was no way to identify all individuals with ASDs in southern Alberta, and as this was an anonymous survey, strategies to minimize bias could not be used.

Cross sectional surveys are susceptible to selection bias, and this is particularly true for this study. Selection bias is the due to systematic differences in characteristics between those selected for a study and those who are not.[277] Selection bias is also more likely to occur with low response rates. Because one comprehensive recruitment organization that could identify all individuals in southern Alberta with an ASD does not exist, study participants were identified using multiple overlapping patient recruitment sites. Therefore, it is possible that many groups of children with ASDs were systematically excluded by the identification strategy employed. This may have been particularly true for individuals living in rural settings or for individuals residing in urban centres outside of Calgary. Selection bias may occur if there are missed groups, or if those who belong to a group used for patient identification are more likely to be users of CAM than those who are not. This may be possible, for example, with the Autism Calgary Association. If families who are members of this organization are more committed or organized to pursue all therapeutic options for their children, including the use of CAM, they may differ in systematic ways from other families who have children with an ASD.

Another source of bias identified in this study may have been non-response bias, or the systematic error that may occur due to differences between those who responded to the questionnaire and those who did not. Roughly half of the target population did not respond to the questionnaire survey, and hence the results may be impacted by this non-response. One possible manifestation of non-response bias is that those who responded to the questionnaire may have been those parents who were highly interested in the use of CAM for treating their child's ASD, while those who did not respond to the questionnaire were those who were not interested in or did not use CAM for their child. Non-response bias may have also occurred as a result of the length of the questionnaire. This may have been further compounded by the inability of a family to devote time to completing a lengthy survey due to the time commitment and effort required in raising some children and adolescents with ASDs.

Finally, recall bias, which is the systematic error due to differences in accuracy or completeness of recall to memory of past events or experiences, may also have been a factor in this study.[277] Recall bias may have affected parental reporting of medical factors, types of therapies used, practitioners seen, or helpfulness data in particular.

5.13 Implications for Clinical Practice

This study found the use of CAM for children and adolescents with ASDs to be remarkably high. This finding highlights the importance of physician awareness about the use of CAM for children and adolescents with ASDs. Physicians will also need to monitor for potential negative side effects of CAM, as well as for potential treatment interactions between different types of CAM and with conventional medications. Conventional physicians should provide guidance to parents of children and adolescents with ASDs regarding CAM with respect to the available evidence for the efficacy of these treatments, potential side effects, and the need for objective outcome measures. Furthermore, given the high use of CAM by this population, it may be important for conventional practitioners and CAM practitioners to provide collaborative and integrative clinical management for these patients.

This study found that few physicians themselves asked directly about CAM use, contrary to emerging practice guideline recommendations for pediatricians, that encourages physicians to actively enquire about the use of CAM. Therefore, it will be important for physicians to change their clinical management practices to actively enquire about the use of CAM in this population, and to provide a non-judgmental context for ongoing dialogue with parents and their children about the safety and efficacy of CAM.

There is also a need for accurate information with respect to the efficacy, side effects, and potential harms of CAM used in this population, which will meet the needs of conventional physicians, alternative practitioners, parents, and patients. This information will need to be regularly evaluated and updated due to the rapidly evolving and changing

nature of these therapies. Consequently, this research project has a practical application in that it allowed for the systematic collection of the available medical literature with respect to CAM and ASDs. This literature will be made available to researchers, as well as study participants through the organizations from which they were identified. However, literature documenting evidence for the use of CAM for children and adolescents with ASDs is limited. In addition, it will be important to survey different groups, including patients, parents, and health care providers, about how they would like to access information about the use of CAM for ASDs.

5.14 Implications for Research

5.14.1 Future Analysis Plan

Components of the survey data have yet to be analysed, and were outside the scope of this graduate project. First, an analysis of the qualitative textual comments reported by survey respondents at the end of the questionnaire will be undertaken, to identify emerging themes with respect to CAM use in this population. Clearly this is an important area, due to the length and number of textual comments provided by survey participants. The other data element that was not analyzed from the survey data was the use of complementary and alternative diagnostic tests, and this analysis will also be undertaken. Future data analysis will also include a detailed analysis of those who used CAM in the past and stopped compared to those who continue to use CAM with respect to frequently used types of CAM, or those types of CAM identified by parents as being most helpful.

5.14.2 Identified Gaps for Future Research

Future research should be directed towards the systematic assessment of the effectiveness of specific types of CAM. This could be undertaken using a number of different research methodologies, including a retrospective clinical audit of patients with ASDs, a prospective case series, or using N-of-1 methodology within clinical contexts.

Efficacy studies should also be carried out, including randomized controlled trials, based on which therapies are frequently used or endorsed as helpful, but which also have an acceptable safety profile and are not overly costly. However, future research on the efficacy of specific types of CAM for children and adolescents with ASDs should be guided not only by scientific merit, but also by the treatment priorities identified by parents in this survey. Given the common use of complementary and alternative diets for children and adolescents with ASDs, a promising area for research would be a qualitative investigation of dietary interventions for this group. This study would set the stage for future quantitative investigations into the efficacy of specific dietary interventions for ASDs, by identifying which interventions and associated outcomes are meaningful and important from a parent perspective.

Future research will also focus on collaboration between clinical researchers, parent groups, and CAM practitioners to collectively identify research priorities with respect to CAM use for ASDs, and to develop collaborative research proposals and initiatives.

5.15 Dissemination of Research Findings

It will be important to disseminate the findings from this research, and the format will likely be different for different groups. The findings from this study will be summarized and provided to all organizations that were part of the patient identification strategy. These organizations will then be responsible for distributing this survey summary to their members. The study findings will also be presented to interested parent and advocacy groups, such as Autism Calgary Association. In addition, this research will be published in content specific journals, specifically in journals with a focus on general pediatrics, developmental pediatrics, and CAM.

5.16 Conclusion

The use of CAM in children and adolescents with ASDs is very common, but this use is based on limited scientific evidence. Further research is needed regarding the safety and efficacy of these treatments, and should be guided by scientific merit and by the treatment priorities identified by parents through this study. Medical and alternative practitioners should be aware of the high rate of CAM use in children and adolescents with ASDs.

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Appendix A: Questionnaire - Complementary and Alternative Medicine Use in Children with Autistic Spectrum Disorders

Questionnaire

Complementary and Alternative Medicine Use in Children with Autistic Spectrum Disorders

Introduction:

For the purpose of this questionnaire, *complementary or alternative medicine is defined as those therapies or remedies that are not generally provided or prescribed by physicians*. They fall into one of the following categories of treatments: traditional or cultural practices such as Chinese medicine, body therapies such as massage or chiropractic, natural therapies such as homeopathy or herbal remedies, mind-body therapies such as hypnosis or biofeedback, spiritual therapies such as prayer or faith healing, energy therapies such as acupuncture, vitamins and minerals such as oral magnesium or vitamin B-6, and dietary or nutritional therapies such as gluten or casein free diets. However, a number of therapies do not fall into a specific category. Intensive behavioral intervention (IBI) is not generally considered to be complementary and alternative medicine.

Questions in this survey relate to your use of complementary or alternative medicine for your child who has an autistic spectrum disorder. In addition, there will be questions asking you what conventional treatments you may have used for your child, medical questions about your child's autistic spectrum disorder, and socio-demographic information concerning your family. Finally, the survey includes some questions about your use of complementary and alternative types of testing, such as hair testing for heavy metals, or stool testing for yeast infection.

If your family has more than one child with an autistic spectrum disorder, we ask that you fill in only one questionnaire on only one of your children. **We ask that you select the child whose birthday is coming-up next in the year as the child for which the questionnaire should be filled out.** Should you receive more than one questionnaire, please fill out and return only one questionnaire.

The information from parents or guardians who use complementary and alternative medicine for their children is as important as those who have not used complementary and alternative medicine for their children.

Because we are identifying participants from a number of different organizations, you may have received more than one study questionnaire. Please complete only one questionnaire for your family, and indicate that you have done so, by checking the following box.

Yes, I have completed <u>only 1</u> questionnaire for my family ☐

Section 1: Use of Complementary and Alternative Medicine for Your Child With an Autistic Spectrum Disorder

1. The following tables contain lists of complementary and alternative therapies that have been used for the treatment of children with autistic spectrum disorders.

    1. In the columns provided, please check the types of complementary or alternative therapies that you have **used in the past but stopped** for the treatment of your child, **or** which you are **currently using** for your child. If you have both used in the past and are currently using a therapy, please check both.
    2. Please indicate the degree to which you felt the treatment **helped improve** your child's **autistic behaviour**, by circling one number in the column provided according to the following scale.

1 = No Help 2 = A Little Help 3 = A Lot of Help 4 = Unsure 5 = Made Worse

If you **do not remember** which therapies you have used, **or have not used any** of these complementary or alternative therapies for your child, **please leave the tables blank**.

Body Therapies	Have Used in the Past for My Child	Currently Using for My Child	Helped My Child's Autistic Behaviour
1. Chiropractic	☐	☐	**1 2 3 4 5**
2. Massage	☐	☐	**1 2 3 4 5**
3. Reflexology	☐	☐	**1 2 3 4 5**
4. "Body Talk"	☐	☐	**1 2 3 4 5**
5. Other (list):_____	☐	☐	**1 2 3 4 5**

Spiritual Therapies	Have Used in the Past for My Child	Currently Using for My Child	Helped My Child's Autistic Behaviour
1. Faith Healing	□	□	**1 2 3 4 5**
2. Laying-On of Hands	□	□	**1 2 3 4 5**
3. Prayer from Others	□	□	**1 2 3 4 5**
4. Prayer by Yourself	□	□	**1 2 3 4 5**
5. Other (list):_____	□	□	**1 2 3 4 5**

Energy Therapies	Have Used in the Past for My Child	Currently Using for My Child	Helped My Child's Autistic Behaviour
1. Acupressure	□	□	**1 2 3 4 5**
2. Acupuncture	□	□	**1 2 3 4 5**
3. Therapeutic Touch	□	□	**1 2 3 4 5**
4. Magnetic Therapy	□	□	**1 2 3 4 5**
5. Reiki	□	□	**1 2 3 4 5**
6. Other (list):_____	□	□	**1 2 3 4 5**

Traditional or Cultural Practices	Have Used in the Past for My Child	Currently Using for My Child	Helped My Child's Autistic Behaviour
1. Ayurvedic Medicine	□	□	**1 2 3 4 5**
2. Native/Aboriginal Medicine	□	□	**1 2 3 4 5**
3. T'ai Chi	□	□	**1 2 3 4 5**
4. Chinese Medicine	□	□	**1 2 3 4 5**
5. Yoga	□	□	**1 2 3 4 5**
6. Qi Gong	□	□	**1 2 3 4 5**
7. Other (list):_____	□	□	**1 2 3 4 5**

Mind-Body Therapies	Have Used in the Past for My Child	Currently Using for My Child	Helped My Child's Autistic Behaviour
1. Counseling	□	□	**1 2 3 4 5**
2. Support Groups	□	□	**1 2 3 4 5**
3. Hypnosis	□	□	**1 2 3 4 5**
4. Psychotherapy	□	□	**1 2 3 4 5**
5. Relaxation	□	□	**1 2 3 4 5**
6. Meditation	□	□	**1 2 3 4 5**
7. Biofeedback	□	□	**1 2 3 4 5**
8. Music Therapy	□	□	**1 2 3 4 5**
9. Other (list):_____	□	□	**1 2 3 4 5**

Natural Therapies	Have Used in the Past for My Child	Currently Using for My Child	Helped My Child's Autistic Behaviour
1. Herbal Remedies	□	□	**1 2 3 4 5**
2. Evening Primrose Oil	□	□	**1 2 3 4 5**
3. Ginsing	□	□	**1 2 3 4 5**
4. Ginkgo biloba	□	□	**1 2 3 4 5**
5. St. John's Wort	□	□	**1 2 3 4 5**
6. Milk Thistle (Silymarin)	□	□	**1 2 3 4 5**
7. Chamomile	□	□	**1 2 3 4 5**

Natural Therapies Continued	Have Used in the Past for My Child	Currently Using for My Child	Helped My Child's Autistic Behaviour
8. Kava-kava	□	□	**1 2 3 4 5**
9. Cilantro	□	□	**1 2 3 4 5**
10. Valerian	□	□	**1 2 3 4 5**
11. Homeopathy	□	□	**1 2 3 4 5**
12. Aromatherapy	□	□	**1 2 3 4 5**
13. Naturopathy	□	□	**1 2 3 4 5**
14. Other (list below): _____	□	□	**1 2 3 4 5**

Immune Therapies	Have Used in the Past for My Child	Currently Using for My Child	Helped My Child's Autistic Behaviour
1. IV Immunoglobulin	□	□	**1 2 3 4 5**
2. Immunotherapy	□	□	**1 2 3 4 5**
3. Transfer Factor	□	□	**1 2 3 4 5**
4. Ambrotose	□	□	**1 2 3 4 5**
5. Glyconutrients	□	□	**1 2 3 4 5**
6. Colostrum (Bovine)	□	□	**1 2 3 4 5**
7. Monolaurin/Coconut Oil (Medium Chain Fatty Acids)	□	□	**1 2 3 4 5**
8. Sphingolin (Bovine Brain Myelin)	□	□	**1 2 3 4 5**
9. Larch Arabinogalactan	□	□	**1 2 3 4 5**
10. Moducare	□	□	**1 2 3 4 5**
11. Other (list):_____	□	□	**1 2 3 4 5**

Live Cell and Stem Cell Therapies	Have Used in the Past for My Child	Currently Using for My Child	Helped My Child's Autistic Behaviour
1. Live Cell Therapy	□	□	**1 2 3 4 5**
2. Oral Organ Extracts	□	□	**1 2 3 4 5**
3. Lyophilisate Whole Cells	□	□	**1 2 3 4 5**
4. Stem Cell Therapy	□	□	**1 2 3 4 5**
5. Other (list):_____	□	□	**1 2 3 4 5**

Secretin Therapy	Have Used in the Past for My Child	Currently Using for My Child	Helped My Child's Autistic Behaviour
1. Transdermal Secretin	□	□	**1 2 3 4 5**
2. Oral Secretin	□	□	**1 2 3 4 5**
3. Intravenous (IV) Secretin	□	□	**1 2 3 4 5**

Anti-Yeast Therapies	Have Used in the Past for My Child	Currently Using for My Child	Helped My Child's Autistic Behaviour
1. Yeast-Free Diet	□	□	**1 2 3 4 5**
2. Low Sugar Diet	□	□	**1 2 3 4 5**
3. Anti-Fungal Drugs Such as: ➢ Nystatin/Mycostatin, ➢ Diflucan/Fluconazole ➢ Nizoril/Ketoconazole ➢ Fungizone/Amphotericin B	□	□	**1 2 3 4 5**
4. Lactobacillus acidophilus or other Lactobacillus species (a probiotic)	□	□	**1 2 3 4 5**
5. Bifidobacter (a probiotic)	□	□	**1 2 3 4 5**
6. Streptococcus thermophilus (a probiotic)	□	□	**1 2 3 4 5**
7. Saccharomyces boulardii (a probiotic)	□	□	**1 2 3 4 5**
8. Pro-Bio Gold (a probiotic)	□	□	**1 2 3 4 5**
9. Caprylic Acid	□	□	**1 2 3 4 5**
10. Garlic Extract	□	□	**1 2 3 4 5**
11. Grape Seed Extract	□	□	**1 2 3 4 5**
12. MCT Oil	□	□	**1 2 3 4 5**
13. Other (list below): _____	□	□	**1 2 3 4 5**

Dietary or Nutritional Therapies	Have Used in the Past for My Child	Currently Using for My Child	Helped My Child's Autistic Behaviour
1. Omega-3-Fatty Acids	□	□	**1 2 3 4 5**
2. Omega-6-Fatty Acids	□	□	**1 2 3 4 5**
3. Omega-9-Fatty Acids	□	□	**1 2 3 4 5**
4. Royal Jelly	□	□	**1 2 3 4 5**
5. Aloe Vera	□	□	**1 2 3 4 5**
6. Flower of Sulfur	□	□	**1 2 3 4 5**
7. Efalex Oil	□	□	**1 2 3 4 5**
8. DHA Oil	□	□	**1 2 3 4 5**
9. TrueHope Supplements (empowerplus)	□	□	**1 2 3 4 5**
10. Dimethylglycine (DMG)	□	□	**1 2 3 4 5**
11. Trimethylglycine (TMG)	□	□	**1 2 3 4 5**
12. Pancreatic Enzymes	□	□	**1 2 3 4 5**
13. Colloidal Silver	□	□	**1 2 3 4 5**
14. Biopterin	□	□	**1 2 3 4 5**
15. Carnitine	□	□	**1 2 3 4 5**
16. GABA	□	□	**1 2 3 4 5**
17. Glutathione	□	□	**1 2 3 4 5**
18. Taurine	□	□	**1 2 3 4 5**
19. Glutamine (an amino acid)	□	□	**1 2 3 4 5**
20. Tryptophan (an amino acid)	□	□	**1 2 3 4 5**
21. Tyrosine (an amino acid)	□	□	**1 2 3 4 5**
22. 5-Hydroxytryptophan (5-HTP)	□	□	**1 2 3 4 5**
23. N-Acetyl Cysteine	□	□	**1 2 3 4 5**
24. Carnosine	□	□	**1 2 3 4 5**
25. 4-Thought (an amino acid blend)	□	□	**1 2 3 4 5**
26. Any other Amino Acid Blend	□	□	**1 2 3 4 5**
27. Glyconutrients	□	□	**1 2 3 4 5**
28. Phosphatidyl Serine	□	□	**1 2 3 4 5**
29. Inositol Hexaphosphate	□	□	**1 2 3 4 5**
30. MT Promoter (Metallothionein Promoter)	□	□	**1 2 3 4 5**

Dietary or Nutritional Therapies Continued	Have Used in the Past for My Child	Currently Using for My Child	Helped My Child's Autistic Behaviour
31. Organic Food Diet	□	□	**1 2 3 4 5**
32. Pesticide Free Diet	□	□	**1 2 3 4 5**
33. Food Free of Additives and Preservatives	□	□	**1 2 3 4 5**
34. Gluten-Free Diet	□	□	**1 2 3 4 5**
35. Casein-Free Diet	□	□	**1 2 3 4 5**
36. Lactose-Free Diet	□	□	**1 2 3 4 5**
37. Egg-Free Diet	□	□	**1 2 3 4 5**
38. Caffeine-Free Diet	□	□	**1 2 3 4 5**
39. Chocolate-Free Diet	□	□	**1 2 3 4 5**
40. Refined Sugar-Free Diet	□	□	**1 2 3 4 5**
41. Ketogenic Diet	□	□	**1 2 3 4 5**
42. Feingold Diet	□	□	**1 2 3 4 5**
43. Paleo Diet	□	□	**1 2 3 4 5**
44. The Specific Carbohydrate Diet (SC Diet)	□	□	**1 2 3 4 5**
45. Sara's Diet	□	□	**1 2 3 4 5**
46. Other (list below): _____	□	□	**1 2 3 4 5**

Vitamins and Minerals	Have Used in the Past for My Child	Currently Using for My Child	Helped My Child's Autistic Behaviour
1. General Multivitamin	□	□	**1 2 3 4 5**
2. Nu-Thera (A Multivitamin)	□	□	**1 2 3 4 5**
3. Super Nu-Thera (A Multivitamin)	□	□	**1 2 3 4 5**
4. Oral Vitamin A	□	□	**1 2 3 4 5**
5. Oral Vitamin B-1 (Thiamine)	□	□	**1 2 3 4 5**
6. Oral B2 - Riboflavin	□	□	**1 2 3 4 5**
7. Oral Vitamin B-6	□	□	**1 2 3 4 5**
8. Oral Vitamin B-6 – Dose Greater than 30 mg per kilogram per day (e.g. a 20 kg child would receive 600 mg per day)	□	□	**1 2 3 4 5**
9. Oral Vitamin B-12	□	□	**1 2 3 4 5**
10. Oral Biotin	□	□	**1 2 3 4 5**

Vitamins and Minerals Continued	Have Used in the Past for My Child	Currently Using for My Child	Helped My Child's Autistic Behaviour
11. Oral Folic Acid	☐	☐	**1 2 3 4 5**
12. Oral Vitamin B-Complex	☐	☐	**1 2 3 4 5**
13. Oral P5P (Pyridoxal-5-Phosphate)	☐	☐	**1 2 3 4 5**
14. Oral Vitamin C	☐	☐	**1 2 3 4 5**
15. Oral Vitamin D	☐	☐	**1 2 3 4 5**
16. Cod Liver Oil (Vitamin A and Vitamin D)	☐	☐	**1 2 3 4 5**
17. Oral Vitamin E	☐	☐	**1 2 3 4 5**
18. Oral Magnesium	☐	☐	**1 2 3 4 5**
19. Oral Magnesium – Dose Greater than 10 mg per kilogram per day (e.g. a 20 kg child would receive 200 mg per day)	☐	☐	**1 2 3 4 5**
20. Intramuscular Magnesium	☐	☐	**1 2 3 4 5**
21. Intravenous Magnesium	☐	☐	**1 2 3 4 5**
22. Oral Vitamin B-6 and Magnesium Together	☐	☐	**1 2 3 4 5**
23. Epsom Salt Baths	☐	☐	**1 2 3 4 5**
24. Magnesium Sulphate Cream	☐	☐	**1 2 3 4 5**
25. Oral Calcium	☐	☐	**1 2 3 4 5**
26. Oral Chromium	☐	☐	**1 2 3 4 5**
27. Oral Zinc	☐	☐	**1 2 3 4 5**
28. Oral Selenium	☐	☐	**1 2 3 4 5**
29. Oral Copper	☐	☐	**1 2 3 4 5**
30. Oral Iron	☐	☐	**1 2 3 4 5**
31. Oral Lecithin	☐	☐	**1 2 3 4 5**
32. Other (list):_____	☐	☐	**1 2 3 4 5**

Other Therapies	Have Used in the Past for My Child	Currently Using for My Child	Helped My Child's Autistic Behaviour
1. Fibroblast Growth Factor	□	□	**1 2 3 4 5**
2. Homeopathic Dose of Fibroblast Growth Factor	□	□	**1 2 3 4 5**
3. Homeopathic Vaccine Detoxification	□	□	**1 2 3 4 5**
4. Removal of Mercury Amalgams in Your Child's Teeth	□	□	**1 2 3 4 5**
5. Chelation Therapy for Detoxification with DMSA/ DMPS and/or Lipoic Acid	□	□	**1 2 3 4 5**
6. Hyperbaric Oxygen	□	□	**1 2 3 4 5**
7. Oral Vancomycin - an Antibiotic – to Treat Bowel Bacterial Overgrowth	□	□	**1 2 3 4 5**
8. Oral Metronidazole (Flagyl) – an Antibiotic – to Treat Bowel Bacterial Overgrowth	□	□	**1 2 3 4 5**
9. Anti-Viral Drugs Such as: ➢ Zovirax (Acyclovir) ➢ Famvir (Famcyclovir) ➢ Valtrex (Valacyclovir)	□	□	**1 2 3 4 5**
10. Naltrexone (NTX)	□	□	**1 2 3 4 5**
11. Play Therapy	□	□	**1 2 3 4 5**
12. Craniosacral Therapy	□	□	**1 2 3 4 5**
13. Irridean Lenses	□	□	**1 2 3 4 5**
14. Auditory Integration	□	□	**1 2 3 4 5**
15. "Fast Forward" – Computer Training for Language Development	□	□	**1 2 3 4 5**

Other Therapies Continued	**Have Used in the Past for My Child**	**Currently Using for My Child**	**Helped My Child's Autistic Behaviour**
16. Sensory Integration Therapies	□	□	**1 2 3 4 5**
17. Multisensory Stimulation (Claudie Gordon Pomares Method)	□	□	**1 2 3 4 5**
18. EEG Bio-Feedback	□	□	**1 2 3 4 5**
19. Somatic Therapies	□	□	**1 2 3 4 5**
20. Hippotherapy (Horse-Back Riding)	□	□	**1 2 3 4 5**
21. Dolphin Therapy	□	□	**1 2 3 4 5**
22. Dog Therapy – Using a Specially Trained Dog for Treatment of Autism	□	□	**1 2 3 4 5**
23. Urine Therapy	□	□	**1 2 3 4 5**
24. Homeopathic Urine Therapy	□	□	**1 2 3 4 5**
25. Allergy Treatment Using the NAET Technique (Nambudripad Allergy Elimination Technique)	□	□	**1 2 3 4 5**
26. Other (list): _____	□	□	**1 2 3 4 5**
27. Other (list): _____	□	□	**1 2 3 4 5**
28. Other (list): _____	□	□	**1 2 3 4 5**

2. Has your child's **stool** ever been tested for any of the following (check as many as apply)?

Stool Tested For:	Yes	No
1. Yeast/Candida	☐	☐
2. Bacteria	☐	☐
3. Parasites	☐	☐
4. Heavy Metals such as Lead, Aluminium, Mercury, or Cadmium	☐	☐
5. pH	☐	☐
6. Chymotrypsin	☐	☐
7. Fecal Fat	☐	☐
8. Other (describe):_____	☐	☐
9. Other (describe):_____	☐	☐

3. Has your child's **blood** ever been tested for any of the following (check as many as apply)?

Blood Tested For:	Yes	No
1. Amino Acids	☐	☐
2. Organic Acids	☐	☐
3. Vitamin Profile	☐	☐
4. Essential Fatty Acids	☐	☐
5. Heavy Metals such as Lead, Aluminium, Mercury, or Cadmium	☐	☐
6. Chromosomes/Karyotype	☐	☐
7. Fragile-X	☐	☐
8. Complete Blood Count (CBC)	☐	☐
9. Testing for Iron Deficiency (Hemoglobin, Serum Iron, TIBC)	☐	☐
10. Liver Detoxification Profile prior to Chelation Therapy	☐	☐
11. Thyroid Function	☐	☐
12. Zinc	☐	☐
13. Copper	☐	☐
14. Ammonia	☐	☐
15. Ceruloplasmin	☐	☐
16. RBC Essential Elements	☐	☐
17. Other (describe):_____	☐	☐
18. Other (describe):_____	☐	☐

4. Has your child's **urine** ever been tested for any of the following (check as many as apply)?

Urine Tested For:	Yes	No
1. Amino Acids	□	□
2. Organic Acids	□	□
3. Urinary Casein Peptides	□	□
4. Urinary Gluten Peptides	□	□
5. Heavy Metals such as Lead, Aluminium, Mercury, or Cadmium	□	□
6. Yeast Culture and Sensitivity	□	□
7. Bacterial Culture and Sensitivity	□	□
8. Pyrroles		
9. Other (describe):_____	□	□

5. Has your child's **hair** ever been tested for any of the following (check as many as apply)?

Hair Tested For:	Yes	No
1. Heavy Metals such as Lead, Aluminium, Mercury, or Cadmium	□	□
2. Mineral Profile	□	□
3. Other (describe):_____	□	□

6. Has your child ever been assessed for **"yeast overgrowth"** by any of the following tests (check as many as apply)?

Yeast Overgrowth Test:	Yes	No
1. Urine Culture for Yeast	□	□
2. Stool Culture for Yeast	□	□
3. Urine Test for Yeast Metabolites	□	□
4. Blood Test for Yeast Metabolites	□	□
5. Other (describe):_____	□	□

7. Has your child ever had any of the following types of **allergy** or **immune function** testing done?

Allergy/Immune Testing	Yes	No
1. Skin Prick Testing for Food Allergies	□	□
2. Skin Prick Testing for Inhalant Allergies (cause asthma/stuffy nose)	□	□
3. Blood Testing for Specific Food Allergies (IgE Antibodies)	□	□
4. Blood Testing for Specific Inhalant Allergies (IgE Antibodies)	□	□
5. Blood Testing for Specific Antibodies for Celiac Disease (Antiendomesial Antibodies or Antigliadin Antibodies)	□	□
6. Quantitative Immunoglobulens (counting each kind of antibody in the blood such as IgG, IgG Subclasses, IgM, IgA, and IgE)	□	□
7. Anitmyelin Antibodies (Myelin Basic Protein Antibodies)	□	□
8. Serum/Blood Zinc Levels	□	□
9. Natural Killer Cytotoxicity Test	□	□
10. Vaccine Antibody Levels	□	□
11. Herpes Simplex Virus Antibodies	□	□
12. Epstein Barr Virus (EBV) Antibodies	□	□
13. Cytomegalovirus (CMV) Antibodies	□	□
14. Varicella Zoster Virus (VZV) Antibodies	□	□
15. Vega Testing for Allergies or Sensitivities	□	□
16. NAET Testing for Allergies or Sensitivities	□	□
17. Other (list):_____	□	□

8. If you have **never** used complementary or alternative medicine for your child's autistic spectrum disorder, do any of the following reasons apply (check all that apply)?

□ My doctor does not approve.
□ There is not enough scientific evidence to support its use.
□ I do not believe these therapies work.
□ The therapies are too expensive.
□ I am satisfied with the therapy my doctors provide.
□ My family or friends do not approve.
□ I have never heard of any such therapies.
□ I do not know enough about these therapies.
□ I am worried they will decrease the effectiveness of standard treatments.
□ Other (please describe):_____

If you <u>have never used</u> complementary or alternative medicine for your child, then please go to question #19 on page 14.

9. Generally, **why did you choose** to use complementary and alternative medicine for your child with an autistic spectrum disorder (check as many as apply)?

□ To improve the general health of my child.
□ To take charge of the health of my child.
□ To please family members or friends.
□ I believe in a holistic approach to health.
□ I believed that it couldn't hurt my child.
□ To improve the mental and emotional well being of my child.
□ To improve the symptoms of autism in my child.
□ To heal my child of their autistic spectrum disorder.
□ To avoid the side effects of medications.
□ Because conventional medicine did not have any answers or treatment options.
□ Because I have used it in the past with improvement in my own health.
□ Other (please specify):_____

10. In the last 12 months, approximately how much money have you spent on complementary and alternative medicine for the treatment of your child's autistic spectrum disorder (include costs for both diagnostic tests and therapies)?

$_____ (in dollars)

11. Has your private insurance covered any of these costs (insurance either purchased privately, or provided through your employer)?

□ Completely □ A little bit
□ Mostly □ Not at all

12. Have you as the parent or guardian ever used complementary or alternative medicine for **yourself**?

□ Yes □ No

13. From what **sources** do you get your **information about complementary and alternative medicine** for children with autistic spectrum disorders?
In the column provided, place a check beside the **five most important sources**.

Information Source	Check the Five Most Important
1. Advertisements on television, radio, magazines, or newspapers	
2. Stories or articles in magazines, newspapers or on television	
3. The internet	
4. Health food store personnel	
5. Nurse	
6. Physician	
7. Complementary practitioner	
8. Family members	
9. Friends	
10. A parent or guardian who has a child with an autistic spectrum disorder	
11. Someone else who has an illness	
12. Scientific or medical journals	
13. Self-help books on alternative therapies	
14. Books about autism	
15. Books about complementary and alternative therapy	
16. Autism support groups	
17. Other (describe):_____	

14. If your child is cared for by a family physician, pediatrician, or developmental pediatrician, does this physician know about your use of complementary or alternative medicine for your child?

□ Yes □ No

15. If you **answered yes to question 14**, has your physician asked if you used complementary or alternative medicine for your child, or did you volunteer the information?

□ My physician asked
□ I volunteered the information

16. Has your physician(s) recommended any complementary or alternative medicine for your child?

□ Yes (please specify which therapies):_____
□ No

17. Has your physician(s) provided any complementary or alternative medicine for your child?

□ Yes (please specify which therapies):_____
□ No

18. How do you think your physician(s) feel about your use of complementary and alternative medicine for your child?

	Family Physician	**Pediatrician**
Positive/Encouraging	□	□
Neutral	□	□
Negative/Discouraging	□	□

Section 2: Medical History of Your Child with an Autistic Spectrum Disorder

19. Gender of your child: ☐ Male ☐ Female

20. Year of birth of your child: 19____

21. Age when your child was **1st diagnosed** with an autistic spectrum disorder: _____ years and _____months.

22. Age when you **first suspected** that your child might have an autistic spectrum disorder: _____ years and _____months.

23. What is your child's primary diagnosis (check one)?

□ Autism
□ Atypical Autism
□ Rett Syndrome/Disorder
□ Pervasive Developmental Disorder (PDD-NOS)
□ Asperger's Disorder/Syndrome
□ Childhood Disintegrative Disorder

24. Who gave your child the diagnosis indicated in question #23 above?

□ Family Physician □ Child Psychiatrist
□ Pediatrician □ Psychologist
□ Developmental Pediatrician □ Speech Language Therapist
□ Other (please specify):_____

25. Does your child have a seizure disorder: □ Yes □ No

26. If your child has a seizure disorder, what kind of seizures do they have (check as many as apply):

□ Generalized Tonic Clonic/Grand-Mal □ Myoclonic
□ Absence/Petit Mal □ I don't know what kind
□ Complex Partial □ Other (specify):_____

27. The following table is about noteworthy medical conditions that your child **may currently have**, or **have had in the past**. Please list any medical conditions in the columns below. This does not include minor illnesses such as an upper respiratory tract infections, or infectious diarrhea.

Medical Conditions that Your Child **Currently Has** (please list):	Medical Conditions That Your Child **Has Had in the Past** (please list):
1.	1.
2.	2.
3.	3.
4.	4.

28. Does your child have any of the following **genetic conditions** (check as many as apply):

□ Down Syndrome □ Other Chromosomal Problem
□ Fragile-X Syndrome □ Other Genetic Condition
□ Tuberous Sclerosis (please specify):_____

29. Has your child had any surgeries in the past? □ Yes □ No

30. If yes, please list the surgeries below.

1. _____ 4. _____
2. _____ 5. _____
3. _____ 6. _____

31. What medical specialists has your child seen in the past (check any that apply):

□ Audiologist	□ Speech Language Pathologist
□ Occupational Therapist	□ Physiotherapist
□ Optometrist	□ Ophthalmologist
□ Ear, Nose, and Throat (ENT) Surgeon	□ Allergist/Immunologist
□ Gastroenterologist	□ Neurologist
□ General Pediatrician	□ Developmental Pediatrician
□ Child Psychiatrist	□ Medical Genetics Specialist
□ Psychologist	□ Social Worker
□ Family Counsellor	□ Other (please specify below): _____

32. What complementary or alternative practitioners have you seen in the past (check any that apply):

□ Naturopathic Physician	□ Homeopathic Physician
□ Chiropractor	□ Craniosacral Therapist
□ NAET Practitioner	□ Defeat Autism Now – "DAN Practitioner

□ Other (please specify: _____)

Section 3: Use of Conventional Treatments for Your Child With an Autistic Spectrum Disorder

33. The following table contains a list of conventional drugs or medications that have been used for the treatment of children with autistic spectrum disorders.

1. In the columns provided, please check the types of conventional drugs/medications that you have **used in the past but stopped** for the treatment of your child, **or** which you are **currently using** for your child. If you have both used in the past and are currently using a therapy, please check both.
2. Please indicate the degree to which you felt the medication **helped improve** your child's **autistic behaviour**, by circling one number in the column provided according to the following scale.

1 = No Help 2 = A Little Help 3 = A Lot of Help 4 = Unsure 5 = Made Worse

If you **do not remember** which medications you have used, **or have not used any** of these medications for your child, **please leave the tables blank**.

Type of Conventional Medication For Autistic Behaviour	Have Used in the Past for My Child	Currently Using for My Child	Helped My Child's Autistic Behaviour
1. Ritalin (Methylphenidate)	☐	☐	**1 2 3 4 5**
2. Ritalin SR (Sustained Release)	☐	☐	**1 2 3 4 5**
3. Dexedrine	☐	☐	**1 2 3 4 5**
4. Dexedrine Spansules	☐	☐	**1 2 3 4 5**
5. Catapres/Dixarit (Clonidine)	☐	☐	**1 2 3 4 5**
6. Tenex (Guanfacine)	☐	☐	**1 2 3 4 5**
7. Ponderal/Pondimin (Fenfluramine)	☐	☐	**1 2 3 4 5**
8. Haldol (Haloperidol)	☐	☐	**1 2 3 4 5**
9. Risperdal (Risperidone)	☐	☐	**1 2 3 4 5**
10. ReVia/Trexan (Naltrexone)	☐	☐	**1 2 3 4 5**
11. Anafranil (Clomipramine)	☐	☐	**1 2 3 4 5**
12. Norpramin (Desipramine)	☐	☐	**1 2 3 4 5**
13. Tofranil (Imipramine)	☐	☐	**1 2 3 4 5**
14. Prozac (Fluoxetine)	☐	☐	**1 2 3 4 5**
15. Zoloft (Sertraline)	☐	☐	**1 2 3 4 5**
16. Luvox (Fluvoxamine)	☐	☐	**1 2 3 4 5**
17. Paxil (Paroxetine)	☐	☐	**1 2 3 4 5**
18. Effexor (Vanlafaxine)	☐	☐	**1 2 3 4 5**
19. Inderal (Propranolol)	☐	☐	**1 2 3 4 5**
20. Buspar (Buspirone)	☐	☐	**1 2 3 4 5**
21. Tegretol (Carbamazepine)	☐	☐	**1 2 3 4 5**
22. Phenobarbital	☐	☐	**1 2 3 4 5**
23. Phenytoin (Dilantin)	☐	☐	**1 2 3 4 5**
24. Valproic Acid (Depakene)	☐	☐	**1 2 3 4 5**
25. Chloral-Hydrate	☐	☐	**1 2 3 4 5**
26. Melatonin	☐	☐	**1 2 3 4 5**
27. Atarax (Hydroxyzine)	☐	☐	**1 2 3 4 5**
28. Benadryl (Diphenhydramine)	☐	☐	**1 2 3 4 5**
29. Other:_____	☐	☐	**1 2 3 4 5**
30. Other:_____	☐	☐	**1 2 3 4 5**

34. The following table contains a list of **conventional treatments** that have been used for the treatment of children with autistic spectrum disorders. These include treatments that may have been recommended by your child's Doctor, Psychologist, Occupational Therapist, Physiotherapist, or Speech-Language Pathologist.

    1. In the columns provided, please check the types of treatments that you have **used in the past but stopped** for the treatment of your child, **or** which you are **currently using** for your child. If you have both used in the past and are currently using a therapy, please check both.
    2. Please indicate the degree to which you felt the treatments **helped improve** your child's **autistic behaviour**, by circling one number in the column provided according to the following scale.

1 = No Help 2 = A Little Help 3 = A Lot of Help 4 = Unsure 5 = Made Worse

If you **do not remember** which treatments you have used, **or have not used any** of these treatments for your child, **please leave the tables blank**.

Type of Conventional Therapy for Autistic Behaviour	Have Used in the Past for My Child	Currently Using for My Child	Helped My Child's Autistic Behaviour
1. Speech-Language Therapy	☐	☐	**1 2 3 4 5**
2. Occupational Therapy	☐	☐	**1 2 3 4 5**
3. Physiotherapy	☐	☐	**1 2 3 4 5**
4. Picture Exchange Communication (PECS)	☐	☐	**1 2 3 4 5**
5. Intensive Behavioural Intervention (**Home**-Based)	☐	☐	**1 2 3 4 5**
6. Intensive Behavioural Intervention (**School**-Based)	☐	☐	**1 2 3 4 5**
7. Intensive Behavioural Intervention (**Home** and **School**-Based Combined)	☐	☐	**1 2 3 4 5**

35. The following table contains a list of conventional drugs or medications that have been used for the **treatment of seizures** in children with autistic spectrum disorders.

If your child does not have a seizure disorder, please go to question 36.

1. In the columns provided, please check the types of conventional drugs/medications that you have **used in the past but stopped** for the treatment of your child's seizure disorder, **or** which you are **currently using** for your child's seizure disorder. If you have both used in the past and are currently using a therapy, please check both.
2. Please indicate the degree to which you felt the medication **helped improve** your child's **seizure disorder**, by circling one number in the column provided according to the following scale.

1 = No Help 2 = A Little Help 3 = A Lot of Help 4 = Unsure 5 = Made Worse

If you **do not remember** which medications you have used, **or have not used any** of these medications for your child, **please leave the tables blank**.

Type of Conventional Medication for Seizure Disorder	Have Used in the Past for My Child	Currently Using for My Child	Helped My Child's Seizure Disorder
1. Tegretol (Carbamazepine)	☐	☐	**1 2 3 4 5**
2. Phenobarbital	☐	☐	**1 2 3 4 5**
3. Clonazepam (Klonopin)	☐	☐	**1 2 3 4 5**
4. Gabapentin (Neurontin)	☐	☐	**1 2 3 4 5**
5. Lamotrigine (Lamoctal)	☐	☐	**1 2 3 4 5**
6. Phenytoin (Dilantin)	☐	☐	**1 2 3 4 5**
7. Valproic Acid (Depakene/Depakote)	☐	☐	**1 2 3 4 5**
8. Topirimate (Topamax)	☐	☐	**1 2 3 4 5**
9. Zarontin (Ethosuximide)	☐	☐	**1 2 3 4 5**
10. Other (specify): _____	☐	☐	**1 2 3 4 5**

Section 4: Demographic Characteristics of Parents/Guardians

The following questions relate to you as the parent/guardian of a child with an autistic spectrum disorder.

36. **Your** relationship to the child with an autistic spectrum disorder:

□ Mother
□ Father
□ Aunt
□ Uncle
□ Grandmother
□ Grandfather
□ Foster parent
□ Adoptive parent
□ Other (please describe): _____

37. **Your** current marital status:

□ Never married
□ Married
□ Common law
□ Separated
□ Divorced
□ Widowed

38. **Your** current employment status (check as many as apply):

□ Working full-time
□ Working part-time
□ On disability leave
□ Retired
□ Homemaker
□ Student
□ Volunteer work
□ Unemployed
□ Maternity/Paternity Leave

39. Your **spouse's** current employment status, if applicable (check as many as apply):

□ Working full-time
□ Working part-time
□ On disability leave
□ Retired
□ Homemaker
□ Student
□ Volunteer work
□ Unemployed
□ Maternity/Paternity Leave

40. What is **your** highest level of education?

□ High school not completed
□ High school completed
□ Technical training/diploma
□ Undergraduate college/university degree
□ Graduate degree
□ Other (list):_____

41. What is **your spouse's** highest level of education (if applicable)?

□ High school not completed
□ High school completed
□ Technical training/diploma
□ Undergraduate college/university degree
□ Graduate degree
□ Other (list):_____

42. Does your child reside with you at your residence? □ Yes □ No

43. If "No", where does your child reside/live? _____

Thank You for Your Time and Co-operation

If you have additional comments concerning this questionnaire, or about your experience with the use of complementary and alternative medicine for children with autistic spectrum disorders, we would love to hear them. Please write your comments in the space provided below.

_____
_____
_____
_____
_____
_____
_____
_____
_____
_____

Thank You Again for Your Participation in this Survey!

Appendix B: Survey Cover Letter (First Mail-Out)

December 9, 2002

Dear Sir/Madam,

RE: Research Study entitled - "Complementary and Alternative Approaches to Diagnosis and Treatment for Children with Autistic Spectrum Disorders: Patterns of Use."

We are asking for your help in collecting information about the use of complementary and alternative medicine for children with autistic spectrum disorders. Complementary and alternative medicine refers to treatments or remedies that are not part of regular, mainstream medicine. Examples of these therapies would be herbal remedies, special diets, or the use of homeopathy or chiropractic therapies. There is no information available about what types of complementary or alternative medicine parents or guardians use for their children with autistic spectrum disorders. Information of the patterns of use of these therapies could have important implications for the way parents or guardians of children with autistic spectrum disorders manage this condition. **Even if you do not use any of these therapies for your child, we ask that you still fill out the questionnaire, as you will be providing important information.**

Your family has been identified through Autism Calgary Association. The Autism Calgary Association has given us written consent to use their membership list. We are identifying potential study participants from a number of other organizations, some of which you may hold memberships with. Should you receive a second questionnaire from the mailing list of another organization, please reply by filling-in only one of the questionnaires.

Your decision whether or not to complete this questionnaire will not affect the health care of you or your family in any way, either now or in the future. **Your answers to this survey will be strictly anonymous.**

We hope that you will choose to fill out the enclosed questionnaire. It should take less than 20 minutes to complete. There will be no information on the questionnaire that will identify you in any way. Please do not put your name or any other identifying information on the questionnaire or on the return envelope. Upon completion, please return it by mail. A self-addressed envelope has been included for this purpose. **Your decision to complete and return this questionnaire will be interpreted as an indication of your consent to participate in this study.**

Although you will not receive immediate benefits from participating in this study, the information you provide may help people in the future. Everyone who was sent this questionnaire will receive a summary of the findings upon the completion of the study.

This study is being carried out by Dr. Ben Gibbard, M.D., FRCPC, and Dr. Marja Verhoef, Ph.D. If you have any questions related to this research project, please contact Dr. Ben Gibbard (Pager: 403-229-7211, pager 5216), or Dr. Marja Verhoef (Telephone: 403-220-7813). If you have any questions concerning your rights as a possible participant in this research, please contact Pat Evans, Associate Director, Internal Awards, Research Service, University of Calgary, at 403-220-3782.

Thank you for taking the time to consider participating in this study.

Sincerely,

W. Ben Gibbard, M.D., FRCPC

Marja J. Verhoef, Ph.D.

Appendix C: Survey Cover Letter (Second Mail-Out)

January 7, 2003

Dear Sir/Madam,

RE: Research Study entitled - "Complementary and Alternative Approaches to Diagnosis and Treatment for Children with Autistic Spectrum Disorders: Patterns of Use."

Approximately four weeks ago, you were mailed a questionnaire about the use of complementary and alternative medicine for children with autistic spectrum disorders. As the questionnaire did not contain any identifying information, we cannot tell who has completed and returned it, and who has not.

If you have completed and returned the questionnaire, we thank you for your participation, and ask that you ignore this mailing. If you have received a questionnaire from the mailing list of another organization, please ignore that questionnaire as well, as we need to ensure that each family has responded to the questionnaire only once.

We are asking for the help of those who **have not yet completed and returned the questionnaire**. The information that you provide to us in this survey is important for understanding the use of complementary and alternative medicine for children with autistic spectrum disorders. Please take the time to read over the following material and consider participating in this study.

Complementary and alternative medicine refers to treatments or remedies that are not part of regular, mainstream medicine. Examples of these therapies would be herbal remedies, special diets, or the use of homeopathy or chiropractic therapies. There is also no information available about what types of complementary or alternative medicine parents or guardians use for their children with autistic spectrum disorders. Information of the patterns of use of these therapies could have important implications for the way parents or guardians of children with autistic spectrum disorders manage this condition. **Even if you do not use any of these therapies for your child, we ask that you still fill out the questionnaire, as you will be providing important information.**

Your family has been identified through the Autism Society of Alberta. The Autism Society of Alberta has given us written consent to use their membership list. We are identifying potential study participants from a number of other organizations, some of which you may hold memberships with. Should you receive a second questionnaire from the mailing list of another organization, please reply by filling-in only one of the questionnaires.

Your decision whether or not to complete this questionnaire will not affect the health care of you or your family in any way, either now or in the future. **Your answers to this survey are strictly anonymous.**

We hope that you will choose to fill out the enclosed questionnaire. It should take less than 20 minutes to complete. There will be no information on the questionnaire that will identify you in any way. Please do not put your name or any other identifying information on the questionnaire or on the return envelope. Upon completion, please return it by mail. A self-addressed envelope has been included for this purpose. **Your decision to complete and return this questionnaire will be interpreted as an indication of your consent to participate in this study.**

Although you will not receive immediate benefits from participating in this study, the information you provide may help people in the future. Everyone who was sent this questionnaire will receive a summary of the findings upon the completion of the study.

This study is being carried out by Dr. Ben Gibbard, M.D., FRCPC, and Dr. Marja Verhoef, Ph.D. If you have any questions related to this research project, please contact Dr. Ben Gibbard (Pager: 403-229-7211, pager# 5216), or Dr. Marja Verhoef (Telephone: 403-220-7813). If you have any questions concerning your rights as a possible participant in this research, please contact Pat Evans, Associate Director, Internal Awards, Research Service, University of Calgary, at 403-220-3782.

Thank you for taking the time to consider participating in this study.

Sincerely,

W. Ben Gibbard, M.D., FRCPC

Marja J. Verhoef, Ph.D.

Appendix D: Uncommon Conventional Medications Used for Associated Seizure Disorders

Medication	% Used
Valproic Acid	**1.1%** (2/176)
Lamotrigine	**1.1%** (2/176)
Topiramate	**0.6%** (1/176)
Ethosuximide	**0.6%** (1/176)
Clonazepam	**0.6%** (1/176)
Vigabatrin	**0.6%** (1/176)

Appendix E: Uncommon Conventional Medications Used for Behavioral Manifestations of Autistic Spectrum Disorders

Medication	% Used
Sertraline	**4.6%** (8/176)
Fluvoxamine	**2.8%** (5/176)
Phenobarbital	**2.8%** (5/176)
Buspirone	**2.3%** (4/176)
Vanlafaxine	**1.7%** (3/176)
Chloral Hydrate	**1.7%** (3/176)
Citalopram	**1.7%** (3/176)
Haloperidol	**1.7%** (3/176)
Phenytoin	**1.1%** (2/176)
Valproic Acid	**1.1%** (2/176)
Hydroxyzine	**1.1%** (2/176)
Imipramine	**1.1%** (2/176)
Adderall	**0.6%** (1/176)
Amitriptyline	**0.6%** (1/176)
Clobazam	**0.6%** (1/176)
Loxapine	**0.6%** (1/176)
Clonazepam	**0.6%** (1/176)
Tetrabenazine	**0.6%** (1/176)

Appendix F: Other Complementary and Alternative Medicine Used by the Survey Population

Body Therapies	**% Used**
Reflexology	**2.3%** (4/176)
Deep Pressure	**0.6%** (1/176)
Vibration	**0.6%** (1/176)
Vision Therapy	**0.6%** (1/176)
Spiritual Therapies	**% Used**
Faith Healing	**3.4%** (6/176)
Reading Scripture	**0.6%** (1/176)
Energy Therapies	**% Used**
Therapeutic Touch	**3.4%** (6/176)
Magnetic Therapy	**2.3%** (4/176)
Acupressure	**2.3%** (4/176)
Consegrity	**0.6%** (1/176)
Healing Touch	**0.6%** (1/176)
Traditional or Cultural Practices	**% Used**
Chinese Medicine	**2.8%** (5/176)
Yoga	**1.7%** (3/176)
Ayurvedic Medicine	**1.1%** (2/176)
Tai Chi	**0.6%** (1/176)
Aboriginal Medicine	**0.6%** (1/176)

Appendix F: Continued

Mind-Body Therapies	**% Used**
Psychotherapy	**4.0%** (7/176)
Biofeedback	**2.8%** (5/176)
Meditation	**1.1%** (2/176)
Animal Assisted Therapy	**0.6%** (1/176)
Recreational Therapy	**0.6%** (1/176)
Hap Ki Do	**0.6%** (1/176)
Natural Therapies	**% Used**
St. John's Wort	**4.6%** (8/176)
Ginsing	**2.8%** (5/176)
Milk Thistle	**1.7%** (3/176)
Cilantro	**1.7%** (3/176)
Valerian	**1.7%** (3/176)
Kava Kava	**1.1%** (2/176)
Barley Green	**0.6%** (1/176)
Phyt-Aloe	**0.6%** (1/176)
Vitamin Multi OSANA Oil	**0.6%** (1/176)
Immune Therapies	**% Used**
Bovine Colostrum	**2.8%** (5/176)
Monolaurin	**0.6%** (1/176)
Immunotherapy	**0.6%** (1/176)

Appendix F: Continued

Anti-Yeast Therapies	% Used
Grape Seed Extract	**3.4%** (6/176)
Pro-Bio-Gold (a probiotic)	**2.8%** (5/176)
Bifidobacter (a probiotic)	**2.8%** (5/176)
Caprylic Acid	**1.7%** (3/176)
Garlic Extract	**1.7%** (3/176)
Streptococcus thermophilus (a probiotic)	**1.1%** (2/176)
Bio-Strath (a probiotic)	**0.6%** (1/176)
Oregano Oil	**0.6%** (1/176)
Pau D'Arco	**0.6%** (1/176)

Appendix F: Continued

Nutritional Therapies	% Used
Pancreatic Enzymes	**5.1%** (9/176)
Aloe Vera	**4.0%** (7/176)
Glyconutrients	**4.0%** (7/176)
Trimethylglycine	**3.4%** (6/176)
Any Amino Acid Blend	**3.4%** (6/176)
Taurine	**3.4%** (6/176)
DHA Oil	**2.8%** (5/176)
Colloidal Silver	**2.3%** (4/176)
Glutamine	**2.3%** (4/176)
Tryptophan	**1.7%** (3/176)
EM Power Plus	**1.7%** (3/176)
GABA	**1.7%** (3/176)
Phosphatidyl Serine	**1.7%** (3/176)
5-HTP	**1.7%** (3/176)
4-Thought (an Amino Acid Blend)	**1.1%** (2/176)
Tyrosine	**1.1%** (2/176)
N-Acetyl-Cysteine	**1.1%** (2/176)
Carnosine	**1.1%** (2/176)
Carnitine	**0.6%** (1/176)
MT Promoter	**0.6%** (1/176)
Royal Jelly	**0.6%** (1/176)
Glutathione	**0.6%** (1/176)
Glutamic Acid HCl	**0.6%** (1/176)
Colloidal Minerals	**0.6%** (1/176)
Phyto-Bears	**0.6%** (1/176)

Appendix F: Continued

Dietary Therapies	% Used
Pesticide-Free Diet	**4.0%** (7/176)
Feingold Diet	**2.3%** (4/176)
Sara's Diet	**1.7%** (3/176)
Paleo Diet	**1.1%** (2/176)
Ketogenic Diet	**1.1%** (2/176)
SC Diet	**1.1%** (2/176)
Apple Juice-Free Diet	**0.6%** (1/176)
Dr. Michael Lyon's ADHD Elimination Diet	**0.6%** (1/176)
Legume-Free Diet	**0.6%** (1/176)
Reduction of White Flour	**0.6%** (1/176)
Wheat-Free Diet	**0.6%** (1/176)
Coffee	**0.6%** (1/176)
Barley Green	**0.6%** (1/176)

Appendix F: Continued

Vitamins and Minerals	% Used
Oral Vitamin B-6 large dose	**5.1%** (9/176)
Oral P5P	**4.6%** (8/176)
Oral Vitamin B-Complex	**4.0%** (7/176)
Oral Vitamin E	**4.0%** (7/176)
Oral Magnesium – large dose	**4.0%** (7/176)
Oral Vitamin D	**4.0%** (7/176)
Oral Folic Acid	**4.0%** (7/176)
Oral B-6 and Magnesium Together	**3.4%** (6/176)
Oral Vitamin B-12	**2.8%** (5/176)
Selenium	**2.8%** (5/176)
Lecithin	**2.3%** (4/176)
Magnesium Sulphate Cream	**2.3%** (4/176)
Biotin	**2.3%** (4/176)
Oral Vitamin B2	**2.3%** (4/176)
Oral Iron	**1.7%** (3/176)
Oral Chromium	**1.1%** (2/176)
Coenzyme Q10	**1.1%** (2/176)
Oral Vitamin A	**1.1%** (2/176)
Oral Vitamin B1	**1.1%** (2/176)
Copper	**0.6%** (1/176)
Learning Factors	**0.6%** (1/176)
Mineral Mixture	**0.6%** (1/176)

Appendix F: Continued

Other	% Used
Fast Forward	**5.1%** (9/176)
Homeopathic vaccine Detoxification	**4.0%** (7/176)
Chelation Therapy	**2.8%** (5/176)
Allergy Treatment/NAET	**2.8%** (5/176)
Secretin	**2.3%** (4/176)
Secretin – Intravenous	**1.1%** (2/176)
Secretin – Transdermal Patch	**1.1%** (2/176)
EEG Biofeedback	**1.7%** (3/176)
Dog Therapy	**1.7%** (3/176)
Naltrexone	**1.1%** (2/176)
Anti-Viral Drugs	**1.1%** (2/176)
Homeopathic Urine Therapy	**1.1%** (2/176)
Removal of Mercury Amalgams	**0.6%** (1/176)
Oral Metronidazole	**0.6%** (1/176)
Somatic Therapy	**0.6%** (1/176)
Urine Therapy	**0.6%** (1/176)
Brain Gym	**0.6%** (1/176)
Hydrotherapy	**0.6%** (1/176)
Light Therapy	**0.6%** (1/176)
Sequential Detoxification Hahnemannian Homeopathy	**0.6%** (1/176)