A RESOURCE MANUAL ON LOCAL INFORMATION FOR PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS IN THE SACRAMENTO AREA

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B.A., California State University, Sacramento, 2008

PROJECT

Submitted in partial satisfaction of the requirements for the degree of

MASTER OF ARTS

in

EDUCATION
(Special Education)

at

CALIFORNIA STATE UNIVERSITY, SACRAMENTO

SUMMER
2010
A RESOURCE MANUAL ON LOCAL INFORMATION FOR PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS IN THE SACRAMENTO AREA

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Abstract

of

A RESOURCE MANUAL ON LOCAL INFORMATION FOR PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS IN THE SACRAMENTO AREA

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Melissa Rose Small

The difficulties parents may face when looking to gather information concerning autism spectrum disorder (ASD) can be endless. This includes finding resources that are valid, as well as sifting through the wealth of information found on the topic of ASD. This project presents a manual that is designed to serve both parents and professionals information concerning ASD as it relates specifically to the greater Sacramento area. This area includes, but is not limited to: Antelope, Auburn, Citrus Heights, Elk Grove, Folsom, Galt, Lincoln, Rancho Cordova, Roseville, West Sacramento and Wilton. This resource manual gives parents of children with ASD a more localized source of information and services available to them and their child. These services include but are not limited to: behavioral interventions, books, educational rights, online resources and support groups. Additionally, this resource manual will provide parents with an array of valid evidence-based information already noted in articles and journals, but condensed into a single source. By supplying this information, parents may be able to: (a)
take a more empowering role as an advocate in their child’s interventions; (b) become more involved in the special education process as it pertains to the Sacramento region; (c) benefit from local services that this region provides; (d) gain access to more individualized support for both the child and themselves; and (e) participate in events of awareness and support regarding the disability.

__________________________
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__________________________
Date
ACKNOWLEDGEMENTS

To my family; your love and support has been instrumental. Everyday, you motivate me, inspire me and push me to reach the goals I have set. You have never doubted my abilities, and for that I am grateful. To my fiancée; for teaching me to never give up and for having faith in me even when I no longer did. And lastly, to my dad; even though you are not here to see my success, I know you would be proud. You taught me that a break is a good thing and that life doesn’t stop, even when you wish it would. In the words of Bob Dylan “times they are a-changing” and I can’t wait to see what happens next.
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Chapter 1
INTRODUCTION

It is the end of the day and a mother walks into the classroom, where she is picking her child up from an hour-long social skills group. Here, the children, all diagnosed with an autism spectrum disorder, are gathering up their materials to leave for the day. Before the mother leaves with her child, she stops and asks the teacher a question, “Can you tell me where I can go to get information about services in Sacramento to provide support for my child and our family?” While this is a loaded question, one whose answer can be quite individualized for this particular mother, the entire room of parents stops to listen. It is now silent as these parents wait, for they too are looking for an answer to this same question. The teacher, who is quite busy from the hustle and bustle of children leaving the classroom, stops to think. She wonders how, in the five minutes they both have to spare, can she spew her wealth of knowledge to this mother. If only there was a resource manual to which she could direct parents. Simple and easy, the teacher wishes she could tell the mother where to go, where all the information is stored in one easily accessible spot. Unfortunately, there is no such manual and as the parents rush out, the teacher opts to schedule an appointment with this mother at a later time. This is just one illustration of the difficulties parents, teachers and other professionals face when trying to gain insight and local information concerning children with ASD.
Background of the Problem

Autism spectrum disorders (ASD) are a group of neurodevelopmental syndromes characterized by disturbances in: social interactions, communication, and repetitive/stereotyped patterns of behavior (American Psychiatric Association, 2000; World Health Organization, 1993). According to the National Institute of Mental Health, there are five autism spectrum disorders: (1) Asperger’s syndrome, (2) autistic disorder, (3) pervasive developmental disorder, not otherwise specified, (4) Rett's syndrome and (5) childhood disintegrative disorder. Each of these forms of autism overlap significantly. In terms of diagnoses, the fact that there is wide variation in the manifestation of symptoms among children with autism led to the concept of autism spectrum disorders (American Psychiatric Association, 2000). Each disorder will be described in detail in the following sections.

Asperger’s Syndrome

An individual must meet all six areas defined by the DSM-IV TR’s description of Asperger’s syndrome on an Asperger/HFA screening tool in order to be diagnosed with the disorder (American Psychiatric Association, 2000). Diagnostic criteria include qualitative impairment in social interaction, as manifested by at least two of the following: (1) marked impairment in the use of multiple nonverbal behaviors; (2) failure to develop peer relationships appropriate to developmental level; (3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other; (4) lack of social or emotional reciprocity. In addition, the child must demonstrate restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, as manifested
by at least one of the following: (1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus; (2) apparently inflexible adherence to specific, nonfunctional routines or rituals; (3) stereotyped and repetitive motor mannerisms; (4) persistent preoccupation with parts of objects. While there is no clinically significant delay in language or cognitive development, Asperger’s syndrome causes impairment in social, occupational, and other vital areas of functioning (American Psychiatric Association, 2000).

*Autistic Disorder*

An individual must meet all three primary areas defined by the DSM-IV TR’s description for autistic disorder to qualify for a positive diagnosis. A total of six (or more) items from each of the following three categories are needed: (1) qualitative impairment in social interaction; (2) qualitative impairments in communication; and (3) restricted, repetitive, and stereotyped patterns of behavior, interests, and activities. Also, the child must display delays or abnormal functioning in at least one of the following areas: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play (American Psychiatric Association, 2000).

*Pervasive Developmental Disorder, Not Otherwise Specified*

This diagnosis is used when there is a severe and pervasive impairment in the development of reciprocal social interaction, verbal and nonverbal communication skills, or when stereotyped behavior, interests, and activities are present. However, the individual does not meet the criteria for a specific pervasive developmental disorder, including autistic disorder (American Psychiatric Association, 2000).
**Rett’s Disorder**

After apparently typical prenatal and perinatal development, as well as typical psychomotor development and head circumference at birth, a child who is diagnosed with Rett’s disorder exhibits the following: (1) deceleration of head growth between ages 5 and 48 months; (2) loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements; (3) loss of social engagement; (4) appearance of poorly coordinated gait or trunk movements; and (5) severely impaired expressive and receptive language development with severe psychomotor retardation. Rett’s disorder only affects the female population (American Psychiatric Association, 2000).

**Childhood Disintegrative Disorder**

Childhood disintegrative disorder begins with typical development for at least the first 2 years after birth, as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior. In addition, the child must display a significant loss of previously acquired skills, before age 10 years, in at least two of the following areas: (1) expressive or receptive language; (2) social skills or adaptive behavior; (3) bowel or bladder control; (4) play behavior; and (5) motor skills. Lastly, the child must demonstrate at least two of the following: (1) qualitative impairment in social interaction; (2) qualitative impairments in communication; and (3) restricted, repetitive, and stereotyped patterns of behavior, interests, and activities. The loss of skills and challenges in functioning are not better
accounted for by a diagnosis of another specific pervasive developmental disorder or schizophrenia (American Psychiatric Association, 2000).

**Prevalence of Autism Spectrum Disorders**

According to the Centers for Disease Control and Prevention working group (2001) approximately 1 in 150 children, representing various communities in the United States, have an autism spectrum disorder. These findings are based on annual reviews of records from local schools and other clinical service providers. Regionally, California Health and Human Services examined the numbers of people with autism spectrum disorders diagnosed by using the DSM IV TR’s criteria and entering the California Developmental Services system each year from 1987 to 1998. Their findings showed a rise in the disorder in each of the years studied (Centers for Disease Control, 2001).

**Diagnosis and Selection of Intervention Services**

Diagnosing children with autism spectrum disorder early on is crucial when it comes to providing interventions that lead to gains in a child’s verbal and non-verbal communication, social interaction and leisure or play activities. The first randomized controlled trial of comprehensive early intervention to be tested in toddlers with autism has established evidence of the principle that it is possible to alter the natural history of the disorder, at least for a time (Kelley, 2009). The study showed that treatment beginning when children were younger than 2½ years improved their IQ, receptive and expressive language, and adaptive behavior so much that within 2 years nearly 30% no longer met the diagnostic criteria for autism. The American Academy of Pediatrics
now recommends that all 18- and 24-month-old children be screened for autism, which will assist in early diagnosis and the provision of earlier intervention (Kelley, 2009).

After a child is diagnosed with an autism spectrum disorder, parents are given referrals to their state’s agency that is responsible for providing early intervention services to determine the child’s eligibility for the appropriate services. Evaluations of aptitude and achievement tests, adaptive behavior, physical condition, social or cultural background, parent input and teacher recommendations are then made in order to determine if a child is in need of special education and related services ("Eligibility: determining whether," 2009)

The initial diagnosis and subsequent request for services can be a daunting process for parents. The vital decisions that need to be made at this time will impact the subsequent growth and health of their child. Moreover, parents are faced with the task of taking responsibility into their hands. For instance, decisions must be made regarding which interventions and services work best for their child. Not all programs are created equal, and what works well for one child, may not be suitable for another. Also, parents are faced with the emotional burden this process may create. As Osborne, McHugh and Reed (2008) demonstrated, the impact of this emotional burden may result in high levels of parenting stress. In fact, this parental stress was shown even to counteract the effectiveness of early teaching interventions. A concern is that decision making will become more difficult and emotional stress will continue for families as new research emerges and different treatments are implemented resulting in even more
choices becoming available. Furthermore, as the child ages, decisions will continue to need to be made by families of children with autism.

The Need for Well Informed Parents

To help combat the stress associated with decision making about services and interventions that families face, it is imperative that the parents of these children are well informed regarding all aspects of this particular disorder. Well-informed parents and teachers are essential to an America where every child, including those with special needs, will be educated (“Tools for student success,” 2002). Research has indicated that parents who are well informed and participated in interventions lead to a host of positive outcomes for children with special needs (Ingersoll & Dvortcsak, 2006). For example, children exhibited substantial decreases in disruptive behavior when their parents consistently implemented the intervention components that they learned in training sessions. In addition, parent training has been shown to be a very effective method for promoting generalization and maintenance of skills in children with autism as well as significantly increasing the developmental level of the child (Ingersoll & Dvortcsak, 2006). These are just a few examples of the results that may be obtained by providing parents with the resources and skills needed to support their children with an autism spectrum disorder.

Statement of the Problem

Today, parents have a vast array of options when looking for resources to help support their decisions regarding treatment options, available resources and family support. The internet is often one of the first places parents will look to gain access and
information. A recent survey among British business librarians revealed some disadvantages of this tactic, including a lack of: organized information, information quality, relevant information, reliable information; not to mention too much information (Clausen, 1996). This survey illustrated some of the difficulties parents may face when looking to gather information. Along with the fact that not all resources are valid resources, there is simply too much information to navigate. For instance, when conducting an internet search on various terms related to autism, a Google search generated millions of findings. Examples of these resources include, but are not limited to the following:

<table>
<thead>
<tr>
<th>Search phrase used</th>
<th>Number of results found on the internet</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resources for children with autism</td>
<td>5,330,000</td>
</tr>
<tr>
<td>Autism treatments</td>
<td>2,210,000</td>
</tr>
<tr>
<td>Articles on autism</td>
<td>5,880,000</td>
</tr>
<tr>
<td>Help for children with autism</td>
<td>3,750,000</td>
</tr>
</tbody>
</table>

In order to limit the search, one could specifically search for resources in a geographic area such as Sacramento. This still leads to thousands of results for parents through which to sift. Additionally, an internet search for already existing manuals in the Sacramento area turned up a mere three. A review of each found that they lacked comprehensive information and resources aimed at professionals and parents working with children diagnosed with ASD (See Chapter three for a thorough critique of these
Due to the wealth of information available concerning ASD, as well as the lack of comprehensive manuals available in the Sacramento area, a new parent manual is needed.

**Purpose of the Project**

The purpose of this project is to produce a resource manual that is designed to provide both parents and professionals information concerning autism spectrum disorder as it relates specifically to the greater Sacramento area. This area includes, but is not limited to the following communities: Antelope, Auburn, Citrus Heights, Elk Grove, Folsom, Galt, Lincoln, Rancho Cordova, Roseville, West Sacramento and Wilton. By supplying this more localized source of information and services, parents may be able to: (a) take a more empowered role as an advocate in their child’s interventions; (b) become more involved in the special education process as it pertains to the Sacramento region; (c) benefit from local services that this region provides; (d) gain access to more individualized support for both the child and themselves; and (e) participate in events of awareness and support regarding the disability. The services include, but are not limited to: behavioral interventions, books, educational rights, online resources and support groups for family members. Additionally, the resource manual will provide parents with an array of valid, evidence-based information already noted in articles and journals, but condensed into a single source.

**Significance of the Project**

As previously mentioned, there is a wealth of information currently available for parents of children diagnosed with an autism spectrum disorder. With the technological
advances and efficiency of the internet, parents often use it to gain access to information. Despite this ease of access, it is increasingly difficult for parents to discern what information is relevant and research based, versus information that is not critical and not valid. Harris (2007) has succinctly described one of the main problems concerning any search conducted over the internet:

> There is an extremely wide variety of material on the Internet, ranging in its accuracy, reliability, and value. Unlike most traditional information media (books, magazines, organizational documents), no one has to approve the content before it is made public. It's your job as a searcher, then, to evaluate what you locate, in order to determine whether it suits your needs (p.1).

The proposed resource manual would assist in alleviating this problem by evaluating local resources and current research in order to provide parents and professionals with comprehensive, valid, accessible and meaningful information.

With this manual, educators and other professionals (e.g. mental health practitioners, related service providers) will have the resources to give to parents who have questions regarding what autism is, what interventions and services are available and where to go to access those interventions and services in the local community. No longer will parents need to search multiple places for this information. It will be compiled into one manual, focusing on resources provided in Sacramento County. This resource manual could potentially serve as a model for other areas in California, as well as other states where such information would also be useful.
Limitations of the Project

While there are countless reasons to create a resource manual for parents of children with autism spectrum disorder, this endeavor also faces a multitude of limitations. First of all, this manual will serve to assist parents in the Sacramento area, so it will include resources specifically for those residing in this area. Each region is different in its ability to support parents and the resources that can be found in each community will differ greatly. For parents living in other regions, this manual may not provide the support and information necessary to answer questions concerning their children. For instance, the Sacramento area provides specific support groups to families of children with ASD. Depending on the location of the parent, attending these support groups may not be feasible.

Another limitation includes the access to this manual. This resource manual will be disseminated by donating a copy to not only the professionals listed in the resource manual, but by also donating copies to each school district in the Sacramento region. It would be up to educators and other professionals who have access to the manual to disperse as they felt necessary. Since this manual is not found via the internet, it may not reach as many individuals.

Lastly, because this manual has been compiled in 2010, another limitation is it being time limited. In other words, the information within this manual states current research practices, methodologies, and services. What may be resourceful and informative now may not be in the future once more research has been conducted and new practices emerge. In addition, federal and state laws, support groups and
professionals in the field may change and expand. This leaves a relatively short time that this manual will be most effective before revisions and updates will need to be made.

Definition of Terms

*ABA or Applied Behavior Analysis*

ABA is a well researched and data based strategy for teaching children with disabilities. Interventions are based upon the principles of learning theory to improve socially significant behaviors to a meaningful degree, and to demonstrate that the interventions employed are responsible for the improvement in behavior. It is most often used with children with autistic spectrum disorders, but is an effective tool for children with behavioral disorders, multiple disabilities, and severe intellectual disabilities. It is the only intervention for autistic spectrum disorders currently approved by the FDA (Rogers, 2000).

*Advocate*

An individual who is not an attorney, but who assists parents and children in their dealings with school districts regarding a child’s special education program and services (Rogers, 2000).

*Age of Majority*

The age of majority is the threshold of adulthood as it is conceptualized (and recognized or declared) in law. It is the chronological moment when a minor is no longer legally considered a child and assumes control over their own person, actions
and decisions, thereby terminating the legal control and legal responsibilities of their parents or guardian over and for them (O'Leary, & Trotter, 1990).

**Alta Regional Center**

Alta is a private non-profit corporation working under contract with the California Department of Developmental Services. Alta California Regional Center serves and maintains partnerships to support all persons with developmental disabilities, children at risk, and their families in choosing services and supports through individual lifelong planning to achieve satisfying lifestyles in their own communities. Alta Regional Center serves the following counties: Auburn, Placer County, Grass Valley, Placerville, Roseville, Sacramento, South Lake Tahoe, Truckee, Woodland, Yuba City ("Alta California Regional," 2008).

**Early Intervention**

Identifying disabilities early is essential for children to obtain the support they need to be successful and reach their potential in school, at home and in the community. Early diagnosis leads to earlier support and greater opportunity to ensure the needs are met regardless of the learning disability. Much research indicates greater student success occurs with early identification and intervention. This intervention can be in the form of occupational therapy, speech therapy, behavior therapy, etc. (Rogers, 2000).

**Individuals with Disabilities Education Improvement Act of 2004 (IDEA)**

This is the current reauthorization of the federal government legislative act passed initially in 1975, which ensures individuals with disabilities from birth to 21
years receive access to a free and appropriate public education, including special education and related services, in the least restrictive environment. The act also defines and requires procedural safeguards for the individual with disabilities and his/her guardians. ASD is one of the 13 categories of disabilities that qualify for services under IDEA (Manasevit, Plagata-Neubauer & Winters, 2006).

*Individualized Educational Program (IEP)*

A written statement, required by law (IDEA), developed by the IEP team (school administrator, child's special education teacher, child's general education teacher(s), parent(s), child's related services professional(s), and child, translating the child's evaluation assessment and information into a practical plan for instruction and delivery of services (Rogers, 2000).

*Individualized Family Service Plan*

Required by law (IDEA), the Individualized Family Service Plan (IFSP) is both a process and a document intended to assist families and professionals in a community in their combined efforts to meet the developmental needs of a young child from birth to age three with special needs (Adams, Edelson, Grandin, & Rimland, 2004).

*Least Restrictive Environment*

The concept that each child with a disability is to receive services in an educational environment that most closely approximates the educational environment of his/her non-disabled peers (i.e. general education classrooms) AND provides for the most appropriate educational opportunities and access to core curriculum for the child (Rogers, 2000).
No Child Left Behind

No Child Left Behind (which is the reauthorization of the Elementary and Secondary Education Act) is a federal law signed by President George W. Bush in 2002 and is meant to guarantee accountability and provide freedom for communities and school districts and more choices for parents (Rogers, 2000).

Occupational Therapy

Treatment provided by a therapist, usually acting on a physician's prescription, trained in helping the patient develop mental as well as physical well-being in all areas of daily life (e.g., self-care and/or pre-vocational leisure skills) (Rogers, 2000).

Parent

Any one of the following individuals: the student’s biological or adoptive parent; a foster parent (dependent on state law); a student’s guardian who is authorized to act as a parent; an individual acting in place of an adoptive or biological parent with whom the student lives; an individual legally responsible for the child’s welfare; or an authorized surrogate parent (Manasevit, Plagata-Neubauer & Winters, 2006).

Physical Therapy

Treatment of disorders of bones, joints, muscles, and nerves. With the prescription of a physician, the therapist applies treatment to the patient in the form of heat, light, massage, exercise, etc (Rogers, 2000).

Special Education

Special education can be defined as a statement of the special education and related services and supplementary aids and services, based on evidence based practice
to be provided to the child, or on behalf of the child. This includes a statement of the program modifications or supports for school personnel that will be provided to enable the child to: (1) advance appropriately toward attaining the annual goals; (2) to be involved in and make progress in the general education curriculum in accordance with paragraph; and (3) to be educated and participate with other children with disabilities and nondisabled children in the activities (National Dissemination Center, 2010).

School Psychology

Therapy involving the administration of psychological tests, interpretation of results, and suggestions concerning appropriate educational approaches to students with learning or behavioral problems (Rogers, 2000).

Speech Pathology or Speech Therapy

Therapy providing analysis and diagnosis for speech and language impairments, including but not limited to help with: annunciation, pragmatics, etc (Rogers, 2000).

Evidence Based Practice

Evidence based practice refers to the use of mental and behavioral interventions for which systematic empirical research has provided evidence of statistically effectiveness as treatments for specific populations (Wikipedia, 2010).

Organization of the Remainder of the Project

The remainder of this project will be organized as follows. Chapter 2 will provide the reader with a review of the literature related to: a) the roles played by families with children who have ASD; (b) the information families need in order to
support their children; (c) the challenges that families face in locating needed resource information; (d) the ways to organize and make resources accessible for families; and (e) the current available resources to address the needs of families with children who have ASD. Chapter 3 will discuss the methodology used in developing the resource manual. Chapter 4 will provide the reader with a brief description of the project as well as final conclusions and recommendations for practice and future research related to providing needed resources to families with children who have ASD. Lastly, the appendix will include the actual resource manual.
Chapter 2

REVIEW OF THE LITERATURE

This review of the literature will explore current research regarding: (a) the roles played by families with children who have ASD; (b) the information these families need in order to support their children; (c) the challenges that these families face in locating needed resource information; (d) the ways to organize and make resources accessible for families and lastly, (e) a critique of the current available resources to address the needs of families with children who have ASD.

Roles and Responsibilities of Families of Children with ASD

The roles and responsibilities parents face when raising children are endless. From providing the necessities of shelter and food to education and values, the role of the typical parent can be exhaustive. However, what happens when you add a diagnosis of ASD to the mix? Parents begin to take on new roles and challenges, including finding educational and social supports to assist them in teaching their child to learning how to make adjustments and modifications to daily life activities. The roles and responsibilities of families with children who have ASD can be extensive and are beyond roles and responsibilities that typical families face. In order to support their child’s needs, parents often become teachers, advocates, collaborators and educational decision makers (Turnbull, Turnbull, & Wehmeyer, 2006).

As an advocate, parents must first have an understanding of their child’s diagnoses (Huhtanen & Huhtanen, 2008). This includes such information as knowing the milestones their child has reached and the ones with which their child has more
difficulties. This may become particularly important when a parent reviews proposed goals during an IEP meeting. Parents should be reviewing goals to ensure that they are appropriate and will assist in supporting their child’s needs. Also, as an advocate, the parent must be proactive. They must ensure that their child is not only receiving the proper services for their diagnoses, but that those services are targeting the needs and challenges they were intended to target (Huhtanen & Huhtanen, 2008). Finally, being an advocate means networking with other parents. Simply communicating with others who have gone through the same process can be helpful not only for the child, but for the family as a whole.

Parents must also play the role of teacher and are encouraged to be the providers/implementers of interventions. As emphasized by Lovaas and colleagues (1973), following intensive treatment, children whose parents were trained to carry on at home an intervention taught by professionals continued to make gains, whereas children who returned to an institutional setting without this home intervention lost their previously acquired skills (Lovaas, Koegel, Simmons, & Long, 1973). This is just one illustration of the benefits of teaching parents to become teachers themselves. By having parents facilitate interventions, they are helping the child to not only master their skills, but they are also helping to increase generalization of the skills to new environments (Ingersoll & Dvortcsak, 2006). Furthermore, parents who are trained are less stressed, which can lead to a better quality of life (Ingersoll & Dvortcsak, 2006).

Taking on the role of a collaborator is also an important role parents must pursue. Being a collaborative parent means working with professionals in a
cooperative manner to achieve the quantity and quality of services best suited for their child (Stoiber, Gettinger, & Goetz, 1998). Ideally, parents and professionals create a mutual respect for one another in order to work together to solve problems and achieve the goals of the child. Because the needs and resources available to the child are constantly changing as the child grows, collaboration is an ongoing process. Unfortunately, research has shown that limited time and limited opportunities for collaboration often exists between parents and professionals which then create barriers to inclusion (Stoiber, Gettinger, & Goetz, 1998). For instance, when little to no previous collaboration occurs, parents and teachers sometimes seem to be talking about different children at IEP meetings. Parents have more complete knowledge about their individual child while teachers are informed about learning and behavior appropriate for the age and grade level. Each sees the child in different settings and may have different expectations for performance. Therefore, effective collaborative planning time with parents playing a valued part is essential for a child with ASD.

Finally, the critical role of educational decision maker is frequently required of parents of children with ASD. It is the parents that are responsible for meeting the child's varied and challenging daily needs, and they likely direct, coordinate, and manage the child's team of therapists, physicians, teachers, nutritionists, and others from initial diagnoses through their child’s lifespan (Pullen, 2009). As an educational decision maker, the parent may request an evaluation of their child to determine his or her needs for special education and/or related services. This evaluation may include such assessments as psychological and educational testing, a speech and language
evaluation, occupational therapy assessment and a functional behavioral analysis. Additionally, the findings of school's evaluation team are not final. Because parents are a part of the eligibility team, they have the right to appeal their conclusions and determination (Yell, 2006). This right demonstrates the importance of the role as an educational decision maker. Throughout their child’s life, parents must continue to make decisions for their child that they feel will best suit their child’s individual learning style and needs.

In summary, it is important to stress that the roles of the parent are infinite and not mutually exclusive. In other words, parents may play multiple roles at the same time. The roles and responsibilities they have as it pertains to their child with ASD are important for the growth and well being of the child. In order to be effective at fulfilling the roles and responsibilities of advocate, teacher, collaborator and educational decision maker, parents need information regarding ASD and all that it entails. In the following section, the specific information that families may need is described.

Information Families Need to Support Their Child with ASD

Family members are the most consistent influence in a child’s life (Dunn & Wolfberg, 2008). After the initial diagnoses, family members are often bombarded with information about new treatments; some that even go as far as to promise a recovery. As Dunn and Wolfberg stated (2008):

Many parents walk away from the assessment process scared and confused. One parent told us that he and his wife went home, curled up in bed with their
beautiful little boy, and cried for 24 hours. Other parents decide that they are going to become ASD experts and hit the internet, only to be stymied by 18,300,000 hits on a Google search about autism, conflicting reports in the scientific and popular press, and long waiting lists of services in their communities (p.70).

To help overcome this challenge, parents must first identify what key topic areas to guide the search. While there are many topic areas for which information is available to parents, some are particularly essential in order to fulfill the previously discussed roles and responsibilities. These areas involve, but are not limited to: (a) early intervention; (b) educational service delivery options; (c) teaching techniques; (d) social supports; (e) childcare and respite services; (f) legal and advocacy issues; (g) finances; (h) healthcare; and lastly (i) recreational activities (Turnbull, Turnbull, & Wehmeyer, 2006).

*Early Intervention*

If parents do not make educational decisions early on, their child may be at a considerable disadvantage. Research states that intensive early intervention and appropriate programming can make a significant difference in a child’s ability to learn and keep pace with their peers (Schreibman, 2000). In fact, The National Research Council (2001) recommended that children with ASD begin to receive specialized, intensive early intervention as soon as they receive a diagnosis or are even suspected of having a diagnosis. This means that families have little to no lag time when it comes to finding and implementing interventions for their children. As findings supporting early
intervention for children with ASD become more defined, it is even clearer that families need information regarding early intervention and all that it entails (i.e. service delivery options, the number of hours of intervention needed) through their local school district.

**Educational Service Delivery Options**

Once a child turns three and begins to receive educational services, parents will need information regarding service delivery options. Depending on the child’s age, on what their needs are based, and the quality of available supports and services, parents can decide whether their child should receive services in a program designed to serve those solely with special needs or receive integrated services while in a typical school setting (Adams, Edelson, Grandin, & Rimland, 2004). Once the decision is made about where their child receives services, parents must also decide whether the supports they are receiving are best for the child. For instance, if that child is placed in a typical education classroom, what amount of support from an instructional aid will be necessary? Regardless of placement, are the teaching styles of the professionals a good fit for the child’s learning style? What other accommodations might that child need to succeed? These are all valid questions for which the parent must seek out answers in order to better serve their child with ASD.

Of course, before all of this can be accomplished, parents must first be informed about the process through which these services are acquired. It is important that parents work with their child’s teacher on an Individual Education Plan (or an Individual Family Service Plan if the child is under the age of three), which outlines in
great detail the child’s educational program (Adams, Edelson, Grandin, & Rimland, 2004). This plan is an educational document focusing on special education and related services that help the child reach their individualized goals. Once this plan is implemented, parents need to be able to evaluate whether the services their child is receiving continues to be appropriate. For instance, parents must be well informed on the specific needs of their child, as identified by various assessments, and on whether the goals created are aimed at meeting these needs. While the plan is underway, parents also should be able to recognize whether their child is making progress toward their goals as a result of those services. Last but not least, parents need to be informed about the disability from the outset to ensure that the child is receiving services that follow "best practices." Best practices mean the methods of treatment or therapy are endorsed by the available evidence/research and by the majority of professionals at the current time (Goldberg, Goldberg, Anderson, & Bill, 2010).

Information regarding education will always be needed for these parents, no matter what stage of intervention their child is currently receiving. Yet, as parents become experienced and well versed in the issues regarding early intervention and the IFSP/IEP process after several years of receiving treatment services, the initial information is no longer useful (National Research Council, 2001). In other words, a child’s needs continue to vary over a lifetime and parents must consider services in relation to not only their disability, but their age. For example, families with teenagers may now be focusing on transition services as opposed to families who have a child
who has been recently diagnosed and may be focusing their efforts on researching in-home treatments.

*Teaching Techniques*

Not only do parents need to be aware of educational services, but they should know a range of techniques designed to help support their child with ASD at home, school and in the community. Oftentimes, minimal training is provided by the regional center to parents before their child begins to receive services. Without proper training, parents may not know how to effectively implement the techniques available to them that would assist in helping to meet their child’s needs. For instance, Koegel et al. (1996) reported that teaching parents how to use pivotal response training (PRT) as part of their applied behavior analysis instruction resulted in positive parent-child interactions, more interest by the parents in the interaction, less stress, and a more positive communication style. Without this knowledge, these parents may have had to rely solely on the behaviorist working with their child to implement PRT procedures. By learning these methods and others themselves, parents can supplement and generalize the skills that their child learns from specialists to their home environment. While this is just one example of training parents on an approach, it illustrates the impact of knowing and using treatment techniques that can be used to help one’s child.

*Social Supports*

Parents need information that lead them to believe that they are cared for and loved, valued and esteemed, and are important in a network of mutual obligation and communication. Examples of support that parents may receive include, but are not
limited to: support from one’s spouse, extended family, and friends as well as support
from community programs, professional help and programs geared toward families
with similar needs (Siklos & Kerns, 2006).

While parents tend to focus their efforts on creating the best possible outcomes
for their child, they are also urged to consider their own mental health (e.g. knowledge
and expectations), physical health (e.g. stress and energy level), and emotional needs
(“Practical Suggestions,” 1986). Too often, we discover that parents become
overwhelmed and stressed by the amount of knowledge needed and come to need
support and guidance for themselves ("Parenting an autistic," 2004). In fact, studies
have revealed that parental stress and depression are negatively associated with
parenting capability, or the parents’ way of interpreting feelings of efficacy in the
parenting role. Feeling strong self-efficacy has also been associated with well being
among parents and has been shown to reduce the effect of the child’s behavior on
parents’ anxiety and depression. A better outlook on one’s abilities and feelings about
parenting a child with autism may lead to a more active involvement that enhances the
parent’s well being ("Parenting an autistic," 2004). Clearly, ongoing social support has
far reaching affects.

Parents of children with ASD may even need more social support than those of
parents with other disabilities ("Parenting an autistic," 2004). Mothers of children with
autism experience more psychological distress than mothers of children with other
cognitive challenges. This may be attributed to the psychological legacy in which
“refrigerator” mothers were blamed for their children’s autism disorder, contributing to
the social shame some mothers feel ("Parenting an autistic," 2004). This is one reason why social networking and support for parents of children with ASD is of importance. Parents need these social supports in order to remain informed, psychologically stable and feeling competent which ultimately creates a healthier environment for themselves and their child with special needs.

Childcare and Respite Services

Among the countless challenges parents face when attempting to accommodate their child’s special needs, are researching the ins and outs of child and respite care for children with special needs, hiring in-home aides, and paying for special equipment when necessary. Each of these searches take time and attention. Childcare may include, but is not limited to: preschool, nursery school, day-care and babysitting. When looking to find childcare, parents must know which centers have the resources available to accommodate children with ASD. For instance, if the child attends preschool, is the classroom a safe haven? Can services that are being provided through a child’s IFSP/IEP be met no matter where the child is located? While in childcare, is there room to participate in occupational therapy and are their devices available to assist communication between the child and adult? If respite services are needed, are their qualified personnel available to help assist with potentially challenging behaviors? Because of these varying needs, research has noted that the process of choosing childcare can be one of the toughest challenges for parents (Post, 2007).

Another related challenge faced by parents is the need to know whether care givers are trained to work with their child. A concern is that childcare providers may
have little training in working with children with special needs and are not familiar with how to integrate children with disabilities into the classroom or program (Gould, & Sullivan, 1999). This preparation can be especially important if the child will be in a typical preschool classroom or childcare program. Parents need to know whether these caregivers are able to implement the accommodations and modifications required by the child. Parents must also realize that some children with ASD may require a personal aide to attend day care with them. This requirement often adds another layer to the process for parents, as it is one more need that they must make sure is being met (Post, 2007).

**Legal and Advocacy Issues**

In addition to sifting through current research regarding ASD, choosing treatment options and enlisting the appropriate support for their children, parents need to learn to become an advocate for their child. Parent advocacy involves being knowledgeable about current legislation and research regarding the effectiveness of services (National Research Council, 2001). Part of this role as an advocate also means parents must learn to understand the legal rights of their child and therefore according to federal, state and local law and regulations.

While parents often obtain advice from attorneys, case managers and other professionals in the field, it is imperative that they learn to read and comprehend the laws and regulations in special education. IDEA 2004 even mandates that parents receive a document explaining their educational rights and responsibilities (Fitzgerald, & Watkins, 2006). When parents receive this information, it is assumed they
understand what they are reading and can make appropriate decisions based off of that information. Unfortunately, research shows that a majority of parents do not understand the information regarding their child’s rights provided to them (Fitzgerald & Watkins, 2006). In fact, only 4% to 8% of parents' rights documents were written at the recommended reading level (Fitzgerald & Watkins, 2006). These findings suggest that parents of students with special needs are likely to find parents’ rights documents from local school districts to be very difficult to read and understand. While parents' rights documents should be written to make them accessible to all parents of children with special needs, parents also need to know where to get help if they cannot understand them.

Beyond knowledge about their child’s diagnosis and the law, parents need specific skills in order to be an effective advocate. For instance, an advocate must keep an open mind and possess listening skills. These listening skills often lead to more creative problem-solving techniques. An advocate must also have the ability to persuade, be persuaded and analyze problems. In order to be an effective advocate, parents must keep files, negotiate, take comprehensive notes, including recording dates of meetings and questions. Lastly, an effective advocate clarifies their responsibilities. Parents need to know what their role is in order to best support their child with ASD. Of course, the role of parent advocate does not stop here.

*Finances and Estate Planning*

Parents need to know how to handle finances now and in the future as it pertains to their child with ASD. This can be especially important when it comes to making
decisions once the child’s guardians are deceased. While it can be a difficult subject, parents must continually look toward the future when financially planning for the child. This planning includes preparing for what will happen after the death of the parent(s). Parents must know how their resources, property and estate are to be divided as it pertains to their child with ASD. Parents need to determine the capacity of their child to manage the property and the support he/she will need in order to take an active role in doing so. Also, the resources being left behind, as well as those resources that may jeopardize eligibility for certain government benefits (i.e. social security, inheritance) (O'Leary, & Trotter, 1990). Thus, parents should know the value and amount of the assets with which their child may be left. Additionally, it is important that parents designate another guardian or conservator to provide support and opportunities for that child when the child has been deemed incompetent and/or has not reached the age of majority. These decisions require parents to have information regarding the logistics and facts concerning conservatorship.

*Healthcare Resource and Insurance Coverage*

There is a wealth of information parents must know when it comes to healthcare for their child with ASD. For instance, parents need to know if their child is covered and how much coverage they have under their current insurance policy. This can be crucial when it comes to gaining services and items for their child, including, but not limited to: medications; adaptive equipment; respite care; hospice; speech; augmentative/alternative devices or technology; language and hearing services;
physical and occupational therapy; mental health services; counseling; case management; and nutrition services (O'Leary, & Trotter, 1990).

Aside from the details regarding specific healthcare coverage, parents must also know how much their insurance will cover allowable healthcare costs. Oftentimes, children with special needs require a wider scope and depth of benefits than is generally offered by many health insurance plans (O'Leary, & Trotter, 1990). Parents need to know whether their insurance covers the child’s needs and/or when it does not cover those needs, how they may attempt to gain those benefits (i.e. by documenting how receiving a particular service or item will create a more independent child). Because of this wide scope of benefits, it is also important that parents keep a record of all phone calls, including the date, time, person they spoke with and the content of the conversation. It is recommended that parents always address their child’s medical needs and how long they are expected to last (O'Leary, & Trotter, 1990). Prior to seeking assistance from a healthcare provider, parents may go through such entities as the school district or regional center. Although, it should be noted that while the school district may cover related services, medical services, (other than for a diagnosis) are never covered and would have to be covered elsewhere (i.e. private insurance company).

While it is vital that parents have information regarding such entities as healthcare coverage, they must also be aware of which healthcare professionals can best serve their child. Because of the complex nature of ASD and the fact that every child with ASD is different, meeting the needs of these children may be especially
difficult for healthcare professionals. Not all professionals have the expertise and background to know how to meet the needs of children with ASD. In fact, specific documents and resources are created specifically to assist these professionals in meeting those needs. For instance, the Autism Listen, Act, Refer, Monitor (A.L.A.R.M.) document is designed to provide guidance to health care professionals on how to make visits go as smoothly as possible ("Caring for children,” 2010). This document also includes such steps as what office staff can do to better prepare for visits, as well as advice for healthcare professionals during these medical, dental and other healthcare visits. Finding an appropriate healthcare professional is also important because of the myriad of disorders and health concerns that often coincide with ASD. For instance, it is important that professionals are educated on seizures, sleep, nutrition, gastrointestinal disorders, behavior, education, complementary and alternative medicine ("Caring for children,” 2010). Therefore, it is not enough that they be informed on ASD, but the disorder and symptoms that may also be involved.

Recreational Activities

Participation in recreational activities is associated with increased quality of life and life satisfaction in children with ASD (Potvin, Prelock, & Snider, 2008). Individuals with ASD often experience restriction in the range of recreational activities in which they participate. Factors such as minimal language use and difficulties with social skills impede participation in recreation activities of children with ASD, when no support is available, underscoring the need for professionals to work with parents to enhance participation in recreational activities (Potvin, Prelock, & Snider, 2008).
According to current research, social interactions in children diagnosed with ASD rarely develop into typical peer relationships without support (i.e. prompting by adults) (Orsmond, Krauss, & Seltzer, 2004). This is why participating in recreational activities is vital in order to give these children more opportunities to develop typical social interactions and relationships with peers with and without ASD. Parents need to know what activities are available with necessary support provided in their area for their children to join. These activities include anything from participating in gymnastics to joining a club or athletic team. By providing their child with these recreational activities outside of the education environment, they are helping their child to enhance their verbal skills as well as increasing appropriate social behaviors (Orsmond, Krauss, & Seltzer, 2004). Given opportunity and adaptations, individuals with ASD can participate and enjoy the same recreation activities as others.

Challenges to Meeting the Needs of Families

From resources for childcare to recreational activities, it is critical that parents are informed on all aspects of their child’s life. As parents begin to look for answers, it is no surprise that they face countless challenges when looking for accurate information to meet the needs of their child with ASD. First, the amount of information available can be overwhelming. It is up to the parents to sift through information from a variety of sources (i.e. internet, books, etc.) in order to find resources that apply to their specific wants and needs. Then, not only must families find information that pertains to them, but they must also decide which information is valid and research-based. For a practice to be valid and evidence based, it must have an impact on what it
was intended to do as well as have empirical research providing evidence of its effectiveness (Rogers, 2000). When parents feel a lack of competence in dealing with their child with autism, they may be open to trying procedures that are not evidenced-based. Consequently, some parents will continue to try any treatment available that promises a recovery for their child with ASD. Then again, even if procedures are valid, some treatments can simply be too difficult for parents to understand or implement on their own.

Another challenge parents face when trying to meet the needs of their child with ASD is the fact that the professionals working with these parents often become the “gatekeepers.” Doctors, teachers, case workers and other professionals become the primary source of information. In other words, these professionals have the information parents want and need, resulting in parents becoming reliant on them for answers. One reason for this reliance is the fact that these professionals have gone through extensive schooling, resulting in their expertise. Another reason professionals become the primary source of information is because parents do not know where else to go for the information. After being overwhelmed by the amount of information available, parents may seek assistance and guidance by these professionals in order to weed out which information is considered valid. Perhaps, if these parents were given this information in a cohesive resource manual, they would not have to rely so heavily on professionals for answers.

In general, there is a lack of comprehensive resource manuals available to parents of children with ASD that are specific to their local area. When researching
manuals and resources online, parents may once again become overwhelmed by the amount of information available. Manuals can be found for nearly every disorder. In fact, one hit on a Google search will turn out nearly 1500 pages of manuals available for parents of children with ASD alone. Also, finding manuals that are specific to one’s needs can be yet another daunting process. While these manuals may all provide helpful information, they are not localized to a specific area or region. It is the lack of localized manuals that is cause for concern. A concern for the fact that parents must continue to seek out assistance from other sources in order to get their needs and these of the child met.

Ways to Organize Information for Families

Not only is there few localized resource manuals available to assist parents needing information on ASD, but existing manuals are not created equal. Blachman (2006) noted that there are specific guidelines one must follow in order to create a more useful manual specific to the needs of individuals with disabilities. The first of these guidelines is the decision to choose a specific geographic area that the manual intends to cover. Oftentimes, it is helpful to limit the area in order to serve a more specific target population. Secondly, Blachman (2006) stated that it is best to create a list of categories of services or agencies that should be included. It is recommended that a manual minimally includes support, education, information and family activities for parents. Also, as the manual becomes more in depth, other suggested categories include counseling and psychotherapy referrals as well as in-home and practical support (Blachman, 2006).
Once the geographic region and categories to be covered are chosen, a web search on parenting and services for your city or region must be performed. Blachman (2006) recommended that using different terms in the search engines may result in more resources. Once sources are explored, it is crucial that specific information for each source be written down for entry into the manual. This information includes: (1) name of the organization, (2) address, (3) telephone numbers and e-mail addresses, (4) information about possible services for parents or their children, and (5) the links or resources listed on the site; which may lead you to other local resources (Blachman, 2006).

After composing an initial list, Blachman (2006) recommended that the researcher begin calling public and private agencies or groups that have services available for parents and their children. Use the telephone in order to establish a relationship, get detailed information, and enlist support and other possible contacts. Blachman (2006) also suggested that by asking questions and having a conversation, you are raising interest in the project and validating the needs of these families (Blachman, 2006). The author also noted tactics to use when making phone calls to agencies regarding services. First, ask to speak with someone who is familiar with psychosocial support and/or education services provided by the agency (e.g., the program director, social worker or nurse, support group leader, resource center coordinator). Tell the person what you hope to accomplish and find out if they would like their services listed in your resource guide. If so, ask them for the more detailed information. Always ask, “Is there anything else at your agency we should include
(e.g., a resource center that has books for parents or children)? At the end of the conversation, ask for leads to other local services for parents or children that could be listed in the guide. Get names and telephone numbers. For these services, you can also ask about any print, audio, or video materials they can recommend. Lastly, thank the representative and say that before printing the information, the agency or individual will be able to review it for accuracy (Blachman, 2006).

Once a list of valid resources is created, it may need to be edited once the research is completed. Blachman (2006) suggested that this information be edited by the author and to seek advice from other resource guides in the area. Also, it is important to have someone else proofread for coherence and accuracy as well as to check for accuracy with the agency or individual offering the service. If recommending services, one should always be aware that not all services should be recommended, and so the author has to determine the worthiness of the information to be included in the manual. Once the manual is complete, one must print copies to deliver to the agencies and individuals for duplication. It is also recommended that this information be made available on a web site, in order to more easily inform the target population (Blachman, 2006).

Local Resources Available to Parents

While there are specific guidelines recommended when creating resource manuals for parents of children with special needs, few manuals have been developed utilizing these guidelines. In fact, only a handful of resource manuals were found specific to the current geographic area of interest that appeared to use such
recommendations. One of these manuals was created by Autism Speaks, and had designated information specifically geared towards those residing in Sacramento, California. This web-based manual titled *Sacramento Autism Speaks* includes information regarding local autism assessment and treatment options, books available via the parent to parent exchange as well as advocacy in the Sacramento region. This website also relays information regarding future community events that are designed to motivate families and bring awareness to those diagnosed with ASD. Although, even this manual does not include vital information parents need to know, including, but not limited to, information regarding local healthcare providers and educational rights.

Because of the challenges in finding information for parents after their child is diagnosed with autism, agencies have created resource manuals in order to support these families. While each of these manuals is different, in regards to the information they provide and the target audience they aim to direct this information towards, they all aim to provide information that may be otherwise unheard of. More locally, the Families for Early Autism Treatment (FEAT) resource manual is a good example from which to base what information should be included. The FEAT resource manual is designed to provide information about ASD. Within this manual, information is made available to the public regarding education, treatment and autism.

In the education portion of the FEAT manual, it discusses topics including, but not limited to: (1) parent suggestions for education, (2) websites for curriculum, (3) public and non-public agency information and (4) education agency resources. In the treatment portion of the FEAT manual, it covers such topics as: (1) parent suggestions
for treatment, (2) genetics, (3) bilingual educational consultants, and (4) applied behavior analysis. For information regarding autism, the FEAT manual includes information regarding: (1) DSM IV TR criteria, (2) autism related websites, and (3) parent suggestions for autism. Each of these topics is a good starting point from which to base a parent manual. While this manual offers a range of information regarding ASD, the information was found to be dated. For instance, several of the services recommended for families of children with autism were no longer offering services (e.g. social programs).

Another manual geared towards assisting those in the Sacramento region is called *A Parents Guide to Asperger’s Syndrome and High Functioning Autism*. This manual covers information regarding the steps once diagnosis has taken placed. It also includes a comprehensive reading list for families as well as resources on advocacy and social supports. This short manual gives a brief overview of some of the services that can be in the Sacramento region, as well as information that relates to all families with children diagnosed with ASD. While the information within this manual was well planned and formatted, it was a difficult read. In other words, it was geared to a more academic clientele (i.e. professionals).

In conclusion, a more localized parent manual is needed for parents of children with ASD in order to better fulfill their child’s needs. This project presents a parent manual for the Sacramento area, focusing on providing information families need to know in order to support their child with ASD.
Chapter 3

METHODS

This chapter provides information on the methods used to develop this project, including: a) criteria for selecting information to be used in the resource manual; b) how information was gathered and formatted for the resource manual; and c) the process of writing and editing the resource manual for families of children with ASD.


In order to select which information was to be used, the first crucial component in developing the resource manual was reviewing the relevant literature and research that was available regarding the needs of parents of children with ASD. Due to the fact that there is a wealth of information available regarding ASD (as previously discussed in the literature review), each source (i.e. internet website, published books, and local agencies) that will be listed in the resource manual had to meet the following criteria: a) each source had to be current (e.g. books not older than 10 years); b) internet websites had to be from national organizations to which families are referred to by professionals for reliable information about ASD; c) published books and peer reviewed journal articles had to be written by professionals who have published widely on the topic of ASD within the last decade; and d) agencies must be a member of the provider advisory committee (PAC). The PAC is comprised of service providers contracted with Alta Regional Center. This criterion was created based off the Credibility, Accuracy, Reasonableness, and Support (CARS) checklist (Harris, 2007). This checklist was designed for researchers to evaluate sources. While sources may not
meet every criterion in the list, by using this checklist, it is more likely that the source possess the highest level of quality possible (Harris, 2007). A source is deemed credible if it is: trustworthy; the quality of evidence and argument is evident; the author's credentials are available; quality control is evident; it is a known or respected authority; and if it has organizational support. A source is accurate if it is: up-to-date, factual, detailed, exact, and comprehensive. Its purpose reflects intentions of completeness and accuracy. When a source is reasonable, it is: fair, balanced, objective, and reasoned; there is no conflict of interest; there is an absence of fallacies or slanted tone. And lastly, if a source has support, it will have: listed sources, contact information, and available corroboration its claims will be supported; and documentation will be supplied (Harris, 2007).

After using the CARS checklist, there continued to be an abundance of information available. From this point, the researcher whittled her way down each source, only selecting those that were the most relevant to the subject at hand. Relevancy was based on whether or not parents would find this information useful to their lives in today’s society. Further, if the source was not found within the Sacramento area, it was not used.

How Information was Gathered

In order to gather information for this project, brief telephone interviews with agencies thought to serve children with ASD within the Sacramento region were conducted. A representative from these agencies was reached by telephone and, after describing the reason for the interview, was asked three questions. The first question
was whether or not they served children with ASD. If the agency did not serve these children, no more information was asked of the interviewee. The second question was how much experience the agency had in working with this population. The third and final question was what the agency stood for in regards to treating children with ASD and/or helping families of children with ASD meet their needs. From these interviews, agencies were chosen to be documented in the resource manual.

Books, on the other hand, were chosen using two methods. The first method was to go to *The New York Times* best seller list. From this list, the top selling book related to autism was chosen based off the number of people who have purchased that book (popularity). The second route taken to identify books for the manual was to research authors and editors known for their work on the topic of autism. These authors and editors must also have been used as a reference for various other publications regarding autism. Books included in the manual are *Behavioral Intervention for Young Children with Autism: A Manual for Parents and Professionals* by Catherine Maurice and *Facing Autism: Giving Parents Reasons for Hope and Guidance for Help* by Lynn Hamilton. The websites chosen for the manual are *Autism Speaks, The Autism Society of America*, and *UC Davis MIND Institute*. These websites were chosen based on credibility within the autism community (i.e. are they recommended by professional agencies).

Once the author decided on what services and information would be included in the manual, she then took each of the categories of information parents need (listed in
Chapter two) and organized them into three categories: social support, interventions and services, and recreational activities.

The Process of Writing and Editing

As previously discussed, in order for a user-friendly resource manual for families to be developed, the present author gathered several previous resource guides, handbooks, and books aimed for parents on the topic of ASD. Each of these resources was examined on how the information was organized and the depth of empirical data provided regarding the information presented.

This review also enabled the present author to write for a diverse audience and to figure out how to best organize and present all the information obtained in the present resource manual. The organization of the manual was based off previous manuals written for the same audience. The FEAT parent manual and *A Parents Guide to Asperger’s Syndrome and High Functioning Autism* manual were both referenced in order to create a layout and structure for the current manual. This resource manual was created with the help of a project advisor, as well as the assistance of colleagues and other professionals, who read the work, suggested which information to add and to extract until the point of completion.
Chapter 4

DESCRIPTION OF PROJECT AND RECOMMENDATIONS

This chapter describes the resource manual that was created for this project, makes recommendations for evaluation, use and dissemination of the resource manual, and summarizes implications for future practices and research.

Description of Resource Manual

As previously discussed, parents of children with ASD need information in order to better support their child’s needs. Sifting through information can be a daunting task. In order to assist parents in sorting through this information, this project was created so that: a) parents will have a local guide that will inform them about ASD; b) educators and other professionals will have the a resource to give to parents who have questions regarding their children with ASD; and c) it will enable parents to become advocates for their child. By providing such information, parents and professionals working with children with ASD will have a source from which to reference when questions arise regarding the disability.

The content of the parent manual focuses on available services in the Sacramento area. These services include, but are not limited to: behavior consulting, diagnosticians, medical doctors, occupational therapy, physical therapy, psychologists, and speech and language pathologists. Along with these local services, the manual recommends select books and internet sites found helpful to those who want to learn about ASD and evidence based practices. Also, information regarding educational rights and advocacy is included in the parent manual. This information includes
websites for answers to legal questions, as well as sources for finding service delivery options. Recreational activities, including social programs for children with ASD and support groups are also discussed in the manual. Finally, the parent manual includes information regarding respite services and childcare for children with ASD. Each section provides additional space for the user to add information and notes.

Recommendations for Evaluation and Dissemination of Resource Manual

Because the resource manual has not been piloted, it is not known whether those who have used this manual have benefited from its information. While this manual has yet to be field tested, the current author may do so by first allowing the manual to be read and critiqued by colleagues and other professionals, including coworkers and family members of children with ASD with whom she currently works. By allowing others to give constructive criticism, the manuals content, appearance and appropriateness of reading level can be adjusted. The manual can then be further tested by potential users; more specifically, parents of children with ASD, as well as professionals and educators that would be referencing and disseminating the manual. Parents would also give constructive criticism, allowing the author to make necessary changes for the betterment of the manual.

After the manual has been critiqued and reviewed by colleagues, other professionals and potential users, the author would give the manual to the regional center (i.e. Alta) to disseminate. Here, the manual can be given to families of children with ASD who receive services through the regional center. Also, agencies included in the manual will be given copies to give to their current and potential clientele.
This resource manual was created to be a source from which families can pull information to use in order to aid them in making decisions regarding their child with ASD. Because parents often pull information from the internet, it is also recommended that this manual be posted on a webpage. This way, the resource manual will be more easily accessible to families. Other recommended places for this resource manual to be available includes other regional centers, hospitals, behavior consulting agencies, diagnostic and research centers (e.g. M.I.N.D Institute) and schools in the Sacramento area.

Implications for Future Practices and Research

While this resource manual was designed for families of children with ASD, in practice it may have a wider and more diverse audience. For instance, students and aspiring professionals in the field of education can use this as a starting point from which to gain information regarding ASD. In terms of research, professionals may use this manual as a point from which to begin to explore how to meet the needs of families of children with ASD. After looking through the manual trying to find a specific service for their student, a professional may come up with limited options. This, in turn, may cause the professional to conduct research on the lack of resources and information in that specific area for children with ASD. Also, the impact of this resource manual has on these families will need to be further researched. Questions such as “Does this manual decrease stress in parents and professionals working with children with ASD?” or “Are manuals such as these helpful in finding information regarding services for children with ASD?” may be investigated. Perhaps, in the future,
this resource manual could serve as a model for other geographic areas in California as well as other states.
APPENDIX A

Resource Manual
RESOURCE MANUAL ON LOCAL INFORMATION FOR PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS IN THE SACRAMENTO AREA
DISCLAIMER

Everything contained herein is provided for general informational purposes only and should not be misconstrued as legal, medical, or any other type of professional advice. Nothing contained herein is intended as a substitute for obtaining advice from your own medical and legal professionals. All information provided is current as of July 2010.
With this manual, families, educators and other professionals will have the resources available to answer questions regarding what Autism is, what interventions and services are available and where to go to access those interventions and services.

All of the information included in this manual (i.e. internet websites, published books, local agencies) met the following criteria: a) each source had to be current (not older than 10 years); b) internet websites had to be from national organizations to which families are referred to by professionals for reliable information about ASD; c) published books had to be written by professionals who have published widely on the topic of ASD within the last decade.

This criterion was created based off the credibility, accuracy, reasonableness, and support (CARS) checklist. This checklist was designed for researchers to evaluate sources. While sources may not meet every criterion in the list, by using this checklist, it is more likely that the source possess the highest level of quality possible (Harris, 2007). Information was also gathered through brief telephone interviews with agencies thought to serve children with ASD within the Sacramento region.
This resource manual provides information and resources aimed at assisting families of children with autism spectrum disorder (ASD).

The following is an outline of each section of the manual:

What is Autism .....................................................................................Page 53

Books ..................................................................................................Page 55

Social Supports ....................................................................................Page 62

Interventions and Services ....................................................................Page 66

Recreational Activities and Respite ....................................................Page 78

References ............................................................................................Page 84
What is Autism?

Autism spectrum disorders are a group of neurodevelopmental syndromes characterized by disturbances in: social interactions, communication, and repetitive/stereotyped patterns of behavior (American Psychiatric Association, 2000; World Health Organization, 1993). For more information on prevalence, statistics and general information regarding autism spectrum disorders, visit:

- **The Autism Society of America**
  http://www.autism-society.org

  The Autism Society is the nation’s leading grassroots autism organization, existing to improve the lives of all affected by autism. This website lends help to parents seeking questions/advice on the basic statistics of autism spectrum disorder.

- **Autism Speaks**
  http://www.autismspeaks.org

  Autism Speaks has grown into the nation’s largest autism science and advocacy organization, dedicated to funding research into the causes, prevention and treatments for those with autism. This website supplies families with resources, including early signs of the disorder and expert interviews to watch.

- **UC Davis MIND Institute**
  http://www.ucdmc.ucdavis.edu/mindinstitute/

  This collaborative international research center, located in Sacramento, supplies both professionals and families with information concerning awareness, understanding, prevention and care of neurodevelopmental disorders.
Additional Information:

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Not only do parents need to seek out information on internet sites to prepare for their role as a caregiver to a child with ASD, but it is also recommended that these caregivers read books pertaining to ASD. The education process will continue and evolve long after the initial diagnosis. It is especially important for families to continue to read about suggested treatments and new perspectives in order to help guide the decision making process (Ackerman, 2006). Research and information on ASD can rapidly change and continuing one’s education is a necessity. The following books are recommended for families:

- **Behavioral intervention for young children with autism: A manual for parents and professionals (1996).**

  By Catherine Maurice, this book provides a wealth of practical information for parent’s professionals, & others concerned with helping children with autism.

- **Facing autism: Giving parents reasons for hope and guidance for help (2000).**

  By Lynn M. Hamilton, this best selling book is a story about a mother learning to raise a son with autism. The author combines an inspiring and very personal story with the nitty-gritty practical details of all the interventions that have helped her son. This book helps give a face to autism and the challenges a parent can expect to face.
Overcoming autism: Finding the answers, strategies, and hope that can transform a child’s life (2004).

By Lynn Kern Koegel & Claire LaZebnik, this book tells the story of a mother of a child with Autism and the professionals with whom she works and shares intelligent, well-planned early interventions can improve the symptoms of autism enormously.
Additional Information:

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Educational Rights and Advocacy

Once a child turns three and begins to receive educational services, parents will need information regarding service delivery options. Depending on the child’s age and what their needs are based on, parents can decide whether their child should receive services in a program designed to serve those solely with special needs or whether it would be best to receive integrated services while in a typical school setting (Adams, Edelson, Grandin, & Rimland, 2004). Once the decision is made about where their child receives services, parents must also need to decide whether the supports they are receiving are best for the child.

- California Department of Education
  Website: www.cde.ca.gov/
  Phone: (916) 319-0791
  Address: 1430 N Street P.O. Box 944272 Sacramento, CA 94244-2720

The California Department of Education (CDE) oversees the state’s diverse and dynamic public school system. The CDE and the State Superintendent of Public Instruction are responsible for enforcing education law and regulations; and for continuing to reform and improve public elementary school programs, secondary school programs, adult education, some preschool programs, and child care programs.
Cal-TASH
Website: www.tash.org/chapters/caltash/
Phone: (510) 981-8115
Address: 2001 Center Street, Ste. 500 Berkeley, CA 94704
Email: caltash.president@gmail.com

Cal-TASH organization supports practices that promote resolution that all people, regardless of their label or perceived level of disability, should have the supports they need to direct the course of their own lives, and to live and participate successfully in inclusive schools and communities.

Developmental Disabilities Area Board 3
Website: http://www.areaboard3.org/
Address: 1507 21st Street, Suite 220 Sacramento, California 95814
Phone: (916)324-7426
Email: michaelr@areaboard3.org

This site has numerous pages of very informative information regarding services and supports that may be available to families of those with special needs. The Area Board provides advocacy services to many families in both educational issues as well as regional center matters.

Disabilities Rights California
Website: www.disabilityrightsca.org/
Phone: (800)776-5746
Address: 100 Howe Ave., Suite 235-N Sacramento, CA 95825

Their vision is a barrier free, inclusive world that values diversity, culture, and each individual. This year they also helped tens of thousands of Californians with disabilities fight discrimination, prevent abuse, obtain education, benefits and other services, and made sure that thousands more had opportunities to learn about their rights. Their stories show that even in challenging times, California can become a more barrier free and inclusive place to live.
➢ Parent Advocacy Coalition for Educational Rights
Website: www.pacer.org/
Phone: (952)838-9000
Address: 8161 Normandale Blvd. Minneapolis, MN 55437
E-mail: pacer@pacer.org

Founded in 1977, PACER Center was created by parents of children and youth with disabilities to help other parents and families facing similar challenges. Today, PACER Center expands opportunities and enhances the quality of life of children and young adults with disabilities and their families. PACER is staffed primarily by parents of children with disabilities and works in coalition with 18 disability organizations.

➢ Wrightslaw – Special Education Law
Website: www.wrightslaw.com
Email: petewright@harborhouselaw.com

Parents, educators, advocates, and attorneys come to Wrightslaw for accurate, reliable information about special education law, education law, and advocacy for children with disabilities. This website provides thousands of articles, cases, and resources about dozens of topics. Wrightslaw also has special education law and advocacy training programs which are designed to meet the needs of parents, advocates, attorneys, educators, health care providers, and others who represent the interests of children with disabilities and their families.
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Social Supports

Research has shown that social networking and support for parents of children with ASD can be extremely beneficial ("Parenting an autistic," 2004). Parents need social supports in order to remain informed and psychologically stable, ultimately creating a healthier environment for themselves and their child with special needs. While there are endless resources that can be found on the internet and in books, it can be beneficial for parents to speak face to face with others in discussing struggles, teaching techniques, etc. Social supports available in the Sacramento region include:

- **FEAT Family Resource Meetings**
  Website: [http://www.feat.org/](http://www.feat.org/)
  Meetings: Third Wednesday of each month at 7:00pm - 9:00pm at UC Davis M.I.N.D. Institute, 2825 50th Street, Sacramento, Calif.

Meetings are open to everyone with an interest in individuals on the autism spectrum including PDD-NOS and Asperger Syndrome. Meetings are designed to provide information to families in addition to a network of support where families can meet each other and discuss issues surrounding autism, advocacy and treatment options. Learn more about FEAT (Families for Early Autism Treatment).
- **FEAT Elk Grove Parent Resource Group**
  Website: http://www.feat.org/
  Meetings: Every third Sunday of each month from 4:00pm - 6:30pm at Holiday Inn Express, Lodi Room, 9175 W. Stockton Blvd., Elk Grove, Calif. (916) 683-5652

  Local resource group that assists parents who have children with a autistic spectrum disorder. Their primary focus is children with Autism, but assist anyone who has children with disabilities.

- **Nor-Cal Kids Club**
  Website: NorCalKidsClub.com
  Meetings: Every Tuesday or Wednesday of each month, starting August 14, from 7:00-9:00pm, in the Auburn Library’s Beecher Room.

  This group offers support, information, community connections and fun for families with any type of special needs child. Contact Ron: (530) 315-0393 or NorCalKidsClub@Aol.com.

- **The Father’s Circle**
  Website: http://thefatherscircle.blogspot.com/
  Meetings: Each 4th Thursday of each month from 6:30pm - 8:30pm at Trinity Lutheran Church, Fellowship Wing Room, 1225 Hopyard Rd., Pleasanton, Calif.

  Our mission is to celebrate and support men raising children with special health care needs and developmental disabilities. The Fathers Circle provides a forum for men to share current information, resources and their experiences, with one another.
The Sacramento Asperger Syndrome Information and Support Website: http://www.sacramentoasis.com/
Meetings: Every 2nd Tuesday of each month from 7:00pm - 9:00pm at UC Davis MIND Institute, 2825 50th Street, Sacramento, Calif.

Three groups meet at the same time and location in separate rooms/areas: Parents & Caregivers, ASD Adult Support Group, 18 and older, and ASD Coaching Group, 16 and older. Child care is not available at the meetings.
Interventions & Services

There is a vast amount of treatments and services currently available designed to help those with ASD. It is important for parents to choose treatments and services that are scientifically based as well as those that best suite their child’s individual needs. Listed are a few of those services available in the Sacramento region:

Behavioral Interventions: These interventions all utilize Applied Behavior Analysis, which is a style of teaching using series of trials to shape desired behavior or response. Skills are broken into small components and taught to child through a system of reinforcement ("Autism Speaks," 2010).

- **Applied Behavior Consultants**  
  4540 Harlin Drive Sacramento, CA 95826  
  (916) 364-7800  
  (916) 364-7888 fax  
  Website: www.ABCreal.com

This company provides day school and In-home (ABA) for children with autism. ABC school provides a 25.5 to 30 hour weekly program on site, utilizing 12 classrooms and serving students from ages 1 to 22 years. ABC also provides in-home ABA programs ranging from 15 to 40 hours per week, which include tutor training and supervision and weekly team meetings. ABC’s concentration is on communication, including use of ABA techniques to teach verbal imitation, PECS, and some sign language. An infant/ toddler program is also on-site providing early development/behavioral services.
BECA is an educational agency that provides early, intensive, behavioral education for children with ASD. BECA uses a team approach to programming and strives to help children acquire developmentally appropriate skills with comprehensive, individualized programs. Consultants are trained in a variety of methodologies and are able to create a program that meets your child’s specific needs. Consultants carry limited caseloads so each family is assured personalized attention.

Capitol Autism Services (CAS) provides services to children with autism, ages 18 months to 14 years, through behaviorally based in-home programs that address each individual in a humanistic and holistic manner with the goal of promoting quality of life. Based on a positive programming philosophy, CAS works with team members to develop skills to increase each child’s ability to participate in family, school, and community settings. Emphasis is placed on the inclusion of parents and the development of their ability to provide their child functional education and functional adaptive skills to promote generalization and success across environments. CAS utilizes a team approach to meet the goals of the individuals we serve by combining the expertise of our well-trained staff and consultation with other community professionals, specialists, and agencies with knowledge in the field of autism.
Learning Solutions Behavior Consultants
3031 C Street Sacramento, CA 95816
(916) 442-2396
(916) 442-2525 fax
Website: www.learningsolutionskids.com

Learning Solutions is a non-public agency offering a range of services for children with special needs in the Sacramento, Placer, Yolo, and Nevada counties. Trained staff provide a range of services from in-home behavioral services to behavioral support in schools, socialization groups, adaptive skills training, parent coaching, as well as various trainings. Learning Solutions offers a range of services to children with a variety of diagnoses. The programs here range from in-home early autism interventions to parent trainings to socialization groups and more.

Lovaas Institute
2701 Cottage Way, Suite 12 Sacramento, CA 95825
(916) 979-9398
(916) 979-9399 fax
Website: www.Lovaas.com

The Lovaas Clinic in Sacramento provides services for children with autism, including tutors, senior therapist, and Lovaas consultant/supervisor. The intervention curriculum includes all areas of development and particularly focuses on language and cognitive development, socialization and play skills, social language, self-help, reduction of inappropriate behaviors, and generalization of skills.
Therapeutic Pathways, Sacramento
2775 Cottage Way, Suite 7 Sacramento, CA 95825
(916) 489-1376
(916) 489-1386 fax
Website: Sacramento@TPathways.org

Therapeutic Pathways provides intensive in-home and clinic-based behavioral and language interventions for children diagnosed with autism spectrum disorders. Programs typically begin between the ages of 15 months and 4 years of age. Treatment averages 25-40 hours of direct intervention per week and reflects the child’s age and needs. Intervention is extended into community and school settings as soon as possible.

**Occupational Therapy**: Occupational Therapy (OT) brings together cognitive, physical, and motor skills. The aim of OT is to enable the individual to gain independence and participate more fully in life. For a child with autism, the focus may be on appropriate play, learning and basic life skills. An occupational therapist will evaluate the child’s development as well as the psychological, social, and environmental factors that may be involved. The therapist will then prepare strategies and tactics for learning key tasks to practice at home, in school and other settings ("Autism Speaks," 2010).

Occupational Therapy Association of California
PO Box 276567, Sacramento, CA 95827-6567
(916) 567-7000
(916) 567-7001 fax
Website: info@otaonline.org

The Occupational Therapy Association of California was incorporated in 1976 as the result of the merging of the southern and northern California groups. It is a not-for-profit professional society designed to represent the nearly 10,000 occupational therapists (OTs) and occupational therapy assistants (OTAs) within all of California. We are membership driven and that is our main source of revenue. Our goal is to help assure the highest competency for the profession so that consumers may expect the highest level of service.
**Physical Therapy:** Physical Therapists design and implement physical therapy programs and may work within a hospital or clinic, in a school, or as an independent practitioner. Physical Therapy uses specially designed exercises and equipment to help patients regain or improve their physical abilities ("Autism Speaks," 2010).

- **Sutter Children's Center Pediatric Rehabilitation Services**
  2801 L Street Sacramento, CA 95816
  (916)733-1040
  Website: www.checksutterfirst.org/children/services/rehab.cfm

Children come to rehabilitation for follow-up services following a hospitalization or surgery and also directly through referral by their pediatricians. Pediatric Rehabilitation Services treats children with motor and sensory dysfunction, decreased functional and developmental skills, and speech, language and hearing disorders.

**Psychiatrists:** A Psychiatrist is a doctor specializing in prevention, diagnosis & treatment of mental illness. These professionals may also have additional training in specialty, such as child psychiatry or neuropsychiatry. Psychiatrists can prescribe medication, which psychologists cannot do ("Autism Speaks," 2010).

- **Dr. Lesley Deprey**
  2118 P Street Sacramento, CA 95816
  (916)524-7545
  (916)254-0315 fax
  Email: dr.lesley@yahoo.com

Dr. Deprey's clinical interests include autism spectrum disorders, parent-child relations and childhood trauma. Her research interests include attachment quality in children with autism, and the relationship between autism spectrum disorders and affective instability.
Amita Upadhyay, MD, MPH  
1420 Rocky Ridge Road #230 Roseville, CA 95661  
(916)783-9697  
(916)783-9720 fax

Amita Upadhyay is board certified in child, adolescent and adult psychiatry. She finished a child and adolescent psychiatry fellowship at Millard Fillmore Hospital, State University of New York at Buffalo. She completed her adult psychiatry residency in 2005 at St. Elizabeth’s Hospital, Washington DC where she was their chief resident. In addition to her medical degree, she also holds a Masters of Public Health from Ohio State University.

Pediatricians: Pediatricians play an important role in early recognition of autism spectrum disorders, because they usually are the first point of contact for parents ("Autism Speaks," 2010).

Sutter Children's Center Pediatric Rehabilitation Services  
2801 L Street Sacramento, CA 95816  
(916)733-1040  
Website: www.checksutterfirst.org/children/services/rehab.cfm

Sutter Health is supported by over 500 doctors who provide excellent routine, acute and advanced care. Should your medical condition require highly specialized care, you have access to leading specialists in and around the greater Sacramento region.

Terrance Chang, M.D.  
8723 Sierra College Blvd Suite 220 Roseville, CA 95746  
(916)791-0797

Dr. Chang has completed residency training and/or Fellowship in a Sub-Specialty, and passed a qualifying exam given by a medical specialty board. Dr. Chang specializes in pediatrics.
Speech & Language Pathologists: Speech and Language Therapy addresses problems for people who have trouble using spoken language to communicate. Because children with autism show delays in development of communication skills and the use of language to relate to others, speech therapists are often asked to evaluate children for the diagnosis before delivering services to help children learn to communicate ("Autism Speaks," 2010).

- **American River Speech**
  11344 Coloma Road, Suite 810 Gold River, CA 95670
  (916) 631-0428
  (916) 631-0624 fax
  Email: ARSgoldriver@aol.com
  Website: www.AmericanRiverSpeech.com

  American River Speech is a private agency specializing in the evaluation and treatment of Autism Spectrum Disorders and other related syndromes. ARS provides a full range of communication and socialization related services to client’s age 0-3 years through adolescence.

- **California State University, Sacramento- Speech Pathology and Audiology Dept. The Maryjane Rees Language, Speech and Hearing Center**
  6000 J Street Sacramento, CA 95819-6071
  (916) 278-6601
  (916) 278-7730 fax
  Website: www.hhs.CSUS.edu/SPA/Clinic

  CSUS Speech and Hearing Center provides speech/language/learning evaluations and therapy through the use of Master's candidate students.
The Center for Speech Pathology is a private clinic providing speech, language, and learning assessments and therapy to clients 18 months to seniors. They offer individual therapy including home programs to reinforce treatment instruction. Family training is also a priority. All staff hold masters degrees, state licenses, and certification by the American Speech and Hearing Association.

Kaary Ogard, M.S., CCC; Pediatric Speech-Language Pathology
3416 American River Drive, Suite B Sacramento, CA 95864
(916) 971-9481
(916) 972-9500 fax

Provides individual, relationship-based speech and language therapy for children on the autism spectrum, ages 18 months to 12 years. Also provides school-based, in-home, and clinic-based consultations and evaluations. Family participation and training are an integral part of this intervention.

Optima Therapies, Inc.; Speech Language Communication
2115 J Street, Suite 210 Sacramento, CA 95816
(916) 444-7680
(916) 444-9070 fax

The mission of the Optima Therapies’ Early Intervention Program is to meet the communication goals of children with special needs. Here, therapists collaborate with parents, extended families, and other members of the family’s support team. Therapy focuses on play techniques that help the child and family to optimize their child’s interaction, communication, socialization, and learning.
**Diagnosticians:** Presently, there is no specific medical test for diagnosing autism; a diagnosis is based on observed behavior and educational and psychological testing. From birth to at least 36 months of age, every child should be screened for developmental milestones during routine well visits. If concerns about a child’s development are raised, their doctor should refer the child to Early Intervention and a specialist for a developmental evaluation. Hearing and lead exposure screenings should be performed and an autism-specific screening tool. In some cases, a team of specialists may evaluate your child and provide recommendations for treatment ("Autism Speaks," 2010).

- **Dr. Lesley Deprey**  
  2118 P Street Sacramento, CA 95816  
  (916)524-7545  
  (916)254-0315 fax  
  Email: dr.lesley@yahoo.com

  Dr. Deprey’s clinical interests include autism spectrum disorders, parent-child relations and childhood trauma. Her research interests include attachment quality in children with autism, and the relationship between autism spectrum disorders and affective instability.

- **M.I.N.D. Institute; UC Davis**  
  2825 50th Street Sacramento, CA 95817  
  (916)703-0280  
  Website: www.ucdmc.ucdavis.edu/mindinstitute

An internationally renowned research center for understanding autism, fragile X syndrome, Tourette, chromosome 22Q11.2 deletion syndrome and ADHD. What makes the UC Davis MIND Institute a world-class leader in state-of-the-art research is a partnership of acknowledged experts in neuroscience, education, psychiatry, immunology, genetics, molecular biology, psychology and developmental pediatrics.
Sacramento Counseling Services
7739 Oakshore Drive Sacramento, CA 95831
(916)284-6712
Email: marilynlperry@gmail.com

The mission of the Sacramento Counseling Services Team is to value and respect each person as unique and special, to assist each person to live rich and fulfilling lives of their own choosing and to strive to provide interventions and programs based on past success. Asperger’s Resource and Support is also available.

Sutter Neuroscience Institute; Autism Treatment Center
2800 L Street, Third Floor Sacramento, CA 95816
(916)454-6667
Website: checksutterfirst.org

As the only Clinical Autism Treatment Program in the Sacramento Region and one of the only programs in California, Sutter Neuroscience Institute takes great pride in treating an underserved population with compassion and clinical excellence.

Dr. Cynthia Zierhut
2118 P Street Sacramento, CA 96816
(916)337-9305
(916)703-0396
Email: czierhut@comcast.net

This clinical and developmental psychologist has been working as a private practitioner conducting assessments, individual and family therapy, and running therapy groups for persons (child & adult) on the Autism Spectrum.

Audiology: Audiology is the study of hearing and hearing related disorders. An Audiologist is a "hearing health care professional" who identifies and assesses individuals with auditory (hearing) and/or balance concerns, problems or disorders. Rehabilitation of hearing loss can be administered by an Audiologist through fitting of hearing aids and/or Assistive Listening Devices (ALD’s) ("Autism Speaks," 2010).
Pediatric Audiology Program at Children's Center at Sutter Medical Center, Sacramento
(916) 733-1040 for Sutter Medical Center, Sacramento
(916) 782-1421 for Sutter Roseville Medical Center.

The Pediatric Rehabilitation Services program provides comprehensive diagnostic hearing evaluations for infants and children from birth through 15 years of age. These evaluations determine hearing loss and eardrum and middle ear pathology. The Pediatric Rehabilitation Services is approved by the California Children Services (CCS).

Teaching Techniques: Not only do parents need to be aware of educational services, but they should know a range of techniques designed to help support their child with ASD at home, school and in the community. Oftentimes, minimal training is provided by the regional center to parents before their child begins to receive services. Without proper training, parents may not know how to effectively implement the techniques available to them that would them in helping to meet their child’s needs. By learning these methods and others themselves, parents can supplement and generalize the skills that their child learns from specialists to their home environment.

Autism Internet Modules
Website: www.autisminternetmodules.org/

The Autism Internet Modules were developed to make up-to-date and usable information on autism accessible and applicable to professionals and families who support individuals with ASD. Written by experts in the field, modules provide information about specific interventions (e.g. pivotal response training) as well as discuss specific challenges and strategies to address them (e.g. supporting successful completion of homework).
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Recreational Activities and Respite

Recreation: By providing children with recreational activities outside of the education environment, parents are helping their child to enhance their verbal and pre sound skills as well as decrease challenging behaviors (Orsmond, Krauss, & Seltzer, 2004). Because recreational activities can have such a profound affect on children with ASD, listed are a few local recreational activities found to be beneficial for those with ASD.

➢ Challenge Basketball and Soccer
Contact: Julie Ambauen (916) 554-0889

Challenge basketball operates a winter indoor league for beginning or experienced players. Fees are reasonable and cover all playing costs. Fun end-of-season party includes trophy.

➢ Kids Camp
2425 Sierra Blvd. Sacramento, CA 95825
(916) 435-2020

Kids Camp is designed to provide recreation for children in a safe, caring environment. Activities are designed to promote improved self-confidence, sportsmanship, and friendship skills. All counselors have experience with kids with ASD.
Land Park’s Social Recreation Program is a center where children and adolescents (ages 3-18 years) diagnosed on the autism spectrum can come to enhance their social, leisure, and play skills in a safe, caring, recreational environment. The program is open M-F 1:30-6:00 p.m., Sat 10 a.m.-6p.m. Groups and activities cycle every 30 minutes including organized sports, science and cooking projects, sensory exploration, art, music, games, free play and indoor/outdoor exercise. Weekly community outings are available.

Project P.L.A.Y. (Play-Oriented Lifetime Activities for Youth)
CSU, Sacramento, School of Health & Human Services
6000 J Street Sacramento, CA 95819-6073
(916) 278-504
(916) 278-7664 fax
Email: ModellS@CSUS.edu

Project P.L.A.Y. is designed to expand opportunities for children with disabilities to participate in purposeful fitness, play, and leisure activities in the community.

Project R.I.D.E. Inc.
8840 Southside Avenue Elk Grove, CA 95624
(916) 685-7433
(916) 686-0500 fax
Website: www.projectride.org

Project R.I.D.E. serves many families with a child diagnosed as being on the Autism Spectrum with our therapeutic horseback riding program. Through interaction with specially trained horses and volunteers, students learn interpersonal skills, build physical strength, and work on academic skills, all while enjoying the soothing rhythm of the horse's gait.
Sacramento Valley Region Care Coalition; Champion Special Needs Program
Sacramento, CA 95817
(916) 856-5605
Website: www.sacvalleycares.org

The Sacramento Valley Region Care Coalition Champion Special Needs Program is dedicated to serving the needs of families with disabilities. They believe in paving the way for every child in their care by removing barriers through modifying curriculum and assisting in social activities.

UCP/Saddle Pals Therapeutic Center
9267 Greenback Lane, Suite B-94 Orangevale, CA 95662
(916) 726-7257
(916) 989-2969 fax
Website: www.UCPsacto.org
Email: SaddlePals@UCPsacto.org

Saddle Pals is a non-profit organization that has been providing therapeutic horsemanship to physically, mentally, and emotionally challenged individuals since 1993. Therapeutic horsemanship is recreational therapy that uses the horse, its relationship to the rider, and the activities associated with horseback riding as rehabilitative tools. Saddle Pals offers services to individuals of any age and disability whose needs can be safely met through therapeutic horsemanship.

Yoga Therapy of Sacramento
8030 Sacramento Street Fair Oaks, CA 95628
(916) 769-3366

Yoga Therapy of Sacramento specializes in therapeutic yoga for special needs children and adults in a one-to-one or group setting. Positive behavioral interventions are implemented to complement the individual’s current therapies. Concentration on the development of mental focus, fine motor, gross motor, midline flexibility, endurance, and eye-hand coordination. Therapy can be provided in the home by arrangement.
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Respite and Childcare: Respite care refers to a qualified individual giving a primary caregiver a break by caring for their child with autism for a period of time—45 minutes, a few hours, a week. That break may allow a primary caregiver to get to their dentist appointment, go to the movies, or travel to a conference. Being the primary caregiver can be overwhelming and exhausting. Because of your commitment to your special needs child, your other responsibilities and interests may suffer. Or you may simply need a moment to yourself. It is important to remember to take care of yourself. Utilizing services such as respite care is essential to maintain your health and well-being ("Autism Speaks," 2010).

- **Friday Night KidzKlub**
  Contact Melynda: (916)746-8697
  Email: KidzKlub@Surewest.net.

  A three-hour respite for parents of special needs kids (ages 1-16), KidzKlub offers free compassionate and competent child care on the first Friday of each month, 6:15-9:15pm at Bayside Church in Granite Bay. Siblings welcome, nurse on hand. Advance reservations required.

- **UCP (United Cerebral Palsy) of Greater Sacramento**
  191 Lathrop Way Suite N Sacramento, CA 95815
  (916)283-8312
  Website: www.ucpsacto.org

  UCP of Greater Sacramento is the leading provider of comprehensive services to children and adults with all developmental disabilities and their families. UCP serves children and adults with more than 40 types of developmental disability, including autism. UCP in-home respite care for families.
Additional Information:
RESOURCE GUIDE REFERENCES


REFERENCES


Eligibility: Determining whether a child is eligible for special education services.


