

*Alta California Regional Center
Guide for*

**Parents
of Children
with
AUTISM**

*This Guide Provides Families with
Information about Autism
And Highlights Key Points About
Service Options*

ACRC

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916-978-6400
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Introduction

Learning that your child has autism can be a confusing, frightening, and frustrating experience. As a family, you may have many unanswered questions and may be eager to find more information. If you believe that your child has autism you are likely feeling a rush to identify and secure appropriate services for your child as soon as possible.

As a family, you will no doubt receive a great deal of information about autism that sometimes can be conflicting. Following years of evidence-based research, there are services and supports available that are proven to be very helpful in diagnosing and treating many children with autism. Because there is so much information, and misinformation, available about autism and the range of services appropriate to treating autism, you may feel overwhelmed. This guide will address some of the most essential elements that you should consider as you plan for services and supports for your child.

This family guide was developed to be a resource in helping your family to understand and make decisions regarding your child's diagnosis of autism. It is based on the research available at the time of its creation. In this guide, we will look at autism as a diagnosis, causes of autism, and the treatments and services available to you through Alta California Regional Center. This guide is a tool to help you and your family explore options and begin to identify services that are appropriate for your specific needs.

What is Autism?

Autistic Spectrum Disorder (ASD) is a neurological disorder that appears early in life and significantly impacts a child's ability to learn. ASD includes three separate diagnostic conditions: Autistic Disorder, Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) and Asperger's Disorder. All of these disorders are characterized by varying degrees of impairment in communication skills, social interactions, and restricted or repetitive patterns of behavior. Individuals with autism may have different variations of symptoms and may be affected in varying degrees. Every child who is touched by autistic symptoms is unique, just like any other child.

Autism affects the development of social skills. Children with autism have significant impairments in the way they interact with other people. For example, they may have trouble looking others in the eye or playing with other children their age. Some children with autism have problems with communication. This can include delayed development of spoken language, difficulty holding a conversation or repeating what others say to them.

Autism also affects behaviors. A child with autism may show a strong focus on particular objects while excluding other objects that are usually interesting to children. This behavior is sometimes called perseveration. Children with autism sometimes insist on sameness or they may follow the same routines ritualistically. For example, your child may want to perform certain activities in an exact order or become anxious if the routine changes. Some children with autism repeat movements over and over for no apparent reason. This is referred to as "stimming" or self-stimulation. They may also use objects in ways the object was not intended to be used. All of these behaviors interfere with learning.

There is no specific cause for autism. It is known that parenting practices do not cause autism and that children are either born with the disorder or the potential to develop it. Some children with autism do have known genetic disorders, such as Fragile X Syndrome, Angelman Syndrome, Tuberous Sclerosis and other chromosome abnormalities. Research is currently focusing on the relationship between genetics and autism.

Diagnosing Autism

A diagnosis is made based on a set of behaviors; there are no medical tests for autism. An accurate diagnosis must be based on observation and evaluation of the individual's communication, behavior, and developmental levels. Because many of the behaviors associated with autism are shared by other disorders, various medical tests may be ordered to rule out or identify other possible causes of the symptoms being exhibited.

Psychologists, developmental pediatricians, neurologists and psychiatrists are the most likely clinical professionals to make the diagnosis of autism. To obtain an accurate diagnosis, the qualified professional must follow a specified set of best practice procedures (see Appendix C). The criteria clinicians use to make the diagnosis are outlined in the Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition –Text Revised, also referred to as the DSM IV - TR (see diagnostic criteria in Appendix B).

Guidance for Parents

Every child has his or her own unique combination of strengths and needs. It's important to understand what your child's strengths and needs are, and develop an individualized program plan that best meets the needs of your child and your family. What works well for one child may not be the appropriate approach for your child. Programs that produce the best results are based on carefully documented assessment data and direct observation of your child. There is no "one size fits all" way of treating a child with autism or suspected autism.

There are four important steps parents should take to address their child's needs and set the foundation for appropriate services and supports:

- Ensure An Accurate Diagnosis
- Get Help
- Know Your Rights
- Seek Support

Gathering Information about Treatment

As you begin exploring treatment options for your child it is important to remember the following:

- **Match the treatment to the needs of your child and family.** Not all treatment approaches will be right for your child or family. A complete assessment should be done by a qualified professional to examine your child's specific strengths and needs. This assessment should also look at your family's ability to participate in treatment. Effective autism treatment programs require a high degree of family involvement. Before you commit to an intervention, make sure you know what your family's role in treatment will be.
- **Insist on ongoing evaluation of your child's progress.** Ongoing evaluation ensures that your child is making progress and that treatment is effective. It also helps service providers to provide therapy based on your child's changing needs.
- **Treatment progress will vary between children.** It is important to remember that not every treatment methodology will be appropriate or effective for your child. If you find that your child is no longer making progress in his or her treatment, it may be time to consider another approach.

- **Be prepared for potential roadblocks.** Although it can be frustrating, you may encounter roadblocks to your child's treatment. Be prepared for the possibility of staff turnover, waiting lists for treatment and changes in your family's daily routines.
- **Be open-minded but skeptical of treatment.** Although there are many treatment options available to your child, some have not been shown to be effective by research. Be cautious of treatments that claim to "cure" autism or ones that are experimental. Remember to ask critical questions of the person who is suggesting a particular treatment for your child (see below). Do not hesitate to ask for a second opinion or research supporting intervention techniques.

The National Institute of Mental Health suggests that parents ask these questions when planning for their child's intervention program:

- How successful has the proposed program been for other children?
- How many children have gone on to placement in a regular school and how have they performed?
- Do staff members have training and experience in working with children with autism?
- How are activities planned and organized?
- Are there predictable daily schedules and routines?
- How much individual attention will my child receive?
- How is progress measured? Will my child's behavior be closely observed and recorded?
- Will my child be given tasks and rewards that are personally motivating?
- Is the environment designed to minimize distractions?
- Will the program prepare me to continue the therapy at home?
- What is the cost, time commitment, and location of the program?

Diagnostic and Clinical Support Services at ACRC

Diagnostic Evaluations: ACRC has worked with multiple professionals and organizations in Sacramento and surrounding counties to develop evidence-based, best practice procedures for evaluating children suspected of having autism. The best diagnostic approach includes a developmental psychologist and/or pediatrician, pediatric nurse, with input from you and other professionals currently serving your child (teacher, speech therapist, etc.)

Clinical Consultation: ACRC's pediatrician, autism specialists and clinical psychologist are available to meet with parents and answer questions and provide information about your child's needs. The child's Service Coordinator and other clinical team members involved in serving the child are available to review service recommendations, and address parents' questions and concerns regarding their child's diagnosis and developmental needs.

Services offered through ACRC

There are a variety of services available from ACRC and your local special education infant programs, preschools and elementary schools that are appropriate for children with autism or suspected autism. You will be working with your child's Service Coordinator and members of an interdisciplinary team, including teachers and other service providers, to help determine which services would be the most appropriate in order to help your child achieve his or her individual goals.

Early Intervention Services (0 – 3 years)

Early Intensive Behavioral Treatment (EIBT): EAT is a service offered by ACRC's Early Intervention program. It is an intensive one-to-one teaching technique using behavioral methods (Applied Behavior Analysis or "ABA") for children under 3 years old. Intensive programs can occur at home or at a center that specializes in delivering intensive services. This service may extend beyond 3 years of age based upon child's progress and readiness for school.

Infant Development Programs: These programs involve home visiting or small infant treatment services from an infant specialist who uses developmentally appropriate play activities to enhance the areas of concern in a child's development. Infant specialists address speech and language, motor development, social skills, learning readiness, self-help skills and play skills.

After your child reaches three years of age, your local special education preschool program will consider educational services at your child's first Individual Education Plan (IEP) team meeting. Planning for this transition will begin when your child is 2 years, six months old. Please see information on transition and service coordination for more details.

Speech and Language Therapy: This service may be recommended by the planning team if your child would benefit from speech therapy. If an infant specialist is working with your child, speech therapy may be recommended if your child is not making progress toward his/her speech and language goals.

Occupational Therapy: This service addresses sensory processing difficulties and motor skill development. If an infant specialist is working with your child, occupational therapy may be recommended if your child is not making progress toward his/her sensory processing, fine or gross motor goals.

Parent Training: This service may be recommended by the Planning Team if parents request training to improve their own teaching skills and learn to better manage their child's behavior. This service does not focus on developmental skills training and relies on parent training and involvement rather than a behavior specialist working directly with your child.

Other Regional Center Services: See the section entitled "On-Going Regional Center Services" listed below for a description of other services that may be appropriate for your family such as respite, day care, and adaptive equipment.

Service Coordination/Transition: When your child reaches three years of age, your Early Intervention Service Coordinator will assist you in transitioning from the Early Intervention program to Special Education and Regional Center services. With your permission, your Early Intervention Service Coordinator will prepare to have your child's eligibility reviewed by the eligibility team. The eligibility team, consisting of a medical doctor, psychologist, nurse practitioner and social worker, will review updated medical records and available updated developmental evaluations including the evaluation used to diagnose autism. Regional Center eligibility is based on having a diagnosed developmental disability that is considered substantially handicapping, as defined in the Lanterman Developmental Disabilities Service Act. The term "substantially handicapping" refers to significant impairments in at least three of the following areas: communication, mobility, self care, economic self sufficiency, learning, self direction, capacity for independent living. Although autism is a qualifying category, not all children with autism spectrum disorders have the degree of impairment required to meet eligibility.

Preparing for your child's first IEP (Individualized Education Plan) An IEP involves a step-by-step process. Assessments need to be updated, new goals will

need to be written, then the services and setting(s) that will best meet your child's needs/goals will be decided on.

“Will my child get the same services in preschool that he received in Early Intervention?”

The services for your child will be different. Early Intervention follows an Individual Family Service Plan (IFSP), but preschool special education services follow an Individual Education Plan (IEP). The parent-infant focus of the IFSP will change to a more child-centered focus. There may also be less individual therapy as your child spends more of their day in small group instruction. However, there are many things you can do to assure that your child gets needed services.

- * Take advantage of IEP trainings and transition meetings.
- * Be sure that the assessment team has an accurate picture of your child's abilities and needs, as well as the services which have previously been provided.
- * Be sure that well-written, comprehensive goals are the focus of your child's IEP.
- * Keep the lines of communication open between yourself and school staff.
- * Keep track of your child's progress on their IEP goals. Make sure you understand how your child's progress will be measured.

On-Going Regional Center Services (3 years and over)

Special Education Planning Support: The Service Coordinator can assist you in preparing for your child's Individual Education Plan (IEP) meetings, and can attend the meetings with you to provide support. Since parents are the most important members of their child's IEP team, they can invite their Service Coordinator, a parent advocate, and other people important to them, to their child's IEP meetings.

Behavior Intervention Services (BIS): This service may be recommended by the Planning Team if parents request training to improve their teaching skills and learn to better manage their child's behavior. This short term service focuses on reducing behavioral excesses and replacing them with more functional skills.

Functional Adaptive Programs: These programs focus on teaching children specific skills that are directly related to increasing a child's level of independence. These programs may include goals related to self-care skills, functional language, social skills, and safety. Functional adaptive programs rely heavily on parent involvement. They aim to teach parents ABA techniques that will help maintain learned skills and the strategies for teaching skills in the future.

In-Home or Center-based Programs: At age 3, the local school district becomes the responsible agency for providing educational services. If your child is receiving intervention services at home before your child turns three, key elements of the successful home program can be designed into the school program via the IEP. Planning for a smooth transition from the in-home or center-based program to the school program begins when the child is two years, six months old. Both programs should focus on development of the foundation, cognitive and social skills necessary for the child to be successful at school. Depending on a child's needs, these programs may continue for a short period beyond a child's third birthday, in order to facilitate a smooth transition into school.

Parent Training: Parent training is a resource provided by the regional center to help increase the number of learning opportunities in their home. It focuses on the principles and techniques of (ABA) Applied Behavior Analysis. Training parents to be teachers has several advantages because children with autism exhibit behaviors that occur outside of school. As parents become part of the teaching process they can also teach functional skills in the child's home.

Respite Care: The purpose of this service is to relieve your family of the constant care and supervision of your child with special needs. Parents, their Service Coordinator and other team members can work together on an appropriate respite plan. Options include agency respite services, family member(s) as vendored respite, camp respite and Out-of-Home respite plans.

Socialization Group: The purpose of this service is to help your child progress in developing social skills. Groups with structured learning opportunities for social skills building may be available through your child's school program.

Daycare Voucher: The purpose of this service is to reimburse parents who are working for the cost of daycare services for their child that exceed what is typical for non-disabled peers. Ask your Service Coordinator for information about your local child care resource and referral agency if you need help locating a provider.

Diaper Voucher: The purpose of this service is to reimburse parents for the cost of diapers for their child, age 4 years and over, when Medi-Cal funding is not an option. Behavioral consultation services may also help with toilet-training your child.

Adaptive Equipment: An occupational therapist or physician may recommend clinically appropriate equipment to meet your child's safety, daily living or sensory processing needs at home. Your Service Coordinator can help you with the process for acquiring needed equipment.

A Family's Rights

Early Intervention, regional center and special education services are regulated by state and federal legislation. School districts work together with regional centers to ensure that appropriate services are available for your child. A family's rights should be provided in writing and can assist you if you do not agree with the team's recommended plan for your child. Service planning for your child should be based on your concerns and your child's developmental and educational needs. **You should always keep in mind your child's needs and goals in all service planning or review meetings.**

Resources for Advocacy

Protection and Advocacy, Inc. (PAI)

100 Howe Ave., Suite 185-N
Sacramento, CA 95825
916-575-1615
800-776-5746
www.pai-ca.org

PAI is a private non-profit organization that protects the legal, civil and service rights of Californians that have developmental or mental disabilities. PAI and CASE (Community Alliance for Special Education) produce the ***Special Education Rights and Responsibilities*** guide, a valuable resource available to parents by contacting the above toll-free number. PAI also assigns a Clients' Rights Advocate to ACRC who can be contacted at 916-575-1615.

Office of Client Rights Advocate

100 Howe Avenue, Suite 240-N
Sacramento, CA 95825.

Developmental Disabilities Area Board III

1507 21st Street, Suite 220
Sacramento, California 95814
Telephone: 916-324-7426, Fax: 916-324-7621

Support for Families

Understanding and coping with a diagnosis of autism can be difficult at times. Other parents in similar situations can provide much needed support, advice, ideas, and tips for accessing resources. Family Resource Centers (FRC) provide parents of children with special needs various services including local support groups, parent trainings, information and parent advocacy services. They also have parent match services so you can talk one-on-one with a parent of a child with special needs who has shared similar experience or invite him or her to a planning team meeting for your child. The local FRC for the ACRC community is Warmline.

Warmline

2035 Hurley Way, Suite 250
Sacramento, CA 95825.
916-922-9276
800-660-7995
warmline@warmlinefrc.org

ACRC's Family Advisory Committee discusses issues related to obtaining services from ACRC. This committee is open to all family members and other concerned individuals. Please contact ACRC for meeting times and locations.

ACRC

2135 Butano Drive
Sacramento, CA 95825
916-978-6400

Other Local Support Resources:

Quick Reference Guide for Autistic Spectrum Disorders

Best Practice Guidelines for Screening, Diagnosis and Assessment

Available at no charge at www.ddhealthinfo.org or contact DDS Children and Families Services Branch 916-654-1596.

ACRC's website has links to resources for persons with disabilities and their families. www.altaregional.org

Autism Resources

Autism Coalition

Phone: 1-914-935-1462

Web: www.autismcoalition.org

Autism Information Center

Centers for Disease Control and Prevention

404-639-3534

800-311-3435

www.cdc.gov/ncbddd/dd/ddautism.htm

Autism Society of America

301-657-0881

800-328-8476

www.autism-society.org

Autism Speaks

Phone: (212) 252-8584:

www.autismspeaks.org

Autism Treatment Network

503-783-2710

www.autismtreatmentnetwork.org

Cure Autism Now

323-549-0500

888-828-8476

www.cureautismnow.org

Families for Early Autism Treatment FEAT

Sacramento Chapter

916-979-9700

www.feat.org

First Signs

Phone: 1-978-346-4380

www.firstsigns.org

Indiana Resource Center for Autism

Indiana Institute on Disability & Community

812-855-6508

812-855-9396 (TTY)

www.iidc.indiana.edu/irca

MAAP Services for Autism & Asperger Syndrome

219-662-1311

www.asperger.org

MIND Institute, UC Davis Medical Center

Phone: 916-703-0280

www.mindinstitute.org

National Alliance for Autism Research

888-777-6227

www.naar.org/

National Institutes of Health Autism Research Network

www.autismresearchnetwork.org/AN/

National Institute of Mental Health

Phone: 1-866-615-6464

<http://www.nimh.nih.gov/healthinformation/autismmenu.cfm>

O.A.S.I.S. Online Asperger Syndrome Information and Support

www.aspergersyndrome.org/

Professional Development in Autism Center

206-543-4011

<http://depts.washington.edu/pdacent/>

Yale Child Study Center Yale Social Learning Disabilities Project

www.autism.fm

Appendix A:

So much of what is discussed at team meetings or referred to in reports about your child is like alphabet soup. Clinicians or professionals in case management and special education often use acronyms when making service plans for young children. This can be very confusing to parents who are new to the service delivery system.

Commonly used acronyms:

ABA	Applied Behavior Analysis
ACRC	Alta California Regional Center
ADHD	Attention Deficit Hyperactivity Disorder
ASD	Autistic Spectrum Disorder
BCBA	Board Certified Behavior Analyst
BIP	Behavior Intervention Plan
CH	Communicatively Handicapped
DD	Developmental Disability
EAT	Early Autism Treatment
EI	Early Intervention
EIBT	Early Intensive Behavior Treatment
FA	Functional Analysis
IEP	Individualized Education Plan
IFSP	Individualized Family Service Plan
IPP	Individual Program Plan
MR	Mental Retardation
NPS	Non-Public School
NPA	Non-Public Agency
OT	Occupational Therapy or Therapist
PDD, NOS	Pervasive Developmental Disorder, Not Otherwise Specified
PECS	Picture Exchange Communication System
PT	Physical Therapy or Therapist
RSP	Resource Specialist
SC	Service Coordinator
SDC	Special Day Class
SED	Severely Emotionally Disturbed
SELPA	Special Education Local Plan Area
SH	Severely Handicapped
SI	Sensory Integration
SIB	Self-Injurious Behavior
SLP	Speech and Language Pathologist
ST	Speech Therapy or Therapist
TEACCH	Treatment and Education of Autistic and related Communication Handicapped Children

Appendix B:

This appendix summarizes information from the DSM IV-TR that health professionals use to diagnose children with autism. It is not meant to substitute for specific information about your child. Children with autism show a “qualitative impairment” of skills in all three of the following areas.

Social Relatedness

1. Difficulty using and understanding non-verbal behaviors such as eye contact, facial expressions, and other gestures to regulate social interaction. The child may have a withdrawn appearance to his body language.
2. Child does not develop peer relationships appropriate to developmental level. May seem to prefer to play alone, away from other children.
3. There is a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people. Child does not bring things to others to show and share, point at interesting things, or look at what others point to.
4. Child shows difficulty understanding and responding to the thoughts and feelings of other people.

Communication

1. A significant delay in the development of spoken language. Does not use gestures such as pointing, or finds other ways to make needs known.
2. Children with expressive language skills show significant difficulty with initiating or maintaining simple conversations with others.
3. Child has unusual use of speech, including repeating things often or using odd words or vocalizations. The child does not use this type of speech to communicate.
4. There is little imaginative play alone or with others, or little imitative play appropriate to developmental level.

Behavior

1. Child is overly interested in unusual modes of play or patterns of activity.
2. Child does not tolerate changes in routines, and may insist on doing things in a very set pattern.
3. Child has unusual, repetitive body movements such as rocking, hand flapping, or spinning.
4. Child is overly focused on the parts of toys or objects.

Appendix C

Accurate Diagnosis

The fastest access to accurate information about screening and diagnosis can be found in the Department of Developmental Services' publication entitled: Autistic Spectrum Disorders: Best Practice Guidelines for Screening, Diagnosis and Assessment. This guideline provides recommendations, guidance and information about current "best practice" in the field. Go to www.ddhealthinfo.org to read about how an accurate diagnosis is achieved. There is an abbreviated version of this document at the same website entitled: Quick Reference Guide for Autistic Spectrum Disorders.

A comprehensive diagnostic evaluation involves multiple components. The following is a summary of the elements of a comprehensive diagnostic evaluation taken from the Autistic Spectrum Disorders Quick Reference Guide to Screening, Diagnosis and Assessment. To properly recognize autistic spectrum disorders as different from other developmental disorders and to provide an appropriate foundation for planning and intervention, a diagnostic evaluation includes:

- **Review of Relevant Background Information**: The essential purpose of background information review is to guide the diagnostic evaluation related to the specific parental concerns and questions, and to guide the selection of appropriate assessment measures. This includes documentation of previous tests (medical or other) and information about the child's developmental history.
- **Parent/Caregiver Interview**: A parent/caregiver interview provides additional information that may not be available in background information about the child or through any other means. Components of a parent/caregiver interview include the child health history, developmental and behavioral history of the child and family medical and mental health history.
- **Medical Evaluation**: The purpose of the medical evaluation is to assist with determining the cause of the disorder and find any associated medical problems.
- **Direct Behavior Observation**: Direct observation of the child's behavior is essential to a diagnostic evaluation. The clinician directly observes the child in structured and unstructured situations and can clarify issues that arise during the parent interview. Direct behavior observation of the child in both structured and unstructured settings improves the accuracy of the diagnosis of autism.

- **Cognitive Assessment:** Research has established that children with autism vary widely in their cognitive potential. In addition, experts recognize that assessment of cognitive functioning is crucial to the differentiation of autism from other disabilities and to the identification of co-existing impairments in a child with autism. Cognitive ability also has an important role in prognosis and intervention planning. Consequently, evaluation of cognitive functioning in both verbal and nonverbal domains is a necessary component of the complete diagnostic profile of a child. The goal of standardized assessment is to find out where the child is functioning relative to his or her same-age peers.
- **Adaptive Functioning:** Children with autism often demonstrate large differences between their nonverbal cognitive potential and their ability to function adaptively at home and in their communities. An evaluation of adaptive functioning measures the child's capacities for personal and social self-sufficiency and problem solving in real life situations. Ideally, a representative assessment of typical adaptive function would include information from as many sources as possible. Domains of adaptive function include:
 - communication—receptive/expressive and pragmatic language
 - socialization
 - fine and gross motor development
 - self-help/daily living skills—eating, dressing, hygiene
 - social-emotional functioning

Appendix D

Glossary of Terms

Adaptive Physical Education (APE): APE is an individual program of developmental activities, games, sports, and rhythms suited to the interests, capacities, and limitations of students with disabilities who may not safely or successfully engage in unrestricted participation in the vigorous activities of the general physical education program.

ADOS (Autism Diagnostic Observation Schedule): A diagnostic assessment tool that allows professionals to accurately assess and diagnose autism and pervasive developmental disorder across ages, developmental levels, and language skills.

Advocate: a person who supports and represents the rights and interests of another individual in order to ensure the individual's full legal rights and access to services. The advocate can be a friend, relative, Case Manager, or any other interested person.

Age-Appropriate: Consideration of the chronological age of the person in the use of activities, instructional locations, and techniques.

Aphasia: One in a group of speech disorders in which there is a defect or loss of the power of expression by speech, writing, or signs, or a defect or loss of the power of comprehension of spoken or written language.

Applied Behavior Analysis (ABA): Applied behavior analysis is a science in which procedures derived from the principals of behavior are systematically applied. The purpose of using applied behavior analysis is to improve socially significant behavior to a meaningful degree and to demonstrate experimentally that the procedures employed were responsible for the improvement in behavior

Asperger's Syndrome (AS): A developmental disorder on the autism spectrum defined by impairments in communication and social development and by repetitive interests and behaviors. Unlike typical autism, individuals with Asperger's Syndrome have no significant delay in language and cognitive development.

Assistive Technology: Assistive Technology includes any item or piece of equipment that is used to maintain, increase or improve the functional capabilities of individuals with disabilities.

Autism: a neurologically based developmental disorder that affects several areas of functioning including: social interactions, communication, abstract thought processing, and executive functioning. As the name implies, these disorders reside on a spectrum with many levels of severity. Individuals with autism spectrum disorders (ASD) present with a wide range of strengths and weaknesses. Autism is one of just five Pervasive Developmental Disorders (PDD) defined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR). PDDs are characterized by significant impairments in social interaction and communication. Individuals with autism may have difficulty in responding to change or transition. They may exhibit over- or under-sensitivity to pain or other sensory stimulation. Autism often results in deficits in imaginative play and abstract thought. Parents report that the child with autism does not want to be cuddled and that he or she avoids eye contact or demonstrates unusually intense eye contact. Children with autism often become preoccupied with parts of toys (the wheels of a truck), but rarely play with toys in the traditional manner. Left untreated, the communication and sensory problems associated with autism may result in tantruming or aggressive behaviors. In the past, autism was defined as a rare disorder, but current estimates indicate that approximately one in 150 children have an autism spectrum disorder. Recent years have seen a dramatic increase in the diagnosis of autism spectrum disorder. It is thought that at least some of this increase is due to heightened awareness and improved diagnostics.

The cause of autism spectrum disorders is not known; however, there is evidence to suggest that there is a genetic component. Early identification and early intervention can help children with ASD reach their own unique potential.

Autism Behavior Checklist (ABC): A diagnostic device for autism. A checklist containing a list of behaviors and weighted scores which appear to be capable of measuring the level of autistic behaviors in individuals.

Autistic Spectrum Disorders: A term that encompasses autism and similar disorders. More specifically, the following five disorders listed in the DSM-IV: Autistic Disorder, Asperger's Disorder, Pervasive Developmental Disorder - Not Otherwise Specified, Childhood Disintegrative Disorder, and Retts Disorder.

Childhood Autism Rating Scale (CARS): A test developed by the University of North Carolina to diagnose autism. The child is rated in 15 areas on a scale up to 4 yielding a total of up to 60. Ranges are then considered to be non-autistic, autistic or severely autistic.

Childhood Disintegrative Disorder: Development in persons with this disorder proceeds normally for several years, with age-appropriate verbal and non-verbal communication, social skills, play, etc. There is a subsequent (after 2 years of age and before 10 years) marked regression in skills in multiple areas, and the development of various autistic-like features.

Developmental delay: Late appearance of normal developmental milestones achieved during infancy and early childhood, caused by organic, psychological, or environmental factors.

Developmental disorder: One of several disorders that interrupt normal development in childhood. They may affect a single area of development (specific developmental disorders) or several (pervasive developmental disorders). With early intervention, most specific developmental disorders can be accommodated and overcome.

Discrete Trials: A short, instructional training which has three distinct parts: e.g. a direction a behavior - a consequence. Many discrete trial programs rely heavily on directions or commands as the signal to begin the discrete trial. Principles of ABA are the theoretical foundation for Discrete Trial Training.

DSM-IV: The 4th edition of "Diagnostic and Statistical Manual of Mental Disorders" The (DSM) is a comprehensive classification of officially recognized psychiatric disorders.

Early Intervention (EI): A federally funded program that is designed to identify and treat developmental problems or other disabilities as early as possible. Eligibility for this program begins at birth.

Echolalia: Repeating words or phrases heard previously. The echoing may occur immediately after hearing the word or phrase, or much later. Delayed echolalia can occur days or weeks after hearing the word or phrase.

Established Risk: An established risk condition exists when an infant or toddler is diagnosed with a condition which has a high probability of resulting in a developmental delay, although that delay may not be evident at the time of diagnosis.

Extinction: The removal of consequences currently maintaining a behavior.

Facilitated Communication Board: Facilitated communication (FC) is an augmentative communication strategy, that is, a communication strategy used by people without functional speech.

FEAT (Families for Early Autism Treatment): a non-profit organization of parents, educators, and other professionals dedicated to providing Education, Advocacy and Support for the Autism Community

Fine Motor: The use of small muscle groups for controlled movements, particularly in object manipulation.

Fragile X Syndrome: (FXS), the most common cause of inherited mental impairment. This impairment can range from learning disabilities to more severe cognitive or intellectual disabilities. (Sometimes referred to as mental retardation.) FXS is the most common known cause of autism or "autistic-like" behaviors. Symptoms also can include characteristic physical and behavioral features and delays in speech and language development

Free Appropriate Public Education (FAPE): Education must be provided to all children with disabilities ages three through twenty-one at public expense in the least restrictive environment.

Functional Behavior Analysis: a precise description of a behavior, its context, and its consequences, with the intent of better understanding the behavior and those factors influencing it. A functional behavior analysis can be used to modify the antecedents and consequences in order to change a behavior or shape a new one.

Functional Skills: Skills which enable an individual to communicate and interact with others, and to perform tasks which have practical use and meaning at home, in the community or on the job.

Generalization: The concept that something taught in one situation with a particular person can be applied to other places with other people.

Gluten-free casein-free (GF/CF) diet: Gluten is found mainly in wheat, oats and barley; casein in milk products. Certain people on the autistic spectrum have found that a diet free from these things can help their concentration and prevent digestive problems. The effectiveness of this diet has not been scientifically-evidenced as effective.

Gross Motor: The movements that involves balance, coordination and large muscle activity.

High Functioning Autism: Individuals with autism who are not cognitively impaired are called 'high functioning'.

Individualized Educational Plan (IEP): A plan that identifies the student's specific learning expectations and outlines how the school will address these expectations through appropriate special education programs and services. It also identifies the methods by which the student's progress will be reviewed. For students 14 years or older, it must also contain a plan for the transition to postsecondary education, or the workplace, or to help the student live as independently as possible in the community.

Individualized Family Service Plan (IFSP): The IFSP is a written document developed by a multidisciplinary team that includes the family as a primary participant. The IFSP describes the child's developmental levels in all areas; the family's resources, priorities, and concerns relating to enhancing the development of their child; and the services to be received, including the frequency, intensity, and method of delivering services.

Individual Program Plan (IPP): A planning document that is developed for each consumer which specifies the desired outcomes he/she is trying to achieve. The IPP also specifies the steps and actions that will be taken to try to reach a desired outcome, and lists any needed supports and services. The IPP is developed through a process of individualized needs determination and embodies an approach centered on the person and family.

Individuals with Disabilities Education Act (IDEA): Federal legislation mandating that all children with disabilities are entitled to a free and appropriate public education (FAPE) in the least restrictive environment (LRE). This legislation was created and continues to guide special education programs for children ages three through twenty one.

Interdisciplinary Team: A group of persons who have individual areas of professional expertise and/or know the consumer and his/her skills and behavior.

Least Restrictive Environment (LRE): LRE is the setting that least restricts opportunities for a child with disabilities to be with their peers without disabilities. The law mandates that every child with a disability be educated in a Least Restrictive Environment.

Mainstreaming: A term that typically refers to the placement of a child with special developmental, physical, emotional or educational challenges into a regular classroom setting. The long-term goal is helping the child make a gradual adjustment into regular education where he or she can learn and socialize with typically developing peers.

Manipulatives: Toys that children use their hands to play with.

M-CHAT (Modified Checklist for Autism in Toddlers): a checklist used to screening young children that are at risk or show signs of autism. Pediatricians can use this questionnaire during a child's 18-month check-up. The M-CHAT should be used only as a screening tool to alert health professionals of the need for further diagnostic assessments.

MMR vaccine (Measles, Mumps and Rubella): A vaccine against measles, mumps and rubella, given to children at 18 months and again at around 4 years. Some parents believe it to be directly responsible for autism developing in their child. There currently is no scientifically evidenced research supporting this claim.

Natural Environment: The natural environment is defined as the home and other community settings in which children and families normally participate in activities.

Occupational Therapist (OT): Individuals who specialize in the analysis of purposeful activity and tasks to minimize the impact of a disability on independence in daily living. The therapist then helps the family to better cope with the disorder, by adapting the environment and teaching sub-skills of the missing developmental components.

Occupational Therapy (OT): This is a therapy provided by an occupational therapist that assists in the individual's development of motor skills that aid in daily living. It also can focus on sensory issues, coordination of movement, balance, and on self-help skills such as dressing, eating with a fork and spoon, grooming, etc. It can also address issues pertaining to visual perception and hand-eye coordination.

Perseveration: Repetitive movement or speech, or sticking to one idea or task, which has a compulsive quality to it.

Pervasive Developmental Disorder (PDD): used as a non-specific term referring to a group of related disorders which share certain essential features: qualitative impairments in both verbal and non-verbal communication, difficulty with reciprocal social interaction and a restricted stereotypic pattern of behaviors. The most well known example of PDD is autism.

Pervasive Developmental Disorder, Not Otherwise Specified (PDD, NOS): This category is used when there are impairments across all three areas of characteristics for autism, but the number of

characteristics needed to meet criteria for other types of PDD is not met. In some children it is very difficult to distinguish the subtle differences between Autism and PDD NOS.

Picture Exchange Communication System (PECS): PECS is an alternative communication system that uses picture symbols. Individuals learn to use picture symbols to construct complete sentences, initiate communication, and answer direct questions.

Refrigerator Mother: Slang jargon phrase previously used to describe mothers of autistic children. The phrase was used in descriptions of the Freudian psychological theory of the cause of (infantile) autism, specifically by theorist Bruno Bettelheim. It has been proven that parenting styles, personalities and techniques are NOT the cause of Autism

Relationship Development Intervention (RDI): developed by Steven Gutstein, RDI is rooted in the belief that building dynamic intelligence competencies is the key to improving the quality of life of those with ASD. The program's core philosophy is that individuals with autism spectrum disorders can participate in authentic emotional relationships if they are exposed to them in a gradual, systematic way.

Respite Care: Respite is temporary, short-term care provided to individuals with disabilities. Services can be delivered in the individual's home for a few hours or in an alternate licensed setting for an extended period of time. Respite care allows caregivers to take a break in order to relieve and prevent stress and fatigue.

Rett syndrome: An X-linked dominant neurological disorder that affects females. Girls with the syndrome show normal development during the first 6-18 months of life followed first by a period of stagnation and then by rapid regression in motor and language skills. A main symptom of Rett syndrome is the loss of purposeful hand use and its replacement with stereotyped hand-wringing.

Secretin: a gut hormone that has been used in controversial treatment of autism. There is no scientific evidence of its effectiveness in treating Autism.

Self-Injurious Behavior: Self-stimulatory, stereotypic or learned behaviors. Examples include head-banging, hand-biting, scratching or rubbing.

Sensory Integration (SI): This is a term applied to the way the brain processes sensory stimulation or sensation from the body and then translates that information into specific, planned, coordinated motor activity. Sensory Integration has not been scientifically-evidenced as an effective treatment for autism.

Social Stories: A technique, made popular by Carol Gray, which is used to help individuals with autism to "read" and understand social situations, and thus interact more appropriately in social situations.

Speech-Language Pathologist: Individuals who specialize in the area of human communication. Their focus is on communication, not speech, to increase the child's ability to impact and to understand their environment.

Stim: Short for 'self-stimulation', a term for behaviors whose sole purpose appears to be to stimulate one's senses. Many people with autism report that some 'self-stims' may serve a regulatory function for them (ie. calming, increasing concentration, or shutting out an overwhelming sound).

Tactile Defensiveness (hypersensitivity to touch): An individual with tactile defensiveness appears to overreact to sensation(s) that most people do not particularly notice. Common signs of tactile defensiveness include: sensitivity to certain types of clothes or fabrics; preference or aversion to foods which seem texture related; avoidance of touching substances such as finger paint or mud, or of getting

one's hands messy. Those with tactile defensiveness have a tendency to prefer to touch rather than be touched.

T.E.A.C.C.H. (Treatment and Education of Autism and Related Communication of Handicapped Children): This is a therapeutic approach broadly based on the idea that individuals with autism more effectively use and understand visual cues. It focuses on promoting independence by using items such as picture schedules to break down tasks step-by-step. This enables an individual to better comprehend and perform the task independently. This approach often aids receptive communication and sequential memory.

Transition: The process of bridging the time and environments between two settings, programs, or life situations.

Tuberous sclerosis: A genetic disorder characterized by abnormalities of the skin, brain, kidney, and heart. The skin abnormalities are present in all cases and may include tiny benign tumors (angiofibroma) on the face and depigmented areas anywhere on the body. The brain abnormalities are mainly benign cortical tumors (tubers) which cause seizures, developmental delay, and mental retardation. The kidneys often contain multiple cysts and benign tumors the heart problems include arrhythmias and benign heart muscle tumors.

Vendor: A provider of services who has applied for and received a vendor identification number from the regional center. Regional centers may only purchase services from community agencies, programs and professionals who have completed this vendor process.

Vineland Adaptive Behavioral Scales (VABS): A scale that assesses personal and social sufficiency of individuals from birth to adulthood. These scales are applicable to handicapped and nonhandicapped individuals.

Wechsler Intelligence Scale for Children (WISC-III): An individually administered clinical instrument for assessing the intellectual functioning of children. The same format as the WAIS-R, except for ages 6-0 through 16-0.

Wechsler Preschool and Primary Scale of Intelligence - Revised (WPPSI-R): A clinical instrument similar to the WISC-III and the WAIS-R, except for children ages 3-0 to 7-0.

Wechsler Adult Intelligence Scale Revised (WAIS-R): An individually administered clinical instrument for assessing the intellectual ability of adults aged 16-74. The individual's performance on various measures is summarized in to 3 components - the verbal, perceptual-motor or performance, and the full scale IQ. These scores provide estimates of the individual's level of functioning.

Definitions from the following websites:

www.harborrc.org

www.geocities.com/autismandpdd/Glossary.htm

www.medicinenet.com/autism/glossary.htm

www.theautismprogram.org/glossaryofterms.asp

ca.geocities.com/peiautism/glossary.html

IMPORTANT PHONE NUMBERS:

(Birth – 3 Years)

My Child’s Early Intervention Team:

Service Coordinator: _____

Service Providers: _____

(3 Years and Older)

ACRC Emergency After hours number: 916-978-6400 push 0 after hours.

Service Coordinator: _____

ACRC Service Providers: _____

Education Team: _____

Mentors, Professionals and Other Helpful People: _____
