



PARENT/CAREGIVER RESOURCE GUIDE

UPDATED: FEBRUARY 27, 2019

TABLE OF CONTENTS

Introduction and welcome from ASVC	4
Newly Diagnosed, What is ASD?	4
Learn the signs: Early identification can change lives	4
Early Intervention: Ages 0-3 years	6
School Age; Ages 4-12 YEARS.....	8
The IEP – Individualized Education Program	8
504 Plan & Student Success Team.....	9
Seven Steps of the IEP Process.....	9
Sample Form – SELPA Assessment Plan	12
SELPA – Navigating the school district	13
Resolving Disagreements.....	13
Parent-to-Parent Support	13
Sample Form – IEP Binder Checklist.....	14
Sample Form – Parent/School Communication Log	15
Sample Form – Contact List: Who to call at your child’s school	16
Transition to High School; Ages 13-22 YEARS.....	17
Adulthood – 22+.....	18
Social Relationships	19
Tri-Counties Regional Center	21
Ventura County Offices	22
Services Provided by Tri-Counties Regional Center	22
Rainbow Connection Family Resource Center.....	25
Safety & Communicating With Law Enforcement.....	27
Law Enforcement Agencies in Ventura County	28
Health and Wellness.....	31
Self Advocacy	35
SSI And Other Benefits	36
Extended Family (Siblings/Family (Siblings/Grandparents/Etc.).....	41

Welcome to Autism!

We are the board members of Autism Society Ventura County. We understand that an Autism diagnosis can be scary and hard for the person being diagnosed and their families. What you will soon learn is that Autism can be awesome, and we hope you embrace it. It is often said that if you know one person with Autism, you know one person with Autism! You (or your family member) are a unique individual, and a label can't begin to define you. We are here for you and we celebrate you! We would love for you to engage with us. You are not alone.

We have heard from countless individuals with Autism and their parents that the number one issue they run in to is understanding and obtaining services. We hear you loud and clear that the systems designed to support you are much more complicated than they should be. That's why the board members at Autism Society Ventura County decided to put together this welcome packet – to give you the tools you need to be successful in this new world.

Here are a few things to note as you go through your welcome packet:

- 1) If you see a hyperlink (blue text underlined), please refer to our digital version to find the clickable link.
- 2) Remember to make a copy of the forms so you can reuse them in the future.
- 3) Check our online resource guide for an up to date list of resources.
- 4) This guide is meant to be all inclusive, so if you find a section that doesn't pertain to you, feel free to skip over it.

Make sure to sign up for our e-newsletter to get information on our events and programs. You can find all of the information on our website - autismventura.org.

We can't wait to meet you!

Autism Society of Ventura County Board

WHAT OUR KIDS WITH DISABILITIES

- You are loved and are worthy of love.
- You belong in this world as you are. I will support you by helping others understand this.
- You deserve to be treated with respect and dignity. I will model this behavior for others in how I speak and respond to you.
- I will stand by your side when other people and systems fail you.
- In spite of my best efforts, I will make mistakes. I am a work in progress. Forgive me when my judgement falters.
- You are capable of great things.
- You deserve a life of fulfillment and purpose.
- You got this.

- Dr. Edlyn Peña
Autism Researcher,

INTRODUCTION AND WELCOME FROM ASVC

NEWLY DIAGNOSED, WHAT IS ASD?

Autism spectrum disorder (ASD) is a complex developmental disability; signs typically appear during early childhood and affect a person's ability to communicate and interact with others. ASD is defined by a certain set of behaviors and is a "spectrum condition" that affects individuals differently and to varying degrees. There is no known single cause of autism, but increased awareness and early diagnosis/intervention and access to appropriate services/supports lead to significantly improved outcomes. Some of the behaviors associated with autism include delayed learning of language; difficulty making eye contact or holding a conversation; difficulty with executive functioning, which relates to reasoning and planning; narrow, intense interests; poor motor skills and sensory sensitivities. Again, a person on the spectrum might follow many of these behaviors or just a few, or many others besides. The diagnosis of autism spectrum disorder is applied based on analysis of all behaviors and their severity.

LEARN THE SIGNS: EARLY IDENTIFICATION CAN CHANGE LIVES

Autism is treatable. Individuals with autism do not "outgrow" autism, but studies show that early diagnosis and intervention lead to significantly improved outcomes. For more information on developmental milestones, visit the CDC's "Learn the Signs. Act Early" site. The characteristic behaviors of autism spectrum disorder may be apparent in infancy (18 to 24 months), but they usually become clearer during early childhood (24 months to 6 years).

As part of a well-baby or well-child visit, your child's doctor should perform a "developmental screening," asking specific questions about your baby's progress. The National Institute of Child Health and Human Development (NICHD) lists five behaviors that warrant further evaluation:

- Does not babble or coo by 12 months
- Does not gesture (point, wave, grasp) by 12 months
- Does not say single words by 16 months
- Does not say two-word phrases on his or her own by 24 months
- Has any loss of any language or social skill at any age

Any of these five "red flags" does not mean your child has autism. But because the disorder's symptoms vary so widely, a child showing these behaviors should be evaluated by a multidisciplinary team. This team might include a neurologist, psychologist, developmental pediatrician, speech/language therapist, learning consultant or other professionals who are knowledgeable about autism.



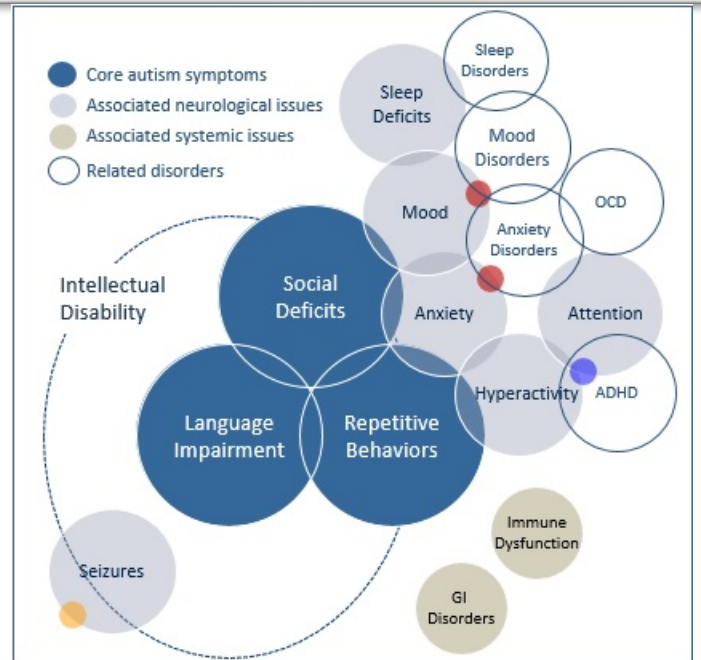
Here are some signs to look for:

- Lack of or delay in spoken language
- Repetitive use of language and/or motor mannerisms (e.g., hand-flapping, twirling objects)
- Little or no eye contact
- Lack of interest in peer relationships
- Lack of spontaneous or make-believe play
- Persistent fixation on parts of objects



After your child’s diagnosis, he or she is likely to undergo a series of formal and informal assessments for the rest of his or her life. Assessments are intended to provide information about your child in such areas as:

- Strengths and skill deficits
- Specific problem areas and/or needs
- Performance in relation to others
- Performance in relation to set standards or goals
- Effectiveness of instruction and/or intervention for your child
- Eligibility for services



This ASVC Parent’s guide is intended to give parent and caregivers an overview of options and resources available in Ventura County and provide practical understanding of the assessment process, equip you with tools and information to help individuals and caretakers become a key participant in the process, and help you learn to use assessment outcomes to improve services and interventions for your child.

EARLY INTERVENTION: AGES 0-3 YEARS

The first three years of life are crucial to a child's development. Children make several visits to their pediatrician during this period for well-baby/child check-ups, vaccinations and general developmental screenings. The American Academy of Pediatrics now recommends that the 18- and 24-month well check-ups also include developmental screening for autism spectrum disorders (ASDs) for all children. If [symptoms](#) warrant and/or the child has a sibling with ASD, further screenings should be conducted. [Click here](#) for more in-depth information on early signs, including developmental milestones parents should look for, starting at 3 months.

Early identification of an ASD is crucial, as it means [early intervention services](#) can begin, making a huge impact on a child's behavior, functioning and future well-being. Without early intervention, the symptoms of autism can worsen, resulting in more costly treatment over the course of a lifetime. [The estimated lifetime cost](#) of caring for someone with autism ranges from \$1.4-2.4 million, but this cost can be reduced by two-thirds through early diagnosis and intervention.

AT 3 MONTHS	AT 7 MONTHS	AT 1 YEAR (12 MONTHS)	AT 2 YEARS (24 MONTHS)	AT 3 YEARS (36 MONTHS)
<ul style="list-style-type: none"> • Begins to develop a social smile • Becomes more expressive and communicates more with face and body • Raises head and chest when lying on stomach • Brings hand to mouth • Takes swipes at dangling objects with hands • Grasps and shakes hand toys • Watches faces intently • Follows moving objects • Recognizes familiar objects and people at a distance • Smiles at the sound of your voice • Begins to babble • Begins to imitate some sounds • Turns head toward direction of sound 	<ul style="list-style-type: none"> • Enjoys social play • Is interested in mirror images • Struggles to get objects that are out of reach • Responds to own name • Begins to respond to "no" • Babbles chains of sounds • Rolls both ways (front to back, back to front) • Sits with, and then without, support on hands • Reaches with one hand • Transfers object from hand to hand 	<ul style="list-style-type: none"> • Is shy or anxious with strangers • Cries when mother or father leaves • Enjoys imitating people in play • Repeats sounds or gestures for attention • Is able to finger-feed • Finds hidden objects easily • Begins to use objects correctly (drinking from cup, brushing hair, dialing phone, listening to receiver) • Responds to "no" • Uses simple gestures, such as shaking head for "no" • Babbles with inflection (changes in tone) • Says "dada" and "mama" • Uses exclamations, such as "oh-oh!" • Tries to imitate words • Crawls forward on belly • Pulls self up to stand • Walks holding onto furniture • Bangs two objects together • Puts objects into and takes objects out of container • Pokes with index finger • Answers to name when called 	<ul style="list-style-type: none"> • Imitates behavior of others, especially adults and older children • Is more excited about company of other children • Demonstrates increasing independence • Begins to show defiant behavior • Finds objects even when hidden under two or three covers • Begins to sort by shapes and colors • Begins make-believe play • Points to object or picture when it's named • Says several single words (by 15-18 months) • Uses simple phrases (by 18-24 months) • Uses 2- to 4-word sentences • Follows simple instructions • Repeats words overheard in conversation • Walks alone • Pulls toys behind him or her while walking • Scribbles on own 	<ul style="list-style-type: none"> • Imitates adults and playmates • Spontaneously shows affection for familiar playmates • Takes turns in games • Understands concept of "mine" and "his/hers" • Expresses affection openly • Expresses a wide range of emotions • Separates easily from parents by 3 • Makes mechanical toys work • Plays make-believe with dolls, animals and people • Sorts objects by shape and color • Completes puzzles with three or four pieces • Understands most sentences • Uses 4- to 5-word sentences • Can say name, age and sex • Walks up and down stairs, alternating feet (one foot per stair step) • Runs easily • Pedals tricycle • Holds a pencil in writing position



Unfortunately, many state and federal services aimed at early intervention are being cut. These drastic cuts mean that **the wait for services may exceed the window of opportunity for the best treatment outcomes.**

Currently, the average age of diagnosis in the United States is between 3 and 6 years of age, though some children can be diagnosed as young as 2. It is important for parents to discuss the diagnosis with their medical practitioner(s) and devise a [treatment plan](#) that best addresses the needs of the/your child and family. **The Autism Society encourages applied research to identify the most effective [early intervention approaches](#).** We also encourage the sharing of research advances across states so all people with autism can benefit.

The Autism Society recognizes the importance of intensive early intervention for young children across the autism spectrum. Because of each child's different needs and abilities, the Autism Society supports an individualized approach that addresses the core deficits of autism spectrum disorders (e.g., communication, social, sensory, academic difficulties) and matches the family's preferences and needs.

In designing effective programs, the Autism Society encourages professionals and family members to consider the following components:

- A curriculum that **addresses deficit areas**, focuses on long-term outcomes, and considers the developmental level of the child. Deficit areas include:
- Attention to relevant aspects of the environment, shifting attention, and imitating the language and actions of others
 - Social interactions, including appropriate play with toys and others, and symbolic and imaginative play
 - Language comprehension and use, and functional communication
- Programs that **capitalize on children's tendency to respond to visual structure**, routines, schedules and predictability.
- A focus **on generalization and maintenance of skills**, using technology such as incidental teaching approaches.
- Effective instruction that uses **technology associated with Applied Behavior Analysis**, including chaining, shaping, discrete trial format and others.
- **Coordinated transitions** between service providers, including 0-2 programs, early intervention/preschool programs and kindergarten environments.
- **Use of technology** associated with functional behavioral assessment and positive behavioral supports with a child who presents behavioral challenges.
- **Family involvement**, including coordination with involved professionals, an in-home training component, and family training and support.

The Autism Society encourages applied research to identify the interventions and approaches that are most effective for all children with autism spectrum disorder. We also encourage the use of these practices for each child with autism spectrum disorder, regardless of geographic location. – Prepared by the Autism Society Panel of Professional Advisors. Approved by Autism Society Board of Directors, April 2000

SCHOOL AGE; AGES 4-12 YEARS

The school years bring innumerable challenges for a child with autism, but they also hold incredible opportunity for growth. For parents, the challenge is to discover and leverage resources to maximize the child's avenues of academic learning, social experience and physical fitness. Having a team of professionals is essential throughout this long-life stage – getting help from those who know the system can reduce stress on the family and improve outcomes for the child with autism.

There are many [treatment approaches](#) available to school-aged children with autism –

- Applied Behavior Analysis
- Occupational therapy
- Supplemental therapies
- Dietary regimens and more

Similarly, there are many different educational programs that provide stimulating learning environments to children with different needs and abilities.

It is important to match a child's potential and specific needs with treatments or strategies that are likely to help him/her reach established goals and greatest potential. The Autism Society does not want to give the impression that parents or professionals will select just one treatment from a list. A search for appropriate treatment must be paired with the knowledge that all treatment approaches are not equal – what works for one will not work for all. The basis a treatment plan should come from a thorough evaluation of the child's strengths and weaknesses.

1. [Connect with Tri-Counties Regional Center, intake meeting and assessment](#)
2. [Prepare for transition to school with plans for an IEP Program](#)
3. [Start documenting all assessments, treatments and build your Team](#)

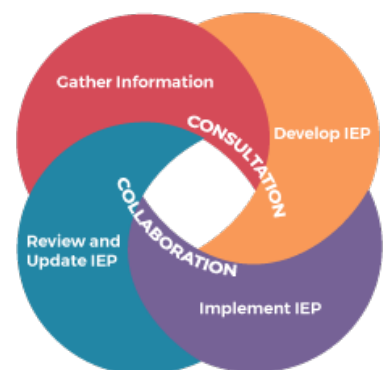
THE IEP – INDIVIDUALIZED EDUCATION PROGRAM

Subsequent to the [Individuals with Disabilities Education Act](#), or IDEA, children with disabilities are entitled to a “free appropriate public education” (FAPE), meaning schools must provide eligible children with appropriate accommodations including specially designed instruction to meet their unique needs at no cost to the children's parents. IDEA also includes regulations to protect the rights of parents and children.

The most crucial element is **creating a plan for your child's education**. This plan is called the [Individualized Education Program](#), or the IEP, it lists the special education services your child will receive, based upon his or her individual needs. **It helps to think of the IEP both as a process and as a document to be written.**

The IEP might seem overwhelming, we are including some information and tips to assist in the process. There are also various resources including workshops, and service providers available.

Individualized Education Program Process



504 PLAN & STUDENT SUCCESS TEAM

A 504 Plan provides services and changes to the learning environment to meet the needs of the child as adequately as other students. To get a 504 Plan, there are two requirements.

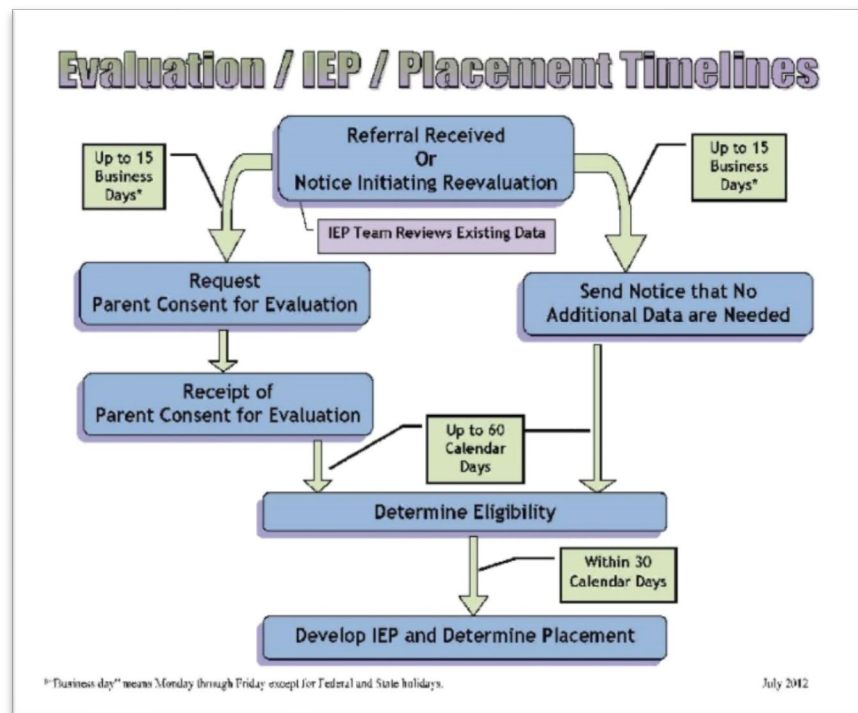
1. The child has any disability, which can include many learning or attention issues.
2. The disability must interfere with the child's ability to learn in a general education classroom. Section 504 has a broader definition of disability than IDEA (it says a disability must substantially limit one or more basic life activities, such as learning.) That's why a child who doesn't qualify for an IEP might still be able to get a 504.

By contrast, an IEP provides individualized special education and related services to meet **the unique needs of the child**.

Your child might be at a state where an IEP is not needed, but if you have a diagnosis of Autism it is within your rights to request a full IEP.

SEVEN STEPS OF THE IEP PROCESS

1. **Pre-referral:** Early diagnosis and intervention. Documenting challenges or difficulties and missed milestones exhibited by the child.
2. **Referral:** Someone, usually your child's teacher or another school professional, suspects your child may have a learning disability or need extra services, such as speech pathology or occupational therapy. Your child is then referred to the school district for an evaluation, and you will be asked to give parental consent. As a parent, if you suspect your child may need additional help, you have the right to request an evaluation as well. Once the parent requests assessment, the district has 15 calendar days to respond. The district

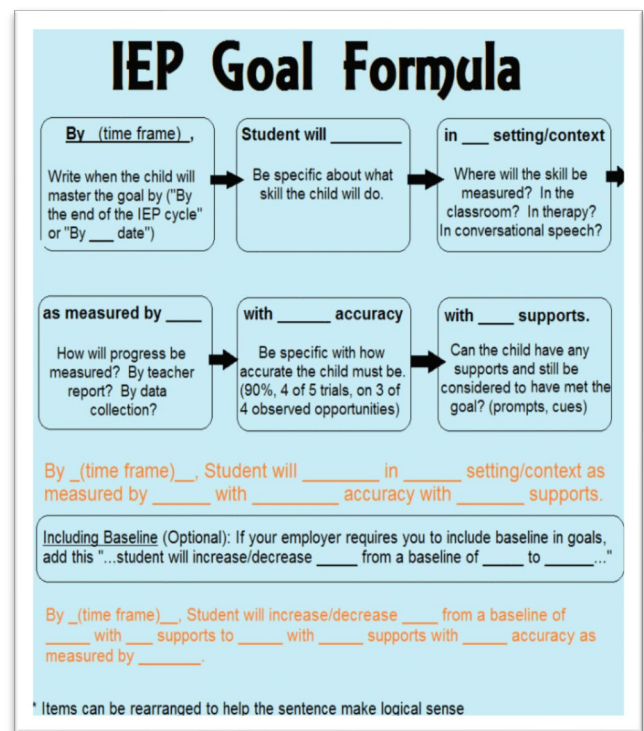


will either develop an Assessment Plan which indicates the areas to be assessed and the persons who will be conducting the assessment, or it will inform you that the district declines to initiate assessment at this time. If the district declines to initiate assessment, they must give reasons why.

3. **Identification:** The members of the evaluation team differ according to your child’s special needs. The team leader is often a school psychologist or special education professional from your district, and the others may include a physical therapist, a vision specialist, a speech and language pathologist, or another specialist whose expertise is required in assessing your child. The parent has the right to have a description of the areas to be assessed and the proposed assessors. If you have any questions about the Assessment Plan for your child, do not hesitate to contact the appropriate professional for further explanation. If you have additional assessment information from another specialist (i.e., doctor, therapist), be sure to give it to a member of the Assessment Team to be considered. After the assessment is completed the parent must be fully informed of assessment results, including a written copy of the findings. If you disagree with school district assessment results, you have the right to request an independent assessment at no cost. However, if the district disagrees that an additional assessment is necessary, it may request a Due Process Hearing to prove that its assessment is appropriate.

4. **Eligibility:** After the evaluations, the team members write their reports and determine whether your child qualifies for services. According to the Individuals with Disabilities Education Act (IDEA), to receive services, your child must be determined a “child with a disability” — which can mean anything from an articulation issue to ADD to a hearing impairment and many others. If your child isn’t found eligible for services and you disagree, it’s your right to challenge the decision.

5. **Development of IEP:** The IEP meeting is scheduled by the school district, and it’s the coordinator’s job to contact you well in advance and attempt to accommodate your schedule. On the call, the coordinator is required to list the meeting’s attendees and invite you to bring anyone you feel would be an advocate for your child, such as a teacher or therapist. At the meeting, your child’s IEP will be written, including the specific services he’ll receive, how many times per week and for how many minutes he’ll get them, and whether they’ll be one-on-one or with a group. If you disagree with the IEP, you have the right to request a due process hearing and mediation.



Sample Goal Development Table

Goal	Present Level of Performance (PLOF)	Benchmarks/ Small Steps	Observations/ Questions for School

IEP Should Include:

- Student Information
- Present Level of Educational Performance
- Annual Goals
- Services (In Detail)
- Progress Reporting
- Supplementary Aides
- Participation
- Parent Consent

6. **Implementation:** Once the IEP is written, your child’s school is responsible for making sure it’s followed. Your child’s teacher, service providers, and you will all be given copies of the IEP. Often, you’ll meet at the beginning of the academic year with the school’s IEP coordinator to discuss how the program will be carried out. As often as your child’s report cards are sent out, you should receive official IEP progress reports, though usually you’ll be given informal updates on a more frequent basis. At least once a year, the IEP will be reviewed. At the meeting you can request changes or make suggestions, and if you disagree with the results, you can ask for additional evaluations or a hearing and mediation.

7. **Evaluation and Reviews:** According to the U.S. Department of Education, kids with IEPs must be reevaluated every three years to determine whether they’re still eligible for services. If you or your child’s teacher requests it, however, reevaluations can be done sooner or more often.

**Ventura County Special Education Local Plan Area
Prior Written Notice to Parent of Action
Proposed or Refused by School District
(300.503 – Code of Federal Regulations)**

Date: [Click here to enter a date.](#)

District: [Click here to enter text.](#)

Student’s Name: [Click here to enter text.](#)

Parent (s): [Click here to enter text.](#)

This notice is to inform the parent(s) of the above named student regarding the school district’s: Proposal to initiate or change the: Identification of Evaluation of Placement of Provision of a free appropriate public education for

Refusal of your request to initiate or change the: Identification of Evaluation of Placement of Provision of a free appropriate public education for your child.

1. Description of action proposed or refused by district: [Click here to enter text.](#)
2. Explanation of reason for proposal or refusal: [Click here to enter text.](#)
3. Description of any other options district considered and why they were rejected or selected: [Click here to enter text.](#)
4. Evaluation procedure(s), test(s), record(s) or report(s) used as a basis for the proposed/refused action: [Click here to enter text.](#)
5. Other relevant factors: [Click here to enter text.](#)

As a parent(s) of a child with a disability, or suspected of having a disability, you have protections under state and federal laws. Please see attached “Parent Rights.” If you need assistance in understanding these rights, you may call Ventura County SELPA at (805) 437-1560.

Additional resources for parents are available on our website: www.venturacountyselfpa.com. If you have questions or need further assistance, please do not hesitate to call.

Signature

[Click here to enter text.](#)
Title

[Click here to enter text.](#)
Phone

SAMPLE FORM – SELPA ASSESSMENT PLAN

For Staff Only
Date Received _____

ASSESSMENT PLAN

- Initial Evaluation
- Triennial Review
- Other

Ventura County Special Education Local Plan Area (SELPA)

Student Name _____ D.O.B. _____ Age _____ Grade _____ Date _____
 Parent/Guardian/Surrogate Name _____ Address _____
 Phone(s) Home _____ Cell _____ Work _____ Email _____
 School _____ ID# _____ EL Status _____ Primary Language _____
 REASON FOR ASSESSMENT/AREAS OF CONCERN _____

For Initial Evaluations only	
Referral Source _____	Date Referred _____
School years interventions were provided in general education _____	

The following assessments are proposed to assist in determining your child's educational needs. All assessments will be given by appropriately qualified personnel. The assessment will be in the areas checked below and may include pupil observation in a group setting, classroom work samples, district or statewide group assessments, individualized testing, teacher interview(s) and an interview with you. It also may include a review of reports you have authorized us to request or that already exist in current records. Assessments will be non-discriminatory, and alternative means of assessment may be used in situations when standardized assessments are inappropriate. Within 60 days of receipt of this signed assessment plan, an Individualized Education Program (IEP) team meeting will be held. You will be invited to attend and review assessment results and participate in determining your child's educational needs and eligibility for special education services.

PRE-ACADEMIC/ACADEMIC ACHIEVEMENT: Special Education Teacher Early Childhood Specialist Other: _____
Purpose: To determine current reading, writing, and math skills or pre-academic skills such as matching or sorting.

SOCIAL/EMOTIONAL BEHAVIOR: Psychologist Behavior Specialist Intensive School-Based Therapist
 Other: _____
Purpose: To evaluate how the student handles feelings and emotions and how he/she gets along with other people.

SELF HELP/ADAPTIVE SKILLS: Psychologist Special Education Teacher Other: _____
Purpose: To evaluate how the student functions in daily life activities needed in the educational setting.

MOTOR SKILLS DEVELOPMENT: Occupational Therapist Physical Therapist Adapted Physical Education Specialist
 Psychologist Early Childhood Specialist Other: _____
Purpose: To evaluate small and large motor functioning and/or psycho-motor skills related to access and performance in the educational environment.

LANGUAGE/SPEECH/COMMUNICATION DEVELOPMENT: Speech-Language Pathologist Early Childhood Specialist
 Other: _____
Purpose: To determine an individual's ability to understand, relate to, and use language and speech clearly and appropriately.

INTELLECTUAL DEVELOPMENT: Psychologist Early Childhood Specialist Other: _____
Purpose: To determine how well individuals remember what they have seen and heard, how well they can use that information to solve problems, and to assist in predicting the student's learning rate. Verbal and performance instruments may be used as appropriate.

HEALTH ASSESSMENT: School Nurse Audiologist Other: _____
Purpose: To evaluate developmental patterns and current health status as they relate to school functioning.

VOCATIONAL/PREVOCACTIONAL: Special Education Teacher Psychologist Other: _____
Purpose: To determine the individual's interests and aptitudes as related to future job and/or career.

OTHER: Deaf/Hard of Hearing Functional Behavior Analysis Assistive Technology Augmentative/Alternative Communication
 Functional Vision Orientation & Mobility Special Circumstances Paraprofessional Other: _____
 Responsible Personnel: _____

If you have any questions contact: _____
Name/Title Phone/Email

PARENTAL CONSENT FOR PUPIL ASSESSMENT

I understand the purpose of the proposed Assessment Plan and have received a copy of my Parent Rights. I authorize the use of a suitable interpreter or prerecorded tests in my child's primary language as appropriate. I further understand that no Individualized Education Program will result from this assessment without my consent. The box(es) checked below indicate my decision(s).

Yes, I give my permission to conduct the assessment as described above and will make my child available for the assessment. I understand that assessment cannot begin until a copy of this form has been signed and returned.

If yes, check any that apply:
 I give permission to the school district to bill the LEA Medi-Cal Billing Option Program for this assessment, if applicable. (Income from this program is used by the district to offset costs of providing special education services and will not affect the child's individual benefits.)
 Please consider the following Independent Educational Evaluation report(s) as part of the assessment process: _____
 No, permission is denied.

Please sign and return, keeping one copy for your records.

Parent/Legal Guardian/Adult Student/Person Acting as Parent (Specify) _____ Telephone Number _____ Date _____

For more information about special education and your rights contact your district special education office or visit the Ventura County SELPA website at www.venturacountyselfpa.com

Copy to: District Office Cumulative File Case Manager Parent/Adult Student Related Services



SELPA – NAVIGATING THE SCHOOL DISTRICT

The Ventura County SELPA provides information and support to families of children with special needs so that they can be informed partners in the educational process of their children. There are numerous activities and resources that are provided to fulfill that mission. These include:

[Community Advisory Committee \(CAC\)](#)

[FREE Programs Available for Students with Disabilities](#)

[Information Alerts for Parents](#)

[Parent-to-Parent Support](#)

[2018 Parent Information Flyer](#)

[Parent Rights for Special Education](#)

["Ability Awareness"](#)

[Parent's Guide to Special Education](#)

RESOLVING DISAGREEMENTS

On occasion, parents and the school district may have disagreements. Special education law provides specific steps for resolving those conflicts. It is always a good idea to try to resolve things at the lowest level possible. If you haven't spoken to the Special Education Director in your district, you are encouraged to give them a call to express your concerns ([phone list](#)). If there is a disagreement between a parent and the district on what is best for the child (usually at the IEP Team level) either party may file for Due Process. Due Process is a system for increasing levels of intervention in resolving the conflict. Please visit the [Office of Administrative Hearings](#) website to download the Mediation or Due Process form. Also available from the Office of Administrative Hearings is a [Free/Reduced Cost Special Education Attorney Advocate List](#).

Solving Special Education Disputes Between Parents and School Districts

[Special Education Handbook](#) (PDF, new window) A comprehensive guide to understanding Special Education Due Process Hearings at OAH.

If a parent feels his or her rights or the rights of their child have been violated by the district or an employee of the district, the parent has a right to file a complaint. A complaint may be filed with the District Complaint Resolution Office. If not resolved, or if the parent chooses not to file the complaint with the district, a complaint can be filed directly with the California Department of Education using this form.

[Complaint Process Brochure](#)

[Request for Complaint Investigation](#)

[Helpful Hints When Requesting Direct State Intervention](#)

PARENT-TO-PARENT SUPPORT

[Rainbow Support Groups](#)

[United Parents](#) - Educational Advocacy, Parent Partners, Respite Services

[California Parent Organizations](#)

SAMPLE FORM – IEP BINDER CHECKLIST

IEP Binder Checklist <i>Put the newest items on top in each section</i>				
Communication	<i>To be updated:</i>	<i>Date updated:</i>		
School contact list	Yearly or as new members join the team			
Communication log	Every time you have a meeting, call or other important interaction with the school			
Letters and emails to and from the school	As often as needed (File after noting them in the communication log)			
Evaluations				
Request/referral for evaluation	Every three years or more often, if needed			
Consent to evaluate	(Tip: Keep this—and the referral—on top to help check if the evaluation is done in a timely manner)			
School evaluations	At least every three years			
Private evaluations (if your child has had any)	Every time your child is evaluated privately			
IEP				
Copy of Parent's Rights & Safeguards	Yearly (Keep this on top so you can easily show the school you don't need another copy)			
IEP	Yearly or more often, if changes are made (and, if your child has had a 504 plan, include that too)			
Prior Written Notice and meeting notes	Yearly or more often, if additional meetings take place			
Report Cards/Progress Notes				
Reports cards and progress reports	As often as they come from the teacher or school			
Sample Work				
Samples of schoolwork	At least monthly or as often as you see signs of progress or concern			
Standardized tests	Whenever the results are sent home			
Behavior				
School handbook and school calendar	Yearly			
Behavior Intervention Plan (if your child has one)	Yearly or as often as changes are made			
Disciplinary notices	Any time your child receives one			

SAMPLE FORM – PARENT/SCHOOL COMMUNICATION LOG

Parent-School Communication Log	
Date:	<input type="checkbox"/> Phone <input type="checkbox"/> Email <input type="checkbox"/> Letter <input type="checkbox"/> In Person
Who initiated:	Who participated, received or attended:
What prompted the communication:	
What was discussed:	
What was decided:	
Date:	<input type="checkbox"/> Phone <input type="checkbox"/> Email <input type="checkbox"/> Letter <input type="checkbox"/> In Person
Who initiated:	Who participated, received or attended:
What prompted the communication:	
What was discussed:	
What was decided:	
Date:	<input type="checkbox"/> Phone <input type="checkbox"/> Email <input type="checkbox"/> Letter <input type="checkbox"/> In Person
Who initiated:	Who participated, received or attended:
What prompted the communication:	
What was discussed:	
What was decided:	

Contact List: Who to Call at Your Child’s School

Your child’s teacher is a terrific resource, but some questions may be better for other staff members. Ask the school office or parent coordinator for the information you need to fill out this contact list.



<u>Afterschool Programs</u> (supervisor info, activity questions, social issues)	Name: Phone / Email:
Athletics (issues with coaches, student-athlete codes of conduct)	Name: Phone / Email:
Behavior (support plans, periodic check-ins)	Name: Phone / Email:
<u>Bullying</u> (classmate issues before, during and after school)	Name: Phone / Email:
Class Placement (general vs. special education, inclusion classrooms)	Name: Phone / Email:
Discipline (detention, suspension, etc.)	Name: Phone / Email:
<u>Evaluation for Special Education</u> (response to intervention, evaluation requests)	Name: Phone / Email:
Field Trips (ways to prepare chaperones and prevent meltdowns)	Name: Phone / Email:
Food (sensory processing issues, food allergies)	Name: Phone / Email:
Health Issues (daytime rest or breaks, medications)	Name: Phone / Email:
<u>Homework</u> (concerns about overall workload)	Name: Phone / Email:
<u>IEPs or 504 plans</u> (requests and concerns, issues with specialists)	Name: Phone / Email:
Schoolwide Testing and Curriculum (state standards, standardized testing accommodations)	Name: Phone / Email:
<u>Social/Emotional Issues</u> (coping skills, conflict resolution, crisis intervention)	Name: Phone / Email:
<u>Teacher-Related Issues</u> (communication help, parent-teacher relationship)	Name: Phone / Email:

TRANSITION TO HIGH SCHOOL; AGES 13-22 YEARS

The transition to the teen years are difficult enough without the added challenges of ASD. More than ever inclusion is happening in schools and students with various disabilities are attending inclusive classrooms and having inclusive recreation time. With some planning including school teachers, utilizing a one-pager and having an introduction period, this transition can be eased with some understanding and assistance with inclusion in social activities.

Along with social needs, annual review of the IEP process is important to ensure planning and growth through transition periods.

The transition from federally mandated services provided through the school system to adult services can be a challenge

The transition from federally mandated services provided through the school system to adult services can be a challenge. While entitlement to public education ends at age 21, the Individuals with Disabilities Education Act requires that transition planning begin at age 16 and become a formal part of the student's [Individualized Education Plan \(IEP\)](#).

This transition planning should include the student, parents and IEP team members working together to help the student make decisions about his/her next steps. An [Individualized Transition Plan \(ITP\)](#) should be developed to outline transition services, which may include education or vocational training, employment, living arrangements and community participation, to name a few aspects.

The first step in transition planning is to look at the individual's **interests, abilities and needs**. For example, what [educational needs](#) must be met? Where can the young adult find [employment](#) and training services? What types of [living arrangements](#) are best for him/her? How will he/she [socialize and pursue relationships](#)?

Entering adulthood is challenging and exciting. Advance preparation and plenty of support are needed so the young adult with autism can get a good start to the next chapter of his/her life.

EMPLOYMENT

Employment should take advantage of the individual's **strengths and abilities**. [Temple Grandin, Ph.D.](#), suggests that "jobs should have a well-defined goal or endpoint," and that your "boss must recognize your social limitations." She recommends that parents begin helping their children find jobs before they leave grade school, to prepare them with job skills and experience. The authors of *A Parent's Guide to Asperger Syndrome and High-Functioning Autism* describe three types of employment possibilities: competitive, supported, and secure/sheltered.

- **Competitive employment** is the most independent, with no support offered in the work environment. Some people might be successful in careers that require focus on details but only limited social interaction with colleagues, such as computer sciences, research or library sciences. It could also help to ask for accommodations, such as a workspace without fluorescent lights, to feel more comfortable at work. For more about attaining competitive employment, [read this article](#).
- (Self-employment is also an option some people with ASD pursue. This requires strong motivation but can be more flexible than working for a company.)
- In **supported employment**, a system of supports allows people with ASD to pursue paid employment in the community, sometimes as part of a mobile crew, other times individually in a job developed for them.
- In **secure or sheltered employment**, an individual is guaranteed a job in a facility-based setting. People in secure settings generally receive work skills and behavior training as well, while sheltered employment might not provide training that would allow for more independence.

To look for employment, begin by contacting agencies that may be of help, such as state employment offices, vocational rehabilitation departments, social services offices, mental health departments and disability-specific organizations. Many of these agencies, as well as other valuable services and supports, can be found in the Autism Society's nationwide online database, [Autism Source](#). Search or call today to find programs in your area!

For more information, read these *Autism Advocate* articles:

[Adult Employment: Digital Imaging Leads to Job](#)

[Moving Into the World of Employment](#)

[Off to Work for Individuals with Autism: A Supported Employment Approach](#)

[When the School Bus Stops Coming](#)

DEPARTMENT OF REHABILITATION

The California Department of Rehabilitation (DOR) administers the largest vocational rehabilitation program in the country. They have a three-pronged mission to provide services and advocacy that assist people with disabilities to live independently, become employed and have equality in the communities in which they live and work.

DOR provides consultation, counseling and vocational rehabilitation, and works with community partners to assist the consumers they serve. <http://www.dor.ca.gov/services-to-youth/index.html>

HOUSING

Whether an adult with ASD continues to live at home or moves into the community is determined in large part by his/her ability to manage everyday tasks with little or no supervision. Can he/she handle housework, cooking, shopping and paying bills? Is he/she able to use public transportation? Many families prefer to start with a supported living arrangement and move toward greater independence.

SUPERVISED GROUP HOME

A **supervised group home** usually serves several people with disabilities. These homes are typically located in average family houses in residential neighborhoods. Trained professionals assist each resident based on individual needs. The residents usually have jobs away from home during the day.

SUPERVISED APARTMENT

A **supervised apartment** might be suitable for those who prefer to live with fewer people, but still require some supervision and assistance. There is usually no daily supervision in this setting, but someone comes by several times a week. The residents are responsible for getting to work, preparing meals, and meeting personal care and housekeeping needs. A supervised apartment is a good step in transitioning to independent life.

INDEPENDENT LIVING

Independent living means just that – individuals live in their own apartments or houses and require little, if any, support services from outside agencies. Services might be present but limited to helping with complex problem-solving issues rather than day-to-day living skills. For instance, some people might need assistance managing money or handling government bureaucracy. It is also important for those living independently to have a “buddy” who lives nearby and can be contacted for support. Coworkers, friends, local business employees or other community members could be integrated into a support system, whether informally through social interaction or as part of a more organized effort. Many people think of adulthood in terms of getting a job and living in a particular area but having friends and a sense of belonging in a community is also important. People with ASD may need assistance in encouraging friendships and structuring time for special interests. Many of the support systems developed in the early years may be of continued use, as they can provide consistency and a framework for expansion.

SOCIAL RELATIONSHIPS

Although young children with autism sometimes seem to prefer to be by themselves, one of the most important issues, especially for older children and adults, is the development of friendships with peers. It can take a great deal of time and effort for people with ASD to develop the social skills needed to interact successfully with others, so it is important to start [developing social ability](#) early. Furthermore, bullying in middle and high school, not to mention at the workplace for some adults, can be a major problem for people with autism, and the development of friendships is one of the best ways to prevent it.

Personal friendships generally are built on one or more shared interests. Personal friends share their thoughts and feelings as well as experiences. Some people on the autism spectrum tend to be very open, honest and willing to share themselves with others – traits close personal friends will value.

Close personal friends will stick up for each other in front of others, answer questions honestly (in a kind way), help each other when there is a need, and enjoy spending time together. Most people, whether neurotypical or on the autism spectrum, only have a few friends who meet this definition of a close friend.

Casual acquaintances and coworkers, however, might not want to share or be shared with as much. They might not be as ready to be open and honest and share personal information about themselves with you, so they feel uncomfortable when you share too much about yourself too soon. Some neurotypicals like to develop friendships slowly. When someone asks you questions about yourself, such as where you were born or went to school or what things you like, they are indicating that they have a possible interest in becoming your friend. That doesn't mean they will become your friend, only that they are interested in finding out whether the two of you share enough interests to possibly become friends.

Making friends has less to do with whether people like you than it does with whether you have interests or experiences that are like theirs, and whether you are also willing to share in their interests that are different from yours. It's easy to lose potential friends if you share more than they want to hear, or if you don't give them equal time to share their interests with you.

Many people with autism have particularly strong interests in certain areas. Unfortunately, it might be that very few other people share those interests. Clubs where people with your special interest are likely to gather are excellent places to find friends. You could find people who share your special interests at museum workshops on your favorite topic, while volunteering to take care of your favorite animal at the zoo or animal rescue, in classes in your field or subject of interest, or at local events centered on your special interest. For example, some universities open their star observatories for special community nights. The type of people who attend such an event likely will be as interested in stars as you are. The Internet might also be a place where you can find people who share your special interests. They might not live near you, but you can still exchange ideas and [discuss your favorite topics virtually](#). One popular forum for people on the spectrum is [Wrong Planet](#), and many others are out there.

It is important to self-advocate, to let others know what makes you happy or uncomfortable. Most neurotypicals are willing to respect these differences if they know about them. If you struggle with verbal communication, you can carry a card in your wallet or purse that explains what you need and share it with others as you choose.

Miscommunication can make it harder for people on the autism spectrum to make and keep friends, too. The reason for this is our autism neurology, meaning that unlike typical people's, our brains are not wired to automatically pick up, incorporate and effectively use the often elusive and transient social information all around us. This information is called the "[hidden curriculum](#)." Whether for boys and men or [girls and women](#) with the social learning challenges of autism, the rules can be vague and confusing. Getting social experience and discussing social rules are good ways to clarify the hidden curriculum and make socializing easier and more rewarding.

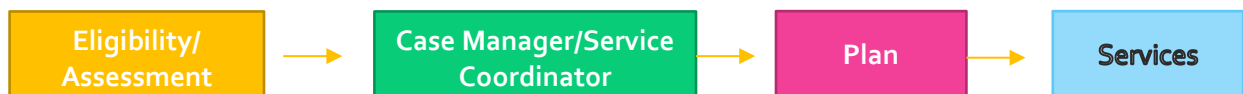
TRI-COUNTIES REGIONAL CENTER

Tri-Counties Regional Center is one of twenty-one non-profit regional centers in California providing **lifelong services and supports** for people with developmental disabilities residing in **San Luis Obispo, Santa Barbara and Ventura Counties**. Regional centers provide diagnosis and assessment of eligibility and help plan, access, coordinate and monitor the services and supports that are needed because of a developmental disability.

Behavioral services provided through the Regional Center do not supplant those provided by a day program, a residential facility, or a generic agency such as a school district. Families should pursue private health insurance coverage and follow their insurance company's process for accessing services. A letter of denial and or proof of appeal from an insurance provider is required before TCRC funding can be approved. Medi-Cal also may provide behavioral services for individuals under age.

The Department of Developmental Services (DDS) is the agency through which the State of California provides services and supports to children and adults with a diagnosed developmental disability. Services were originally provided through state-operated developmental centers, but today DDS contracts with twenty-one nonprofit agencies called regional centers, through which most treatment and services are provided in the community.

Once eligibility is determined, a case manager or service coordinator is assigned to help develop a plan for services, communicate available services and assist with access. Many services are provided at no cost to the family or person served. Families are required to share costs for select services, one example being 24-hour out-of-home placements for children under age 18. Services are funded through a combination of state revenues and federal reimbursement.



An Individual Program Plan (IPP) is tailored to meet the individual needs of each person eligible for TCRC services. A plan for a child or adult with autism may include some or all the following: **Behavioral Supports, Therapy and Family Support.**

HOW TO GET STARTED WITH TRI-COUNTIES REGIONAL CENTER

The following are general criteria for regional center services for any person:

- Any person believed to have a developmental disability, and any person believed to have a high risk of becoming the parent of a developmentally disabled infant, is eligible for **initial intake and assessment services.**
- In addition, any infant having a high risk of becoming developmentally disabled is eligible for initial intake and assessment services.

To begin services, contact your local office and request an initial intake and assessment appointment. Make sure to collect any information from school teachers/administrators, counselors or medical care providers.

VENTURA COUNTY OFFICES

Oxnard [View Location on Map](#)

2401 East Gonzales Road, Suite 100
Oxnard, CA 93036
(805) 485-3177 (800) 664-3177

Simi Valley [View Location on Map](#)

2635 Park Center Drive, Suite A
Simi Valley, CA 93065
(805) 522-8030 (800) 517-2524

SERVICES PROVIDED BY TRI-COUNTIES REGIONAL CENTER

Family Support Services

Family Support Services are provided either in or out of the family home. They help the child or adult with a disability continue to live and be supported in their family home. These services are intended to support both the person served and the rest of the family to prevent or delay unwanted out-of-home placement.

Specific supports consist of:

- 1) **In-Home Respite** is designed to give the family a break from the care of the person served and is provided in the family home.
- 2) **Out of Home Respite** is designed to give the family a break from the care of the person served and is provided outside of the family home, in a licensed facility.
- 3) **Parent Coordinated Personal Assistant/Personal Assistant** supports the person served to be successful in both the home environment and out in the community.
- 4) **Day Care Supplement** may partially offset the fee a family is paying for day care that is needed while a parent is at work. It may be provided when a child's care needs exceed those of a typical child of their age and the cost of day care is higher based on that additional need

Social Skills

Social skills training may be provided to children entering Junior High and young adults to develop appropriate social interaction skills, so they may participate in their home and community. Social skills training is provided individually or in a group format. It addresses significant challenges in engagement and awareness, social interaction, social communication and play skills.

Behavioral Intervention Services

Behavioral intervention services may be provided to address maladaptive, harmful, socially unacceptable, dangerous, or developmentally inappropriate behaviors. They are provided directly by, or under the supervision of, a qualified licensed or certified professional or a person trained in behavior management. Behavior intervention services use specialized methods of teaching important skills and provide training for family members, or primary care givers, in the effective use of positive behavior management skills. TCRC endorses only the use of non-aversive behavior intervention techniques which are evidence-based. The participation of parent(s) of minor children is required.

Independent Living Supports (ILS)

ILS is available for adults that are no longer receiving services from their local education agency and would like help living a more independent life in their community. ILS can provide individual assessment and training in skills needed for independence such as: money management, accessing public resources such as transportation, grooming and hygiene, and soft skills needed for employment. ILS can be provided to someone living in the family home or independently, if they can benefit from the supports.

Supported Living Services (SLS)

For adults who wish to live independently, Supported Living Services may be an option. They are provided to a person served in his/her own home and community. Services are provided in environments that support participant comfort, independence, preferences and the use of technology.

The person's choices are incorporated into the services and supports received. The specific services provided to each person served will vary based on the individual, their preferences, abilities, and the community setting chosen. The specific types and mix of supports that an individual receives as well as any special provider qualifications shall be decided by the Planning Team.

Types of help that SLS can provide:

- Personal skill development
- Access to education
- Being part of:
 - Social activities
 - Leisure activities
 - Community activities
 - Religious/Spiritual activities
- Budgeting
- Decision making
- Managing other services such as IHSS)
- Access to routine medical and healthcare services
- Assistance following doctor's orders
- Self-advocacy

It is important to note that payments for Supported Living services do not include the cost of general living expenses such as rent, utilities and food as this is the responsibility of the person served.

Community Care Facilities

A CCF is a licensed residential home that provides 24/7, non-medical care and supervision. CCFs offer care that is individually tailored and in the comforts of a typical home in the community. Community Care Facilities (CCF) are for children and adults served who are not able to, or choose not to, live with their family or independently.

Housing Access/Modification Supports

Housing Access Supports is a service that helps a person served and their family to find housing. These services help people identify and secure affordable, accessible housing.

Services include help with:

- Finding affordable and safe housing options
- Making choices with respect to the person's preferences of locations and types of housing
- Identifying the person's accessibility needs
- Home modification for accessibility – support to access funding sources.
- Identifying and applying for financial assistance as well as housing subsidies and other benefits.

The service does not include payment of deposits or other expenses associated with setting up a household.

Family Home Agency (FHA)

Licensed by the State Department of Social Services, Family Home Agencies train and certify families to support a person served in their home. The family does not replace the person's served own family, but ideally becomes an extension of the family system.

Day Services for Adults

Day services for adults are structured, comprehensive and provide access to the community for those no longer eligible for public school programs. Program activities help people to define and reach their goals.

Community-based programs for adults are expected to meet a variety of individual needs. These supports, services and/or programs should include opportunities for persons served to participate in self-advocacy, pre-employment and employment training, community integration and the development of social and self-care skills. The Planning Team will first consider skill development supports and services in natural environments and under realistic conditions. Based on individual needs and preference, some programs are center-based.

Employment

California's Employment First Policy means that competitive employment in the community can become a real choice for individuals with developmental disabilities. Competitive employment means finding a job within the community where an individual is paid the same as other people doing the same job and at least minimum wage. Some of the employment options that are available are: full or part time employment, self-employment, micro-enterprise, or contract jobs and skilled work. TCRC can provide support for any of these employment options.

Safety Supports

Services may include:

- Med-alert bracelets – provide needed information to first responders
- Life-line services – used to call for help from home, if a phone cannot be reached
- Tracking devices – help find a person who is at risk of getting lost
- Crisis Support Services – help resolve a crisis by phone or in person
- Repairs and maintenance to devices and equipment are the responsibility of the person served or their family.

Transportation/Travel Training

Travel training teaches individuals how to safely use specialized or public transportation.

Sometimes private, specialized transportation will be provided to those individuals who cannot safely access and utilize public transportation services to and from day services.

RAINBOW CONNECTION FAMILY RESOURCE CENTER

Family Resource Centers offer information, training and support to families striving to raise their children with special needs to reach their fullest potential.

Rainbow Support

- Talking to a trained staff member who is a parent.
- Parent to Parent Matches – Connecting parents with similar concerns and interests.
- Rainbow has support groups for specific disabilities, military families, and general ones for all special needs. We also list the groups available in the community. We encourage parents to attend a support group at least once. They might be surprised at how much it will help them and how much they can help others.

Socializing

- Social time for teens and adults receiving services from TCRC
- Sibling Club

Information on various disabilities

- on local, state, & national resources
- on parent's Rights & Responsibilities when raising a child with special needs

Education and training

- Presentations on topics of interest for parents
- Basic training on Individualized Family Service Plans (IFSPs) and Individualized Education Plans (IEPs).
- Workshops to help parents organize all the paperwork that comes with a child with special needs

Spanish Outreach Assistance

- Support for Spanish speaking families, some resource materials are available in Spanish.

Library

A large multi-media library is available at the Tri-Counties Regional Center office in Oxnard. A satellite library is available in the Simi Valley Tri-Counties Regional Center office and at Channel Islands Social Services. Internet access is available at both Regional Center sites. A mobile library is available for group meetings. The library is open to the public.

CONTACT

E-Mail: rainbow@tri-counties.org Website: <http://rainbowconnectionfrc.weebly.com>

Facebook: <http://www.facebook.com/RainbowConnectionFRC>



Oxnard Office

2401 East Gonzales Road, Suite 100,
Oxnard CA 93036
Main Phone: (805) 485-9643
Toll Free: (800) 332-3679
Spanish Line: (805) 485-9892
Monday through Friday 9 am to 5 pm

Simi Valley Office

2635 Park Center Drive, Suite A, Simi
Valley, CA 93065
Main Phone: 805-823-2325
Spanish Line 805-485-9892
Monday through Thursday 9 am to 1 pm
and by appointment

On-Going SUPPORT GROUPS TRAININGS & ACTIVITIES



We encourage you to attend a support groups at least once. You will be surprised at how much it will help you and how much you can help others. As there might not always be a support group available for a specific diagnosis, we try to provide a parent match upon request. To register to attend or for a copy of the current "What's Happening at Rainbow?" schedule of activities, please call 805 485-9643; 800 332-3679; E-mail: rainbow@tri-counties.org or go to our Website: www.rainbowconnectionfrc.weebly.com

ACTIVITIES

Social Time for Adults Receiving Services from TCRC (Bilingual) Santa Paula

Meets 1st Saturday of the month.
Come, bring a friend or just come meet new people, for conversation, playing games or for refreshments and some fresh air.

Teddy Bear Brigade *No meetings during the summer. Thousand Oaks 1-3pm
Meets 3rd Saturday of the month, except for summer months. For children 3 -13 years old with special needs and their siblings.
It includes stories, sensory themes, crafts and music planned each month.
Visit www.bearsandcompany.com to register or call Rainbow. Parents meet separately for social and networking time.

AUTISM



Autism Spectrum Disorder (ASD) Parent Support Group (English)

Oxnard 7 – 8:30pm * No meetings during the summer. Meets 2nd Wednesday of the month. Families meet to share the experiences they've had with their children with special needs and learn about resources. You can connect with the group at asdparentsupportgroup@gmail.com

Autismo Support Group (Spanish)

Oxnard 7 - 8:30pm
Meets 3rd Thursday of the month. Families meet to share the experiences and resources.

CEREBRAL PALSY

Cerebral Palsy Support Group - Simi (meets separately in English & Spanish) 9:30 – 11:00 am

Meets 3rd Monday of the month.
Join other parents to talk about issues related to raising children with cerebral palsy and share resources and information.

G-tube/J-tube/NG-tube Networking (meets separately in English & Spanish) 6:30 – 8:00 Oxnard

Meets 3rd Thursday of the month. Does your child have a G-tube, J-tube, or NG-tube? Or has it been suggested? Families share stories of frustrations, fears, and successes (large & small).

DOWN SYNDROME

Down Syndrome Support Group (meets separately in English & Spanish)

Oxnard 7pm – 8:30pm Meets last Thursday of the month. Families have open discussions on issues related to raising children with Down syndrome.



Please RSVP as soon as you can!
(805) 485-9643 or rainbow@tri-counties.org
On-Going Events - Page 1 of 4

SAFETY & COMMUNICATING WITH LAW ENFORCEMENT

According to the [National Autism Association](#), accidental drowning was responsible for approximately 91 percent of the total deaths in the U.S. reported in children with autism aged 14 years and younger due to wandering/desertion from 2009 to 2011. Plus, nearly 50 percent of autistic children escape a safe environment. The figure is four times higher than non-autistic children. The Autism Society began the Safe and Sound™ initiative in 2005 to provide much-needed resources on topics such as general safety, emergency preparedness and prevention, and risk management. Safe and Sound works to develop information and strategies to benefit individuals on the spectrum, their families and the professionals who work with them. Another significant aspect of Safe and Sound is to provide information and training to first responders — those who are first on the scene in an emergency.

Ten Things You Can Do Related to Safety — Starting Now

1. **Get to know your neighbors and those who make up your community** (fire, police, grocers, etc.); be a resource so they understand ASD and your child.
2. Fill out a **Personal ID Record** (such as the one offered by the Autism Society) and make various copies to keep in key locations. Flag your address in the 911 system.
3. **Anticipate issues** that could arise and contemplate solutions. When you need assistance, reach out to others in the autism community for ideas.
4. Ensure the individual with ASD has an **effective method of communication**.
5. **Practice providing personal information** — name, address, phone number — in an understandable manner in various situations.
6. Have concrete, detailed and frequent conversations with your child about the rules (e.g. talking to strangers, staying in the yard or with caregivers, etc.)
7. Talk with others about your concerns and rules. **Establish a phone tree and action plan** that can be engaged if the worst happens.
8. **Listen, watch and learn**. Try to understand why your child does things, anticipate potential issues, and develop good solutions.
9. Address issues such as **bullying at school** — ensure policies are in place and increase awareness of autism in the entire student population.
10. **Stress water safety** — it can mean the difference between life and death. Enroll your child in swimming lessons if he/she does not know how to swim.

ELOPEMENT AND WANDERING

The issue of wandering for individuals living with autism remains a serious concern for all of us. This year, it appears that more children living with autism are dying from wandering and as a nation, we must address these tragedies. At the Autism Society, we are very concerned about this alarming trend and doing all we can to help support families and individuals who are living with autism.

The Autism Society has been a leader since the 90's in working with First Responders, launching our Safe and Sound Program in 2005. This program helps First Responders fully understand autism and various other situations requiring an informed and sensitive response, like wandering.



It is a priority of the Autism Society to provide support and guidance to those who are concerned or affected by wandering. In Ventura County, the ASVC works with local law enforcement to provide training to Law Enforcers and Families alike to prepare when crisis situations occur.

LAW ENFORCEMENT AGENCIES IN VENTURA COUNTY

Ventura County Sherriff's Department; <http://www.vcsd.org/contact-directory.php>

EMERGENCY: CALL 911

NON-EMERGENCY: CALL (805) 654-9511

SHERRIFF'S PATROL STATIONS

Camarillo Patrol Station

3701 East Las Posas Road
Camarillo, CA 93010
(805) 388-5100 Reception
(805) 388-4280 Patrol Deputies Voicemail
(805) 388-5155 Community Resource Unit

Fillmore Patrol Station

524 Sespe Avenue
Fillmore, CA 93015
(805) 524-2233 Reception

Lockwood Valley Patrol Station

15021 Lockwood Valley Road
Frazier Park, CA 93225
(661) 245-3511 Emergency
(661) 245-3829 Reception

Ojai Patrol Station

402 South Ventura Street
Ojai, California 93023
(805) 646-1414 Reception

East County Patrol Station

2101 East Olsen Road
Thousand Oaks, CA 91360
(805) 494-8200 Reception
(805) 449-2760 Thousand Oaks Blvd Resource Center
(805) 375-5630 Newbury Park Resource Center

Headquarters Patrol Station

800 South Victoria Avenue
Ventura, CA 93009
(805) 654-2890 Reception

Moorpark Patrol Station

610 Spring Road
Moorpark, CA 93021
(805) 532-2700 Reception

Sheriff's Communication Center (SCC)

800 South Victoria Avenue
Ventura, California 93009
(805) 654-9511 Dispatch & Watch Commander

Ventura County Harbor Patrol

Channel Islands Harbor
3900 Pelican Way
Oxnard, CA 93035
(805)382-3000

[Agency Website](#) 

Ventura Police Department

1425 Dowell Dr.
Ventura, CA 93003
(805) 339-4400
(805) 650-8010

[Agency Website](#) 

Oxnard Police Department

251 South "C" Street
Oxnard, CA 93030
(805) 385-7740

[Agency Website](#) 

Port Hueneme Police Department

250 North Ventura Road
Port Hueneme, CA 93041-3094
(805) 986-6530

[Agency Website](#) 

Santa Paula Police Department

210 South 10th Street
Santa Paula, CA 93060
(805) 933-4231

[Agency Website](#) 

Simi Valley Police Department

2929 Tapo Canyon Road
Simi Valley, CA 93063
(805) 583-6700

[Agency Website](#) 

Ventura County Crisis Intervention TEAM (CIT):

Collaboration of local law enforcement and Behavioral Health offices.

(805) 383-4806 <http://www.venturacountycit.org/index.html> Email: VenturaCo.CIT@ventura.org

CRISIS SUPPORT SERVICES (CSS TEAM)

Services available for a person in crisis are the same services that are available for anyone served by the Regional Center. However, when a person is in crisis, a different mix of services may be required to meet his or her short-term needs. When a person served by the Regional Center experiences a crisis and the IPP needs to be revised to meet the new needs, the Planning Team must be convened and agree upon a plan of action before new services are authorized. This meeting can happen quickly and by phone, if necessary.

A crisis intervention agency that is available on a 24/7 basis assists TCRC in responding to crisis situations. They can make home visits, help to defuse volatile situations and provide advocacy for services from generic resources, such as mental health. TCRC has a manager on-call when the offices are closed to assist in developing appropriate crisis plans, including:

- Crisis Prevention as part of CSS
- Prevent and De-escalate Crisis
- Non-Aversive and Non Confrontational Methods
- Assessment for Crisis Potential
- Assist with Transitions
- Remain available for Support and Assurance
- Stabilize and Maintain Placement
- Avoid Hospitalization and Police Involvement
- Assist with Hospitalization and Police Involvement when necessary
- Prioritize Crisis based on Severity and Available Resources

Ventura County (24/7): 888-566-1666 or 911

Tell the Operator to "Call" the Crisis Team and give them your name and number along with the individual's name and a brief description of the issue. Calls are returned as quickly as possible, if you do not receive a response within 5-10 minutes, call again to ensure your message was received by the CSS Team. For prevention appointments call Monday through Friday 10am-6pm

Ten Crisis Prevention Strategies

1. **Be Compassionate:** Avoid being judgmental to individual's feelings. Their feelings are real even if they are not based on reality.
2. **Reflective Listening:** Listen to what is being said, ask reflective questions, listen attentively and respond with a feeling statement
3. **Verbal Venting:** Allow individual to release as much energy as possible by communicating out loud when appropriate.
4. **Avoid Overreacting:** Remain calm, rational and professional. Your response will directly affect the individual's behavior.
5. **Personal Space:** Invading personal space increases anxiety and may lead to escalated behavior. When possible stand at least one arm length away from individual.
6. **Body Position:** Standing toe to toe and eye to eye with individual sends a challenging message. Standing off to the side of the individual will be more successful.
7. **Non-Verbal Cues:** More attention is paid to non verbal communication. Be aware of gestures, facial expressions, movements and tone of voice.
8. **Setting Limits:** If the individual becomes argumentative, defensive or disorderly, communicate the directives and limits concisely and clearly.
9. **Redirect Challenging Questions:** When an individual challenges your policy, position or training, redirect the individual's focus to the presenting concerns. Answering these questions can create a power struggle.
10. **Least Restrictive:** Use the least restrictive method of intervention possible.

WATER SAFETY #1 GOAL - WHY IS WATER SAFETY SO IMPORTANT?

ASVC strongly believes that teaching individuals how to be safe around water is not a luxury; it is a necessity. We have partnered with local YMCA and other swim programs to provide training to instructors on how to best work with individuals with ASD.

The YMCA's Safety Around Water program can help parents and caregivers make sure individuals learn essential water safety skills, which can open a world of possibilities for individuals to satisfy their curiosity safely. Through learning how to perform a sequenced set of skills over eight lessons of 40 minutes each, the risk of drowning is reduced, giving your child confidence in and around water.

A typical session includes:

- Exercises to help kids adjust to being in water
- Instruction in "Jump, Push, Turn, Grab" and "Swim, Float, Swim," two skill sets kids can use if they unexpectedly find themselves in the water
- Specific safety topics, like what to do if you see someone in the water who needs help
- Fun activities that reinforce skills

WATER SAFETY CLASSES - HELPING CHILDREN FEEL COMFORTABLE

Talk to the child about swimming. Use a social story to talk to your child about learning how to swim and what to expect at their swimming lesson. Social stories are an effective way to get your child accustomed to the idea of taking swimming lessons.^[5]

- You can find books at the library or examples of social stories online that you can adapt to your child's situation, or you can write your own.
- Include each step of the process, including the days and times the child will be participating in swim lessons, where those lessons will take place, how they'll get there and back home again, and what will happen at the lessons.
- For example, your story might start: "My name is Andy. Each Saturday I take swimming lessons at the YMCA. My mommy drives me to the YMCA in the blue car. We say hello to the person at the desk. I go to the locker room and change into my wetsuit. My mommy keeps my things for me while I go to the pool. At the pool I meet my instructor. I stand beside the pool until my instructor says I can get in the water."
- Read the story with the child several times before the lessons begin and answer any questions he or she might have about the process. You may want to incorporate some of those answers into the overall story.

Show the child photos or videos of people swimming. Use pictures to augment your social story and continue the process of getting your child used to the idea of swimming lessons.^[6]

- Photos and videos can be particularly beneficial to children who are nonverbal or who are visual thinkers generally.
- It can help to go to the pool where the child will be taking swimming lessons and take pictures there.

NUTRITION

People with ASD often repeat behaviors and have narrow, obsessive interests. These types of behavior can affect eating habits and food choices, which can lead to the following health concerns.

Limited food selection or strong food dislikes. Someone with autism may be sensitive to the taste, smell, color and texture of foods. They may limit or totally avoid some foods and even whole food groups. Common dislikes include fruits, vegetables and slippery, soft foods.

Not eating enough food. Kids with autism may have difficulty focusing on one task for an extended period of time. It may be hard for a child to sit down and eat a meal from start to finish.

Constipation. This problem usually is caused by a child's limited food choices. It typically can be remedied through a high-fiber diet, plenty of fluids and regular physical activity.

Medication interactions. Some stimulant medications used with autism, such as Ritalin, lower appetite. This can reduce the amount of food a child eats, which can affect growth. Other medications may increase appetite or affect the absorption of certain vitamins and minerals. If your child takes medication, ask your healthcare provider about possible side effects.

Caring for a child with ASD can be challenging on many levels, and healthful eating is no exception. For children with ASD, a nutritious, balanced diet can make a world of difference in their ability to learn, how they manage their emotions and how they process information. Because children with ASD often have restricted diets as well as difficulty sitting through meal times, they may not be getting all the nutrients they need, particularly calcium and protein. If you have a child with ASD, you might try these nutrition strategies suggested by www.eatright.org.

1. **Be Prepared for Pickiness:** Many parents find their child's sensitivity to tastes, colors, smells and textures the biggest barriers to a balanced diet. Getting your child to try new foods — especially those that are soft and slippery — may seem nearly impossible. You may find that your child avoids certain foods or even entire food groups. One of the easiest ways to approach sensory issues is to tackle them outside of the kitchen. Have your child visit the supermarket with you to choose a new food. When you get home, research it together on the internet to learn about where it grows. Then, decide together how to prepare it. When you are done, don't worry if your child doesn't want to eat it. Simply becoming familiar with new foods in a low-pressure, positive way eventually can help your child become a more flexible eater.
2. **Make Mealtimes Routine:** A child with ASD will have to work harder at mealtimes because a busy kitchen, bright lights and even the way the furniture is arranged all are potential stressors. Making meals as predictable and routine as possible can help. Serving meals at the same time every day is one of the simplest ways to reduce stress. In addition, think about what concessions you can make for easier mealtimes. If your child is sensitive to lights, try dining by candlelight. Let your child pick a favorite food to include at every meal. Or, let your child choose a favorite seat at the table.

3. **Seek Guidance for Special Diets:** You may have heard that a gluten- or casein-free diet can improve symptoms of ASD. Gluten is a type of protein found in wheat, rye and barley. Casein is a protein found in milk. Proponents of the diet believe people with autism have a "leaky gut," or intestine, which allows parts of gluten and casein to seep into the bloodstream and affect the brain and central nervous system. The belief is that this may lead to autism or magnify its symptoms. While some studies indicate that these diets may be effective for certain children, controlled scientific studies have not proven this to be true so more research is needed. Keep in mind that restrictive diets require careful planning to make sure your child's nutrition needs are being met. Consult with a registered dietitian nutritionist before making any drastic changes to your child's diet as there can be side effects and potential nutrient shortfalls when a gluten- or casein-free diet is self-prescribed.
4. **Working With a Registered Dietitian Nutritionist:** Most children, with or without autism, can be choosy and particular about the foods they eat. A registered dietitian nutritionist can identify any nutritional risks based on how your child eats, answer your questions about diet therapies and supplements advertised as helpful for autism and help guide your child on how to eat well and live healthfully.

Reviewed March 2018

Karen Ansel, MS, RDN, CDN is a nutrition consultant, journalist and author specializing in nutrition, health and wellness.

PHYSICAL ACTIVITY

APPROPRIATE FITNESS PROGRAMMING, *Eric Chessen, M.S., YCS, is the founder of Autism Fitness*

From an educational and life skills perspective, our job as parents, teachers and professionals is to regularly identify an individual's areas of need and address them in the most adaptive way possible. There is a reason so many students have difficulty in a standard classroom setting. The focus on taking tests rather than "learning how to learn" leads to skills that are not necessarily applicable to future needs and goals. For fitness programming, my hierarchy tends to look something like this (in order of importance):

1. Develop, maintain and enhance movement skills
2. Pair exercise and physical activity with reinforcement to ultimately make the activities themselves fun and part of a lifestyle
3. Increase initiation and creativity skills through exposure to various modalities of exercise (different equipment and activities)
4. Support socialization through small group activities that include elements of teamwork and helping behaviors

For those with autism who often have difficulty attending to a task for durations longer than 10 or 20 seconds, creativity and socialization behaviors are not an immediate goal. It is far more.

By categorizing movement categories, parents, educators, therapists and other professionals can develop balanced programs that are appropriate for any individual or group. Instead of focusing on a particular sport or individual muscle group (arms, legs, shoulders), movement-based exercise teaches the body to function as a cohesive, optimized unit. For example, upper-body pulling motions, from pull-ups to monkey bars to resistance band pulls, incorporate the upper back muscles, shoulders, arms and hands. In addition to developing strength and stability, these exercises can aid with posture. Have you ever told someone to "sit up straight?" The fact is that you cannot force good posture. It has everything to do with the proper muscle stability. Again, a program that includes pulling as a component, as opposed to walking on a treadmill for 40 minutes, has tremendous benefit for a variety of physical and adaptive abilities. How do we put together a program that is suitable for an individual or group of people with autism? It is important to consider the participants' current level of ability and tolerance for new activities or tasks. I have found much success with using animal-based movement patterns for mobility and movement assessment.

Bear walks, crab walks, frog hops, gorilla steps and various improvised movements allow for creativity while exposing the athlete to multiple forms of the five fundamental patterns. Other favorites are hops, jumps, overhead carries with soft medicine balls or SandBells, a variety of throws and swinging long segments of rope. Many of these modalities would be considered non-traditional, but historically speaking, they have a far more embedded and proven place in physical culture than any machine or aerobics class out there today. They are also fun, inexpensive and conducive to providing fitness for any age or functional level.

Eric Chessen, M.S., YCS, is the founder of Autism Fitness. In addition to working with his athletes on the autism spectrum, Eric consults with parents, educators, fitness professionals, and therapists around the world. He is the creator of the Autism Fitness Toolbox/PAC Profile Method and the author of several E-Books. For more information, visit www.AUTISMFITNESS.com and his blog, www.EricChessen.com. The following abbreviated post appeared in the Summer 2014 edition of the Autism Advocate. Read the post in its entirety [here](#).

There are several agencies including special Olympics, YMCA, and Parks and Rec who have adapted programs available.

STRESS

Stress – something parents in general are all too familiar with. When a family has a child on the autism spectrum, unique stressors are added.

An individual with autism may not express their basic wants or needs in the manner we would expect. Therefore, parents are left playing a guessing game. Is the child crying because he/she is thirsty, hungry, or sick? When parents cannot determine their child's needs, both parties are left feeling frustrated. The child's frustration can lead to aggressive or self-injurious behaviors that threaten his/her safety and the safety of other family members (e.g., siblings). Stereotypic and compulsive behaviors concern parents since they appear peculiar and interfere with functioning and learning. If a child has deficits in social skills, such as the lack of appropriate play, stress may be increased for the family. Individuals lacking appropriate leisure skills often require constant structure, not a feasible task in the home environment.

Finally, many families struggle with the additional challenges of getting their child to sleep through the night or eat a wider variety of foods. All of these issues and behaviors are physically exhausting and emotionally draining for families. For families of children on the autism spectrum, these can be a particularly difficult challenge. Scheduled dinnertimes may not be successful due to the child's inability to sit appropriately for extended periods. Bedtime routines can be interrupted by [difficulties sleeping](#). Maladaptive behaviors may prevent families from attending events together – for example, Mom might have to stay home while Dad takes the sibling to his/her soccer game. Not being able to do things as a family can impact the marital relationship. In addition, spouses often cannot spend time alone due to their extreme parenting demands and a lack of qualified staff to watch a child with autism in their absence.

Taking an individual with autism out into the community can be a source of stress for parents. People may stare, make comments or fail to understand any mishaps or behaviors that may occur. For example, individuals with autism have been seen taking a stranger's food right off his/her plate. As a result of these potential experiences, families often feel uncomfortable taking their child to the homes of friends or relatives. This makes holidays an especially difficult time for these families. Feeling like they cannot socialize or relate to others, parents of children on the autism spectrum may experience a sense of isolation from their friends, relatives and community. For information on how to deal with stress, read [Stress: Take a Load Off](#).

SELF ADVOCACY

Adapted from "The Secrets of Self-Advocacy: How to Make Sure You Take Care of You" by Stephen M. Shore, Autism Advocate, 2006, Vol. 44, No. 4

Self-advocacy involves knowing when and how to approach others to negotiate desired goals, build better mutual understanding and trust, and achieve fulfillment and productivity. Successful self-advocacy often involves an amount of disclosure about oneself to reach the goal of better mutual understanding. In other words, it can be necessary to explain that you have autism and what that means to explain why an accommodation is needed or helpful.

Ideally, parents lay the groundwork for self-advocacy when the child is young. An important precondition for successful self-advocacy and disclosure is self-awareness. **People with ASD need to understand how autism affects their interactions with others and the environment.** Also, they need to be familiar with their strengths and challenges. A parent or caretaker can do this with a child from a very early age. **In fact, the earlier a child has an explanation about his differences, the better off he will be.**

Parents should let their child know of their strengths in any way they can. In addition to developing greater self-understanding, it means talents can be fostered for future academic and professional pursuits.

SELF-ADVOCACY ORGANIZATIONS

These groups promote equality for people with disabilities, share community news, and provide forums for learning and sharing opinions. Following their activities is a great way to learn about self-advocacy and show your support for the community.

[Autistic Self Advocacy Network](#)

[Global and Regional Asperger Syndrome Partnership](#)

[Self-Advocates Becoming Empowered](#)

TEACHING SELF-ADVOCACY SKILLS

Just as social skills and an understanding of nonverbal communication are necessary for those on the autism spectrum, self-advocacy and disclosure requires direct instruction to develop skills.

Areas of instruction can include a variety of topics and skill areas, including:

- Using a child with autism's IEP as a tool to teach her about [self-advocacy and disclosure](#)
- Teaching children or adults about sensory systems and how to ask for environmental accommodations
- Supporting a person on the spectrum in learning how and when to self-disclose
- Introducing a person with ASD to the basics of the [Americans with Disabilities Act](#) and [other important laws](#).
- Assisting a child or adult in creating self-advocacy scripts to use a variety of settings and situations.

SSI AND OTHER BENEFITS

SUPPLEMENTAL SECURITY INCOME (SSI): THE BASICS

People who are disabled, blind, or elderly may not be able to work or afford to live on their own. If you can't work, have no other sources of [income](#), and have limited [resources](#), you may be eligible for [Supplemental Security Income](#) (SSI).

The federal government created the SSI program to help people in this situation. Those who qualify for SSI benefits get monthly cash payments to pay for those basic needs. The SSI program is run by the [Social Security Administration](#). In California, people who get SSI also get a smaller benefit from the [State Supplemental Program](#) (SSP) included with their monthly SSI benefit. For most people, the maximum possible SSI benefit (including the SSP) is \$910.72 for an individual and \$1,532.14 for a couple. If you're blind, the maximum is \$967.23 for an individual and \$1,683.19 for a couple.

In California, people who qualify for SSI also get [Medi-Cal](#) benefits automatically. **Don't get SSI mixed up with other programs. Three disability benefits have very similar names: SSI, SSDI, and SDI:**

- [Supplemental Security Income](#) (SSI) is a federal program that gives a cash benefit to people who have disabilities and have low income and resources. You do not need to have worked in the past to get SSI. **SSI is explained in this article.**
- [Social Security Disability Insurance](#) (SSDI) is a federal program that gives a cash benefit to people with long-term disabilities who qualify because they used to work or have family members who worked.
- [State Disability Insurance](#) (SDI) is a state program that gives a cash benefit for one year or less to Californians with disabilities who worked before becoming disabled.

You may be able to qualify for more than one of these programs at the same time. For example, if you become disabled, you might get SDI at first and later start getting SSDI. If you get SSDI and also have low resources, you may qualify for SSI as well. Make sure you know which benefits you get and which you might qualify for if you applied.

Social Security

- The Red Book- The Red Book is a general reference tool designed to provide a working knowledge of these provisions. <https://www.ssa.gov/redbook/documents/TheRedBook2018.pdf>
- Benefits Planning Query- This provides information about a beneficiary's disability cash benefits, health insurance, scheduled disability reviews, representative payee, and work history, as stored in SSA's electronic records. This is an important planning tool for a beneficiary, benefits counselor, or other person who may be developing customized services for a disability beneficiary who wants to start working or stay on the job.
- Work Incentives through SSI <https://www.ssa.gov/ssi/text-work-ussi.htm>

2. Disability Benefits 101

- Gives you tools and information on health coverage, benefits, and employment. You can plan and learn how work and benefits go together. <https://ca.db101.org/>

3. Disability Rights CA

- Disability Rights California advocates, educates, investigates, and litigates to advance the rights, dignity, equal opportunities, and choices for all people with disabilities.
<http://www.disabilityrightsca.org/>

According to SCDD Central Coast, with very rare exceptions, you are better off working than relying on SSI or SSDI. You can keep Medicare or Medi-Cal long after you begin working.

Supplement Security Income (SSI)

To calculate the impact of your wages on your SSI monthly benefit, subtract the \$85 exemption from gross earnings, (\$65 if you also receive SSDI) and then divide the remainder in half. This number is the amount that will be subtracted from your monthly SSI benefit check. Below is an example of a person earning \$1085 per month and receiving \$910 per month in SSI Benefits.

$$\$1085 - 85 = 1000 \quad 1000 \text{ divided by } 2 = 500 \quad 910 - 500 = 410$$

$$\text{Monthly income equals } \$1085 + \$410 = \$1495$$

Wages must be reported to Social Security by the 6th of each month. Once your monthly SSI check is zero, and you continue to report earnings, you are automatically enrolled in the 1619(b) provision that continues Medi-Cal coverage, at no cost to you, as long as your annual income (in 2018) is below \$37,202. Certain conditions apply but SSI recipients almost always meet them.

If you continue reporting your earnings once your benefit checks have stopped and your income drops or you lose your job, your benefits check will start coming right away – usually within 30 days. If you stop reporting your income (not recommended!) and your income drops or you lose your job and it has been longer than 12 months, you will not automatically receive benefits again and you will need to reapply. There is an SSI resource limit (including checking & savings, stocks, 401k, and other retirement plans, etc.) of \$2,000 for individuals.

SOCIAL SECURITY DISABILITY INSURANCE (SSDI)

The 9-month Trial Work Period (TWP) lets you work and get benefits at the same time no matter how much you make and most people qualify for an additional 3-month Grace Period for a total of 12 months of benefits with unlimited earnings! (This provides a great opportunity to save money with double income) There is not limit on savings and resources. A TWP month is any month in which gross earnings are above \$850 (in 2018). All changes in employment and/or wages should be reported immediately to Social Security. There is not a monthly reporting requirement.

When the Trial Work Period ends, the 3-year Extended Period of Eligibility (EPE) begins and lets you work and get benefits for every month that you earn less than the Substantial Gainful Activity (SGA) level (\$1180 in 2018). If you earn above SGA, you will not get cash benefits. After the EPE, the first time you earn above SGA, your benefits are terminated but if you quit work due to your disability, you have up to 5 years to request Expedited Reinstatement (EXR) of benefits. When you request EXR, you receive benefits while your case is being reviewed. If approved, you will begin a 24-month Initial Reinstatement Period after which you are again eligible for a new Trial Work Period and Extended Period of Eligibility. SSDI Medicare recipients continue to be eligible for Medicare for many years after working but will have to continue to pay for some or all of it, but most will have medical insurance through their employer.

MEDICAID WAIVERS

Most states have a program for individuals with developmental disabilities called a Medicaid Waiver (also known as 1915(c) Home and Community Based Services). A Medicaid Waiver is designed to provide support services and care to allow an individual to remain at home or in the community, rather than in an institution, nursing home, or hospital. The benefits provided by these waiver programs vary by state, but most generally provide coverage for medical treatments, respite care, transportation, in-home support, and more. In some states, children **do not** need to meet eligibility criteria for Medicaid to qualify for a waiver. However, just like insurance laws, waiver criteria and availability vary from state to state.

You should also note that waivers may have different names in your state. For example, the “Katie Beckett waiver” is one type that is available in a number of states. Others may have names such as “Autism waiver,” “Person Directed Support waiver,” “Developmental Disabilities waiver,” or “Individual and Family Support waiver.”

WAIVERS IN CALIFORNIA:

California currently has seven Home and Community Based Services 1915(c) waivers.

- CA HCBS Waiver for Californians w/DD
- CA Nursing Facility/Acute Hospital Waiver
- CA HIV/AIDS Waiver
- CA Pediatric Palliative Care
- CA Assisted Living
- [CA Multipurpose Senior Services Program](#)
- CA In Home Operations

Click Here for updated waivers search: <https://www.medicaid.gov/medicaid/section-1115-demo/demonstration-and-waiver-list/index.html>

ABLE ACCOUNTS

A new type of savings option was made available for families of individuals with disabilities through the Achieving a Better Life Experience (ABLE) Act of 2014. The ABLE Act authorized the establishment of private tax-advantaged savings accounts that can help you save for long-term expenses without sacrificing eligibility for public benefits such as Medicaid and Supplemental Security Income (SSI).

These accounts are modeled after the current 529 education savings plans that help families save for future college costs. Once an account is established for a beneficiary, account contributions will accumulate tax deferred and any earnings will be tax free at the federal level if the money is used for qualified expenses.

Each state is responsible for establishing and operating an ABLE program. For information of California’s Able Act, Click Here: <https://www.treasurer.ca.gov/able/>

HOUSING ASSISTANCE

The [Department of Housing and Urban Development](#) (HUD) can provide you with advice on finding affordable housing. HUD sponsors housing counseling agencies throughout the country to provide free or low cost advice. For more information, you can call HUD's interactive voice system at: (800) 569-4287.

You can locate your local HUD office on https://www.hud.gov/program_offices/field_policy_mgt/localoffices#CA.

They can give you information on affordable housing programs, rental assistance, and more. There are also a number of programs through the federal government to help families purchase a new home. Some resources below:

- [U.S. Department of Agriculture \(USDA\)](#)
- [U.S. Department of Housing and Urban Development \(HUD\)](#)
- [Federal Housing Administration \(FHA\)](#)
- [AmeriDream, Inc.](#)

OTHER PLACES TO SEARCH FOR FINANCIAL ASSISTANCE

The United Way can help you connect with many resources and services in your area, and answer many questions about obtaining assistance. Call 2-1-1 or visit 211.org to learn about some of the options available to you.

NeedHelpPayingBills.com is a website which lists many sources of financial assistance. Follow [this link](#), then scroll down and click on your state to locate additional sources of assistance.

USA.gov maintains information on a variety of government and other assistance. In particular, see the page on [Government Benefits, Grants, and Loans](#).

The *Patient Advocate Foundation* is also a good place to search for grants and other financial assistance, particularly if someone in your family has a medical condition. You can search for resources based on medical diagnosis. [Click here](#) to search their page.

EMERGENCY ASSISTANCE

In a crisis, it is often helpful to go to your *Community Action Agency* ([click here](#) to find the agency for your area). Staff can connect you with any available resources, financial or otherwise, that are available in your area.

You can also contact your local *United Way* by calling **2-1-1** to be connected with many services and resources to help, or visit 211.org.

The *Salvation Army* can often assist in emergency situations as well, although funding may be limited. They can provide rental and housing assistance, utility help, food, shelter, and more. You can find your nearest center by [clicking here](#).

You can also use the following links to locate shelters in your area:

- homelesshelterdirectory.org
- shelterlistings.org
- womenshelters.org

EXTENDED FAMILY (SIBLINGS/FAMILY (SIBLINGS/GRANDPARENTS/ETC.)