**EAST MISSOURI AUTISM PROJECT**

**PARENT ADVISORY COMMITTEE**

**BY-LAWS**

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**INTRODUCTION**

The Bylaws of the Parent Advisory Committee (PAC) of the East Missouri Autism Project (EMAP) are established pursuant to and in accordance with Title 9 of the Missouri Code of State Regulations, Division 45, Chapter 3 (Care and Habilitation), Section 060 (Autism Services). Accordingly, in any instance where the EMAP PAC bylaws are in conflict with the Autism Rule (9 CSR 45-3.060) or the statewide Missouri Advisory Committee on Autism established by the Rule, the Rule or the statewide committee shall prevail.

# ARTICLE I

**Definitions**

(A) *Autism* – a complex lifelong developmental disability that typically appears during the first three years of life resulting from a neurological disorder that affects brain functioning which interferes with communication, learning, behavior and social development, and often interferes with the processing of sensory information. Autism and its behavioral symptoms occur in approximately one of every 166 individuals, affecting as many as 1.5 million Americans in 2003. Unfortunately, that number is on the rise, with various Government agencies estimating autism is growing at a rate of 10-17% per year. At these rates, autism could reach 4 million Americans in the next decade. Autism is four times more prevalent in boys than girls. It has been found throughout the world in families of all racial, ethnic and social backgrounds. Family income, lifestyle and education levels do not affect the change of autism’s occurrence. No know factors in the psychological environment of a child have been shown to cause autism.

The most common behavioral symptoms of autism include:

1. Communication: language develops slowly or not at all; use of words without attaching the usual meaning to them; communicate with gestures instead of words; short attention spans.
2. Social Interaction: spends time alone rather than with others; shows little interest in making friends; less responsive to social cues such as eye contact or smiles.
3. Sensory Impairment: unusual reactions to physical sensations such as being overly sensitive to touch or under-responsive to pain; sight, hearing, touch, smell, taste, sense of balance or self may be affected to a lesser or greater degree.
4. Play: lack of spontaneous or imaginative play; does not imitate other’s actions; doesn’t initiate pretend games.
5. Behaviors: may be overactive or very passive; throw tantrums for no apparent reason; may persevere on a single item, idea or person; apparent lack of common sense; to the extreme may show aggressive or violent behavior or self-injure when presented with certain situations.

Autism is often referred to as a *spectrum disorder*, meaning that the symptoms are characteristics of autism can present themselves in a wide variety of combinations, from mild to severe. Most professionals will agree that there is no standard or typical person with autism. Contrary to popular understanding, many individuals with autism make eye contact, show affection, smile and laugh, and show a variety of other emotions, but in varying degrees. Like other people, they respond to their environment in positive and negative ways. The autism may affect the range of responses and make it more difficult to control how their body and mind react. They live normal life spans and the behaviors associated with autism may change or disappear over time.

Autism is not a mental illness. Autism may occur in association with other conditions such as mental retardation, epilepsy and Down ’s Syndrome. Autism is not known to be curable. Since there is no commonly accepted explanation for the cause of autism, it is not preventable.

AUTISM IS TREATABLE – Early diagnosis and intervention are important to the future development of the individual. Individuals with autism can learn and function productively and show gains with appropriate education and treatment. Experience has shown that individuals with autism respond well to a highly structured, specialized education and behavior modification program, tailored to the individual needs of the person. A well-designed intervention approach will include some level of communication therapy (speech/language), social development, sensory impairment therapy (integration), and behavior modification at a minimum, delivered by trained professionals in a consistent, comprehensive and coordinated manner. Specialized therapies, such as music therapy, have proven highly effective in some persons with autism.

Despite the advances in the understanding and treatment of autism, the majority of the public, including some professionals in the medical, educational and vocational fields, are still unaware of the prevalence of autism, how autism affects people, and how to work effectively with individuals with autism.

(B) *Family support* – services and helping relationships for the purpose of maintaining and enhancing family care-giving. Family support may be any combination of services that enable individuals with autism to reside within their family homes and remain integrated within their communities. Family support services are --

1. Based on individual and family needs;
2. Easily accessible for the family;
3. Family-centered and culturally sensitive;
4. Flexible and varied to meet the changing needs of the family members;
5. Identified by the family; and
6. Provided in a timely manner contingent upon availability of resources.

(C) *Service provider* – an entity or individual that provides and receives reimbursement for autism programs and services as specified in Article III of these bylaws.

# ARTICLE II

# Purpose and Objectives

Section 1 The purpose for which the EMAP was formed is:

1. To monitor and assure that all individuals with autism within the project territory and their families have access to adequate and appropriate services;
2. To recommend objectives, policies, goals and procedures for developing and improving the system of the St. Louis Regional Center;
3. To provide a means of liaison between the Division of Mental Retardation and Developmental Disabilities (MR/DD), appropriate agencies and the general public;
4. To review, advise and recommend on programs, policies, methods of treatment and service delivery, and to disseminate this information to the families of individuals with autism;
5. To perform all other advisory functions as may be agreed upon with the Division of MR/DD;
6. To assess the needs of individuals with autism and their families in the St. Louis City, St. Louis County, St. Charles County and Jefferson County;
7. To provide recommendations regarding service providers and monitor their performance;
8. Public education and awareness.

# ARTICLE III

# Services

Section 1 The EMAP may provide, but shall not be limited to, the following services:

1. Adaptive Equipment;
2. Advocacy training;
3. Applied Behavioral Analysis/Discrete Trail Training;
4. Assessment;
5. Auditory Integration;
6. Behavior Management Training and Supports;
7. Camps:
8. Communication and Language Therapy;
9. Conference Registration;
10. Consultation on Individualized Education or Habilitation Plans;
11. Crisis Intervention;
12. Counseling;
13. Evaluations;
14. Family Support;
15. Habilitative Training;
16. Information and Referral Assistance;
17. Like Skills’
18. Music Therapy;
19. Nutritional Supplements;
20. Occupational Therapy, Sensory Integration Therapy, and Consultation;
21. Parent or Caregiver Training;
22. Physical Therapy;
23. Planning & Consultation;
24. Public Education and Information Dissemination;
25. Relationship Development Intervention;
26. Respite Care:
27. Socialization;
28. Speech Therapy;
29. Staff Training; and
30. Therapeutic Horsemanship.

# ARTICLE IV

# Membership

Section 1 The East Missouri Autism Project will serve persons eligible for services from the St. Louis Regional Center.

Section 2 The East Missouri Autism Project shall have a parent advisory committee composed of from seven (7) to nine (9) persons, and one (1) or two (2) alternates, that have family members with autism, including family members that are young children, school-age children, and adults. These members shall be Missouri residents and the family members with autism shall be receiving services, or be on the waiting list for services from the EMAP.

Section 3 Starting July 1, 1998 one-third of the incumbent members serving shall continue to serve a one year term. One-third of the members shall serve a two year term, and the remaining one-third shall serve a three year term. Length of those terms shall be determined by drawing lots. Subsequent new members, other than mid-term replacement members, shall serve three year terms. No member shall serve more than two (2) consecutive three (3) year terms, unless extended on one-year additional increments by recommendation of the PAC and approval of the Division Deputy Director.

Section 4 Upon expiration of the terms, new members shall be appointed by the Division Deputy Director from the recommendations of a nominating committee comprised of at least three members of the remaining PAC. The nominating committee shall inform the eligible families of the EMAP that this process is taking place by the PAC meeting held in March of that year. Applications from any interested qualified person should be received by the chairperson no later than the PAC meeting held in May of that year. The committee shall make every effort to maintain membership from each county within the region and the City of St. Louis. The committee shall make every effort to nominate member to represent the diversity of the project area and to represent persons with autism of all ages and capabilities.

Section 5 If a PAC member cannot fulfill their three year term, the PAC member will be replaced by an alternate, or the nominating committee will review applications on file and nominate a replacement to fulfill the term. The Division Director will appoint the member replacement.

## ARTICLE V

# Officers

Section 1 Officers of the Parent Advisory Committee shall be a chairperson, vice-chairperson, recording secretary and corresponding secretary. Annual elections shall occur in July.

Section 2 Term of offices shall be - one year for chair, one year for vice chair, one year for recording secretary and one year for corresponding secretary. Officers may serve consecutive terms.

Section 3 The Chairperson is the principal executive officer. S/he will preside over all meetings. S/he will sign all instruments agreed upon by the committee. S/he shall perform all other duties incident to the office as prescribed by the committee. Chairperson will present all information relative to the project to the committee. Chairperson will, in conjunction with the committee and Deputy Director, prepare the agenda for upcoming meetings.

Section 4 Chairperson shall be empowered to appoint standing committees for the purpose of administrative, planning, service, advocacy and temporary committees as may be necessary. Members of these committees, excluding administrative, may include persons other than voting members of the advisory committee. Persons on these committees will report to the chair or a person designated by the chair.

Section 5 In absence of the chairperson, or in the event of chairperson's inability to act, the vice-chair shall perform the duties of the chairperson and such other duties as may be assigned by the chairperson or committee.

Section 6 Recording Secretary shall keep minutes of the meetings and shall secure that all notices of meetings are duly given. Recording Secretary shall perform other duties as assigned by chairperson or committee.

Section 7 Corresponding Secretary shall be responsible for all written communication from the PAC, unless the chairperson otherwise performs said duties. Corresponding Secretary shall perform other duties as assigned by chairperson or committee.

Section 8 If any officer cannot fulfill their term, the following shall take place;

1. An alternate member, if necessary, will be appointed to the PAC.
2. An election by the PAC members will be held to fill that position.

Section 9 The EMAP PAC shall nominate two (2) representatives and one (1) alternate to serve on the statewide Missouri Advisory Committee on Autism, which meets quarterly in Jefferson City. The statewide committee is appointed by the Division Director. The Division Director will make every effort to appoint members nominated by the PACs. The membership should represent the cultural diversity of the state and represent persons with autism of all ages and capabilities. The EMAP PAC shall from time to time nominate successor representatives and alternates as required to serve on the statewide committee as terms expire and/or positions are made available.

## ARTICLE VI

**Meetings**

Section 1 The Parent Advisory Committee shall hold regular meetings at 6:00 p.m. on the third Monday of each month. This can only be changed if notification is made at the previous monthly meeting. A committee vote is required for any changes made in meeting time or place.

Section 2 Special meetings may be called by the chair or by one-third of the committee by written request to the chair. Notice shall be given at least 48 hours in advance and shall state purpose of meeting. No other business shall be transacted at a special meeting other than the purpose of the meeting.

Section 3 All meetings shall be open to the public in accordance with Sections 610.010 through 610.022, RSMo.

Section 4 In absence of chair and vice-chair, meeting will be conducted by a member of the committee.

Section 5 A quorum is a simple majority of the PAC.

## ARTICLE VII

# Voting

Section 1 Any item that is voted on must be motioned and seconded by a member of the committee. Any item taken to a vote can be passed with a simple majority.

Section 2 A proxy vote is permitted. A phone vote must be witnessed by two people.

## ARTICLE VIII

# Committee Members

Section 1 Members are expected to attend all meetings. If not able to attend a meeting, contact the chair or coordinator in advance to be excused.

Section 2 If a member fails to attend three consecutive meetings without prior notification, the member may be removed from the committee by a vote of a simple majority.

Section 3 Prospective committee members are required to fill out a membership application for the EMAP PAC. This application is to be submitted to the chairperson of the nominating committee. The application is then reviewed by the nominating committee who will make their recommendations to the Division Deputy Director for review and appointment. S/he will send notice of appointment to the new members.

## ARTICLE IX

**Committee Responsibilities**

Section 1 The committee’s responsibilities shall include but not be limited to the following:

A. Advocacy;

B. Contract Monitoring;

C. Review of annual Department of Mental Health audits of EMAP;

D. Recommending the services that are to be provided based on input from families;

E. Recommending policy, budget and service priorities;

F. Monthly review of service delivery;

G. Planning;

H. Public education and awareness;

* 1. Recommending of service providers to the Division of MR/DD for the administration of the project;

1. Recommending contract cancellation;
2. Nominating committee members;
3. Maintaining the Parent Center.

Section 2 In the event the EMAP PAC disagrees with a decision of the Division Deputy Director related to the operation of the project, the issue may be referred to the Missouri Advisory Committee on Autism for its recommendation to the Division Director.

## ARTICLE X

**Conflict of Interest**

Section 1 All committee members and all providers of the committee shall avoid any conflicts of interest and shall comply with the applicable provision of Sections 105.450 through 105.454, RSMo.

Section 2 Committee members are required to sign a conflict of interest statement annually.

## ARTICLE XI

# Parliamentary Authority

Section 1 Robert Rules of Parliamentary procedures shall govern the conduct of business in all cases in which they are applicable and not in conflict with the by-laws.

## ARTICLE XII

**Ratification**

Section 1 These by-laws shall become effective upon their ratification by a two-thirds majority of the committee.

Section 2 By-law revisions require written notice to all members thirty (30) days prior to vote for ratification, and must be ratified by a two-thirds majority of the committee.