

MC 770: Children with Special Health Care Needs Summer Session I 2007

Course objectives

- Familiarize students with knowledge base concerning issues which confront families raising children and youth with special health care needs and social response to the needs of those families at national, state, and local levels.

- Expose students to important cultural concepts and values relevant to design and implementation of programs and policies for children and youth with special health care needs. Important concepts explored in the class will include:
 - Disability awareness
 - Family-centeredness as a component of quality of care
 - A systems approach to services.

- Advance student ability and confidence in the application of public health skills to address the needs of a defined population.

Class objectives

Class 1:

1. Students will understand requirements of the course. They will grasp the trajectory of course content and the progression of assignments;
2. Students will be alert to language which belittle individuals with disabilities and with alternative “people-first” language;
3. Students will be aware of different approaches to defining “children with special health care needs” and of the policy and program implications of those approaches;
4. Students will be able to identify at least 3 national efforts to count children and youth with special health care needs and understand their methodological implications and their results.

Class 2:

1. Students will be able to identify at least four national programs that are critical to children and youth with special health care needs and to describe the goals, scope, impact and limitations of each;
2. Students will recognize key attributes of federal programs in terms of their scale, impact and political sensitivity;
3. Students will be able to identify the six components of the national 2010 agenda for children and youth with special health care needs and discuss their significance and limitations.

Class 3:

1. Students will be able to identify at least three state programs that are critical to families of children and youth with special health care needs and to describe the goals, scope, impact and limitations of each;
2. Students will understand how states implement national policies and programs;
3. Students will understand how states interact with communities as programs are implemented at the local level.

Class 4:

1. Students will be aware of the cost of care and the elements that make up the cost of care for children and youth with special health care needs;
2. Students will be able to identify and characterize the major sources of coverage for children and youth with special health care needs;
3. Students will understand the special significance of Medicaid as a funder of care for children and youth with special health care needs;
4. Students will be able to describe the impact of financing on the design of systems of care for children and youth with special health care needs;

Class 5:

1. Students will be familiar with key components of the medical home model of care;
2. Students will be able to identify at least 3 barriers to implementation of the medical home model;
3. Students will be able to discuss the relationship of the medical home model to a family-centered and a systems approach to care of children and youth with special health care needs.

Class 6:

1. Students will understand the breadth of specialty services required by children and youth with special health care needs;
2. Students will be able to describe at least three ways primary care may interact with specialty services for children and youth with special health care needs;
3. Students will be able to identify at least 3 potential barriers to specialty services for children and youth with special health care needs.

Class 7:

1. Students will recognize the extent of care provided by parents of children and youth with special health care needs;
2. Students will appreciate the unique challenges faced by families of children and youth with special health care needs;
3. Students will be able to identify at least 3 common impacts of raising a child with special health care needs on family life and well-being.

Class 8:

1. Students will be able to describe at least 3 strategies for involving families in decision-making at clinical, program and policy levels in shaping care of children and youth with special health care needs;

2. Students will be able to identify at least two policies that reflect parent input at national and state levels;
3. Students will be aware of data suggesting disparities in access and quality based on race and class among families of children and youth with special health care needs.

Class 9:

1. Students will understand the importance of evaluation of programs for children and youth with special healthcare needs;
2. Students will be able to identify at least 3 challenges to evaluation of programs for children and youth with special health care needs
3. Students will be aware of emerging strategies for evaluation of programs for children and youth with special health care needs;
4. Students will be aware of the importance of parent perceptions in relation to evaluation of services for children and youth with special health care needs.

Class 10:

1. Student will be able to identify at least 4 domains of transition for youth with special health care needs;
2. Students will be able to identify the major entitlement program related to transition for youth with special health care needs;
3. Students will be aware of at least 3 challenges to effective health transition for youth with special health care needs;
4. Students will be able to identify at least 3 important strategies for program design to serve youth with special health care needs.

Class 11:

1. Students will be able to identify three important strategies for needs assessment related to services for children and youth with special health care needs;
2. Students will be sensitive to the complex politics of program design and implementation for children and youth with special health care needs;
3. Students will be able to define two strategies to promote collaboration in design of programs for children and youth with special health care needs.

Class 12:

1. Students will gain practice synthesizing information from multiple sources to inform the design of public health programs;
2. Students will gain practice identifying key issues in presenting the rationale for program concept papers;
3. Students will enhance presentation skills.

Class Schedule

Class 1, Monday, May 21

- Introduction to Class
- Who are children with special health care needs: defining and counting the target population

Class 2, Wednesday May 23

- The federal framework for addressing special health care needs
- National agenda for CYSHCN

Class 3 Wednesday May 30

- Program implementation at state and local levels

Guests:

Ron Benham, Director, DPH Division of Perinatal, Child and Special Health Care Needs

Rosalie Edes, President, Minuteman ARC

Class 4 Monday June 4

- Structure and financing of health services for children and youth with special health care needs

Class 5 Wednesday June 6

- Clinical care of CYSHCN
 - Quality of care – the medical home model

Guests:

Beverly Nazarian MD

Katherine Roussos, MS, Med

Class 6 Monday June 11

- Clinical care of CYSHCN
 - Specialty care for CYSHCN

Guests: **PJ Meriot, CNP**

Class 7, Wednesday June 13

- Families as caregivers for CYSHCN

Guests:

Dalene Basden, parent

Vojislaz Djordjic, parent

Class 8 Monday June 18

- Programmatic issues
 - Family participation in programs and advocacy
 - Disparity, race, and culture

Guests: **Elaine Gabovitch, parent**

Class 9 Wednesday, June 20

- Programmatic issues
 - Indicators, impacts and outcomes: evaluating programs for CYSHCN

Class 10 Monday June 25

- Programmatic issues
 - Transition and beyond

Guests:

TBD staff facilitator and youth panel from Partners for Youth with Disabilities

Class 11 Wednesday June 27

- Programmatic issues
 - Needs assessment in action: planning pediatric HIV care in MA
 - Collaboration in action: the Minnesota medical home initiative

Class 12, Monday July 2

- Student presentations: concept paper presentations

Assignments and Grading

Assignment 1: State data from the National CSHCN Survey Due Friday, May 25	5%
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We will look at data from the National Survey on Children and Youth with Special Health Care Needs in class 1. To complete this assignment, which is due by email at the end of the first week of class, choose a state and go to the CSHCN Survey data website (www.cshcndata.org). Look at data for the state you have chosen; compare it to national data and data for other states. Look at answers to the data queries available at the site.

If you were the Title V CSHCN director for that state, what would you make of these data? Write a memo to brief your state public health commissioner, highlighting what the data suggest about the state. Your role is both to inform the commissioner for your own programmatic purposes, and to assure that the commissioner is knowledgeable about information that might show up in the press.

There's no need to report everything. Pick out points that you think are most important, and comment on them. Include a general point or two describing the CSHCN population and how they fare in your state. Then focus in on a few issues that suggest areas of strength or weakness. Do remember that if you shy away from problem areas, you will leave the commissioner, your boss, defenseless in the face of press questions that may focus right in on those topics.

The assignment should be no more than 2 double-spaced pages.

Assignment 2: The Significance of EPSDT Due Friday, June 1	5%
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The quotation which follows comes from a recent article discussing implications of the Deficit Reduction Act, which gives states an option for backing away from EPSDT.

The EPSDT amendments redefined the Medicaid entitlement for people under age twenty-one. They were structured to reflect the professional pediatric standard of care, at whose core lies early and preventive health care emphasizing child development.

Assume the role of a health policy consultant assisting a grassroots parent organization. Write a brief article for their newsletter explaining the significance of EPSDT as part of the Medicaid entitlement for children. Note that you DON'T have to address the DRA – other articles in the newsletter will do that. Your task is just to discuss EPSDT. Do use references if your response is informed by research on the topic but don't make this overly academic. It is intended for a lay audience.

Because of space limits in the newsletter your article should be no more than 1 double-spaced page.

Assignment 3: State support for medical home implementation Due Friday June 8	10%
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You have just been hired by the [Joint Committee on Children, Families and Persons with Disabilities](#) of the Massachusetts General Court as a policy analyst. Several stakeholder groups, the state chapter of the Academy of Pediatrics, a large parent organization, and a Consortium concerned with systems of care for children with special health care needs have been pressing hard for state effort in this area, but have not identified a single, common agenda.

The chairs of the committee have asked you to do your own analysis, identifying the optimal place to spend \$1 million in state funds in the next fiscal year. You may put it in one or more programs, existing or new. The committee's only requirements be used where they will make a real difference, that there not be any obvious inequity in the way they be used, and that your proposed use draw either on successful models for medical home implementation in other states or on models used to promote coordinated, family-

Assignment 4: Completion of family home visit and visit report Due Monday June 25	30%
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centered care in other settings.

Given a tight timeline, they are asking that you provide a report of no more than 2 double spaced pages describing your proposal.

Assignment 4: Completion of family home visit and visit report Due Monday June 25	30%
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All of the programs and policies discussed in MC 770 affect the day-to-day lives of families. It is in the lives of families that programs and policies prove useful or inadequate, supportive or burdensome, coherent or fragmented.

Each student in MC 770 will be put in touch with a family that is willing to be interviewed at home about experiences raising a child with special health care needs in the context of current programs and policies. Students will work out logistics with their assigned families, and then conduct their interviews using questions developed by the class to get at the impact of programs and policies. Students will write up interviews drawing on family responses to address a set of predefined questions (see Family Interview Report Framework under Assignments in CourseInfo).

Concept Paper:
Due Monday July 2

40%

As the course final for MC 770, each students will select a “problem” of interest and write a concept paper, identifying and characterizing the problem, and then broadly describing a program or policy to address it. Detailed requirements for this 8-10 page (double-spaced) are provided under Assignments in CourseInfo.