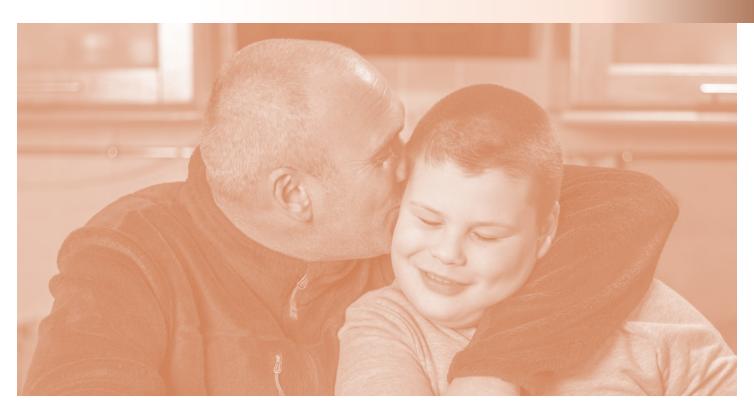


INLAND EMPIRE

# AUTISM SAFETY NET

COLLABORATIVE PLAN





# **Acknowledgements**

The Autism Safety Net Collaborative Plan represents the collective efforts, expertise, and dedication of many individuals and organizations committed to improving the lives of individuals with Autism and their families. This plan is the product of meaningful collaboration, shared vision, and a deep commitment to fostering a safer, more inclusive community. We would like to extend our heartfelt gratitude to the members of the Autism Safety Net Tiger Team, whose expertise, passion, and dedication have been instrumental in shaping this plan. Your insights and perspectives have ensured that the plan reflects the needs and priorities of the Autism community.

A special thank you to the Autism Society of the Inland Empire (ASIE) for serving as the backbone organization, providing coordination, leadership, and unwavering support throughout this process. Your commitment to this work has been a cornerstone of its success.

Finally, we wish to acknowledge the families, individuals with lived experience, educators, healthcare providers, behavioral specialists, first responders, and community advocates who contributed their time, stories, and expertise. Your voices have ensured that this plan is inclusive, actionable, and rooted in the real-life experiences of those it seeks to support.

Together, we are building a safety net that reflects compassion, equity, and commitment to creating a brighter future for individuals with Autism and their families.

This project was made possible by the commitment and funding investment of the Make Waves Family Foundation.





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# **Executive Summary**

The Inland Empire Autism Safety Net Collaborative Plan (referred to as "the Plan") is a region-wide initiative developed by a multidisciplinary "Tiger Team" to address systemic gaps in services and crisis response for individuals with Autism Spectrum Disorder (ASD). The Plan provides a framework for improving support systems, expanding access to resources, and enhancing crisis intervention strategies for individuals with Autism and their families. It is guided by best practices, evidence-based strategies, and input from stakeholders, including healthcare providers, law enforcement, educators, families, and individuals with Autism.

# **Background and Purpose**

Autism Spectrum Disorder affects over 92,000 residents in the Inland Empire, including approximately 5,340 individuals with profound Autism and 4,000 with severe behavioral challenges. ASD is characterized by difficulties with communication, sensory sensitivities, and self-regulation, which can lead to behavioral dysregulation, including self-injurious behavior, aggression, and elopement.

In March 2024, a tragic incident in Apple Valley, California, underscored systemic challenges in responding to individuals with Autism during crises. Fifteen-year-old Ryan Gainer, diagnosed with Autism, was fatally shot by San Bernardino County Sheriff's deputies at his home. The family had contacted emergency services due to Ryan having an episode of dysregulation, during which he reportedly assaulted family members and damaged property. Upon arrival, deputies encountered Ryan wielding a garden tool with a sharp blade. Body camera footage shows Ryan advancing toward a deputy, who retreated while issuing warnings. Despite these commands, Ryan continued to approach, leading another deputy to discharge his firearm, resulting in Ryan's death. In response to this tragedy, the Autism Society of the Inland Empire convened the Tiger Team, a collaborative network of experts and advocates, to design a proactive, inclusive, and sustainable action plan.

# How the Autism Safety Net Collaborative Plan Was Established

The Plan was developed through a structured and collaborative process led by the Autism Safety Net Tiger Team, a multidisciplinary group of experts and advocates. Over three focused meetings, the team assessed existing strengths and weaknesses, reviewed best practices, and co-created goals and strategies to address systemic challenges. Discussions emphasized prevention, intervention, and crisis response, resulting in prioritized actions and implementation mechanisms designed to improve safety and support systems for individuals with Autism and their families.

# Plan Goals and Objectives

The Plan establishes four overarching goals to address gaps in services and improve safety net systems.

Enhance the system used to respond to individuals with ASD, I/DD, and co-occurring diagnosis who become dysregulated and may require law enforcement and/or first responder intervention.

Enhance the approach to care and expand services for individuals with ASD across the lifespan.

Continuously train emergency responders, schools, parks and recreation, faith-based institutions and community service providers as well as families on ASD specific approaches and challenges.

Enhance multi-disciplinary and cross-sector collaboration.

Each of the goals have corresponding objectives which were prioritized as either short-term: urgent, to be addressed within the next 1-2 years; mid-term: important but not urgent, to be completed within 3-5 years; or long-term, which are considered important but can wait.



Goals and Objectives	Short- Term	Mid- Term	Long- Term
Goal #1: Enhance the system used to respond to individuals with ASD, I/DD, and co-occurring			
become dysregulated and may require law enforcement and/or first responder intervention.  Objective 1.1: Expand efforts beyond law enforcement to respond to crisis situations.			
(Inland Regional Center & Autism Society Inland Empire)	•		
Objective 1.2: Review and revise the model used for involuntary psychiatric holds to ensure			
it meets the needs of individuals with ASD and/or co-morbidities.			
Objective 1.3: Engage local and statewide legislators to advocate for policy change than			•
enhances supports for individuals with ASD who become dysregulated.			
Objective 1.4: Establish a standard of practice in co-response that ensures the safety of all parties involved.		•	
Goal #2: Enhance the approach to care and expand services for individuals with ASD across	the lifes	pan.	
Objective 2.1: Provide universal access to early identification.		•	
Objective 2.2: Establish ongoing monitoring for individuals with ASD to understand how their condition and corresponding needs change over time.		•	
Objective 2.3: Develop a more robust and timely transition process for individuals with ASD who are moving from the children's system of care to the adult system of care.		•	
Objective 2.4: Re-envision the adult system of care, transforming it from a compliance framework to a self-determination framework focused on empowerment and autonomy.			•
Objective 2.5: Establish navigational supports that provides consistent coordination of care across disciplines and service systems. <i>(Easter Seals Southern CA)</i>	•		
Objective 2.6: Enhance support for parents and caregivers of individuals with ASD.	•		
Goal #3: Continuously train emergency responders, schools, parks and recreation, faith-base community service providers as well as families on ASD specific approaches and challenges.	d institu	itions ar	nd
Objective 3.1: Create a system-wide inventory of trainings offered throughout disciplines and at all levels to support individuals with ASD. (Riverside Office of Education)	•		
Objective 3.2: Establish a baseline and three-tiered best practice/certified (if applicable) training and education system for service providers, law enforcement, and families.			•
Objective 3.3: Establish baseline and ongoing ASD education within the medical and mental health field.			•
Objective 3.4: Ensure all caregivers and individuals with ASD are provided training on how to respond to crisis needs. <i>(Inland Regional Center)</i>	•		
Goal #4: Enhance multi-disciplinary and cross-sector collaboration.			
Objective 4.1: Create a unified and integrated system to communicate diagnosis and individual needs that respect individuals and ensure efficient relay of necessary information.			•
Objective 4.2: Develop a shared definition of emergency/crisis situations versus dysregulation (as well as other issues) amongst professionals serving individuals with ASD. (Potentially Behavioral Health)	•		
Objective 4.3: Establish a regional transdisciplinary team (which includes individuals with ASD and caregivers) to address the systems issues that influence the various needs of individuals with ASD.		•	



# **Implementation Approach**

To ensure the Tiger Team continues to grow, thrive, and effectively implement the goals and objectives identified in this plan, an implementation structure has been established. This structure includes a backbone organization, the Tiger Team, Workgroups, and a diverse partnership base composed of providers, advocates, and individuals with lived experience.

# **Backbone Organization**

The Autism Society of the Inland Empire (ASIE) serves as the backbone organization for the Plan, providing leadership, logistical coordination, and direct support to the Tiger Team and Workgroups. ASIE facilitates meetings, maintains documentation, and oversees annual action plans while promoting collaboration, effective communication, and alignment among partners. It ensures equity remains central to strategies and decision-making, fosters engagement, and supports data sharing to guide actions and measure progress.

# Tiger Team

The Tiger Team meets quarterly to provide leadership, guidance, and advocacy for implementing the Plan. Serving as community ambassadors, members collaborate within their networks to advance efforts, track progress, and align initiatives with emerging trends and best practices. They evaluate strategies, address complex issues, and ensure the Plan remains focused on achieving its goals through effective implementation and accountability.

# Workgroups

The Collaborative Plan Workgroups meet regularly to provide input, develop action plans, and implement strategies that support Plan objectives. Members act as community ambassadors, coordinate activities, monitor progress through data evaluation, and adapt efforts to meet changing priorities. They collaborate across sectors, secure resources, and align work to advance implementation goals effectively.

In addition to these formal structures, it is expected that the broader partnership base, encompassing behavioral specialists, educators, healthcare providers, advocates, and caregivers, will actively contribute to the Team's efforts, ensuring the voices of all impacted communities are represented and central to the plan's success.

# **Monitoring and Evaluation**

Progress will be tracked through mid-year status reports, annual assessments, and updates to the action plan. Continuous data collection will inform improvements, ensuring accountability and alignment with evolving needs.



The Inland Empire Autism Safety Net Collaborative Plan represents a unified, strategic approach to addressing the challenges faced by individuals with Autism and their families.

By fostering collaboration, prioritizing inclusion, and implementing evidence-based strategies, the Plan seeks to build a safer, more supportive, and equitable community for all.



# **Introduction and Background**

# **Autism and Dysregulation**

# Autism Spectrum Disorder...What is It?

Autism Spectrum Disorder (ASD), referred to as Autism, is a complex, lifelong developmental condition that typically appears during early childhood and can impact a person's social skills, communication, relationships, and self-regulation. The Autism experience is different for everyone. It is defined by a certain set of behaviors and is often referred to as a "spectrum condition" that affects people differently and to varying degrees.

While there is no known single cause of Autism, early diagnosis helps a person receive resources to support the choices and opportunities needed to live fully.

The prevalence of Autism in the US has drastically increased from 1 in 1,000 in 1995 to 1 in 36 by 2023.1



# Common Behaviors Found in People with Autism



# Social Communication and Interaction Skills

- Avoids or does not keep eye contact
- May not respond to their name
- May not show facial expressions like happy, sad or surprised
- Does not notice when others are hurt or upset
- Uses few gestures and/or does not point to things to demostrate a point
- Preference for predictable, structured activities



# Restrictive or Repetitive Behaviors or Interests

- Repeats words or phrases over and over (called echolalia)
- Interact with items (like toys) the same way every time
- Is focused on parts of objects
- Gets upset by minor changes
- Has obsessive interests
- Must follow certain routines
- Flaps hands, rocks body, or spins self in circles
- Has unusual reactions to the way things sound, smell, taste, look, or feel



# Other Behavior

- Delays in language, movement or cognitive skills
- Hyperactive, impulsive, and/or inattentive behavior
- Unusual mood or emotional reactions
- Anxiety, stress or excessive worry
- Lack of fear or more fear than expected



<sup>&</sup>lt;sup>1</sup> Center for Disease Control and Prevention: Data & Statistics on Autism Spectrum Disorder. Downloaded on April 15, 2024, from: <a href="https://www.cdc.gov/ncbddd/autism/data.html">https://www.cdc.gov/ncbddd/autism/data.html</a>



Individuals with Autism may experience dysregulation (sometimes referred to as complex or challenging behaviors and/or aggression) due to differences in brain development and sensory processing. These neurological variations can lead to behaviors such as repetitive movements, unusual responses to people or surroundings, and difficulties with changes in routine, as they may rely on these behaviors to self-regulate emotional states or manage overwhelming sensory input. Understanding these behaviors and the purpose they serve for individuals with Autism is important in developing effective strategies for support.

# **Aggression Towards Others**

Behaviors that may cause physical harm to others including hitting, biting, kicking, or throwing objects. These aggressive actions are typically not malicious but are often expressions of frustration, fear, or overwhelming sensory stimulation that the individual cannot communicate verbally or manage effectively.

# Self-Injurious Behavior

Actions taken by individuals that cause harm to themselves. This can include behaviors such as head-banging, hand-biting, hair-pulling, and scratching their own skin. These behaviors often serve as coping mechanisms to deal with emotional distress, sensory overload, or to communicate needs and discomfort when verbal communication is challenging.

# **Property Destruction**

Damage or destroy objects around them. This can include breaking items, tearing clothes or papers, knocking down furniture, or other acts that result in physical damage to their surroundings. Such behaviors are typically not intended as defiant or malicious acts; rather, they often stem from intense emotions, sensory overload, or frustrations that the individual cannot express verbally.

# Elopement

Tendency to leave a safe environment, such as home, school, or a caregiver's presence, and wander off without permission or awareness of potential dangers. This behavior is often driven by impulsivity, stress from sensory overload, or the desire to escape from a stressful or uncomfortable situation.

## Pica

Persistent ingestion of non-food items that are not nutritionally beneficial. Common items consumed can include dirt, clay, chalk, paper, plastic, or metal. Pica often stems from sensory-related issues, where the person may be attracted to certain textures or sensations in their mouth and throat. It can also be a manifestation of compulsion, nutritional deficiencies, or an improperly developed perception of what is edible.

A more comprehensive data brief regarding Autism and dysregulation is available in Appendix A.

Understanding the complexities of Autism and the challenges associated with dysregulation underscores the importance of creating supportive systems that respond effectively during crises. When individuals with Autism experience dysregulation, their behaviors—often driven by sensory overload, fear, or frustration—may escalate, requiring a nuanced and compassionate response. The tragic case of Ryan Gainer, as described on the following page, serves as a call to action to examine and improve the ways our systems support individuals with Autism during moments of heightened vulnerability.





# Tragic Incident Highlights Need for Systemic Change in Crisis Response for Individuals with Autism

In March 2024, a tragic incident in Apple Valley, California, underscored systemic challenges in responding to individuals with Autism during crises. Fifteen-year-old Ryan Gainer, diagnosed with Autism, was fatally shot by San Bernardino County Sheriff's deputies at his home. The family had contacted emergency services due to Ryan having an episode of dysregulation, during which he reportedly assaulted family members and damaged property. Upon arrival, deputies encountered Ryan wielding a garden tool with a sharp blade. Body camera footage shows Ryan advancing toward a deputy, who retreated while issuing warnings. Despite these commands, Ryan continued to approach, leading another deputy to discharge his firearm, resulting in Ryan's death.

This incident highlights systemic inadequacies in addressing mental health crises, particularly involving individuals with developmental disabilities. Sheriff Shannon Dicus acknowledged the need to strengthen the social safety net for those experiencing mental health challenges, emphasizing the complexities deputies face in rapidly evolving situations. Advocates and family representatives have called for changes, arguing that law enforcement personnel may benefit from training to manage situations involving neurodivergent individuals effectively. They have advocated for alternative response models, such as deploying mental health professionals, to prevent similar tragedies. This case underscores the imperative for systemic reforms to ensure that individuals with Autism receive appropriate and compassionate responses during crises, aiming to prevent future tragedies and enhance community safety.



# **Inland Empire Autism Safety Net Tiger Team**

The Autism Safety Net Tiger Team (herein referred to as "Tiger Team") was established as a multidisciplinary collaboration in response to the tragic death of Ryan Gainer, underscoring the urgent need for systemic improvements in addressing crises involving individuals with Autism. This team brings together diverse professionals, including healthcare providers, educators, law enforcement representatives, mental health specialists, family advocates, and Autism service providers. Their collective expertise ensures a comprehensive understanding of the complex challenges faced by individuals with Autism and their families.

The primary purpose of the Tiger Team is to develop and implement a regional plan focused on prevention, intervention, and crisis response for individuals with Autism who may experience dysregulation. By leveraging the unique perspectives and skills of each member, the team aims to co-create innovative, inclusive, and actionable strategies that enhance safety and support at all levels of the system.

The multidisciplinary approach is essential for this mission. It fosters collaboration across sectors, ensuring that all stakeholders are represented and that solutions are holistic rather than siloed. This inclusive framework enables the identification of gaps in resources, the alignment of services, and the creation of effective prevention, intervention, and crisis response protocols. By working together, the Tiger Team aims to transform the Inland Empire into a region where individuals with Autism receive compassionate and effective support during times of need.

# **Autism Society of the Inland Empire**

The Autism Society of the Inland Empire (ASIE) is a trusted nonprofit organization dedicated to improving the lives of individuals with Autism and their families in the Inland Empire region. For over two decades, ASIE has served as a cornerstone for advocacy, education, and support, fostering a community where people with Autism can thrive. Through its programs, ASIE connects families with resources, hosts educational workshops, organizes community events, and works to raise awareness about Autism. Its commitment to equity and inclusion has made it a vital resource for individuals across the Autism spectrum, particularly those facing significant challenges.

As the initiator of the Autism Safety Net Tiger Team, ASIE serves as the backbone organization for the team and is intending to support the implementation of the collaborative plan. This role entails providing logistical support, coordinating meetings, and ensuring consistent communication among team members. ASIE's expertise in community engagement and its established partnerships across sectors position it uniquely to drive the plan forward.

# **Tiger Team**

A tiger team is a specialized, crossfunctional group assembled to address a specific challenge or crisis through a focused, collaborative approach.

Originating from the aerospace and military fields, tiger teams are known for their ability to pool diverse expertise and rapidly devise innovative solutions to complex problems. Typically, these teams consist of individuals with a broad range of skills, perspectives, and professional backgrounds, enabling them to examine an issue from multiple angles and propose comprehensive strategies. The hallmark of a tiger team is its multidisciplinary composition and its emphasis on swift, decisive action to tackle systemic issues that require collective insight and coordination.

In the context of the Inland Empire Autism Safety Net Plan, the tiger team model is especially appropriate for addressing the systemic gaps in crisis response for individuals with Autism. This team brings together experts to collaboratively design solutions that bridge existing service gaps and enhance safety outcomes. By leveraging the collective expertise of its members, the tiger team ensures that the resulting plan is both practical and sensitive to the unique needs of individuals with Autism and their families. The multidisciplinary nature of the team underscores the importance of breaking down silos between agencies and creating a cohesive, community-based response system.



# How the Autism Safety Net Collaborative Plan Was Established

The development of the Autism Safety Net Collaborative Plan was guided by a structured and collaborative process involving the Autism Safety Net Tiger Team. This team was tasked with identifying systemic challenges and designing practical solutions to improve the response to individuals with autism who have or may experience dysregulation. Over the course of three full-day meetings, the team leveraged their collective expertise to establish a shared understanding of the issues, prioritize goals, and co-create actionable objectives. Each meeting followed a focused agenda to ensure alignment with the groups charge, fostering inclusive discussions and evidence-based decision-making to lay the foundation for meaningful and sustainable change.

A summary of each meeting is provided below.

# Meeting #1: Coalesce around a Shared Vision & Assess Existing System Strengths and Weaknesses

April 18, 2024



The initial meeting of the Autism Safety Net Tiger Team focused on building a foundational understanding of the factors contributing to dysregulation in individuals with autism and laying the groundwork for collective action. Key objectives included developing a shared commitment to support individuals with autism and their families across prevention, intervention, and crisis response levels. The team also began envisioning necessary system improvements, inventorying existing resources, and identifying gaps in service provision.

# Meeting #2: Review of Best Practices & Identify Systems-wide Goals and Objectives

June 18, 2024



In the second meeting, the team solidified its commitment to collective action and established system-wide goals to guide the development of a comprehensive response. Discussions included reflections on progress since the first meeting, review of best practice models, and development of team goals and objectives. Special emphasis was placed on integrating the perspectives of various stakeholders to ensure an inclusive and actionable framework for crisis response and systemic reform.

# Meeting #3: Prioritize Goals and Objectives & Establish Action Plan and Implementation Mechanisms September 26, 2024



The final meeting prioritized the previously identified goals and objectives into short-, mid-, and long-term priorities. Additionally, an action plan was developed for those goals/objectives that were slared for short-term implementation. The team identified resources needed for implementation of the short term action plan and establishing structures for implementing, monitoring and evaluating progress. This meeting marked a shift from planning to action, positioning the team for ongoing implementation efforts and ensuring alignment with community needs and available resources.



# **Summary of Best Practices**

Supporting individuals with autism who experience dysregulation requires a comprehensive approach that addresses sensory, communication, behavioral, and systemic needs.

Dysregulation can be caused by:

- **Environmental Factors:** Sensory sensitivities can make specific environments overwhelming. Loud noises, bright lights, or crowded spaces can trigger dysregulation.
- Pain or Discomfort: Physical pain or discomfort, which might not be easily communicated, can lead to frustration and emotional outbursts.
- **Communication Challenges:** Difficulty expressing needs or emotions can result in heightened frustration and dysregulation.
- Routine Changes: Unexpected changes in routine or transitions can be particularly challenging, leading to anxiety and emotional dysregulation.
- Social Interactions: Navigating social situations can be stressful, especially if misunderstandings or social demands take work to meet.
- Internal Factors: Co-occurring conditions like anxiety, depression, or other mental health disorders

Best practices emphasize a preventative and proactive framework, multidisciplinary collaboration, and person-centered strategies to ensure safety, dignity, and long-term well-being.

# Developing a Personalized Self-Regulation Plan for Supporting Dysregulation

Proactive and preventative measures are critical in mitigating dysregulation in individuals with Autism. Early identification and monitoring are foundational to these efforts to allow for the timely recognition of developmental needs and emerging challenges. Ongoing assessments are equally important, as an individual's needs may evolve. For example, a child initially requiring support for sensory sensitivities may later need assistance with emotional regulation during adolescence.

Developing a personalized self-regulation plan that highlights strengths, identifies triggers, and includes coping strategies is crucial for supporting individuals with Autism. This approach addresses immediate needs and lays the groundwork for long-term growth and empowerment. Ongoing assessments are equally important, as an individual's needs may evolve.

# Multidisciplinary Team Response for Addressing Dysregulation

A multidisciplinary team response is an essential best practice for supporting individuals with Autism who experience dysregulation. This approach leverages the expertise of educators, behavioral specialists, medical professionals, mental health providers, and caregivers to create a cohesive support system tailored to the individual's unique needs. Each professional contributes specialized knowledge—educators focus on individualized educational strategies, behavioral specialists develop intervention plans, medical professionals address underlying health conditions, and caregivers provide insights into daily routines and triggers. This team-based approach ensures that interventions are holistic, addressing both immediate challenges and long-term developmental needs.





# **Skill Building Activities**

Engaging in activities that promote self-regulation skills can be practical in helping Autistic individuals. These activities might include physical activity, mindfulness and relaxation techniques, social skills training, and recreational and educational activities in a supportive environment. By regularly participating in these skill-building activities, individuals with Autism can develop better coping mechanisms, enhance their social interactions, and improve their overall quality of life. These activities provide immediate benefits and contribute to long-term personal growth and independence, fostering a sense of accomplishment and well-being.

# Family and Caregiver Support for Autism

Providing robust support systems for families and caregivers of individuals with Autism is a vital component of effective care. Resource accessibility is foundational in reducing caregiver stress and empowering families to provide consistent, high-quality support. Access to respite care offers temporary relief to caregivers, allowing them to recharge while ensuring their loved ones are in a safe and supportive environment. Support groups create opportunities for caregivers to connect with others facing similar challenges, fostering a sense of community and shared learning. Educational workshops further enhance caregiver skills, equipping them with knowledge about managing behaviors, navigating systems of care, and advocating effectively. Crisis toolkits are another best practice for empowering families to handle dysregulation effectively. These toolkits often include visual communication aids, sensory tools, and step-by-step guides for de-escalation techniques tailored to the individual's needs. Families who use such resources report greater confidence in managing crises and feel better equipped to advocate for their loved ones in interactions with educators, healthcare providers, or first responders. These supports not only enhance the well-being of individuals with Autism but also strengthen family resilience and stability.

# Training and Education for Supporting Individuals with Autism

ASD-specific training is a cornerstone of effective support for individuals with Autism, particularly during moments of dysregulation. This training equips first responders, educators, caregivers, and community providers with essential skills to recognize and respond to the unique needs of individuals with Autism. Key components include de-escalation strategies tailored to address sensory sensitivities and communication barriers, such as reducing environmental stimuli, using visual aids, and employing clear, direct language.

# Systemic Improvements for Supporting Individuals with Autism

Integrated communication systems are critical to ensuring consistent and effective care for individuals with Autism. These systems enable seamless information-sharing among service providers, caregivers, and other stakeholders, reducing the likelihood of miscommunication and gaps in care. By creating centralized digital platforms, service providers can access up-to-date records, behavioral plans, and medical information to coordinate interventions more effectively. Additionally, shared systems enable consistent documentation and progress tracking, ensuring interventions evolve with the individual's changing needs.



Policy advocacy is another essential aspect of systemic improvements, addressing the need for sustainable funding and broader access to resources. Legislative support can help establish programs, expand training opportunities, and secure funding for specialized services like mobile crisis units or sensory-friendly community spaces. By pushing for policies prioritizing inclusivity and resource allocation, advocacy efforts ensure that best practices are implemented and maintained over the long term. These systemic improvements build a foundation for comprehensive, equitable, and sustainable support systems that benefit individuals with Autism, their families, and the broader community.



Implementing these best practices promotes safety, independence, and inclusion for individuals with Autism, fostering an environment where they can thrive and participate fully in their communities. These strategies address immediate needs and create a foundation for long-term growth, empowerment, and well-being. By reducing stress on families, caregivers, and the systems that support them, these approaches enhance the capacity of all stakeholders to provide consistent, high-quality care. The result is a more compassionate, coordinated, and effective response to dysregulation that benefits individuals, strengthens families and contributes to creating more inclusive and resilient communities.

Here are some examples of organizations that use these best practices to provide comprehensive care and support to adults with autism and severe behavior issues:



# Kennedy Krieger Institute (Maryland)

The Kennedy Krieger Institute in Maryland offers both the Center for Autism Services, Science, and Innovation (CASSI™) and Neurobehavioral Disorders Continuum of Care. The center empowers neurodiverse individuals through state-of-the-science clinical care, innovative research, and high-impact training. They offer both inpatient and outpatient services, utilizing a multidisciplinary approach that includes behavioral psychologists, psychiatrists, medical providers, and other specialists



# **Emory Autism Center (Georgia)**

Emory Autism Center in Georgia offers diagnostic assessments, behavior support and skill building, school consultation, transition to adulthood plans, counseling clinics, medical services, and social engagement programs. The Severe Behavior Program at the Marcus Autism Center provides a continuum of services for individuals with developmental disabilities between the ages of 2 and 21.



# **Regional Collaborative Plan**

# Goals and Objectives

Group discussions regarding the strengths and weaknesses of the service spectrum available to individuals with Autism in the Inland Empire, combined with a review of best practices, were used as the basis for developing the following goals and objectives. These goals and objectives shall serve as a road map to focus Tiger Team efforts over the next five years. The plan guides limited resources at a strategic level and will be used to hold the Team accountable for the work that it does.

Each of the objectives is organized as either short-term: urgent, to be addressed within the next 1-2 years; midterm: important but not urgent, to be completed within 3-5 years; or long-term, which are considered important but can wait. Implementation will depend on leveraging existing efforts as well as establishing new ones.

Goal	Objective	Short- Term	Mid- Term	Long- Term
Goal #1	Objective 1.1: Expand efforts beyond law enforcement to respond to crisis situations. (Inland Regional Center & Autism Society Inland Empire)	•		
Enhance the system used to respond to individuals with ASD, I/DD, and co- occurring diagnosis who	Objective 1.2: Review and revise the model used for involuntary psychiatric holds to ensure it meets the needs of individuals with ASD and/or co-morbidities.		•	
become dysregulated and may require law enforcement and/or first	Objective 1.3: Engage local and statewide legislators to advocate for policy change than enhances supports for individuals with ASD who become dysregulated.			•
responder intervention.	Objective 1.4: Establish a standard of practice in coresponse that ensures the safety of all parties involved.		•	
Goal #2	Objective 2.1: Provide universal access to early identification.		•	
Enhance the approach to care and expand services for individuals with ASD	Objective 2.2: Establish ongoing monitoring for individuals with ASD to understand how their condition and corresponding needs change over time.		•	
across the lifespan.	Objective 2.3: Develop a more robust and timely transition process for individuals with ASD who are moving from the children's system of care to the adult system of care.		•	
	Objective 2.4: Re-envision the adult system of care, transforming it from a compliance framework to a self-determination framework focused on empowerment and autonomy.			•
	Objective 2.5: Establish navigational supports that provides consistent coordination of care across disciplines and service systems. (Easter Seals Southern CA)	•		
	Objective 2.6: Enhance support for parents and caregivers of individuals with ASD.	•		



Goal	Objective	Short- Term	Mid- Term	Long- Term
Goal #3	Objective 3.1: Create a system-wide inventory of trainings offered throughout disciplines and at all levels to support individuals with ASD. (Riverside Office of Education)	•		
Continuously train emergency responders, schools, parks and recreation, faith-based	Objective 3.2: Establish a baseline and three-tiered best practice and certified (if applicable) training and education system for service providers, law enforcement, and families.			•
institutions and community service providers as well as	Objective 3.3: Establish baseline and ongoing ASD education within the medical and mental health field.			•
families on ASD specific approaches and challenges.	Objective 3.4: Ensure all caregivers and individuals with ASD are provided training on how to respond to crisis needs. (Inland Regional Center)	•		
Goal #4  Enhance multi-disciplinary	Objective 4.1: Create a unified and integrated system to communicate diagnosis and individual needs that respect individuals and ensure efficient relay of necessary information.			•
and cross-sector collaboration.	Objective 4.2: Develop a shared definition of emergency/crisis situations versus dysregulation (as well as other issues) amongst professionals serving individuals with ASD. (Potentially Behavioral Health)	•		
	Objective 4.3: Establish a regional transdisciplinary team (which includes individuals with ASD and caregivers) to address the systems issues that influence the various needs of individuals with ASD.		•	

# Implementation Approach

To ensure the Tiger Team continues to grow, thrive, and effectively implement the goals and objectives identified in this plan, an implementation structure has been established. This structure includes a backbone organization, the Tiger Team, Workgroups, and a diverse partnership base composed of providers, advocates, and individuals with lived experience.

The Autism Society of the Inland Empire (ASIE) will serve as the backbone organization, providing ongoing coordination, resource management, and logistical support to ensure the team's efforts are sustained and impactful. The Tiger Team, made up of representatives from key stakeholder groups, will guide decision-making, monitor progress, and address emerging challenges. Workgroups will meet on a regular basis to implement the action plan. It is expected that workgroup members will make and keep commitments to act on behalf of the action plan. The broader partnership base, encompassing behavioral specialists, educators, healthcare providers, advocates, and caregivers, will actively contribute to the Team's efforts, ensuring the voices of all impacted communities are represented and central to the plan's success.

A more detailed description of roles and responsibilities as it pertains to implementation is provided on the following page.



# Backbone Organization

The Autism Society of the Inland Empire will serve as the backbone organization to the Tiger Team. In that role, they will facilitate dialogue between partners, provide direct support for the Tiger Team and workgroups as needed, and generally help to coordinate the actions across efforts.

Specific activities the backbone organization will provide include:

- Organizes, facilitates, and maintains documentation for regular meetings with the Tiger Team and Workgroups.
- Plans and oversees meetings to promote information sharing, foster engagement, support workgroup activities, and develop the annual action plan.
- > Leads communication efforts on behalf of the Tiger Team, ensuring consistent and effective messaging.
- > Cultivates collaboration by engaging new and existing partners as well as key champions in the initiative.
- > Promotes alignment among partners by facilitating the exchange of cross-sector data and insights.
- Ensures equity remains a central focus in all strategies, actions, and decision-making processes.

# Collaborative Plan Workgroups

The Collaborative Plan Workgroups will meet on a regular basis and provide support and advocacy for collaborative plan implementation. They will also serve as community ambassadors and work throughout their own networks to advance efforts.

Specific activities of Workgroups members include:

- Participates in Workgroup meetings to provide input on implementation of action plan activities
- Develops and organizes to implement action plans, and adjusts work to reflect what is learned through action
- Collaborates, coordinates, and aligns work to achieve workgroup objectives
- Uses and shares data to evaluate and monitor work
- > Expands and adapts workgroup structure to meet changing community priorities
- Identifies and secures resources needed to implement action plan strategies

# Tiger Team

The Tiger Team will meet on a quarterly basis and provide support and advocacy for collaborative plan implementation. They will also serve as community ambassadors and work throughout their own networks to advance efforts.

Specific activities of Tiger Team members include:

- Upholds and champions the strategic direction established by the Tiger Team.
- > Provides leadership and ongoing guidance to ensure successful implementation of the collaborative plan.
- > Tracks and evaluates progress toward achieving the identified goals and objectives.
- Monitors developments at the local, regional, and national levels to align efforts with emerging trends and best practices.
- Analyzes complex issues to support and collaborate with workgroups formed to support implementation.
- Reviews, endorses, and facilitates the advancement of strategies proposed by Tiger Team members.

It is important to note that within a multidisciplinary framework, the cascading layers of collaboration may change over time. What is most important is that whatever structure is in place, all efforts tie back to the collaborative plan of action.



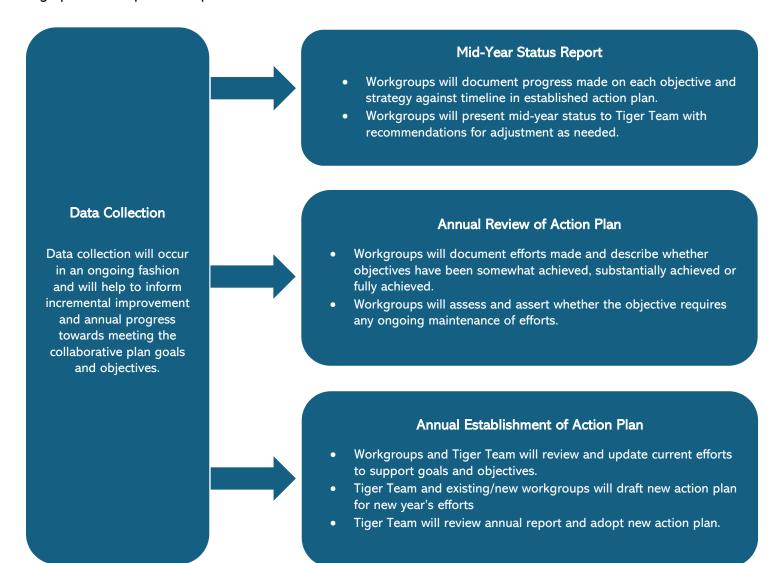
# Review and Updates to the Plan

This plan will be used as a management tool to direct Tiger Team efforts with clarity and in a manner that ensures partnership and transparency in the process. To accomplish this, all activities will be monitored in an ongoing fashion.

- Workgroups will use provide a status report to the Tiger Team on a semi-annual basis to share progress made, identify issues impacting implementation, and modify activities as needed.
- An annual assessment on the collaborative plan progress will be completed. This annual assessment will include an analysis of Workgroup efforts.

The annual assessment will help to inform the establishment of a new annual action plan by the Tiger Team as well as existing and newly formed workgroups. It is expected that the Tiger Team will review the annual assessment and the draft action plan during an annual retreat so that a thoughtful review and adoption can take place while also inviting additional partners into the process.

A graphic of this process is provided below.





# **Appendix**



# Appendix A: Autism Spectrum Disorder Data Brief 2024



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## **Dysregulation in People with Autism**

Individuals with Autism may experience dysregulation (sometimes referred to as complex or challenging behaviors and/or aggression) due to differences in brain development and sensory processing. These neurological variations can lead to behaviors such as repetitive movements, unusual responses to people or surroundings, and difficulties with changes in routine, as they may rely on these behaviors to self-regulate emotional states or manage overwhelming sensory input.

Understanding these behaviors and the purpose they serve for individuals with Autism is important in developing effective strategies for support.

### Aggression Towards Others

Behaviors that may cause physical harm to others including hitting, biting, kicking, or throwing objects. These aggressive actions are typically not malicious but are often expressions of frustration, fear, or overwhelming sensory stimulation that the individual cannot communicate verbally or manage effectively.

### Self-Injurious Behavior

Actions taken by individuals that cause harm to themselves. This can include behaviors such as headbanging, hand-biting, hair-pulling, and scratching their own skin. These behaviors often serve as coping mechanisms to deal with emotional distress, sensory overload, or to communicate needs and discomfort when verbal communication is challenging.

## Property Destruction

Damage or destroy objects around them. This can include breaking items, tearing clothes or papers, knocking down furniture, or other acts that result in physical damage to their surroundings. Such behaviors are typically not intended as defiant or malicious acts; rather, they often stem from intense emotions, sensory overload, or frustrations that the individual cannot express verbally.

Tendency to leave a safe environment, such as home, school, or a caregiver's presence, and wander off without permission or awareness of potential dangers. This behavior is often driven by impulsivity, stress from sensory overload, or the desire to escape from a stressful or uncomfortable situation.

Persistent ingestion of non-food items that are not nutritionally beneficial. Common items consumed can include dirt, clay, chalk, paper, plastic, or metal. Pica often stems from sensory-related issues, where the person may be attracted to certain textures or sensations in their mouth and throat. It can also be a manifestation of compulsion, nutritional deficiencies, or an improperly developed perception of what is edible.

# Autism Spectrum Disorder...What is It?

Autism Spectrum Disorder (ASD), referred to as Autism, is a complex, lifelong developmental condition that typically appears during early childhood and can impact a person's social skills, communication, relationships, and self-regulation. The Autism experience is different for everyone. It is defined by a certain set of behaviors and is often referred to as a "spectrum condition" that affects people differently and to varying degrees.

While there is no known single cause of Autism, early diagnosis helps a person receive resources to support the choices and opportunities needed to live fully.

## Prevalence of Autism

The prevalence of Autism in the US has drastically increased from 1 in 1,000 in 1995 to 1 in 36 by 2023.1



1 in 22 children in California are being diagnosed with Autism.

Estimates in the Inland Empire

4,000 estimate

# Common Behaviors Found in People with Autism

## Social Communication and Interaction Skills

- Avoids or does not keep eye contact
- May not respond to their name
- May not show facial expressions like happy, sad or surprised
- Does not notice when others are hurt or upset
- Uses few gestures and/or does not point to things to demostrate a point
- Preference for predictable, structured activities

# Restrictive or Repetative Behaviors or Interests

- Repeats words or phrases over and over (called echolalia)
- Inteacts with items (like toys) the same way every time
- Is focused on parts of objects (for example, wheels)
- Gets upset by minor changes
- Has obsessive interests
- Must follow certain routines
- Flaps hands, rocks body, or spins self in circles
- Has unusual reactions to the way things sound, smell, taste, look, or feel

## Other Behavior

- Delays in language, movement or cognitive skills
- Hyperactive, impulsive, and/or inattentive behavior
- Unusual mood or emotional reactions
- Anxiety, stress or excessive worry
- Lack of fear or more fear than expected

25-30%

Center for Disease Control and Prevention: Data & Statistics on Autism Spectrum Disorder. Downloaded on April 15, 2024, from: https://www.cdc.gov/ncbddd/autism/data.html





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# What Causes Challenging Behaviors?

## Sensory Sensitivity



Individuals with Autism often have heightened or reduced sensitivity to sensory inputs, such as sound, light, or touch. This sensory overload can be overwhelming, causing stress or anxiety that may manifest as aggressive or complex behaviors as a coping mechanism.

# **Difficulty Communicating**



Many people with Autism have trouble using verbal language and may find it difficult to express their needs, wants, or discomfort. Aggression can sometimes serve as a form of non-verbal communication used to express frustration or to have their needs

### Physical Discomfort or Pain



Undiagnosed physical issues, such as gastrointestinal discomfort or headaches, can cause considerable distress. Those with autism, particularly non-verbal individuals, might display aggression as an indicator of their physical pain.

## Lack of Predictability or Routine



Undiagnosed physical issues, such as gastrointestinal discomfort or headaches, can cause considerable distress. Those with autism, particularly non-verbal individuals, might display aggression as an indicator of their physical pain.

### **Health Related Issues**

Health-related causes of complex behaviors may include:



- Epilepsy: There is a higher prevalence of epilepsy among individuals with autism. Seizures can cause confusion, discomfort, and other cognitive impairments, which may manifest as aggression or other behavioral changes.
- Dental or Oral Health: Problems such as tooth decay, dental abscesses, or gum disease can be painful but hard to communicate about for someone with autism, particularly for those who are less verbal.
- Nutritional Deficiencies: Deficiencies in certain nutrients, such as vitamins B6, B12, D, magnesium, and omega-3 fatty acids, can affect neurological health and lead to mood swings, increased anxiety, and aggressive behavior.
- Medication Side Effects: Medications commonly prescribed to manage symptoms of autism and co-occurring conditions can have side effects that include increased aggression, irritability, or impulsivity.

of individuals with Autism have been diagnosed

# 38% with Intellectual Disabilities

# Common Co-occurring Psychiatric Disorders

25%

of youth with Autism experience suicidal ideations

One in ten youth with Autism attempt suicide



Of people with Autism, the following percentages also have other co-occurring disorders

16% Depression 11% Schizophrenia 7%

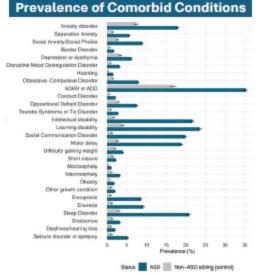
Attention Deficit Disorder 48% Post Traumatic Stress 40% Disorder

40% Obsessive Compulsive 17% Disorder

70-90% of children and adolescents have one co-occurring disorder

Bipolar Disorder

73%-81% of adults with ASD meet criteria for at least one current co-occurring psychiatric disorder







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# **Intersection of Autism and Trauma**

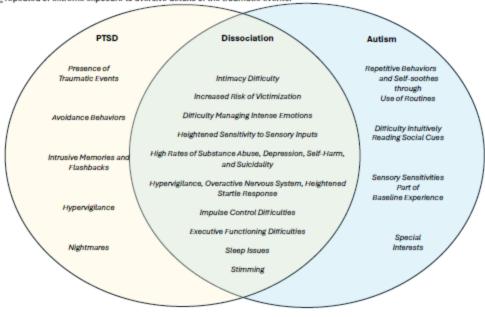


Clinical and scientific data show a higher risk of adverse events and trauma in people with an autism spectrum disorder (ASD).

- Heightened Sensory Sensitivity: Individuals with ASD often experience heightened sensitivity to sensory stimuti. This can make traumatic events particularly overwhelming as they might involve intense sensory inputs (e.g., loud noises, bright lights) that are more distressing for someone with sensory processing difficulties.
- Difficulty with Emotional Regulation: Many people with autism have trouble regulating their emotions. This difficulty can magnify the emotional impact of a traumatic event, making it harder for them to cope with and recover from the stress and anxiety caused by the event.
- Challenges in Understanding and Processing Events: Cognitive differences, including difficulties in understanding social contexts and processing information, may hinder their ability to comprehend the event fully and navigate their responses appropriately. This confusion can prolong the stress and hinder the processing of the traumatic experience.
- Previous Experiences of Being Misunderstood: Negative experiences with being misunderstood or not believed about their own experiences can lead individuals with ASD to expect similar outcomes. This expectation can discourage them from discussing their experiences or seeking help, leading to untreated trauma.

# Autism and Post Traumatic Stress Disorder (PTSD)

To meet the criteria for a post-traumatic stress disorder, one must be exposed to actual or threatened death, serious injury, or sexual violence by either directly experiencing the traumatic event, witnessing the event as it occurs to others, learning about the traumatic event, or experiencing repeated or extreme exposure to aversive details of the traumatic events.



Although research has yet to establish clear prevalence rates, the rates of probable PTSD in autistic people (32-45%) are higher than those in the general population (4-4.5%)





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# Benefits vs Consequences of an Appropriate Community Response

Benefits

Consequence:

## For the Individual



- Enhanced Quality of Life: Tailored support can significantly improve daily living experiences, allowing individuals to enjoy a higher quality of life.
- Increased Independence: Proper interventions help individuals gain life skills that promote independence in various activities.
- Better Educational Outcomes: With the right supports, individuals can achieve at their highest potential, paving the way for future success in vocational or higher educational settings.
- Improved Social Skills: Structured social skills training enhances their ability to interact with others, fostering relationships and community interration.
- Reduced Behavioral Challenges: Effective strategies can mitigate complex behaviors and emotional distress, leading to a more stable and fulfilling life.

- Stigma and Social Isolation: Without support individuals with autism who become dysregulated may face stigma, increased loneliness and isolation from their peers.
- Limited Educational and Vocational Opportunities: Challenging behavior limits academic and vocational achievements, reducing future employment prospects and economic independence
- Mental Health Issues: Insufficient support often correlates with higher rates of mental health disorders, such as anxiety, depression, and PTSD, especially if traumatic experiences are not appropriately addressed.
- Compromised Quality of Life: Tailored support can significantly improve daily living experiences, allowing individuals to enjoy a higher quality of life.

# For the Family



- Reduced Caregiver Stress: When individuals with autism receive the support they need, the burden on caregivers is greatly alleviated, enhancing the wellbeing of the entire family.
- Increased Family Stability: Effective support reduces familial disruption, leading to a more harmonious home environment.
- Enhanced Relationships: Supports that improve the individual's behavior and communication skills can lead to stronger family relationships.
- Empowerment: Families feel empowered and supported when effective resources and communities are accessible, making it easier to navigate the challenges of autism.
- Education and Awareness: Families benefit from increased awareness and understanding, which are often provided through community support programs.

 Heightened Stress and Mental Health Risks: Families dealing with inadequate support often experience increased stress, which can lead to mental health issues like depression

and anxiety among caregivers.

- Financial Strain: The costs of therapies, potential loss of income due to increased care responsibilities, and lack of state or community assistance can create significant financial burdens.
- Reduced Family Functioning: The strain of coping with challenging behaviors can affect the entire family's dynamics, potentially leading to strained relationships.
- Caregiver Burnout: Continuous stress without respite care or community support can lead to burnout among family members, affecting their health and well-being

## For Our Communities



- Economic Savings: Proper support reduces longterm costs related to healthcare, institutional care, and lost productivity, both for individuals and their caregivers.
- Cultural Richness: Inclusion of individuals with diverse neurotypes adds depth and diversity to the community, promoting a more inclusive society.
- Reduced Stigma: Effective community integration and support lead to greater awareness and reduced stigma around Autism.
- Safer Communities: By addressing specific needs, communities can prevent situations that might lead to harm for individuals with Autism or others, such as wandering or encounters with law enforcement.
- Workforce Burn-out: Without the proper supports in place, the workforce serving this population may experience high turnover.
- Lost Potential: Society loses out on the potential contributions that individuals with Autism can make as educated, employed, and active community members when they do not receive necessary supports.
- Increased Healthcare and Legal System Strain: Inadequate support can lead to more frequent encounters with the healthcare and legal systems, such as emergency room visits for injuries resulting from behaviors or legal issues related to inappropriate responses to stressful situations.



# Appendix B: Organizations/Systems that Support Individuals with ASD who Become Dysregulated

When facilitating a multidisciplinary team aimed at coordinating a community response for individuals with Autism who become dysregulated, it's crucial to involve a variety of service providers. Each provider plays a specific role and must aim to meet the needs of the individual in a manner that aligns with their best interests, ensuring safety and promoting dignity and autonomy. Below is a bulleted list detailing various service providers that are intended to support the plan contained herein.

- Local Schools and Educational Institutions: Special education teachers, school counselors, and school
  psychologists who can implement and support educational plans that include de-escalation strategies.
- Mental Health Services: Psychologists, psychiatrists, and therapists specializing in Autism spectrum disorder who can provide ongoing mental health support and crisis intervention.
- Medical Professionals: Pediatricians and neurologists who understand the medical and neurological aspects of Autism and can offer medical interventions to assist in managing behaviors.
- Social Services: Social workers and case managers who can provide families with resources, support, and guidance on navigating the care systems and accessing necessary services.
- o **Behavioral Specialists:** Board Certified Behavior Analysts (BCBAs) and behavioral interventionists who can design and implement behavior intervention plans that include strategies for managing dysregulation.
- Law Enforcement and Emergency Responders: Police and emergency medical technicians (EMTs) trained in crisis intervention techniques specifically designed for individuals with Autism, ensuring safety and appropriate response during high-stress situations.
- Community-Based Organizations: Local nonprofits and community groups that support individuals with
   Autism, offering programs and activities designed to enhance social integration and emotional regulation.
- Respite Care Providers: Organizations and individuals offering temporary care services that provide relief for regular caregivers, allowing them time to rest and recharge.
- Legal and Advocacy Groups: Attorneys and advocates who specialize in disability rights can assist in ensuring that the individual's rights are protected during interventions and in broader care scenarios.
- Autism Advocacy Organizations: National and local Autism organizations that can provide training, resources, and support to all involved parties and advocate for systemic changes to better serve the Autism community.
- Occupational Therapists: Professionals who can address sensory processing issues and suggest environmental modifications that help prevent or mitigate dysregulation.
- Speech-Language Pathologists: These specialists can assist those with communication challenges, which
  are often a root cause of frustration and dysregulation in individuals with Autism.



# Appendix C: Short-Term Objectives Workgroups (2025-2026)

	Short-Term Workgroups							
Goal	Objective	Workgroup Members	Organizations Willing to Lead Efforts					
Goal #1 Enhance the system used to respond to individuals with ASD, I/DD, and cooccurring diagnosis who become dysregulated and may require law enforcement and/or first responder intervention.	Objective 1.1: Expand efforts beyond law enforcement to respond to crisis situations.*	<ul> <li>Maia Pawooskar</li> <li>Melaura Erickson Tomaino</li> <li>Lillian Vasquez</li> <li>Stephani Congdon</li> <li>Lilliana Garnica</li> <li>Marissa R. Congdon</li> </ul>	Autism Society     Inland Empire     (Lead)					
Goal #2 Enhance the approach to care and expand services for individuals with ASD	Objective 2.5: Establish navigational support that provides consistent coordination of care across disciplines and service systems.*	<ul> <li>Angela Yen</li> <li>Mariela Cepeida</li> <li>Allison Cunningham</li> <li>Rick Gutierrez</li> </ul>	Easter Seals     Southern CA (Lead)					
across the lifespan.	Objective 2.6: Enhance support for parents and caregivers of individuals with ASD.	<ul> <li>Maia Pawooskar</li> <li>Cornelius Cherry</li> <li>Mariela Cepeida</li> <li>Regina Weatherspoon-Bell</li> <li>Zachary Ginder</li> <li>Marissa R. Congdon</li> </ul>	<ul> <li>Inland Empire         Health Plan (IEHP)</li> <li>IEHP Foundation</li> <li>Dreamers,         Visionaries and         Leaders Project</li> <li>Bena Park Police</li> <li>Inland Empire         Autism Assessment         Center of         Excellence</li> </ul>					
Goal #3  Continuously train emergency responders, schools, parks and recreation, faith-based institutions and	Objective 3.1: Create a system-wide inventory of trainings offered throughout disciplines and at all levels to support individuals with ASD.	<ul> <li>Maia Pawooskar</li> <li>Melaura Erickson Tomaino</li> <li>Stephani Congdon</li> <li>Edward Miguel</li> <li>Awit Dalusong</li> </ul>	<ul> <li>Riverside Co Office         of Education (Lead)</li> <li>Easter Seals         Southern California</li> <li>Port View         Preparatory</li> </ul>					
community service providers as well as families on ASD specific approaches and challenges.	Objective 3.4: Ensure all caregivers and individuals with ASD are provided training on how to respond to crisis needs.*	<ul> <li>Cornelius Cherry</li> <li>Eric Hamler</li> <li>Mike Ortega</li> <li>Melaura Erickson Tomaino</li> <li>Lillian Vasquez</li> <li>Stephani Congdon</li> <li>Lilliana Garnica</li> <li>Marissa R. Congdon</li> <li>CJ Cook</li> </ul>	Inland Regional     Center (Lead)					
Goal #4  Enhance multi- disciplinary and cross- sector collaboration.	Objective 4.2: Develop a shared definition of emergency/crisis situations versus dysregulation (as well as other issues) amongst professionals serving individuals with ASD.							

<sup>\*</sup>These objectives will be prioritized for action.



# Appendix D: Short-Term Objectives Action Plan

Goal 1: Enhance the system used to respond to individuals with ASD, I/DD, and co-occurring diagnosis who become dysregulated and may require law enforcement and/or first responder intervention.

Objective 1.1: Expand efforts beyond law enforcement to respond to crisis situations.

Strategies to Support Achievement of Objective	Timeline for Completion	Lead Agency or Individual	Supporting Individuals or Agencies	Resources Needed to Act
Develop an alternative crisis response model that includes mental health professionals and ASD specialists in the first response.  • Options to consider will include the establishment of a Crisis Support Service option in Riverside County for Inland Regional Center clients, development of a Systemic Therapeutic, Assessment, Resources and Treatment Program (START) in San Bernardino County and/or the development of a specialized clinic dedicated to addressing patients' complex medical needs.				
Partner with local law enforcement to define scenarios in which mental health teams should lead the response instead of police				
Train all crisis response teams on ASD-specific de-escalation techniques.				
Establish a pilot program in select areas to test the effectiveness of this alternative crisis response model.				
Evaluate the pilot's outcomes to assess if broader implementation is viable.				



Goal 2: Enhance the approach to care and expand services for individuals with ASD across the lifespan.

# Objective 2.5: Establish navigational supports that provides consistent coordination of care across disciplines and service systems.

Strategies to Support Achievement of Objective	Timeline for Completion	Lead Agency or Individual	Supporting Individuals or Agencies	Resources Needed to Act
Identify gaps in current care coordination efforts across different service systems (e.g., healthcare, education, behavioral health)				
Create a navigator role that serves as the single point of contact for families navigating multiple services.				
Develop a shared electronic system where navigators can track the services being accessed by each individual with ASD.				
Provide cross-training for navigators to ensure they are familiar with the full spectrum of services and resources available.				
Launch a pilot program to test this coordinated care model, starting with high-need families.				



# Goal 2: Enhance the approach to care and expand services for individuals with ASD across the lifespan.

Objective 2.6: Enhance support for parents and caregivers of individuals with ASD.

Strategies to Support Achievement of Objective	Timeline for Completion	Lead Agency or Individual	Supporting Individuals or Agencies	Resources Needed to Act
Survey parents and caregivers to determine their highest support needs				
Develop a peer support network for caregivers, where they can share resources, advice, and emotional support.				
Partner with local organizations to provide regular respite care services.				
Offer workshops and online courses on managing stress, navigating services, and advocating for children with ASD.				
Ensure ongoing mental health support for caregivers through counseling or support groups.				



Goal 3: Continuously train emergency responders, schools, parks and recreation, faith-based institutions and community service providers as well as families on ASD specific approaches and challenges.

Objective 3.1: Create a system-wide inventory of trainings offered throughout disciplines and at all levels to support individuals with ASD.

Strategies to Support Achievement of Objective	Timeline for Completion	Lead Agency or Individual	Supporting Individuals or Agencies	Resources Needed to Act
Survey all relevant organizations to compile a list of ASD training programs currently available.				
Build an online database where the inventory of trainings can be easily accessed by professionals and families.				
Categorize trainings by target audience (e.g., law enforcement, healthcare providers, families) and level (introductory, intermediate, advanced).				
Regularly update the database to ensure it includes the latest training opportunities.				
Promote the training inventory to ensure wide usage across sectors.				



Goal 3: Continuously train emergency responders, schools, parks and recreation, faith-based institutions and community service providers as well as families on ASD specific approaches and challenges.

Objective 3.4: Ensure all caregivers and individuals with ASD are provided training on how to respond to crisis needs.

Strategies to Support Achievement of Objective	Timeline for Completion	Lead Agency or Individual	Supporting Individuals or Agencies	Resources Needed to Act
Develop an ASD-specific crisis intervention training program for caregivers and individuals with ASD.				
Include real-life scenarios in the training to help caregivers practice de-escalation techniques				
Offer the training in multiple formats (e.g., in-person, virtual, self-paced online modules).				
Partner with local Autism organizations to distribute crisis response toolkits to families.				
Evaluate the effectiveness of the training program through feedback surveys and adjust as needed.				



# Goal 4: Enhance multi-disciplinary and cross-sector collaboration.

**Objective 4.2:** Develop a shared definition of emergency/crisis situations versus dysregulation (as well as other issues) amongst professionals serving individuals with ASD.

professionals serving marviadals with 765.				
Strategies to Support Achievement of Objective	Timeline for Completion	Lead Agency or Individual	Supporting Individuals or Agencies	Resources Needed to Act
Convene a multidisciplinary team to review current definitions of crisis versus dysregulation.				
Develop a unified definition that distinguishes between emergency situations and dysregulation episodes in individuals with ASD.				
Create a flowchart or decision-making tool for professionals to use in the field to determine the appropriate response.				
Test the new definitions and tools in real-world settings, collecting feedback from professionals.				
Provide training across disciplines to ensure consistent understanding and application of the shared definition.				



# **Appendix E: Existing Efforts to Support Objectives**

At the third meeting of the Tiger Team, participants were asked to identify existing efforts that support plan objectives. The intention is to leverage these efforts where able to prevent a duplication of efforts and to advance progress effectively. These should be used when specific action plans are developed utilizing the template found in Appendix D.

# Objective 1.1: Expand efforts beyond law enforcement to respond to crisis situations.

## **Current Efforts:**

- SBC Department of Behavioral Health (DPBH) may respond to crisis situations if an officer clears the scene, available Monday-Friday.
- o Three cities in the region have HOPE teams (active Monday-Friday, 8 a.m. to 5 p.m.).
- Riverside County has a Behavioral Crisis Assistance Team (BCAT) that includes a therapist and law enforcement to respond to crisis situations.
- Regional Center refers to Crisis Intervention Services, though it differs from the START model preferred by the group.

Objective 1.2: Review and revise the model used for involuntary psychiatric holds to ensure it meets the needs of individuals with ASD and/or co-morbidities.

## **Current Efforts:**

- o Current efforts focus on stabilization, with prevention being less prioritized.
- Families often bear the burden of navigating the system, and information sharing can be difficult unless individuals are under conservatorship.

Objective 1.3: Engage local and statewide legislators to advocate for policy change than enhances supports for individuals with ASD who become dysregulated.

## **Current Efforts:**

Entities such as Disability Rights CA, Inland Regional Center, Autism Business Services, and Autism Society Inland Empire (ASIE) support legislative efforts, but the efforts are not well-coordinated or specific to the Inland Empire.

# Objective 1.4: Establish a standard of practice in co-response that ensures safety of all parties involved.

## **Current Efforts:**

- POST (Peace Officer Standards and Training) certified training is available throughout the state.
- Non-certified training from various perspectives is also available.
- SB 882 mandates the establishment of best practices regarding law enforcement training for ASD.
- o A 1-hour virtual training for dispatchers is available.

# Objective 2.1: Provide universal access to early identification.

# **Current Efforts:**

- Well-child visits mandate developmental screenings at 12, 18, and 36 months.
- o Help Me Grow efforts, alongside First 5 investments, support these screenings.
- First 5 Riverside supports Healthy Steps, which integrates screenings into its process.

Objective 2.2: Establish ongoing monitoring for individuals with ASD to understand how their condition and corresponding needs change over time.

# **Current Efforts:**

- o Re-assessments may occur if requested by a primary care provider or psychologist.
- o In schools, re-assessments occur every three years after the initial identification, with annual plan reviews.



- Kaiser conducts re-evaluations every 12 months, and Regional Center re-evaluates individuals after provisional eligibility.
- o Regular progress reports are issued for individuals receiving ABA services.

Objective 2.3: Develop a more robust and timely transition process for individuals with ASD who are moving from the children's system of care to the adult system of care.

# **Current Efforts:**

- Schools initiate the transition process at ages 15-16, but transition plans are often insufficient and services are lacking.
- IEHP has a pilot with Regional Centers' Behavioral Team for individuals aging out of ABA/BHT services.
- o Easter Seals offers warm hand-offs to families transitioning out of services after age 21.
- o Some pediatricians continue care for individuals who age out due to limited adult service options.

Objective 2.4: Re-envision the adult system of care, transforming it from a compliance framework to a self-determination framework focused on empowerment and autonomy.

## Current Efforts:

- o Regional Center offers a self-determination program.
- o Support groups at ASIE promote self-determination for adults.
- Person-centered thinking is being prioritized to focus on empowerment and autonomy.

Objective 2.5: Establish navigational supports that provide consistent coordination of care across disciplines and service systems.

# **Current Efforts:**

- Easter Seals offers navigational support for individuals with co-occurring disorders and ASD.
- o Regional Center has a family resource network that provides cross-system support for its clients.
- IEHP has a complex services team that supports children ages 0-21 across various needs.
   However, challenges arise once families age out due to a lack of specialty providers and adult care managers.
- o Community navigator programs are in place at North LA Regional Center.
- o ASIE provides navigational support for families in crisis.

Objective 2.6: Enhance supports for parents and caregivers of individuals with ASD.

# **Current Efforts:**

- Regional Center offers short-term support to parents for up to 18 months with a limited caseload.
- A pilot program at Regional Center focuses on supporting ESL/ASL families.
- o Regional Center holds safety fairs to engage families.

Objective 3.1: Create a systems-wide inventory of trainings offered throughout disciplines and at all levels to support individuals with ASD.

# Current Efforts:

- The Inland Regional Center (IRC) has a Learning Management System that can manage training data.
- California Autism (CAPTAIN.CA.GOV) has a training tab for families with descriptions and availability of training.

Objective 3.4: Ensure all caregivers and individuals with ASD are provided training on how to respond to crisis needs.

# **Current Efforts:**

- The START model from the University of New Hampshire is an evidence-based approach.
- Safety Care offers a parent module that could be explored for crisis training.



# Inland Empire Regional Collaborative Plan

Objective 4.1: Create a unified and integrated system to communicate diagnosis and individual needs that respects individuals and ensure efficient relay of necessary information.

# **Current Efforts:**

o Efforts to develop such a system are ongoing but not well-documented in the notes.

Objective 4.2: Develop a shared definition of emergency/crisis situations versus dysregulation (as well as other issues) amongst professionals serving individuals with ASD.

# **Current Efforts:**

• The START model has a definition that could be leveraged for this purpose.

Objective 4.3: Establish a regional transdisciplinary team (which includes individuals with ASD and caregivers) to address the systems issues that influence the various needs of individuals with ASD.

# Current Efforts:

• There are existing efforts to form a team, but specific details were not provided.