State of California—Health and Human Services Agency
Department of Health Care Services

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DATE: December 19, 2019

CCS Information Notice: 19-10

TO: All County California Children's Services and Genetically Handicapped Persons Program Administrators, Medical Consultants, and Integrated Systems of Care Division Staff

SUBJECT: California Children's Services Standards Chapter 3.39 – Epilepsy Special Care Center

The purpose of this Information Notice (I.N.) is to inform county California Children's Services (CCS) Program, Genetically Handicapped Persons Program (GHPP), and CCS Providers about a new section in the CCS Manual of Procedures, Chapter 3.39, "CCS Epilepsy Special Care Center (SCC) Standards" (see Attachment 1).

This I.N. is to be used in conjunction with Chapter 3.37 SCC Core Standards[1]: "CCS SCCs General Information and Core Standards" for outpatient SCCs which is available on the CCS Provider Standards[2] webpage.

In addition to the requirements set forth in Chapter 3.37.1, "SCC General Information and Core Standards", CCS SCCs are also required to comply with CCS Program SCC specialty and subspecialty standards and relevant CCS Numbered Letters[3] that outline other SCC specialty and subspecialty requirements. At the time of this letter, CCS Program specialty or subspecialty standards are currently undergoing revision. In the interim, CCS Providers should refer to the currently listed specialty and subspecialty standards and, if necessary, consult with the State CCS Program.

Effective the date of this letter, all CCS outpatient Epilepsy SCCs are required to comply with the following:

1. CCS Chapter 3.37 "CCS Core Special Care Center (SCC) Core Standards."

2. The attached Epilepsy SCC Standard.

The revised CCS Program specialty or subspecialty standards will be provided to CCS Administrators and Providers as they become available. CCS SCCs shall continue to refer to the specialty or subspecialty standards in effect as of the date of this letter and any relevant CCS Letters on the CCS website.

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If you have any questions regarding this I.N., please e-mail the CCS Facility Unit at CCSFacilityReview@dhcs.ca.gov.

Sincerely,

ORIGINAL SIGNED BY

Roy Schutzengel
Medical Director
Integrated Systems of Care Division

Attachment(s):
Attachment 1: CCS Epilepsy SCC Standards
Attachment 2: Criteria for Epilepsy Surgery
Attachment 3: Recommended Pediatric Epilepsy SCC Quality Measures

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[1] Chapter 3.37 SCC Core Standards: http://www.dhcs.ca.gov/services/ccs/Documents/CCSCoreStandards.pdf
[2] CCS Provider Standards: https://www.dhcs.ca.gov/SERVICES/CCS/Pages/ProviderStandards.aspx
[3] CCS Numbered Letters: http://www.dhcs.ca.gov/services/ccs/Pages/Letters.aspx

In addition to the specialty and subspecialty requirements outlined in this standard, the Epilepsy Special Care Center (SCC) is required to comply with Chapter 3.37, California Children's Services (CCS) Core SCC Standards.

A. Epilepsy SCCs – Definition for CCS Eligibility

1. Epilepsy is: "a disease of the brain defined by any of the following conditions: (1) at least two unprovoked (or reflex) seizures occurring greater than 24 hours apart; (2) one unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next ten years; (3) diagnosis of an epilepsy syndrome."[1]

   Epilepsy is medically eligible for CCS services only when it is 1) a component of or secondary to a CCS-eligible condition, or 2) of unknown origin and requires: over four changes in dosage or medication types in the year of diagnosis; 3) requires two or more antiepileptic drugs to control seizures; or 4) frequent (at least monthly) medical office visits to monitor status and periodic blood tests; or 5) there is a history of status epilepticus within the past 12 months. [See California Code of Regulations, Title 22, section 41517.3 (a)(3)].

2. A CCS client may be authorized to an Epilepsy SCC when he or she has drug resistant epilepsy (defined as failure of two appropriately chosen medications), has disability caused by the seizures, or is a possible candidate for surgical intervention.

3. An approved Epilepsy SCC is staffed with a multidisciplinary team of specialists and staff who provide epilepsy care to pediatric patients with refractory epilepsy.

4. The Epilepsy SCC provides comprehensive epilepsy evaluation and management services to clients with epilepsy as described in A.2.[2] The goal of Epilepsy SCC care is to eliminate seizures or improve seizure control with minimal side effects, improving the client's health, safety, and quality of life. All Epilepsy SCCs must conduct comprehensive epilepsy evaluations, provide an interdisciplinary approach, safety protocols and quality measures, patient education, and provide medically necessary procedures, specified in 4.a. and 4.b. below.

   a. Epilepsy SCCs provide the following services:

      (1) Basic medical, laboratory, pharmacy, neuropsychological and psychosocial services needed to evaluate and treat clients with refractory epilepsy.

(2) Non-invasive epilepsy evaluation including:

(a) 24 hour video-electroencephalogram (EEG) monitoring with surface electrodes supplemented with sphenoidal or appropriate additional electrodes, consistent with current standards of care,

(b) Specialized brain imaging including high quality magnetic resonance imaging (MRI) and other appropriate neuroimaging,

(c) Intracarotid amobarbital testing (Wada test),

(d) Neuropsychological and psychological services including cognitive testing.

(3) Intraoperative electrocorticography

(4) Implantation and management of neuromodulatory devices such as vagus nerve stimulator (VNS).

(5) Lesional epilepsy surgery (lesionectomy and anterior temporal lobectomy as described in Attachment 2).

(6) Pharmacological, neuropsychological and imaging services described in Section D of this document.

(7) Access to rehabilitation services, both inpatient and outpatient, when appropriate.

b. Regional Epilepsy SCCs, offer the services listed in 4.a., and some or all of the services described in this section:

(1) 24 hour video-EEG recording with intracranial electrodes (subdural, epidural or depth electrodes) under continuous supervision and observation by certified EEG technologists. Congruent with National Association of Epilepsy Centers (NAEC) Level 4 centers, regional Epilepsy SCCs should average at least 6 cases with indwelling or intraoperative electrodes annually over four years.

(2) Functional cortical mapping by stimulation of subdural electrodes either extra-operatively or intraoperatively.

(3) Evoked potential recording that can be used safely with intracranial electrodes.

(4) Electrocorticography

(5) Epilepsy surgery including services described in 4.a. above and neurosurgical services including:

(a) Open and stereotactic biopsy,

(b) Anterior temporal lobectomy without mesial temporal sclerosis,

(c) Placement of intracranial electrodes,

(d) Resection of epileptogenic tissue in the absence of structural lesions,

(e) Corpus callosotomy and hemispherectomy, or referral procedures to SCCs offering these services.[3]

B. CCS Program Requirements

1. The Epilepsy SCCs shall be located within CCS-approved tertiary hospitals with a CCS-approved Pediatric Intensive Care Unit (PICU), or special hospitals demonstrating equivalent expertise.

2. Satellite centers[4] for the Epilepsy SCC shall meet core team staffing standards described in CCS Provider Standards 3.3.1 H.2., and shall require separate CCS approval.

3. The Epilepsy SCC shall provide comprehensive outpatient and inpatient interdisciplinary services and neuro-diagnostic testing and services to children under 21 years of age who have a CCS-eligible seizure disorder.

4. The Epilepsy SCC shall operate as an identifiable team, which shall be responsible for the coordination of all aspects of patient epilepsy evaluation and care, including coordination between the inpatient and outpatient departments of the hospital and with the local county CCS Program office.

   a. All members of the team shall be paneled when applicable, according to the standards for panel participation established by the state CCS Program.

   b. Changes in professional staff whose qualifications are required in any portion of these standards shall be reported to CCS within 30 days of occurrence. Directory updates of all core team members and designated consultants shall be submitted to the CCS Program, at a minimum, on an annual basis.

5. Specialized epilepsy treatment services as described in A.4.b. shall be

authorized only when requested by a CCS-approved Epilepsy SCC.

C. Epilepsy SCC Core Team Members and Specialty Consultants

1. There shall be a core team that meets regularly to evaluate patients, to initiate or modify care plans, and to perform other functions as needed to provide on-going, multidisciplinary care. The personnel on the core team shall be assigned to the team on a permanent basis. The core team and members responsibilities shall meet the criteria described in the CCS Core Standards, Section C.3., and shall consist of the following:

   a. The Medical Director shall be a CCS-paneled neurologist or pediatric neurologist with expertise and training in pediatric epilepsy, clinical neurophysiology, video-EEG monitoring, and selection of patients for epilepsy surgery. The medical director shall have certification in epilepsy by the American Board of Psychiatry and Neurology (ABPN) Epilepsy or in clinical neurophysiology by American Board of Clinical Neurophysiology. The medical director shall have at least two years of experience in pediatric epilepsy care post-fellowship and at least 50 cases of video monitoring in past year.

      (1) The Medical Director shall have responsibilities described in CCS Core Standards, Section C.3.

      (2) The Medical Director shall coordinate referrals to other epilepsy centers or to appropriate clinical trials when medically necessary surgical or imaging services are not available at the Epilepsy SCC.

      (3) The Medical Director shall oversee quality improvement projects consistent with recommendations of the American Academy of Neurology (AAN) or the American Academy of Clinical Neurophysiology (AACN).

   b. A second board certified CCS-paneled neurologist with expertise in epilepsy, clinical neurophysiology, video-EEG monitoring, and selection of patients for epilepsy surgery shall be available as part of the core team or to provide coverage.

   c. The Coordinator, who may be the Medical Director or any member of the core team, shall be responsible for

      (1) Functions described in CCS Core Standard, Section 3.b. as well as the following:

         (a) Assuring coordination of services and communication with the local Medical Therapy Unit (MTU) when appropriate,

(b) Coordination between inpatient and outpatient services and testing sites, if located elsewhere.

d. A CCS-paneled Nurse Specialist in neurology or seizure disorders (See Chapter 3.12 CCS Core Standards), with pediatric experience who has received epilepsy specific training for patients undergoing video EEG monitoring and other diagnostic testing, shall be responsible for:

(1) Responsibilities described in CCS Core Standards, Section 3.C. and,

(2) Implementing protocols related to patient safety.

e. A CCS-paneled Medical Social Worker (See Chapter 3.81 CCS Core Standards) who shall be responsible for the psychosocial aspects of the patient's disorder, for defining a care plan with each patient/family, and for coordinating care with other agencies.

f. A Registered Dietician with responsibilities described in CCS Core Standards, Section 3.C.

g. An EEG Technician with certification by the American Board of Registration of Electroencephalographic and Evoked Potential Technologists (ABRET), and the American Association of Electrodiagnostic Medicine.

2. The members of the epilepsy surgical team may also be part of the general Epilepsy SCC described above, and shall include the following:

a. A Neurologist with training and experience caring for pediatric patients with refractory epilepsy, and an adequate annual volume of video EEG monitoring. Experience is defined as at least two years post fellowship and an adequate volume of video EEG monitoring annually (at least 50 cases).

b. A Pediatric Neurosurgeon (or neurosurgeon with pediatric experience) with special interest in epilepsy, resective epilepsy surgery, placement of intracranial electrodes and implantation of the vagus nerve stimulator (VNS) and experience caring for pediatric patients with refractory epilepsy.

c. A Pediatric Anesthesiologist

3. CCS-paneled consultants with pediatric training and expertise shall be available as appropriate for the treatment of children with physical disabilities and their complications. These shall include, but not be limited to the following subspecialties psychiatry, neuro-genetics, neuroradiology, (neuro) pathology,

rehabilitation medicine, pulmonology, gastroenterology, nephrology, urology, otolaryngology, ophthalmology, cardiology, endocrinology, orthopedics and adolescent medicine. These specialists shall be listed in the Epilepsy SCC directory and shall participate in the Epilepsy SCC activities as necessary.

4. There shall be allied health personnel with pediatric expertise available for consultation, and/or treatment. Allied health professionals who are CCS-paneled (as applicable) shall include, but are not limited to, occupational and physical therapists, and speech-language pathologists. Other essential allied health professionals include clinical pharmacists, psychologists, psychometrists, biomechanical engineers, IT specialists, and school nurses and/or educational specialists. All clinical staff shall maintain applicable licensure or accreditation. These allied health personnel shall be listed on the Epilepsy SCC directory and shall participate in the Epilepsy SCC activities as necessary.

D. Epilepsy SCC Facilities and Equipment

1. Facilities and equipment shall meet the standards described in CCS Core Standards, Section D, as well as the items listed below:

   a. Pharmacy services shall be available 24 hours, including pharmacist with expertise in pharmacology of anticonvulsive drugs, access to antiepileptic drug level and pharmacokinetic expertise.

   b. 3 Tesla MRI and other appropriate imaging equipment, pharmacological expertise, neuropsychological/psychosocial services shall be available to support clients of the Epilepsy SCC.

   c. Electrodiagnostic EEG services with capability of long-term monitoring shall be available as appropriate for the level of epilepsy center care.

   d. Surgical suite appropriate for the Epilepsy SCC clients shall be at the same facility as the Epilepsy SCC, or the Epilepsy SCC shall have contractual agreement with the center providing the surgical services.

   e. The facility with the Epilepsy SCC shall have, or have access to, a CCS-approved inpatient rehabilitation center that provides the medically necessary inpatient rehabilitation.

   f. The facility with the Epilepsy SCC shall have a CCS-approved outpatient rehabilitation center, to be used for clients not eligible for the Medical Therapy Program (MTP), or when the MTP services do not meet the client's post-inpatient rehabilitation needs.

E. Epilepsy SCC—Patient Care

1. The Epilepsy SCC shall have policies and procedures related to intake, ongoing treatment, follow up, and core team reports as described in the CCS Core Standards, Section E.1-3.

2. Children referred to the Epilepsy SCC may be seen for (1) ongoing management, (2) one-time consultations, (3) diagnostic procedures, or (4) a specified intervention. The CCS-authorization shall specify whether referral to the Epilepsy SCC is for ongoing management, consultation, testing, and/or a specific intervention.

3. The Epilepsy SCC shall have policies to ensure that, when appropriate, the Epilepsy Quality Metrics in Attachment 3 or comparable are addressed for each client.

4. The Epilepsy SCC shall be responsible for assessing children who are candidates for specialized treatment or surgical procedures for the management of epilepsy. Surgical procedures shall be authorized for CCS-eligible children only upon the recommendation of an Epilepsy SCC.

5. The Epilepsy SCC shall provide follow-up after surgical intervention, including:

    a. Post-operative rehabilitation, including physical, occupational, and speech therapy, as medically necessary, as well as pharmacy and nutrition services.

    b. The provision of written documentation to family/caregiver and community based services, including the school.

6. The Epilepsy SCC shall provide appropriate neuropsychological services including neuropsychological test batteries to evaluate cerebral dysfunction and refer for management of psychogenic non-epileptic events.

7. The Epilepsy SCC shall address rehabilitation needs:

    a. MTP eligible children whose medically necessary rehabilitation needs can be met by the local CCS Medical Therapy Center (MTC) shall not receive rehabilitative or therapeutic services through the Epilepsy SCC.

    b. When the post-epilepsy surgery rehabilitation needs of the MTP-eligible client cannot be met by the MTU, the CCS County Medical Consultant, in conjunction with the MTC physician or the state CCS Program for dependent counties, shall authorize these services to the Epilepsy SCC or center recommended by the Epilepsy SCC.

8. The Epilepsy SCC comprehensive evaluation report shall be completed after each SCC team visit, and shall include parent input as described in CCS Core Standards, Section E.2.

9. The Epilepsy SCC shall submit annual and periodic team reports to CCS and to the primary care physician and/or referring neurologist.

10. The Epilepsy SCC shall provide copies of medical records, individual and summary Epilepsy SCC team reports, transition plans, statistical reports and other information within 30 days of request to the CCS program authorizing the care.

11. The Epilepsy SCC shall follow the transition policy outlined in SCC Core Standards, Section E.6.

12. The Epilepsy SCC service authorization shall cover:

    a. Initial and periodic comprehensive outpatient team evaluations and case conferences by CCS-paneled Epilepsy SCC core team members and other specialty consultants listed in the Epilepsy SCC directory.

    b. Medically necessary outpatient services related to the management of the child's CCS-eligible epilepsy, except those that require specific prior authorization in accordance with CCS policy.

    c. Outpatient laboratory and/or radiology services related to the epilepsy, except those requiring specific prior authorization in accordance with CCS program policy (e.g. MRI, PET scan) when ordered by an Epilepsy SCC physician.

13. Once treatment is started, if care is authorized to a local physician in conjunction with the Epilepsy SCC team, the child must be seen at least annually by the Epilepsy SCC for a comprehensive evaluation and update of a coordinated plan of care until such time as the child no longer requires the specific expertise of the Epilepsy SCC.

14. Medically necessary healthcare services not covered by the Epilepsy SCC service authorization require separate requests for each service. These include:

    a. Services provided by health care professionals listed on the Epilepsy SCC directory as consultants, beyond the assessment and evaluation recommended by the team conferences, require prior authorization. These requests shall specify services needed, number of visits and duration, and include a medical justification. Extensions may be granted when indicated

based on submitted medical justification,

b. Services provided by a specialty consultant or other healthcare professional who is not listed in the CCS Epilepsy SCC directory,

c. Surgical procedures (done either on an inpatient or outpatient basis),

d. Durable medical equipment,

e. Medical supplies,

f. Drugs and diagnostic studies requiring specific prior authorizations (such as MRI and PET scans),

g. Inpatient hospital admissions,

h. Any Physical Therapy or Occupational Therapy services provided by the Epilepsy SCC therapists.

F. Quality Assurance and Quality Improvement

1. The Epilepsy SCC shall have a system of standardized data collection and data exchange so that diagnostic studies do not have to be repeated for referred patients.

2. Epilepsy SCC quality improvement projects shall include data collection to align with an Epilepsy Quality Measure reporting system, (Attachment 3) or comparable epilepsy quality measure set. Epilepsy SCCs shall make data available for review as part of the Epilepsy SCC approval or re-approval.

3. Family satisfaction shall be assessed for Epilepsy SCC clients and families.

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[1] Epilepsia, 55(4):475–482, 2014
[2] National Association of Epilepsy Centers (NAEC) "Guidelines for Essential Services, Personnel, and Facilities in Specialized Epilepsy Centers" released January 12, 2010.
[3] This list is based on guidelines of the National Association of Epilepsy Center
[4] CCS Provider Standards: Tertiary Hospitals
https://www.dhcs.ca.gov/services/ccs/Documents/Tertiary.pdf

Criteria for Epilepsy Surgery

Recommended surgery at non-regional Epilepsy Special Care Centers, consistent with National Association of Epilepsy Centers[1] (NAEC) guidelines:

(a) Lesionectomy: According to NAEC, lesionectomy (for lesional epilepsy) is defined as follows: lesionectomy is “resection of a structural epileptogenic lesion and surrounding tissue that is performed primarily to treat epileptic seizures. In excellent candidates for lesionectomy, a single epileptogenic lesion is present, the lesion is an appropriate distance from cerebral regions necessary for normal function, and noninvasive electrophysiologic evaluation indicates that the lesion and surrounding area is responsible for the patient’s seizures”.

(b) Anterior temporal lobectomy in the presence of clear-cut mesiotemporal sclerosis, According to NAEC, anterior temporal lobectomy (for lesional epilepsy) is defined as the removal of a small amount of lateral temporal cortex followed by aggressive amygdalar, parahippocampal and hippocampal resection. The description continues: ‘in excellent candidates, magnetic resonance imaging detects unilateral mesial temporal sclerosis, noninvasive electrophysiologic evaluation indicates that the same temporal lobe is responsible for the patient’s seizures, and neuropsychometric evaluation including intracarotid amobarbital testing indicates that temporal lobectomy can be safely performed’.

[1] National Association of Epilepsy Centers (NAEC) “Guidelines for Essential Services, Personnel, and Facilities in Specialized Epilepsy Centers” released January 12, 2010.

Recommended Pediatric Epilepsy SCC Quality Measures

Epilepsy Pediatric Quality Measures[1,2] approved by the American Epilepsy Society, the AAN and the American Academy of Pediatrics,

1. Seizure type and current seizure frequency documented
2. Documentation of epilepsy or epilepsy syndrome
3. EEG results reviewed, requested or test ordered
4. MRI/CT scan reviewed, requested or ordered.
5. Querying and counseling about antiepileptic drug side effects.
6. Surgical therapy referral consideration for intractable epilepsy
7. Counseling about epilepsy-specific safety issues

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[1] Quality improvement in neurology: AAN epilepsy quality measures
[2] Report of the Quality Measurement and Reporting Subcommittee of the American Academy of Neurology (Neurology, January 04, 2011; 76 (1))