



DAVID MAXWELL-JOLLY  
*Director*

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



ARNOLD SCHWARZENEGGER  
*Governor*

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TO: ALL COUNTY CALIFORNIA CHILDREN SERVICES (CCS) PROGRAM  
ADMINISTRATORS, MEDICAL CONSULTANTS, AND STATE  
CHILDREN'S MEDICAL SERVICES (CMS) BRANCH

SUBJECT: POLICY RELATING TO CCS NURSE LIAISON POSITION IN  
PARTNERS FOR CHILDREN (PEDIATRIC PALLIATIVE CARE WAIVER  
PROGRAM)

## I. PURPOSE

The purpose of this N.L. is to provide policy and procedures for scope of work and responsibilities of the CCS Nurse Liaison (CCSNL) who will be responsible for utilization management, service authorization and data reporting for children enrolled in Partners for Children (PFC), the pediatric palliative care waiver program.

## II. BACKGROUND

AB 1745 (Chapter 330, Statutes of 2006) requires the Department of Health Care Services to develop and implement a pediatric palliative care waiver that allows an eligible child and the child's family to receive palliative care services while concurrently pursuing curative treatment for the child's condition. PFC is a waiver program designed to provide palliative care through home and community-based services to eligible children who have life threatening, chronic and complex conditions. The waiver, through the Centers for Medicare and Medicaid Services, offers expanded funding to support a set of services that would not otherwise be covered by the State Medicaid program. The waiver requires that participants be offered a choice between waiver services and institutional care (Freedom of Choice), participants have a life-threatening medical condition (Level of Care), and that the

program be cost neutral. Participants in PFC shall be under age 21, reside in a participating county, have full scope, no share of cost Medi-Cal, meet CCS medical eligibility criteria outlined in the Implementation section of this letter, and not be enrolled in any other 1915c waiver. PFC will serve children who would, in the absence of this waiver and as a matter of medical necessity, be expected to require acute inpatient hospital services for at least 30 days during the year.

Services provided will include care coordination, family training, respite care, expressive therapies and bereavement/grief counseling. These services will be provided through participating hospice and home health agencies and will be authorized by the CCSNL in the county CCS program.

Enrollment in the waiver will be limited to a specific number of slots (enrollees) that can be active at any one time during each year of the waiver. If a child transitions off of the waiver before the end of the year, that slot may be taken by another child. There can be no more than the allotted number of children actively enrolled (taking up a slot) at any one time. However, the total number of children served in one year may exceed the total number of slots. The number of slots available will increase each year with the addition of participating counties as identified in Table 1 below:

**Table 1**

<b>Waiver year starting in:</b>	<b>Total Waiver Slots Available</b>	<b>Participating Counties</b>
<b>2009</b>	<b>300</b>	Alameda, Monterey, San Diego, Santa Clara, Santa Cruz
<b>2010</b>	<b>801</b>	<i>2009 Counties</i> + Humboldt, Marin, Orange, Sacramento, San Francisco, Sonoma
<b>2011</b>	<b>1802</b>	<i>2009 and 2010 Counties</i> + Fresno, Los Angeles

### **III. POLICY**

Effective the date of this letter, counties participating in PFC shall have at least one member of the case management staff assigned to be the CCSNL. The CCSNL shall:

- Be a Registered Nurse (RN) case manager with at least six months experience in the CCS program;
- Have an End-of-Life Nursing Education Consortium (ELNEC) basic certificate;
- Complete PFC training provided by the CMS Branch;
- Be responsible for no more than 50 waiver clients.

Each participating county CCS program shall identify a second CCS registered nurse with ELNEC and PFC training as a back-up.

#### **IV. IMPLEMENTATION**

##### **1. Referral Process**

The CCSNL shall be responsible for processing all referrals for enrollment in PFC. [See attachment 1: PFC Flowchart; attachment 2: CCSNL Enroll Responsibilities Table; and attachment 3: CCSNL Ongoing Responsibilities Table]. Referrals may be received from medical providers, family members or other interested parties.

- Referrals from treating physicians must be submitted on the PFC Referral Form [attachment 4] with any medical documentation that the CCS program has not already received. [See attachment 5: Referring Physician Flyer and attachment 6: Referral Eligibility Checklist].
- Referrals from all other sources (including family members and non-medical persons or agencies) must be made by direct communication with the CCSNL. After receiving a referral from a non-medical source, the CCSNL shall verify the child's condition by obtaining the necessary medical records and shall verify the level of care by contacting a physician treating the child to request that a PFC Referral Form be completed and returned.
- The CCSNL may also identify potentially eligible children by searching the current CCS caseload, then contacting families of potentially eligible children about the waiver, and finally, if the family is interested in the program, contacting the treating physician to request a PFC Referral Form.

##### **2. PFC Database**

The PFC database will store basic information for each referral for waiver services, including client identifying information, diagnosis, and source of referral. For those children who are then enrolled in the waiver more detailed information will be entered including dates of Level of Care (LOC) determinations, dates of Family-Centered Action Plan (F-CAP) development and review, all waiver and state plan services requested, incidents/events affecting health and safety, and any remediation needed. The database will be used to track information needed to meet the federal assurances (see Section VIII, Federal Assurances), and to maintain an ongoing list of active participants and waiting lists in all counties and at the state.

The CCSNL shall enter the information into the database starting with the initial referral, and will update when there are changes in the client's care. The CCSNL shall run queries/reports built into the database regularly in order to ensure all assurances are met. Instructions for entering data and running queries/reports will be released soon. For your information, a list of data elements that will be collected in the database is attached. [attachment 7: Database Content Overview]

### **3. Determination of Eligibility to Participate in Waiver**

The CCSNL shall review the case record of each referral to ensure all applicants meet eligibility requirements for PFC.

#### **A. Program Eligibility:**

1. Age: Under 21 years of age
2. Medi-Cal: Full scope, no share of cost
3. Residence: Child resides in participating county

#### **B. Medical Eligibility:**

1. In order to participate in Partners for Children, a child must have at least one of the CCS eligible medical conditions described below. For those conditions in which there are additional criteria, the child must have at least one of these additional criteria to be eligible. Information about the child's medical condition shall be obtained through review of medical records already in the CCS chart or of additional records sent by the referring physician.

- Neoplasms
  - Not responding to conventional protocols, or
  - Advanced solid tumor, stage 3 or 4
- Cystic Fibrosis
  - End stage lung disease, or
  - Dependent on ventilatory assistance, or
  - On transplant list

- CNS injury/hypoxic ischemic encephalopathy/ neurological condition with severe co-morbidities
  - Intractable seizures, or
  - Pulmonary compromise, or
  - Recurrent and frequent hospitalizations
- Spinal muscular atrophy, Type I or II, requiring ventilatory support
- Duchennes muscular dystrophy, requiring ventilatory support
- Short gut syndrome
  - Dependent on Total Parenteral Nutrition (TPN), or
  - Awaiting small bowel and/or liver transplant
- Chronic intestinal failure dependent on TPN
- Liver failure from biliary atresia awaiting transplant
- Heart failure
  - Awaiting transplant (heart or heart/lung) and/or
  - Requiring continuous medication infusions
- Congenital anomalies of the heart
  - Hypoplastic left heart syndrome or
  - Total anomalous venous drainage with residual pulmonary vein stenosis
- Pulmonary hypertension
- Chronic respiratory failure requiring continuous ventilatory assistance

- Post organ transplant
    - Bone marrow
    - Peripheral blood stem cell
    - Lung
    - Heart
    - Liver
    - Small bowel
  - Complication of transplanted organ
    - Bone marrow
    - Lung
    - Heart
    - Liver
    - Small bowel
  - Leukodystrophies
2. PFC participants are also anticipated to need at least 30 days of hospitalization in an acute care facility in the subsequent 12 month period if not enrolled in this waiver. This anticipated need will be documented on the PFC referral form. If the child has come without a referral from the treating physician, the CCSNL shall discuss the case with the treating physician or representative, and will ask that the treating physician complete a PFC referral form.

Level of Care (LOC), documenting that the severity of the child's condition meets criteria for participation, will be determined by applying the eligibility criteria listed above. The CCSNL shall complete the Medical Eligibility and LOC Determination Form [attachment 8:], consulting with the child's SCC physician and the county program medical consultant as needed, for confirmation of the Level of Care determination.

If it is determined that the applicant is not eligible for PFC the CCSNL shall:

- Issue a Notice of Action (NOA);
- Enter applicant enrollment status "not enrolled" into the PFC database.

#### **4. Enrollment of Participants**

The CCSNL shall run an enrollment status report in the PFC database to ensure that there are open waiver slots before proceeding with the enrollment process below, and check the county Agency list for available Care Coordinators. If there are no open slots or available Care Coordinators, see section IV. C. Waiting Lists.

##### **A. Family Communication:**

1. The CCSNL shall contact the family to discuss waiver services and benefits with the family and applicant, as appropriate.
2. The CCSNL shall confirm, through discussion with the family and verification in MEDS, that the applicant is not enrolled in another home and community based waiver.
3. The CCSNL shall review the Freedom of Choice Form [attachment 9a] and Information Sheet [attachment 9b] with the family and applicant, and have the parent/legal guardian and/or the applicant sign the form indicating:
  - Choice between waiver and institutionalization;
  - Choice between available service providers from the list of participating providers serving the county of residence. (For your information, a copy of the agency application is attached. [attachment 10]);
    - A list of participating providers serving the county, based on applications received and approved, will be provided by the State.
4. The CCSNL shall review the Participant Agreement Form [attachment 11a] and Agreement Information Sheet [attachment 11b] with the applicant and family and have the parent/legal guardian and applicant sign the form. The CCSNL shall sign the form to show they have discussed the documents with the family.
5. The CCSNL shall educate the applicant and family on health and safety issues including prevention of abuse, neglect and exploitation.

6. The CCSNL shall educate the applicant and family on how to report events or incidents that could affect health, safety, and welfare of the participant. This includes the use of the Complaint/Incident Intake Report [attachment 12] by any person to whom they report an incident.
7. The CCSNL shall review with the applicant and family the protection of personal health information in Medi-Cal, in the CCS program, and at the Hospice/ Home Health Agencies.
8. The CCSNL shall provide the family with copies of the Participant Enrollment Packet. [Attachment 13: PFC Flyer; attachment 14a: PFC Services Information Sheet (parent version); attachment 14b: PFC Services Information Sheet (participant version); attachment 15a: F-CAP and Circle of Support Information Sheet (parent version); attachment 15b: F-CAP and Circle of Support Information Sheet (participant version); attachment 16: Child Abuse Information].

B. Completed Enrollment Process:

The CCSNL shall take the following steps for all applicants who qualify for and have chosen to participate in PFC.

1. The client will be assigned one of two PFC unique CCS aid codes. If a child participating in the waiver is already a CCS client, the new PFC Aid Code will replace the child's previously assigned CCS aid code, as appropriate. A Numbered Letter describing this process will be released in late October.
2. Enter additional information into the PFC database.
3. Notify the chosen agency Care Coordinator and transmit information regarding the new participant.

C. Waiting Lists:

Enrollment in PFC is limited to a defined number of slots per year and may also be limited based on the waiver Provider Agency capacity in the county.



1. **Statewide Waiting List:** There may be circumstances in which the demand for waiver participation exceeds the number of waiver slots available (see Table 1). In this case, the CCSNL shall take the following steps:

- The CCSNL must contact the CMS Branch to add the applicant to the statewide waiting list and send a letter to the applicant/family indicating the effective date of placement on the waiting list.
- The CMS Branch will maintain the waiting list based on the child's application date in order to ensure the applicant is provided fair and equitable statewide access to waiver slots.
- The CCSNL will enter the applicant's information into the PFC database.
- When a slot becomes available, the CMS Branch will inform the CCSNL who will then determine if the applicant is still eligible and proceed to enrollment.

2. **County Waiting List:** A child may be placed on a waiting list even when there are statewide waiver slots available if there is no available Care Coordinator among the local waiver provider agencies. In this case, the CCSNL shall take the following steps:

- The CCSNL shall record the applicant's name and the date on the county waiver waiting list.
- The CCSNL will enter the applicant's placement on the county waiting list into the PFC database.
- The CCSNL shall notify all local participating waiver provider agencies that there is a child on the waiting list, and request that the agencies contact the CCS office when a care coordinator becomes available.
- When the CCSNL is notified that a Care Coordinator is available, the CCSNL must check the PFC database enrollment status report to determine if there are slots available. If slots are available, the applicant on the top of the county list may be enrolled if they are still eligible.

##### **5. Family-Centered Action Plan (F-CAP)/Care Coordinator**

In conjunction with the participant and family, the Care Coordinator will develop a Family-Centered Action Plan (F-CAP) [attachment 17: F-CAP; and attachment 18: F-CAP Instructions] that will respond to social, emotional, spiritual, physical and environmental issues that affect the participant/family's health and well being.

The Care Coordinator will work with the family to develop and maintain an F-CAP that will identify:

- Current treatment plans from each participating subspecialist and primary care medical provider caring for the child;
- Differences in treatment plans across the multiple providers and method for consolidation into a single plan;
- Qualified local expressive therapists that meet the child and family care needs;
- Participant/family health beliefs and goals of care.

The Care Coordinator will send a completed F-CAP by fax or encrypted email to the CCSNL.

The CCSNL shall ensure that each F-CAP meets waiver requirements by doing the following:

- Review the completed F-CAP and discuss with the Care Coordinator if there are any concerns.
  - When the F-CAP is agreed upon by all parties, sign the last page, put a copy in the child's file, and send signed document back to the Care Coordinator for distribution.
- Authorize state plan and waiver services. PFC services must be on a separate authorization from state plan services even if both are provided by the same provider.
  - Ensure that authorizations do not exceed limits for specified service;
  - Ensure that services are authorized to CCS-approved providers;
  - Include PFC special instructions on the SAR for waiver services.
- Review each F-CAP submission at least every sixty days;
- Enter F-CAP and service information into the PFC database;
- Provide ongoing technical assistance to participating agency, independent, and Special Care Center providers related to waiver participation and services.

## **6. Oversight of Services Provided**

The CCSNL shall be responsible for implementing policies and procedures related to the oversight and monitoring of the delivery of PFC and CCS services to participants. The CCSNL ensures that federal waiver requirements are met by doing the following:

- A. The F-CAP shall be reviewed with the PFC Care Coordinator as described above.
  - Dates of review and changes to the F-CAP shall be entered into the PFC database.
- B. The CCSNL will contact the parent/legal guardian or client at least monthly to ensure that the services authorized were provided as specified in F-CAP and to determine satisfaction with services.
  - Summarize all communications with the family/client and PFC Care Coordinator in CMSNet case notes.
- C. Other responsibilities shall be to:
  - Ensure ongoing participant and family access to CCS resources and care management through telephone and direct contact;
  - Provide information regarding range of services, support groups and community resources in conjunction with the Care Coordinator to participant and family;
  - Oversee ongoing communication between the Care Coordinator and referring CCS providers to improve PFC practices;
  - Participate in waiver medical case management conferences related to a specific waiver participant, within the CCS program and where indicated at various health care facilities, to coordinate medical services needs, state plan and PFC program benefits;
  - Provide ongoing technical assistance to Care Coordinators, other participating agency or independent providers, and Special Care Centers related to waiver participation and services.

## **7. Health, Welfare and Remediation**

### **A. Health and Welfare Reporting:**

1. The CCSNL shall maintain and record all critical incidents or events (such as abuse, neglect, and/or exploitation) reported by the care coordinator, family, service providers or by the participant directly to the local CCS program.
2. The CCSNL shall complete a Complaint/Incident Intake Report [attachment 12].
  - Retain a copy of all forms for review by the CMS Branch;
  - Send a copy of all applicable forms received to Licensing and Certification;
  - Enter information into the PFC database;
  - Notify the appropriate public agency (e.g. CPS) as required by law.
3. The CCSNL shall follow up on any reported critical incidents or events within 30 days:
  - Contact the Care Coordinator and/or family;
  - Document the corrective action taken and follow-up in the PFC database.

### **B. Hospital Visits:**

The CCSNL shall check CMS Net or the participant's F-CAP for any Emergency Department visits and/or hospital admissions and enter the dates and reasons into the PFC database.

### **C. Remediation:**

The CCSNL shall be responsible for participating in and documenting county level remediation actions taken in response to health and welfare reports, as well as to problems with level of care determinations, service authorizations/delivery, F-CAP development/revisions, providers, claims etc. These remediation actions will be a part of the quality improvement and federal assurances outlined below. The CCSNL shall enter all remediation actions into the PFC database.

## **8. Monitoring/Quality Improvement/Federal Assurances**

The county CCS program and the CCSNL are responsible for implementing, at the county level, the Federal Assurances and Quality Improvement activities included in the waiver. The activities include:

- Review of the Level of Care at least annually or when there is a change in health status;
- Participation in the preparation for program review and state audits of local waiver agency providers as required by The Centers for Medicare and Medicaid Services;
- Participation in data collection, including entering information into the PFC database;
- Recording monthly contacts with the waiver participants and parent/legal guardians; and regular contact with providers ensuring that all services were delivered in accordance with the F-CAP;
- Identification of issues with service delivery by waiver service providers and referral to CMS Branch waiver staff and Licensing and Certification, as appropriate, for administrative action;
- Preparation and implementation of corrective action plans and other remediation actions in conjunction with CMS Branch staff;
- Monitoring of all corrective action plans for compliance and resolution;
- Ensuring county level on-going compliance with waiver requirements and assurances [attachment 19: CMS Assurances List; and 20: CMS Assurances and Remediation Description].
  - Level of Care Evaluations
  - Service Plan Development and Revisions
  - Service Delivery
  - Freedom of Choice
  - Health and Welfare Event Reporting
  - Remediation

## **9. Disenrollment from PFC**

A child receiving PFC services will be dis-enrolled from Partners for Children for any of the following reasons:

- The child no longer meets the minimum level of care due to a significant improvement in health status;
- The child has moved to a county not participating in this waiver;
- The child/family does not want to participate any longer, for any reason;
- The child has been hospitalized for more than 30 straight days;
- The child is no longer eligible for full scope, no share of cost Medi-Cal;

- The child/family/home environment poses a health and safety risk to the Partners for Children agency providers and attempts at remediation have not been successful over a 30 day period;
- The child/family misses three scheduled and confirmed PFC appointments despite efforts of the Care Coordinator and CCSNL to accommodate the family's needs;
- The participant enrolls in another 1915(c) Home and Community Based Waiver;
- The participant ages out – reaches his/her 21<sup>st</sup> birthday;
- The child dies.

When there is a reason to disenroll a participant, the CCSNL shall contact the child/family, PFC provider agency, and physicians identified on the F-CAP, to inform them of the decision to dis-enroll the participant. The local CCS program is responsible for end-dating the child's PFC aid code and assigning an appropriate existing CCS program aid code, if applicable. (The CCS local programs are notified by Medi-Cal eligibility alerts and CCS reports when a child loses Medi-Cal).

- Change enrollment status to "dis-enrolled" in the PFC database;
- Once dis-enrolled, the child/family will need to start at the beginning referral step if they wish to re-enroll in PFC.

#### **10. Transition off of PFC**

Transition of participants off this waiver may be needed if participants move from a county where the waiver is active to a county not participating in the waiver. In that case, the CCSNL will assist the participant and family in the dis-enrollment process, and work with the care coordinator in facilitating the transfer to the new county including connecting the participant and family with resources that are available there. Transition assistance may also be needed if a participant and their family decide to enroll in hospice, in which case the CCSNL and care coordinator will work with the hospice agency to ensure the smooth transition to that service. At other times, transition will occur as participants approach their 21<sup>st</sup> birthday. The CCS Information Notice 09-01 provides details related to transition planning for CCS clients. For waiver participants, at age 20, the CCSNL will prepare or update the Adolescent Transition Health Care Plan with client/family to identify any needs prior to the age of 21 years. The CCSNL will also set up a transition planning meeting with the participant/family, including the Care Coordinator in the discussion. The CCSNL shall enter information related to transition into the PFC database.

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Policies in this numbered letter apply only to counties that are eligible for and have elected to participate in the Partners for Children. All attachments will be available on the CMS website <http://www.dhs.ca.gov/cms>, under Pediatric Palliative Care soon. If you have any questions about the content of this letter, please contact Jill Abramson, M.D., M.P.H., at (916) 327-2487 or Sharon Lambton, R.N., at (510) 286-0729.

**Original Signed by Harvey Fry for Luis R. Rico**

Luis R. Rico, Acting Chief  
Children's Medical Services Branch