

Kansas Special Health Services Programs Family Advisory Council Bylaws

1. ARTICLE I: NAME

The name of the council shall be the Kansas Special Health Services Family Advisory Council, officially designated "Family Advisory Council."

2. ARTICLE II: OVERVIEW

2.1. Special Health Services Overview

The following programs are administered through the Special Health Services section at the Kansas Department of Health and Environment:

- Special Health Care Needs (SHCN): Services are provided to children and youth, 0-22, and all ages with genetic/metabolic condition identified through the Kansas Newborn Metabolic Screening program who meet medical and financial eligibility.
- Infant Toddler Part C Early Intervention (Part C): Early intervention, health services, and parental supports are provided to infants and toddlers with disabilities, birth through 2, and their families.
- Newborn Metabolic Screening (NBS): All babies born in Kansas receive a screen for 28 genetic and metabolic disorders. Includes collection, laboratory testing, follow-up and referrals to diagnostic testing and treatment services.
- Early Hearing Detection and Intervention Newborn Hearing Screening (NBHS): All babies born in Kansas receive a screen for hearing loss. Includes screening, follow-up and referrals to confirmatory testing and early intervention.

The Special Health Services also administers the Birth Defect Registry, the State Hemophilia Program, and the Kansas Resource Guide, a phone and web-based resource directory of community-based services for consumers in Kansas.

2.2. FAC Purpose

The purpose of the FAC is to provide guidance and feedback to the Kansas Special Health Services (SHS) programs to provide valuable, quality, and timely services to families and their children in a patient/family-centered manner, with a strong focus on family empowerment, partnership, and collaboration.

2.3. FAC Mission

The FAC aims to achieve satisfaction of special health care services for families of infants, children and youth with special health care needs by advising and promoting opportunities for individuals with health care needs/disabilities to exercise self-determination.

2.4. FAC Vision

The FAC will promote opportunities for family leadership and advocacy while supporting individuals with health care needs/disabilities to exercise self-determination and be independent, productive, integrated, and included in all facets of community life.

3. ARTICLE III: ROLES AND RESPONSIBILITIES OF THE FAC

The FAC will serve as an expert panel to:

- 3.1. Provide ideas and support in the development and implementation of SHS activities based on an understanding of the SHS clients, programs, and services.
- 3.2. Provide consultation to the SHS programs regarding the development of the annual Kansas Maternal Child Health (MCH) Block Grant Application and the MCH five (5) year needs assessment including activity support and feedback of SHS identified objectives and outcomes related to the needs assessment.
- 3.3. Review and make recommendation to further progress towards the projected goals contained in the five (5) year plan.
- 3.4. Advocate for, and on behalf of, each SHS program and the families served through these programs.
- 3.5. Advise and inform the SHS Director regarding other relevant organizations, programs, networks or activities that may provide opportunities for improved services and delivery collaboration.
- 3.6. Provide the family voice as an ambassador to the community service system regarding services available through the SHS programs.
- 3.7. Advise and inform the SHS programs about the best methods to reach and communicate with families in Kansas.
- 3.8. Participate in a minimum of 75% of conference calls and in-person meetings.
- 3.9. Collectively work on identified projects or participate in ongoing (or ad hoc) work groups. Work groups topics may vary and be developed based upon identified needs or priority objectives of the programs or membership.

- 3.9.1. A SHS Program Liaison will be assigned to provide coordination and guidance for work groups.
- 3.9.2. Each work group will identify a FAC member to serve as the work group leader.
- 3.9.3. The work group leader will provide regular updates on work group activities to the council and ensure group activities are completed within identified timelines.

4. ARTICLE IV: MEMBERSHIP

Members must show commitment and be actively involved in the performance of the required activities listed in the roles and responsibilities. Members shall bring their strengths, talents, skills and experience to enhance the work of the FAC.

4.1. Composition of Membership

The FAC shall have a minimum membership of fifteen (15) and a maximum of seventeen (17) family representatives. Membership numbers do not include representatives from SHS programs or their partners.

Desired membership is diverse in geographic representation across the state, including two (2) representatives of each of the seven SHS regions with an additional three from any region across the state. Minimum make up includes:

- 4.1.1. One (1) representative of an individual identified with a genetic disorder as identified by the NBS program.
- 4.1.2. One (1) representative of an individual, ages 0 through 22, with identified hearing loss.
- 4.1.3. Three (3) representatives of an infant or toddler, ages 0 through 2, who are currently receiving services through Part C.
- 4.1.4. Two (2) representatives of children, ages 3 through 5, transitioning out of Part C services.
- 4.1.5. Six (6) representatives of children and youth with special health care needs or disabilities, in kindergarten through 12th grade.
- 4.1.6. Two (2) representative of a young adult, ages 18 through 26, with special health care needs or disabilities.
- 4.1.7. Two (2) “floating” representatives with a vested interest in services provided through the SHS programs.

Membership is limited to one participant per family, with regarding to attendance requirements, voting privileges and reimbursement. All FAC meetings are open to the public and additional participants from the same family unit may be identified as active participants at any time.

The membership roster shall be monitored and updated frequently by the KDHE.

4.2. Selection of Membership

All prospective members shall complete and submit a FAC Application and submit to the KDHE, who will collaboratively review all new applications and make a determination on membership appointment. Appropriate individual accommodations shall be provided to assure access to and participation of all FAC members. Orientation for new members shall be provided by a current member with assistance from KDHE.

4.3. Term of Membership

New members may be appointed anytime throughout the year. Membership terms are for two (2) years, beginning with the date of appointment by the Membership Committee. Members may serve for two consecutive terms or no more than four (4) consecutive years. Members appointed prior to April 2014 are allowed to complete three consecutive terms in accordance with previous bylaws.

Individuals whose terms have expired may be re-nominated upon the recommendation of the Membership Committee for 1 additional term. Members, who have served two (2) consecutive terms, must wait one year before being re-nominated.

In the event the FAC is not at the minimum membership requirement, individuals who have completed their term limitations as described above, are provided an opportunity to continue serving on the council until which time a new member joins and the minimum membership requirement is reached. New members will fill the membership spot of the individual with the longest service record with the FAC.

All FAC meetings are open to the public, however only official FAC members will have voting privileges. A quorum of fifty-one percent (51%) will be required to vote on agenda items.

5. ARTICLE V: EXECUTIVE COMMITTEE

The Executive Committee persons shall be comprised of three (3) parent representatives and representation of KDHE. The Executive Committee members will develop agendas, changes to by-laws, and council objectives. Make up and duties of the Executive Committee are as follows:

- 5.1. KDHE, with support of the Executive Committee when feasible, is responsible for coordinating all FAC meetings and conference calls.
- 5.2. KDHE is responsible for setting council objectives and coordinating council work groups. This shall include:

- 5.2.1. Providing information that will assist the FAC members to be better equipped to advise on identified priority objectives.
- 5.2.2. Provide guidance and coordination for council work groups related to identified objectives.
- 5.3. Parent representatives are responsible for providing guidance and feedback from the parent perspective on all FAC activities.
 - 5.3.1. Provide insight to ensure FAC activities are addressing the concerns of the general parent member population.
 - 5.3.2. Serve as a model for leadership and advocacy for fellow FAC members.

6. ARTICLE VI: OPERATION OF THE FAC

The operating year for the SHCN FAC will be from January 1st to December 31st each year.

6.1. Meetings

The FAC shall meet in person at least four times per year. In-person meetings will rotate between Topeka and Wichita. Additional locations will be added to the rotation based upon current FAC membership and FAC member request.

The FAC will meet every six (6) weeks either in person or by conference call. Members are expected to participate in all meetings. If a member misses two consecutive meetings, without approval by KDHE, she/he may be asked to resign from the FAC and his/her name will be removed from the list of voting members. FAC members who are asked to resign are not eligible for the FAC Alumni and Mentorship Program.

Alternative meeting formats are encouraged (i.e. conference calls, email, “piggy-backing” with other meetings, conferences etc). Scheduling meetings during times when youth are able to attend (summer months, and spring/winter breaks) will be encouraged.

The FAC will make decisions through consensus, recognizing that the Executive Committee may utilize alternative decision making strategies including, as necessary, calling for a majority vote.

7. ARTICLE VI: COMPENSATION FOR PARTICIPATION, TRAVEL AND LODGING

All stipends, travel and lodging expenses will be paid in accordance with the SHS Consumer Advisory Council Reimbursement Policy (Appendix A).