City of Temecula, California
Southwest Riverside Autism Task Force

PAVING THE WAY FOR YOUTH
WITH SPECIAL NEEDS
the roadmap to raise awareness

Community Playbook

A Guide for Parents, Agencies and Communities
First Edition
The Community Playbook is developed through a collaborative effort by the City of Temecula's Community Services Department, regional stakeholders, and interested community members. The City of Temecula has drafted this playbook so that other regions including cities and counties of any size will be able to obtain direction and guidance on how to address the growing need to provide services and programs to youth and families affected by Autism.

The Community Playbook is intended to provide a model and road map on how the Community’s regional efforts come together to form the Southwest Riverside Autism Task Force (SRATF).

Temecula Mayor Pro Tem Mike Naggar led the formation of the Southwest Riverside Autism Task Force, which included elected representatives from County of Riverside and County Board of Supervisors. The Temecula Community Services Department, under direction of the City Council, led the research and development of this Community Playbook.

Please use the following citation when referencing this community playbook:

### Acknowledgements

**Southwest Riverside Autism Task Force**

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<th>Mike Naggar</th>
<th>Jeff Stone</th>
<th>Marion Ashley</th>
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<td>Mayor Pro Tem</td>
<td>Supervisor, 3rd District</td>
<td>Supervisor, 5th District</td>
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<tr>
<td>Task Force Chair</td>
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<td>Melissa Melendez</td>
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Autism Spectrum Disorders

Overview

Autism Spectrum Disorder (ASD) is the fastest growing childhood disorder with a higher prevalence than childhood cancer, MS, and cystic fibrosis combined. Autism is a developmental disorder that appears in the first 3 years of life, and affects the brain’s normal development of social and communication skills. Autism is a spectrum disorder that affects individuals differently and at varying intensities.

Symptoms

The Autism Spectrum Disorders are usually not recognized until a child is 18 months old to 2 years old. Some children with autism might appear to be developing normally before ages 1 or 2 until the parent suddenly observes a “regression” and loss of language or social skills that they might have previously gained. Symptoms may vary from moderate to severe. Some core symptoms might include: social skills deficits, communication deficits, and behavioral challenges. Individuals with autism may have the following symptoms:

Communication Deficits

- Delayed speech or non-verbal
- Repetitive speech
- Sound deficits in words
- Lack of appropriate usage of gestures (e.g., pointing)

Social Skills Deficits

- Trouble relating to others or not have an interest in other people at all
- Limited eye contact, facial expressions, and use of gestures
- Trouble understanding other people’s feelings or talking about their own feelings
- Prefer not to be held or cuddled, or might cuddle only when they want to
- Appear to be unaware when other people talk to them but respond to other sounds
- Does not play “pretend” games (e.g., pretend to “feed” a doll)

Behavioral and Sensory Deficits

- May have unusual distress when routines are altered
- Show an unusual attachment to objects (e.g., an attachment to a vacuum machine)
• Perform repeated body movements (e.g., stimming which is a self-stimulator to help regulate or increase stimulation)
• Be overly sensitive in sight, hearing, touch, smell, or taste (e.g., colors are more vivid, and sounds are more intense)

Having any of these symptoms does not mean a child has autism, however, they indicate that a child should be further evaluated and developmentally screened. Typically, a child will be seen by a multidisciplinary team that may include a neurologist, psychologist, developmental pediatrician, speech/language therapist, learning consultant, or other professionals knowledgeable about Autism (National Institute of Mental Health, 2011).

**Diagnoses**

An early and accurate diagnosis is crucial to the success of a child with autism and serves as the basis for establishing an appropriate and effective education and treatment plan. According to the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) a total of 6 or more items must be identified as a diagnostic criterion for autism. There is no medical test, such as CT scan, blood test or urine sample to diagnose autism. Trained and licensed professionals such as a clinical psychologist or medical doctor conduct a diagnosis. Autism is diagnosed based on a developmental or cognitive assessment and/or a standardized play based assessment as well as a parent/caregiver interview. Children diagnosed with autism are eligible from birth for special education services (National Institute of Mental Health, 2011).

A variety of diagnoses are used for children on the Autism Spectrum:

• **Autistic Disorder**- Children diagnosed with autistic disorder meet the full criteria with having qualitative impairments in all three areas of social interactions, communication, and repetitive behaviors.

• **Asperger’s Disorder**- This is a pervasive developmental disorder that has some similarities to autism. Children with Asperger’s often have difficulties with the development of social skills and behavior. They function at a higher level than the typical child with Autism and usually their intelligence is measured as average to above average. Although speech patterns are somewhat unusual, a child with Asperger’s Disorder has little to no language delay.

• **Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS)**- Children placed on this diagnosis do not fully meet the criteria for autistic disorder or Asperger’s disorder. Children with PDD-NOS have significant challenges in speech and language development. This diagnosis varies and may be considered a sub threshold of Autism.
Causes

There are many theories about the potential cause of Autism; however, scientists have not come to a definitive conclusion. Research has identified a number of genes associated with autism and it is likely that both genetics and environment play a role. Research indicates that individuals with ASD have abnormal levels of serotonin or other neurotransmitters in the brain. And while we still do not know the exact cause of autism or how the brain functioning is impaired, it is important to understand that parental practices are not the cause of autism. Evidence based research also indicates that if a mother has one child with autism, then there is an increased risk of having a second child with autism. This indicates that there is a strong genetic component to the cause of autism (National Institute of Mental Health, 2011).

For more information about Autism Spectrum Disorder or Developmental Disabilities please visit your local healthcare facility or regional center at https://dds.ca.gov/.
Prelude

Living with Autism Spectrum Disorders can be very challenging and a life changing experience, however, when given the proper support and resources, parents are shown to fare well emotionally and have a strong bond with their child. The effort of the Southwest Riverside Autism Task Force was started as a result of an elected leader making his personal story with autism more public. Mayor Pro Tem Mike Naggar is a father of a 6-year-old child on the autism spectrum, and has experienced firsthand how difficult life can be for families of children with special needs. While beset by many questions upon the diagnosis of his son, Naggar reached out to other parents for resources and support. During a council meeting in April of 2009, he shared his family’s experience with autism, and addressed the growing incidence of autism in the community. As a result, the City of Temecula council came together to address the growing epidemic of autism and raise awareness by officially designating April as Autism Awareness Month.

In July 2009, the Temecula City Council directed the Community Services Department to prepare an addendum to the adopted Temecula Youth Master Plan (YMP) that would focus on serving youth with special needs. The goal of the program is accomplished through several strategies and actions developed by a community-based approach for community-driven implementation. The “Youth Master Plan Addendum for Special Needs” casts a wide net in addressing the needs of all youth, particularly those affected by disabilities. The City Council recognized that youth with special needs and their families have unique and complex issues that are not easily addressed. Although not all people with disabilities require support to participate in recreational programs, others, particularly those with more severe disabilities, may not have the same opportunities for integration unless accommodations are available to them.

Research and Incidence

In the past 20 years, an increasing number of children with Autism Spectrum Disorders have been recognized across the nation and the prevalence rates of autism continue to increase. According to The Centers for Disease Control and Prevention (CDC), it is estimated that 1 in 88 children in the United States have been identified as having an autism spectrum disorder (CDC, 2012). Autism spectrum disorders are now almost five times more common among boys than girls, with 1 in 54 boys being identified. Within the public school systems, population rates of autism in Temecula and Lake Elsinore school districts have increased approximately 300 percent. The autistic enrollment, in the Murrieta school district, has increased by 650 percent (Kabbany, 2007). In the Los Angeles Times (2010), a formulated spreadsheet reveals school district rates of autism
As of 2010, Riverside County constitutes 1,432 students or 14.6% of autism rates in public elementary school districts for grade levels K-5 in all of California, and the City of Temecula accounts for 164 students or 1.3% of autism rates. Nearly 12% of students require an Individualized Education Plan for special needs services through the Temecula Valley Unified School District (Los Angeles Times, 2010).

**Southwest Riverside Autism Task Force**

The Southwest Riverside Autism Task Force recognizes that Autism is a complex developmental disorder that appears in the first 3 years of life and affects the brain's normal development of social and communication skills (U.S. National Library of Medicine, 2012). The City of Temecula has a growing number of youth with special needs. Many families are faced with the stresses and challenges of living with a child with autism. The Autism Task Force is trying to provide the answers and support those families are looking for as well as educate the community as a whole.

The City of Temecula has created the “Southwest Riverside Autism Task Force,” (SRATF) a group of elected officials from cities in Southwest Riverside County who have joined together to find solutions to the difficulties faced by individuals and families affected by Autism. The City of Temecula and the Autism Task Force have partnered with surrounding cities and counties to address issues particularly affecting individuals and families with autism. The goal of the task force is to help Southwest Riverside County and other parts of the county prepare for the growing number of children with Autism entering the school district and eventually the work force. The task force focuses on addressing housing, employment, and services offered by the private and public sector.

While the Southwest Riverside Autism Task Force must work towards shrinking the gap in services for families, the region overall must identify ways in which support and resources are enhanced and more efficiently provided. The opportunity to provide solutions, as well as the growing concern over services and resources for individuals affected by Autism Spectrum Disorders, can be addressed through collaborative efforts that best improve the delivery, and coordination of autism services both city and countywide.
The Organizational Practice of the Southwest Riverside Autism Task Force

By 2010, the City of Temecula held the first Autism Task Force meeting that brought the Southwest Riverside County Region together in order to create a strategic roadmap to address autism. The SRATF meets every sixty days to discuss and review programs, services, and resources provided through government and non-government agencies. The committee also assesses and reviews foundational information from organizations throughout the county and surrounding cities. The region in which the SRATF gathers information from is the State of California Department of Developmental Disabilities, Inland Regional Center, Department of Public Social Services and Department of Mental Health, School District, Interagency Council, and non-profit organizations.

The task force consists of twelve members who include the Task Force chair, the Mayor Pro Tem Mike Naggar, Supervisor Jeff Stone 3rd District Riverside County, Supervisor Ashley 5th District Riverside County, Council Member Rick Gibbs, Council Member Melissa Melendez, Council Member Mary Craton, Council Member Rita Rogers, Mayor Jerry Franchville (ret), Council Member Sue Kristjansson, and Council Member Bridgette Moore. The task force brings together southwest Riverside County regions across Temecula, Murrieta, Riverside, Lake Elsinore, Canyon Lake, Perris, Hemet, Menifee, Wildomar and unincorporated areas of Riverside County.

The task force welcomes and encourages parents, professionals, and individuals from the community who are affected or know someone who is affected by Autism to attend the meetings. The task force also invites representatives from the school districts, the medical community, regional center, local churches, and non-profit organizations. Through the development of the task force, it is ensured that throughout their lifespan, an individual with Autism can:

- Be given the same opportunities and integration into their community
- Receive health care services that are readily available to them
- Obtain on-going suitable services and treatments
- Receive legally required services that the state mandates without any difficulties
- Receive family-centered supports
- Receive parent-education and support
- Obtain opportunities for transition into adulthood

The Southwest Riverside Autism Task Force appoints its members to work together on addressing ways to:
a) Assess the availability of services currently provided through the region to help understand common screening measures, early diagnoses, and treatment options

b) Review current services that have been effective with providing the best practices of treatment service options

c) Review effectiveness and accessibility of programs and services provided to individuals and families with autism

d) Review concerns and issues in programming and services and how they can be readily addressed

e) Provide individuals and families a forum and platform to address concerns

f) Assess availability of services in respect to cost, location, and types of services provided.

g) Identify funding sources, social welfare programs, and fundraising opportunities

h) Locate and discuss jobs and post-secondary educational options for transitional independence.

i) Raise awareness through local and countywide communities and agencies

j) Build partnerships with service providers, autism related non-profit organizations, county agencies, state agencies, and local churches.
Outcomes and Achievements

The City of Temecula strives to maintain and provide a quality of life through a strong sense of community and through accessibility to those things that provide for a healthy, safe, viable and enriching life. The implementation of the Southwest Riverside County Autism Task Force has proven to make a significant impact on families, the community, and local private and public businesses. The following are ongoing efforts as a result of the Youth Master Plan Addendum as well as the Autism Task force:

- Community Education - Educate and inform the community about youth with special needs and available services
- Volunteerism - Create and promote volunteerism opportunities
- Training - Expand training among key constituencies that serve or engage youth with special needs such as public safety, youth, volunteers, recreation providers, and food service
- Public-Private Partnerships and Resources - Build new and expand current partnerships among public and private sector organizations that improve coordination, bridge gaps in services, and leverage resources opportunities
- Programs and Services - Provide, facilitate, collaborate and encourage programs and services, including recreation, sports and therapeutic opportunities that build on existing resources

Additionally, the task force has successfully identified and addressed many important issues, and as a result, it has created the following:

- Southwest Riverside County Special Needs Resource Guide
- Press Coverage that has educated and raised awareness to the community
- Hiring of an Inclusion Services Specialist
- Temecula Unified School District Support
- Autism Task Force Community Playbook
- Inclusive play structure
- Our Nicholas Foundation in collaboration with Inland Empire Autism Society created “Exceptional Diners” a program for local area restaurants to provide expedited service, or, if possible call ahead seating and ordering
- Target Holiday Shopping for families affected by Autism
• Our Nicholas Foundation in collaboration with the Inland Empire Autism Society created the Temeku Theatre Sensory Friendly Movie Night for children and families affected by Autism
• Provide training to City Staff on providing Inclusion at all City events and programs
• L.E.A.P. City of Temecula’s Learning Enriched Autism Program
• S.K.I.P. City of Temecula’s Supporting Kids Involving Parents program
• Inclusive Youth Services Programs
• Adaptive Aquatic Lessons
• Inclusive College Internship Program
• Youth Summer Employment Program
• Post-secondary educational opportunities
• Autism Awareness Workshops/Seminars
• Temecula Special Needs Resource Fair

There is an entire community supporting these efforts. However, the efforts do not stop in one community. They will continue to grow throughout the region and exceed all boundaries.

*Photo complimentary of the Temecula Special Needs Resource Fair, 2012.*
Courses for Obtaining Services

The next step in obtaining services is an important and vital part in identifying services and resources. Services will vary depending on the child’s needs and level of functioning. Some types of services might include speech and language therapy, occupational therapy, physical therapy, behavioral health therapy, medical and dental care, sensory integration therapy, educational services, advocacy, socialization, recreation, transitional living, employment programs, post-secondary programs and parent and family education and support.

Roadmap to Services

1. State of California Department of Developmental Services-The California Department of Developmental Services is the agency through which the State of California provides services and supports to individuals with developmental disabilities. These disabilities include mental retardation, cerebral palsy, epilepsy, autism and related conditions. Services are provided through state-operated developmental centers and community facilities, and contracts with 21 nonprofit regional centers. The regional centers serve as a local resource to help find and access the services and supports available to individuals with developmental disabilities and their families (State of California DDS, 2008).

2. Inland Regional Center - A parent who suspects their child has a disability or has already been diagnosed typically would contact the Inland Regional Center. Inland Regional Center is a nonprofit private agency that is in contract with the Department of Developmental Services to provide or coordinate services and supports for individuals with developmental disabilities. Currently, nearly 600 Inland Regional Center staff members provide services to more than 25,000 people with developmental disabilities and their families in San Bernardino and Riverside counties. Once a consumer is found eligible, he/she is paired with a Consumer Services Coordinator (CSC) who then becomes their primary contact at the center. They will meet on an ongoing basis to develop an annual Individual Program Plan (IPP) that lists specific, agreed upon goals and objectives that will enhance opportunities in the life of the consumer. To better meet the needs of consumers, Inland Regional Center designed programs according to age, specialization, and geographic location. Categories include Early Start/Prevention 0-3; School Age 3-15; Transition 16-22; Adult 23-59; and Senior 60+ (Inland Regional Center, 2012).

3. Temecula Unified School District - TVUSD is instructed to meet the unique needs of individuals with exceptional needs whose educational needs cannot be met with
modification of the general instruction program (California Education Code 56031). Their school district provides various programs to fit the needs of elementary school children and high school youth. Some of their programs include: Language and Speech, Adapted Physical Education, Physical and Occupational Therapy, Deaf and Hard Hearing Services, Behavior Management Service and more. For preschoolers, the Temecula Unified School District has an intake and assessment team to determine if the child qualifies for special education services and those qualified will have an assessment plan made to fit their needs (Temecula Valley Unified School District, 2011-2012).

4. Riverside County SELPA stands for “Special Education Local Plan Area”. The SELPA is responsible for supporting member districts in the implementation of the legal requirements of the Individuals with Disabilities Education Improvement Act (IDEIA), the federal law for Special Education.

5. Riverside County Department of Public Social Services - The Riverside County Department of Public Social Services goal is to protect and improve the well-being of the individuals and families who reside in Riverside County—especially those who cannot protect themselves. County services accomplish this by providing many different forms of public assistance from pre-natal Medi-Cal services for low income women to subsidized in-home care for vulnerable seniors and disabled adults (Riverside County Department of Public Social Services, 2010).

6. Riverside County Department of Mental Health - The Riverside County Department of Mental Health is comprised of three major programs: Mental Health Services, Substance Abuse Control Services, and the Public Guardians office. These programs are divided into five services that enable the department to provide prompt, efficient, professional, culturally competent and sensitive community based services throughout the county (Riverside County Department of Mental Health, 2010).

7. Non-Profit Organizations - Our Nicholas Foundation and Autism Society of Inland Empire, among many others, exist to provide supportive services to meet the needs of individuals and the community at large. Through the collaborative effort of the Southwest Riverside Autism Task Force and our local non-profit organizations, we are able to achieve positive outcomes in locating and providing the best services to our community and how to raise awareness.

8. The Temecula-Murrieta Interagency Council is a group of school staff members, city staff members, non-profit community agencies, and parents who work together to provide information and programming to help the youth and families of our valley. The first meeting of this new collaborative took place on September 9th, 2009 and was attended by 58 people. The Temecula Valley Unified School District and Murrieta Valley Unified School District worked together to help organize this meeting. City staff represented the Cities of Temecula and Murrieta and a number of community agencies attended as well. Schools, families, and communities need to work closely with each other to meet their mutual goals. Schools are located in communities, but are often times isolated from the community. Families live in neighborhoods; usually with little connection to each other or the schools their
children attend. Neighborhood entities such as non-profit agencies, youth groups, and parent organizations have major stakes in the community. They all affect each other for good or bad. Due to this and common goals of education and socialization of the young, schools, homes, and communities must collaborate with each other if they are to minimize problems and maximize results. The goal of the Interagency Council is to provide a forum for this discussion to take place. We must continue to identify the assets within our community and develop a comprehensive model for ensuring that our youth are knowledgeable about and can access the people and programs that are available in our community. Although this is not an easy task, establishing a critical mass of resources and strategies to enhance a caring community that supports all youth and their families will enable success at school and beyond (Temecula-Murrieta Interagency Council, 2012).
## ADDENDUM

Figure 1. Centers for Disease Control and Prevention, Data from 2012.

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<th>Surveillance Year</th>
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Identified Prevalence of Autism Spectrum Disorders

ADDM Network 2000-2008

Combining Data from All Sites
Figure 2. Los Angeles Times analysis of California Department of Education Data: Riverside County Unified School Districts

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<th>District</th>
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References


Riverside County Department of Mental Health. (2010). *Department of Mental Health Services: Children’s Services*. Retrieved from http://rcdmh.org/opencms/english/Mental_Health_Services/

