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By courier to: Room 443-G
Hubert H. Humphrey Building
200 Independence Avenue, S.W.
Washington, D.C.

January 7, 2000

Health Care Financing Administration
Department of Health and Human Services
Attention: HHS -20006-P
P.O. Box 8010
Baltimore, Maryland 21244-8010

Re: Comment to the Proposed Rule, "State Child Health; Implementing Regulations for the State Children's Health Insurance Program," 64 Fed. Reg. 60882 (Nov. 8, 1999).

To Whom It May Concern:

The National Health Law Program (NHeLP), a non-profit, civil rights organization that advocates for justice in health care for low-income people, submits these comments on behalf of itself and the organizations listed below in response to the Notice of Proposed Rulemaking, "State Child Health; Implementing Regulations for the State Children's Health Insurance Program," published in the Federal Register on November 8, 1999.

We have summarized our primary concerns and comments, followed by a more detailed, section-by-section analysis. Specific comments and recommendations are followed by a rationale, except where the comment or recommendation is self-explanatory.

We thank you for the opportunity to comment on these proposed rules.

Sincerely,

Jane Perkins for the
National Health Law Program

Comments endorsed by:

Asian and Pacific Islander American Health Forum
Asian Pacific American Legal Center
Barnes-Jewish Hospital, Refugee Health Services, St. Louis, MO
Bazelon Center for Mental Health Law
California Center for Law and the Deaf
California Protection and Advocacy, Inc.
Center for Adolescent Health and the Law, Chapel Hill, NC
Center on Disability and Health, Washington, DC
Consumers for Affordable Heath Care, Augusta, ME
Early Childhood Direction Center, Syracuse, NY
Family Voices of Washington, Olympia, WA
Florida Legal Services
Legal Aid Society, New York, NY
Legislative Coalition of Virginia Nurses
Maryland Disability Law Center
Mexican American Legal Defense and Educational Fund
Michigan Council for Maternal and Child Health
Michigan Protection and Advocacy Service, Inc.
Mississippi Human Services Coalition
National Association of Protection and Advocacy Systems, Inc.
National Council of La Raza
National Organization for Rare Disorders
Northwest Health Law Advocates, Seattle WA
Ocean State Action, Cranston, RI
Oregon Center for Public Policy
Southern AIDS Commission, Inc., Jackson, MS
South Carolina Appleseed Legal Justice Center
Universal Health Care Action Network of Ohio
Virginia Poverty Law Center
Western Center on Law and Poverty

Individuals:
Shiva Bidar-Siealff, Madison WI

Comments to the Proposed Rule, "State Child Health: Implementing Regulations for the State Children's Health Insurance Program," 64 Fed. Reg. 60882 (Nov. 8, 1999)

Submitted by the
National Health Law Program
January 7, 2000

I. Summary

Consumer Protections -We wholeheartedly support and applaud the Department's decision to incorporate the provisions of the Health Care Consumer Bill of Rights into the proposed SCHIP regulations. The right to apply for assistance, to have applications processed in a timely manner, to be informed about benefits, participating providers and coverage decisions and to have access to a fair process to resolve disputes are basic consumer protections that are critical to ensuring that the SCHIP's program's promise of health care coverage is more than an illusion.

While we applaud the inclusion of these basic right's protections, as we explain in greater detail in Section II below, we believe the Bill of Rights protections can and must be strengthened by adopting more consistent terminology, clarifying definitions, providing greater specificity and establishing clearer, more detailed standards. The need for clarity and specificity is greatest in the area of grievances and appeals.

Application and enrollment - HCFA has made clear that one of its highest priorities is to ensure that children who apply for SCHIP who are eligible for Medicaid are enrolled in Medicaid. Another priority is to simplify and streamline application procedures to facilitate the enrollment of eligible children into either SCHIP or Medicaid, whichever is appropriate. HCFA, however, is only requiring States to undertake a limited Medicaid eligibility screening process that will not identify all Medicaid eligible children who have filed SCHIP applications. We believe that these potentially Medicaid eligible children who are not identified through the proposed limited screening process are at high risk either to be enrolled in SCHIP or to fall through the cracks and not be enrolled either in SCHIP or Medicaid. We believe that States can and should devise better screening procedures to avoid both results.

Civil Rights Protections and Data Collection - Racial and ethnic minority children are at highest risk to be without health insurance. The SCHIP program can and must play a significant role to address this glaring disparity in our health care system. We have made numerous recommendations throughout our comments designed to strengthen adherence to civil rights protections so that States act affirmatively to eradicate access barriers and improve minority participation in the SCHIP program. We also firmly believe that HCFA must require States to collect and report data on SCHIP enrollment by race, ethnicity and primary language spoken. We

have appended to our comments a letter to Secretary Shalala, signed by over 118 organizations and individuals asking the Department explicitly to amend the SCHIP rules to mandate such data collection.

II. Section by Section Comments and Recommendations

Subpart A
Introduction; State Plans for Child Health Insurance Programs and Outreach Strategies

1. 42. C.F.R. § 457.10 - Definitions and use of terms

- Grievance - see comment at § 457.902.

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2. 42. C.F.R. § 457.40 - State program administration

- We agree that HCFA must monitor the operation of approved State SCHIP plans and plan amendments to ensure compliance with the requirements of title XXI and title XIX.

- Section 457.40(a) should be amended to clarify that State SCHIP plans and plan amendments also must operate in accordance with federal civil rights laws including Title VI of the Civil Rights Act of 1964 and the Americans with Disabilities Act. HCFA also must monitor the operation of State SCHIP plans and plan amendments for compliance with these laws.

- While recognizing in the preamble that ongoing review of State programs is an evolving process, HCFA needs to identify either in this regulation or in a separate policy document "the core set of key policy areas" that it intends to monitor and to establish a standardized protocol for doing so. One key policy area which ought to be integrated into the ongoing review of State SCHIP programs is how SCHIP is addressing the needs of racial and ethnic minority children, as well as children with disabilities. (*See* preamble at 64 Fed. Reg. 60887).

Rationale: Absent clarity regarding the review standards and protocols, HCFA will have difficulty monitoring and ensuring compliance. The Department's initiative to eradicate racial and ethnic disparities in health care by 2010 dictates that this should be one of the core policy areas that is incorporated into a systematic review of SCHIP programs.

- Language should be included in the preamble that makes clear that HCFA views stakeholders (including families of SCHIP beneficiaries, child health advocates, community-based organizations, providers etc.) as having an important role to play throughout the review process.

Rationale: The preamble makes reference to the important role of the States, but is silent about the critical role that consumers, advocates, providers and others play both in the design, implementation and monitoring of SCHIP programs.

3. 42 C.F.R. § 457.50 - State plan

- We strongly urge HCFA to delete references in the preamble (*see* 64 Fed. Reg. 60888) that provide that "[a]n approved State plan is comprised of the initial plan submission, responses to requests for additional information and subsequent approved State plan amendments." An approved State plan should be a single document that is comprehensive, up-to-date, and easily accessible.

Rationale: In the preamble, HCFA States that an approved State plan consists of the initial submission, subsequent approved amendments *and* the correspondence between the State and HCFA. The correspondence may include the written responses to HCFA to requests for additional information, both formal and informal, as well as "any other written correspondence." HCFA then provides rules for interpreting the various documents comprising the State plan. For example, the preamble States, "information received from a State supercedes any contrary information that is included in the original plan or other earlier submissions. Moreover, if there are several submissions from the State that are inconsistent, the latest submission is the governing document." If States are not expected to maintain a single, comprehensive and updated document, it will be virtually impossible for any one (including HCFA, State authorities and those outside of government) to understand the operational and programmatic features of a State's current SCHIP program without reviewing every piece of correspondence between the State and HCFA.

- HCFA must also make clear that the approved State plan including any amendments is a public document.

Rationale: HCFA has done a good job of posting State plans on its website when they are available electronically. When they are not so available, advocates (and other stakeholders) often have difficulty obtaining copies. If State plans consist of multiple documents and many pieces of correspondence, States may be more reluctant to provide copies.

4. 42. C.F.R. § 457.60 - Amendments

- Eliminate language in the preamble that in practice, States need only submit written plan amendments if changes are "substantial and noticeable."

- Make clear that any change that eliminates, restricts, or otherwise modifies eligibility, even if the change impacts only a small number of beneficiaries, must be submitted as State plan amendments.

Rationale: Whether a change is "substantial and noticeable" is a subjective determination. A change that affects the eligibility of 300 families across the State or 25 families in one community will be substantial and noticeable to the affected families, but likely to be inconsequential and unnoticed by the rest of the State or the community. Likewise, a change that only affects immigrant families is likely to be perceived as insubstantial and unnoticed by unaffected populations in most States. We submit that any change that eliminates or restricts eligibility must be submitted as an amendment to the State plan, regardless of how it may be characterized or who notices it.

5. 42 C.F.R. § 457.65 - Duration of State plans and plan amendments

- Clarify that in order for a State to certify that it has complied with the public notice requirement in § 457.65(b)(1), it must certify that it has complied with all applicable State legal requirements for notice *and* meaningful public comment.

Rationale: Under the statute, a State plan amendment that eliminates or restricts eligibility or benefits may not take effect unless the State certifies that "it has provided prior public notice of the change, in a form and manner provided under applicable State law." Section 2106(b)(3)(B)(i). We read this to require that States must certify that they have complied with applicable State Administrative Procedure Act or similar requirements mandating public notice and comment with respect to the promulgation of rules or regulations of general applicability. Although State processes vary, there is generally a requirement that notice issue for a specified period of time, followed by a period for meaningful public comment.

- Eliminate § 457.65(b)(2).

Rationale: Proposed § 457.65(b)(2) interjects ambiguity into the rule because it could be interpreted to allow State plan amendments that restrict or eliminate eligibility or benefits to become effective as long as the public notice was published before the requested date of the change, regardless of whether or not the State had provided meaningful opportunity for public comment or whether the applicable time frames had run.

- We support § 457.65(c), clarifying that amendments that implement cost-sharing charges, increase existing cost sharing charges, or increase the cumulative cost sharing maximum are amendments that restrict or eliminate benefits.

6. 42. C.F.R. § 457.70 - Program options

- Delete § 457.70(c)(1)(vi) - Subpart H requirements only apply to separate State health insurance programs.

7. 42. C.F.R. § 457.80 - Current State child health insurance coverage and coordination

- Amend § 457.80(a) as follows:

  A State plan must include a description of –

  (A) The extent to which, and manner in which, children in the State, including targeted low-income children and other classes of children, by income level ~~and other relevant factors,~~ race, ethnicity and primary language spoken, have creditable health coverage . . . .

Rationale: It is now well-established in the research that minority children are more likely than non-minority children to lack health insurance. To understand and eliminate this disparity, health policy makers, analysts, providers and government authorities need access to information about how the SCHIP program is meeting the needs of eligible minority children. Collection of the data also gives HHS the tools needed to monitor and enforce Title VI of the Civil Rights Act of 1964. (For additional comments on the need to mandate collection and reporting SCHIP data based on race, ethnicity and primary language spoken, please see letter to Secretary Shalala, dated December 31, 1999, which is incorporated by reference into our comments and attached as Exhibit A).

8. 42. C.F.R. § 457.90 - Outreach

- We urge HCFA to amend § 457.90(a) to require State plans to include a description of outreach strategies to children and families with special needs including LEP populations, and families whose children have disabilities.

- We urge HCFA to include in § 457.90(b) examples of outreach strategies targeted to special populations.

Rationale: The preamble contains a lengthy discussion of many effective and successful strategies, including strategies to target minority children. However, nothing in the preamble elaborates upon a State's obligations under Title VI to ensure cultural and linguistic access to SCHIP benefits and services or under Title II of the ADA to ensure that people with disabilities also have equal access to SCHIP benefits and services.

9. 42. C.F.R. § 457.110 - Enrollment assistance and information requirements

- We strongly support the language in § 457.110(a) with the following addition: The State must make accurate, easily understood and linguistically appropriate information available to families of targeted low-income children and provide assistance to these families in making informed health care decisions about their health plans, professionals and facilities.

- We strongly urge HCFA to rewrite the section of the preamble noted below. In so doing, we suggest HCFA reference the Office for Civil Rights Guidance Memorandum. Title VI Prohibition Against National Origin Discrimination - Persons with Limited English Proficiency (1998), which provides a more comprehensive discussion of language access requirements under Title VI.

Rationale: The preamble states:

> [A] State may overcome language barriers by establishing a methodology determining the prevalent language or languages in a geographic area and making information available in the languages that prevail throughout the State or in limited geographic areas where appropriate. A State may also overcome language barriers by making translation services available to enrollees and potential enrollees. (64 Fed. Reg. 60893).

We are concerned that the above language may be misleading with respect to a State's obligations under Title VI to provide linguistically appropriate services. As drafted, the use of the term "overcome" suggests that States may rely on either one of these strategies to address Title VI compliance. More accurately, the two suggested approaches could be part of a comprehensive plan to ensure linguistic access to services, but neither one alone would necessarily suffice to insulate a State from challenge under Title VI.

- HCFA must elaborate on requirements to provide materials in alternative formats in the preamble and ensure that the rule includes an explicit reference to alternative formats.

Rationale: Although the preamble states that materials must be available to applicants and beneficiaries in easily understood languages and formats, there is no reference to formats in the rule. Under the ADA, States must provide sign language interpretation and have telecommunications devices to facilitate communication with people who cannot hear. Written materials also must be available in alternative formats for people who cannot read due to a disability, e.g., tape recordings, large print, braille, etc.

- In § 457.110(b)(1), add cost sharing and rights to information that States must make available in order for families to make informed health care decisions..

10. 42 C.F.R. § 457.120 - Public involvement in program development

- We strongly support the requirement that a State plan include a description of the method the State uses to involve the public in both the design and initial implementation of the program; and ensure ongoing public involvement once the State plan has been implemented.

- We urge HCFA to include discussion in the preamble of ways to include the parents of SCHIP children in the planning and monitoring of benefits and service delivery systems.

11. 42 C.F.R. § 457.125 - Provision of child health assistance to American Indian and Alaska Native children

- We believe HCFA should strengthen §457.125 by requiring State officials responsible for SCHIP to consult with Federally recognized Tribes and other Indian tribes and organizations in their State on the development and implementation of child health assistance to American Indian and Alaska Native children.

- We fully support the prohibition on imposing cost sharing on American Indian and Alaska Native children.

12. 42 C.F.R. § 457.130 - Civil rights assurance

- We fully support inclusion of a requirement that a State plan provide assurance that the State will comply with all applicable civil rights requirements. However, the regulation must make clear that the State is obligated to ensure that its contractors, subcontractors and grantees also comply with civil rights laws.

13. 42. C.F.R. § 457.160 - Notice and timing of HCFA action on State plan material

- We disagree with proposed rule § 457.160(b)(3) which provides that if HCFA requests additional information, the 90-day review period is stopped but resumes on the next calendar day after HCFA receives all of the requested information. We recommend that HCFA adopt the approach used in Medicaid. *See* 42 C.F.R. § 430.16. Under this rule, if HCFA requests additional information, the 90-day review period for HCFA action on the plan or plan amendment begins on the day it receives that information.

Rationale: Under proposed § 457.150(b), "HCFA approves or disapproves the State plan or plan amendment *only* in its entirety." (Emphasis supplied). Yet, under proposed 42 C.F.R. § 457.160(b)(3), if HCFA has determined that additional information is needed, HCFA will have less than 90 days to review that information once it is submitted. Although we understand the strong interest in moving quickly to implement SCHIP, we see no reason to accelerate a review process when the initial State submission was inadequate or incomplete. We recommend that HCFA adopt the current Medicaid standard for review of plan amendments when additional information has been requested. Not only will use of the current Medicaid standard promote consistency, it will ensure that HCFA has sufficient time for review.

14. 42. C.F.R. § 457.170 - Withdrawal process

- While we recognize that the State should be allowed to withdraw its plan, we would recommend that the State should also be required to provide public notice and a meaningful opportunity for public input prior to any such withdrawal.

15. 42 C.F.R. § 457.190 - Administrative and judicial review of action on State plan material

- We support the proposed procedure for administrative judicial review.

Subpart C - State plan requirements: eligibility, screening, applications, and enrollment

16. 42 C.F.R. § 457.310 - Targeted low-income child

- We fully support HCFA's interpretation in § 457.310(b)(2)(ii) that for a child to be considered covered by a group health plan and therefore, ineligible for SCHIP, the child must have reasonable access to such coverage.

- HCFA must clarify the consequence of being "found ineligible for Medicaid" through a screening process that is less than a full review of Medicaid eligibility.

Rationale: Under § 457.310(b)(2)(i), a child who is found eligible for Medicaid either through the Medicaid application process or *the limited screening process* described in § 457.350, is considered ineligible for SCHIP because the child does not meet the "no other coverage criteria" for SCHIP eligibility. However, in § 457.350(f), if a State uses a screening process that is less than a full determination of Medicaid eligibility and the child is found potentially ineligible for Medicaid, the child's family is given information about how to apply for Medicaid. Thus, it appears that even if a child is potentially found ineligible for Medicaid, the limited screening process does not forestall the need to send families and children through the complete Medicaid application process before SCHIP

eligibility can be established affirmatively. If this interpretation is correct, we urge HCFA to provide guidance to States about how they might streamline, simplify and coordinate these processes to minimize the burden on families applying for benefits on behalf of their children. Alternatively, we urge HCFA to require States to undertake a more thorough screening process. (*See* comment #19 below regarding § 457.350 Eligibility Screening).

- HCFA should reiterate that a child who must meet a spend down before establishing eligibility for Medicaid does not have "other coverage" and is therefore eligible for SCHIP. (*See* HCFA, Question and Answer 33, October 10, 1997).

- We suggest that HCFA define what constitutes a nominal contribution as a percent of the total cost of dependent coverage, rather than a finite dollar amount.

Rationale: HCFA proposed that a child is considered eligible for a State health benefits plan if more than a nominal contribution is available from the State or public agency employer with respect to the child. To calculate the amount available to the child, amounts only available to an adult employee should be deducted from the total State or public agency contribution. HCFA proposes that any contribution over $10 towards the cost of dependent coverage is more than nominal. Whether an employer contribution toward dependent coverage is nominal or not, however, depends in part on the cost of coverage. If dependent coverage is very expensive, and the employer's contribution is only $20, under the proposed definition, income eligible SCHIP children still will be foreclosed from coverage. A more equitable way to define what constitutes a nominal contribution would be to express it as a percent of the total cost of dependent coverage, rather than a finite dollar amount.

- We support HCFA's interpretation, articulated in the preamble, that only children who are confined in penal facilities are considered to be inmates of a public institution. For clarity, we strongly recommend, however, that the reference to "penal" be incorporated into the language of the regulation at § 457.310(c)(2) and that HCFA explain in the preamble or by definition that this refers only to children who are incarcerated after sentencing.

- We support HCFA's interpretation of the statutory exclusion of children who are admitted for treatment to an Institution for Mental Diseases (IMD).

Rationale: Although some children may require intermittent or short-term hospitalization in an IMD, the maintenance of health insurance is critical to assuring that the child can be promptly discharged and can be linked to appropriate community-based treatment services and supports. To terminate SCHIP eligibility upon institutionalization is likely

only to prolong the child's institutionalization and make community placement more difficult.

17. 42 C.F.R. § 457.320 - Other eligibility standards

- Amend § 457.320(b) by adding new subsection (4): use eligibility standards that discriminate on the basis of diagnosis.

Rationale: The statute specifically prohibits States from establishing eligibility standards that discriminate on the basis of diagnosis. *See* Balanced Budget Act, Section 4901, establishing new Title XXI, Section 2102(b)(1)(A).

- Amend § 457.320(a)(10) to make clear that States are prohibited from establishing time limits for eligibility.

Rationale: The objective of the SCHIP program is to give more low-income children access to health care. To allow States to impose durational limits on eligibility is contrary to the intent of the program and would create intolerable discontinuities for children receiving on-going treatment for routine and chronic problems. Moreover, nothing in the statute authorizes States to establish such durational eligibility limits. Rather, the statute merely provides that State plans include "a description of methods of establishing and continuing eligibility and enrollment" and for ensuring that "only targeted low-income children are furnished child health assistance under the State child health plan." *See* Balanced Budget Act, Section 4901, establishing new Title XXI, Section 2102(b)(3)(A).

- We urge HCFA to amend § 457.320(a)(7) to incorporate into the proposed rule several prohibitions that have long been recognized as limitations on the States' authority to establish residency requirements in the Medicaid program. Specifically, States must be prohibited from:

  (1) denying eligibility because a child has not resided in the State for a specific period of time. *See* 42 C.F.R. § 435.403(j)(1);
  (2) denying eligibility to a child in an institution on the grounds that the child did not establish residence in the State before entering the institution. *See* 42 C.F.R. § 435.403(j)(2);
  (3) denying or terminating a child's eligibility because of that child's temporary absence from the State. *See* 42 C.F.R. § 435.403(j)(4); and
  (4) denying eligibility to an otherwise qualified resident of the State because the child's residence is not maintained permanently or at a fixed address. *See* State Medicaid Manual, HCFA Pub. 45-3, § 3230.3.

- The regulations also must explicitly provide that children who live in families where the parent or parents are seeking work or engaged in work of a transient nature, such as migrant labor, may choose to establish residency in the State they are in or claim residency in one particular State to ensure that they are not illegally deprived of the right to apply for SCHIP

Rationale: Notwithstanding the flexibility accorded States under the SCHIP statute, States are prohibited from establishing residency rules that violate the Constitution. Accordingly, we urge HCFA to import into SCHIP the protections that have been incorporated into the Medicaid program in order to bring the program into compliance with the law. *See* State Medicaid Manual, HCFA Pub. 45-3, § 3230.3(B). These prohibitions are specifically designed to promote and preserve the right of low-income families to travel. They also ensure that people who are homeless, migrant workers and others who are transient are not unfairly denied access to benefits.

- We strongly support the language in proposed § 457.320(b)(4) prohibiting States from asking for Social Security numbers from applicants, other household members, or persons applying on behalf of applicants.

Rationale: Asking applicants and family members to provide Social Security numbers is a strong deterrent for immigrant and some other families to apply for and utilize public benefits. Although the Medicaid statute requires an applicant to furnish a Social Security number, there is no parallel requirement under SCHIP. The proposed rule makes clear that States may not deny eligibility based on the failure of the child or any member of the child's household to provide a Social Security number. It should clarify that the same prohibition applies with respect to other individuals who are not household members that apply on behalf of the child.

- We strongly urge HCFA to amend § 457.320 to add (b)(8) as follows: Require that any non-applicant family or household member or other non-applicant applying on behalf of a child provide information regarding or verification of citizenship or immigration status.

Rationale: Nothing in the proposed rule prohibits States from asking questions regarding the citizenship or immigration status of non-applicants even though HCFA has stated explicitly that "the citizenship or immigration status of non-applicant parents (or other household members) . . . is irrelevant to their children's eligibility [for SCHIP]. State may not require that parents disclose this information." (Letter to State Health Officials from Sally Richardson, Director, September 10, 1998); *see also* Interim Guidance on Verification of Citizenship, Qualified Alien Status and Eligibility under Title IV of the Personal Responsibility and Work Opportunities Act of 1996 and proposed rules at 63 Fed. Reg. 41662, 41676 (August 4, 1998) (citizenship and immigration status information

should only be used for purposes of verifying the *applicant's* eligibility for benefits). Thus, unless the State has received a waiver for family coverage, information about the citizenship or immigration status of a non-applicant family or household member is irrelevant to the SCHIP eligibility determination. Requesting such information will only act as a deterrent for children in immigrant families whose parents are fearful about adverse immigration consequences.

- Instead of providing incomplete information in the preamble about what categories of immigrants are qualified and therefore eligible for SCHIP benefits, HCFA should issue guidance in the form of a letter or preferably, an amendment to the State Medicaid Manual, that provides detailed, accurate and complete guidance regarding which categories of immigrants, based on status and date of entry, are qualified and which are not for purposes of Medicaid and SCHIP. The guidance also needs to identify which categories of immigrants are exempted from the five year bar. The guidance needs to clarify that "date of entry" means date of *physical* entry, regardless of whether the individual had a qualified status at the time of entry. Adoption of such a clarification would be consistent with SSI policy. *See* SSI Program Operations Manual System, 00502.135(B)(1) (December 1996). The guidance also needs to incorporate changes in the definitions of qualified alien status enacted by Congress since 1996, and it should be kept up to date if additional changes are enacted. Ideally, this guidance should be posted on HCFA's website in a format that makes it easy to understand and to access. The SCHIP regulation should reference this guidance.

Rationale: The preamble correctly notes that a State must cover those legal immigrant children who meet the Federal definition of qualified immigrant and who are otherwise eligible. Unlike Medicaid, States implementing SCHIP do not have the option of restricting the eligibility of qualified immigrants. However, neither the proposed rule or the preamble language provide clear guidance to States as to which categories of immigrant children are qualified. For example, while the preamble correctly noted that immigrants arriving after August 22, 1996 are barred from receiving SCHIP benefits, it does not list the categories of immigrants who are exempted from the five year bar. Similarly, the eligibility of abused or neglected children under the Violence Against Women Act (VAWA) is often missed in SCHIP programs. Unfortunately, this is an area of tremendous confusion because the rules are complex and are also subject to change. Clear, accurate and complete guidance is needed to ensure that eligible immigrant children are not denied benefits (or the opportunity to apply for benefits) erroneously.

- Delete § 457.320(c).

Rationale: The preamble correctly notes that Section 432 of PRWORA is controlling on the issue of requiring proof of citizenship and verification of immigration status, and that

proposed INS rules defining acceptable practices, have yet to be finalized. However, even after INS rules are finalized, States have two years to come into compliance. As drafted, however, the proposed SCHIP rule merely provides that States must obtain proof of citizenship and verify qualified immigration status without reference to the statutory deadline and without any reference to the need to implement processes and procedures that will not deter or discourage eligible children from applying for benefits. While we recognize that States must come into compliance with the welfare law, including this provision is redundant and may encourage States to act prematurely or precipitously to implement verification requirements that will deter eligible children from applying for benefits.

- Amend the rule to make clear that State procedures to obtain proof of citizenship and to verify immigration status:

  (1) must not discourage eligible children from applying for or receiving benefits;
  (2) must ensure that an applicant who cannot provide proof of US national status may establish proof through alternative means, i.e. attestation by a third party;
  (3) must allow for self-attestation/declaration as temporary evidence of U.S. nationality until required proof is provided; and
  (4) must not condition the applicant's eligibility on the status of a parent or any other household member.

18. 42 C.F.R. § 457.340 - Application

- We strongly support the requirement that States give every individual the opportunity to apply for child health assistance without delay.

Rationale: This language is similar to an existing Medicaid regulation that provides: "The agency must afford an individual wishing to do so the opportunity to apply for Medicaid without delay." 42 C.F.R. §435.906. Including this provision in the SCHIP rule helps ensure that children are not deterred or discouraged from obtaining benefits. Furthermore, its sets a standard against which the processing of all applicants can be evaluated. This helps ensure that minority children and children with special needs are not treated differently than other children and have equal access to SCHIP benefits as required under Title VI of the Civil Rights Act of 1964 and the ADA.

- HCFA must clarify that underlying the requirement that every individual be given an opportunity to apply without delay are the mandatory provisions of the Title VI of the Civil Rights Act and the Americans with Disabilities Act that ensure that racial and ethnic minorities and people with disabilities have equal access to

benefits. For example, States are obliged to ensure that written materials are available in languages other than English and in formats that can be understood by people who cannot read due to a disability. Additionally, States may have to make reasonable accommodations in their policies and procedures to ensure that ethnic and racial minorities, people with low English proficiency and people with disabilities, who are otherwise qualified for the program, are able to fully participate in it. (*See* comment #21 below regarding § 457.361 Application for and Enrollment in SCHIP).

19. 42 C.F.R. § 457.350 Eligibility screening

- We strongly disagree with the thrust of the language in the preamble that requiring States to screen for eligibility under all possible groups "would place an unreasonable administrative burden," and that determinations under Section 1931 of the Act are particularly complex. (*See* 64 Fed. Reg. 60904).

Rationale: First, the preamble language is inaccurate. States have considerable flexibility, particularly under Section 1931, to simplify requirements for Medicaid eligibility. There is no reason why an application for 1931 eligibility has to be any more complex than a SCHIP application, provided States choose to exercise their options. Second, telling States, in essence, that Medicaid eligibility is too hard to figure out does little to encourage States to streamline and simplify their eligibility processes. Further, it will undermine HCFA's efforts to monitor State Medicaid eligibility and redetermination processes and to bring States into compliance with the law. Third, *screening* for eligibility and *determining* eligibility are not the same. Thus, even if it is not possible to combine application forms for SCHIP and all categories of Medicaid eligibility, it is quite feasible to devise a simple, short list of questions to *screen* for eligibility in non-poverty level Medicaid eligibility categories. While a short questionnaire would not establish eligibility for Medicaid, the application could be routed to an outreach worker for appropriate follow-up.

- We strongly disagree with HCFA's decision to require States only to conduct a limited Medicaid eligibility screen for children applying for SCHIP benefits. HCFA should require States to undertake a more comprehensive screen. Specifically, HCFA should direct States to undertake an initial review that would *screen* for all categories of Medicaid eligibility.

Rationale: Under the SCHIP statute, a State's plan must include a description of procedures to be used to ensure that "children found through the screening to be eligible for medical assistance under the State Medicaid plan under Title XIX are enrolled for such assistance under the plan." Despite this statutory provision, HCFA is only requiring limited screening for Medicaid eligibility. Specifically, States will only be required to

determine whether children are eligible for Medicaid as poverty level children under Section 1902(1). We have several major concerns and comments about how HCFA has defined the minimum requirements for eligibility screening. We believe there is ample justification for requiring a more comprehensive screen.

First, the statutory language refers to "children found through the screening to be eligible for medical assistance under the State medicaid plan under title XIX." If Congress had wanted to limit the obligation of States to screen for medicaid eligibility under only poverty level standards, Congress could have explicitly so stated.

Second, although we recognize that States are concerned about the burden and expense of a more demanding screening process, we note that States are already legally obliged to have a Medicaid application and redetermination process in place that enables eligibility workers to screen for eligibility under *all* potential categories of coverage. Therefore, requiring States to undertake a more thorough screen in SCHIP is not requiring them to undertake more than what they are supposed to be doing already in their Medicaid programs.

Third, while many States have accelerated the phase-in of coverage for poverty-level children and have raised the eligibility standard above 100% of FPL, approximately 25 States have not. In many of these States, children ages 6 through 15 lose Medicaid eligibility as a poverty level child if their family income exceeds 100% of FPL. For older adolescent children (those over 16 years of age), poverty level eligibility may end at much lower income levels. Yet, depending on the features of the State's Medicaid program, some of these same children may still be eligible for Medicaid, for example, under Section 1931 or the special rules for Transitional Medicaid Assistance (under which all earned family income is disregarded for the first six months of TMA eligibility). In short, the poverty level category may not be the most inclusive category of eligibility for children within the State.

Fourth, requiring States to effectuate a limited screening process that only looks at poverty-level eligibility will disproportionately screen-out Medicaid eligible children who have serious disabilities. This is because children with disabilities have additional routes to Medicaid eligibility, including categorical eligibility under SSI and Section 4913, "medically needy," and the "Katie Beckett" option. Again, depending on the features of the State's Medicaid program, these alternative routes to Medicaid are likely to have more liberal income and resource standards than eligibility standards under Section 1902(1). For example, SSI treats families with earned income differently, allowing for more generous disregards. Consequently, a child with a serious disability who is income eligible for SSI is entitled to Medicaid even if earned income exceeds 200% of poverty. The following real life example illustrates the point:

> Mrs. G is a single, working mother who lives in North Carolina with her three children. Her 11 year old child has medical problems that allow him to qualify as disabled under SSI rules. Mrs. G earns $410 per week and has child care expenses of $200 per month. Under SSI rules, in most months, only $36 of Mrs. G's earnings are counted in determining her disabled child's eligibility for SSI. However, without SSI this same child would not be eligible for Medicaid. This is because under North Carolina's applicable Medicaid rules, $1473 of Mrs. G's earnings are countable as income every month placing Mrs. G over the State's Medicaid income limit for a child over 5 ($1338 per month or 100% of FPL).

Fifth, even in States that have expanded eligibility for poverty level children, a child with a disability may still be better off receiving Medicaid as an SSI-linked recipient. This is because in many States, the EPSDT scope of benefits is more comprehensive than that of separate SCHIP plans. Moreover, in many States, SSI-linked Medicaid recipients are exempt from having to enroll in managed care plans.

Sixth, under the proposed rule, if a child is found ineligible for Medicaid based on a very limited screening, the State is directed to send the family a written notice advising them that "based on initial review, the child does not appear eligible for Medicaid, but Medicaid eligibility can only be determined based on review of a full Medicaid application." There are at least two problems with this notice. First, it is misleading because it does not clearly state that the "initial" review was a very limited review and did not look at all the categories of eligibility available to the child or family. A more comprehensive screen, but something less than a full application that requires documentation and verification, could indeed identify other Medicaid eligible children. In other words, a limited screening process can only identify someone who is eligible for the category of eligibility reviewed. It cannot determine that someone is ineligible for Medicaid. Second, because it so clearly states the child does not appear eligible, it effectively communicates that there is little point to pursuing the full application. Thus, taken together, HCFA's limited screening process, and the directive to send a notice that says the child does not appear eligible will mean that families with eligible children, including children with disabilities, will be discouraged from applying for Medicaid benefits.

Seventh, recent research studies and news reports, as well as HCFA's own audit of State Medicaid programs, have made clear that many States have been illegally cutting eligible families and children off of Medicaid. In particular, many problems have been identified in the way that States have processed eligibility under Section 1931 and transitional Medicaid. Given the States' failure to properly and effectively implement Section 1931 and TMA, mandating a more comprehensive screening process in SCHIP seems

warranted as a way to remedy past illegal conduct. Furthermore, a more comprehensive screening process will help expedite identification and enrollment of Medicaid eligible families and children in TMA -- a benefit that can be lost because it is time-limited.

- As an alternative to requiring that States screen children for Medicaid eligibility in all categories, we urge HCFA to eliminate the directive in § 457. 350(c)(1) that States screen Medicaid eligibility only under Section 1902(l). Instead, HCFA should direct States to develop a screening process and methodology that considers the most liberal income eligibility standard for that child given the child's age, disability and the family's prior eligibility for 1931 Medicaid. Such an approach would help minimize the likelihood that the process would screen out older children, children with disabilities (eligible under SSI or other disability related categories) and children in families in transition from welfare to work (eligible for transitional Medicaid).

Rationale: We believe that developing this capacity (if it does not already exist) is necessary for the proper and efficient administration of both SCHIP and Medicaid.

- Clarify the treatment of a child found potentially ineligible for Medicaid if the State uses a limited screening process in § 457.350(f).

Rationale: The rule is unclear. If a child is found potentially ineligible for Medicaid based on a limited screen, does that mean that the child is eligible for SCHIP? If so, the child should be enrolled in SCHIP and these provisions are irrelevant. If not, in addition to the information specified in the rule, the State must inform the child that his/her SCHIP application has been denied and that he/she has a right to appeal that denial. If the application filed was a joint SCHIP/Medicaid application, the notice needs to explain the effective date of the Medicaid portion of the application and how the child can complete the application process.

- HCFA should encourage States to use presumptive eligibility to provide Medicaid coverage for children found potentially ineligible for Medicaid based upon a limited screen pending the submission of additional information and a full eligibility determination.

- HCFA should revise proposed § 457.350(f)(1). Specifically, we suggest the following language:

> "Based on a limited review, we could not tell whether your child is eligible for Medicaid. The Medicaid program provides important health benefits to families and children who are low income. Children who have disabilities may be eligible even if the family

income is higher. Families who have left welfare may be eligible for Medicaid, even if they are working. The only way to find out for sure whether you or your children are eligible for Medicaid is to apply. You have a right to apply for Medicaid and to bring some one with you to help you with the process. For more information about how to apply for Medicaid, please contact _____."

Rationale: The notice should accurately describe the limited nature of the screening process. It should also be written to encourage families to pursue the Medicaid application and explain their right to do so. In addition, HCFA should specifically require States to provide a written explanation of ways that children and families may qualify for Medicaid and how to complete the application process.

- HCFA should clarify that if a child has applied for but has been denied SCHIP eligibility because the child was found to be potentially eligible for Medicaid, and the child completed the Medicaid application, but is denied, the child should not be required to reapply for SCHIP under § 457.350(e)(2).

20. 42 C.F.R. § 457.360 - Facilitating Medicaid enrollment

- HCFA should clarify that in States that use a joint application form, the date of application for SCHIP is also the date of application for Medicaid. Thus, if a SCHIP application is denied, the State must provide notice to the applicant and must also continue to process the Medicaid application within the 45 day time frame.

- In addition to forwarding the application form to the appropriate Medicaid office, States must ensure that all supporting documents submitted during the SCHIP application process are also forwarded to Medicaid.

Rationale: Under the statute, States are required to ensure that children found eligible for Medicaid through the screening process apply for and are actually enrolled in Medicaid. Section 2102(b)(3)(B). While the rule sets forth some procedures that facilitate the Medicaid application and enrollment process, the rule does not go far enough.

Of greatest importance is the need to clarify that in States that use a joint application form, the date of application for SCHIP *is* the Medicaid application date. HCFA needs to articulate such a rule to ensure that States do not delay the Medicaid application process. Such a rule is in keeping with long-standing HCFA policy regarding the effective date of a Medicaid application when the application itself involves another program. For example, in situations where applicants are applying for SSI (which results in a finding of categorical eligibility for Medicaid), HCFA policy is clear that the effective date of the

Medicaid application is the date of application for SSI, even if the SSI application is subsequently denied. (*See* Exhibit B, Letter from David Cade, Director, Family and Children's Health Program Group, CMSO. HCFA to Associate Regional Administrator for Medicaid and State Operations, Region VII, Kansas City, dated March 23, 1998).

- HCFA should require States to communicate with families in a culturally competent and linguistically appropriate manner.

Rationale: We fully support the inclusion of rules to require States to ensure that families' make informed decisions about applying for Medicaid. However, families cannot make informed decisions unless information is communicated in culturally and linguistically competent ways or in alternative formats and communication modes for those individuals with sensory impairments.

- HCFA should prohibit States from making the process for applying for Medicaid more burdensome, onerous or time-consuming than the process for applying for SCHIP.

Rationale: The statute establishes an affirmative duty for States to ensure that Medicaid eligible children are actually enrolled in Medicaid.

21. 42 C.F.R. § 457.361 - Application for and enrollment in SCHIP

- We fully support the proposed rules requiring States to establish a time standard for making eligibility determinations that does not exceed 45 days.

- We fully support prohibiting States from using the time standard as a waiting period or as a reason for denying eligibility.

- We fully support the requirement that States provide application assistance. However, we believe HCFA must do more to require States to comply with the mandates of Title VI and the ADA.

- As part of application assistance, HCFA must require States to provide information to all applicants about the SCHIP program including, at minimum, information about covered benefits, waiting periods, cost sharing, provider networks and rights.

- States should be required to specify in their State plan a mechanism to ensure that a child who applies for SCHIP and is found eligible for coverage is provided benefits on a first come, first served basis, at the earliest opportunity.

Rationale: The proposed rules import significant consumer protections into the SCHIP program. States should be familiar with many of these requirements because they are modeled upon existing requirements in the Medicaid program. Given that we have heard complaints about lost SCHIP applications that are never acted upon and cannot be tracked, we are very pleased that HCFA is requiring States to establish a time standard for making eligibility determinations. Nevertheless, we believe the proposed rules can be strengthened. In particular, the rules must provide more specificity regarding when notice of rights and responsibilities must be given. Similarly, the rules fail to state when a State must provide the notice of decision. Although States are required to explain to applicants the process for applying and the eligibility requirements, nothing in the proposed rule requires States to inform applicants, up front, about available benefits, coverage limitations, cost sharing including premiums or other basic features of the State's program. Moreover, the regulations do not address States' obligations under Title VI to provide information and assistance to families who are not proficient in English or under the Americans with Disabilities Act to provide information in alternative formats and make other accommodations of rules and policies.

Another major omission concerns what happens when demand for SCHIP exceeds available funding. Some States already have long waiting lists, and there have been problems with wait-listed children (1) not being able to determine their status, and (2) waiting for long periods before they actually receive benefits. Consequently, we believe additional safeguards are needed. In particular, States should be required to specify in their State plan a mechanism to ensure that a child who applies for SCHIP and is found eligible for coverage is provided benefits on a first come, first serve basis, at the earliest opportunity. Such a mechanism could be a centralized waiting list maintained by the State, or some other mechanism that ensures fair treatment and accountability. A mechanism, such as a waiting list, is also needed to ensure that SCHIP programs are not discriminating against minority children or children with special needs.

19. 42 C.F.R. § 457.365 - Grievances and Appeals

See comments regarding 42 C.F.R. § 457.985.

Subpart D – Coverage and Benefits

23. 42 C.F.R. § 457.402 - Child health assistance and other definitions

- We support the proposed rule's broad definition of coverable "child health assistance."

- We support the requirements in §457.402(b)-(c) that States adopt the prudent layperson standard with regard to emergency services, ensure access to emergency

services without any requirement for prior authorization, and provide post-stabilization services in the same manner as required by the Medicare and Medicaid programs."

24. 42 C.F.R. § 457.410 - Health benefits coverage options

- In § 457.410(b)(1), HCFA should use the same definition for "well-baby and well-child care" that is used in § 457.520 relating to cost sharing. HCFA also should make clear in the preamble that States must adopt the federal definition.

Rationale: As drafted, the proposed rule permits a State to define well-baby and well-child care for coverage purposes (though not for cost-sharing purposes). The preamble encourages States to adopt benefits and periodicity schedules recommended by professional organizations involved in child health care. The preamble refers to the American Academy of Pediatrics, the American Academy of Pediatric Dentistry, and Bright Futures: Guidelines for Health Supervision of Infants, Children and Adolescents. (*See* 64 Fed. Reg. 60906).

Although such encouragement is helpful, these critical services can be guaranteed for children only if HCFA modifies these regulations to apply the same, detailed federal definition (§ 457.520) of "well-baby and well-child care" *both* to cost-sharing and coverage.[1] As proposed, the regulations forbid a State from impeding access to, for example, preventive dental visits by imposing any cost-sharing. However, they permit a State flatly to deny coverage of all preventive dental care. It is difficult to justify this distinction.

In both cost-sharing and benefits provisions of the SCHIP statute, Congress determined that, for preventive services -- which can make a profound difference to a child's lifetime functioning -- safeguarding access to care overrides the general desire to maximize State flexibility. This judgment makes sense, not simply on basic humanitarian grounds, but also because a child born in one State may live in another as an adult; if the former State adopts policies that causes developmental problems to go undetected and untreated, the latter State may pay the price treating serious adult impairments that could have been prevented in childhood. These considerations apply equally to cost-sharing and coverage.

[1] This suggested change is consistent with the view expressed in the regulatory preamble that, absent statutory language or clear Congressional intent to the contrary, Title XXI should not be construed to impose more proscriptive requirements on separate child health programs than Title XIX applies to State Medicaid programs. 64 Fed. Reg. 60907. Both the proposed definition of well-child care for coverage purposes and the definition in § 457.520 for cost-sharing offer far less than the full range of EPSDT services covered for Medicaid children. Likewise, neither includes a specific periodicity schedule.

- We fully support the requirement in § 457.410(b)(2) to require that States cover immunizations in accordance with the recommendations of the Advisory Committee on Immunization Practices (ACIP).

Rationale: The proposed requirement to cover all ACIP-recommended vaccines is vital. The Vaccines for Children ("VFC") program provides such immunizations free of charge for Medicaid-covered and uninsured children. HCFA has ruled that VFC does not cover children enrolled in SCHIP's separate child health programs because they are no longer uninsured. Accordingly, without the requirement that separate programs must cover ACIP-recommended vaccines, children formerly uninsured could actually lose access to essential immunizations when they enroll in separate child health programs -- a result directly contrary to the purpose of the SCHIP statute.

- We support preamble language noting that States can include in their comprehensive health benefits packages "supplemental services for children with special needs or physical disabilities." Alternatively, States may offer multiple comprehensive benefits packages, "including one designed for children with special needs or physical disabilities, as long as the State complies with the Americans with Disabilities Act." Such approaches permit States to expand services to children with special needs without regard to the 10% cap on federally-matchable expenditures "for items other than the comprehensive services package." 64 Fed. Reg. 60907. This laudable approach increases States' ability to help such children.

25. 42 C.F.R. § 457.420 - Benchmark health benefits coverage

- We support the preamble language requiring that States choosing to provide benchmark coverage must "differ . . . only from the reference package as necessary to meet other requirements of Title XXI." 64 Fed. Reg. 60908.

Rationale: This helpful clarification avoids a redundant construction of statutory language while assuring that the purpose of the benchmark coverage option is achieved. A less rigorous interpretation would risk blurring the distinction between benchmark coverage and benchmark-equivalent coverage or applying a less rigorous standard for benchmark than for benchmark-equivalent coverage.

26. 42 C.F.R. 457.430 - Benchmark Equivalent Health Benefits Coverage

- HCFA should promulgate minimum benefits standards for benchmark-equivalent coverage.

Rationale: The regulatory preamble notes that the Secretary chose not to propose "minimum standards for basic sets of required services (for example, a minimum of 14 inpatient hospital days)." HCFA's rationale is that a greatly reduced benefits schedule would be unlikely to meet actuarial value requirements. However, because SCHIP plans may involve much lower cost-sharing requirements than that in commercial plans, a SCHIP benefits package can offer far fewer services than a benchmark commercial plan and still pass actuarial muster. Accordingly, the Secretary is respectfully urged to revisit this decision and promulgate minimum benefits standards for benchmark-equivalent coverage.

- HCFA should strike § 457.420(b)(4), revising the beginning of sub-section (b) to read as follows: "(b) Required services. Benchmark equivalent health benefits coverage must include, in addition to the services described in 42 CFR 457.410(b), coverage for the following categories of service:"

Rationale: One feature of the proposed regulatory language is confusing and potentially troublesome. Two separate regulations require well-child, well-baby care and ACIP-recommended immunizations for benchmark-equivalent coverage: § 457.410(b)(1) and (2), applying to all State child health programs; and § 457.430(b)(4), applying only to benchmark-equivalent coverage. This invites a court to read some distinction into these redundant provisions. To avoid the invitation and its unforeseeable and potentially mischievous consequences, we suggest the above revision.

27. 42 C.F.R. § 457.450 - Secretary-approved coverage

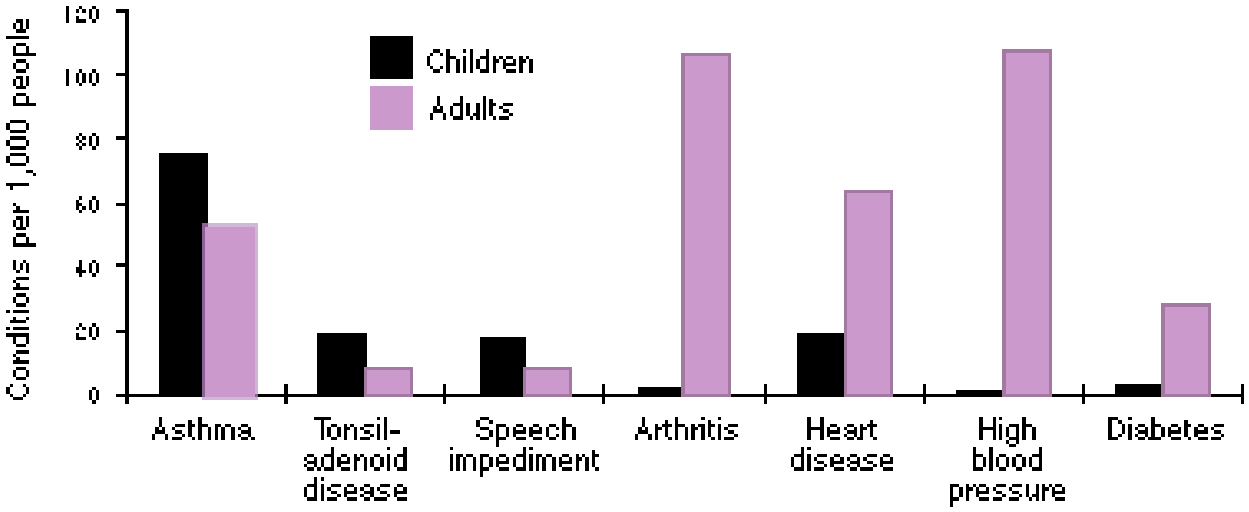
- Secretary-approved coverage should explicitly reference Medicaid services for children, rather than permit States to furnish SCHIP children Medicaid benefits for adults, without any actuarial analysis showing comparability to standard commercial benefits. Specifically, subsections (a) and (b) of § 457.450 should be consolidated and revised to read as follows:

  "(a) Coverage that is the same as the coverage for children provided under the Medicaid State plan."

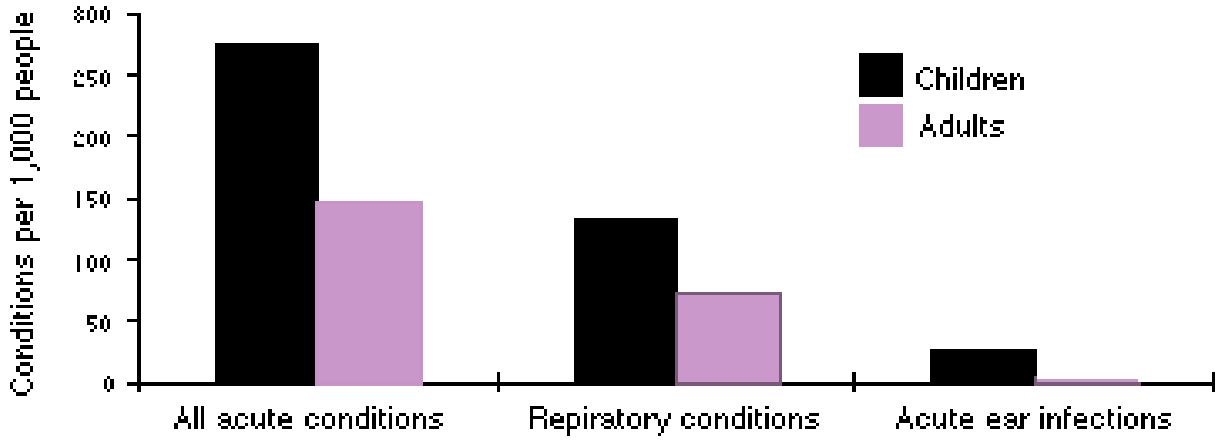
Rationale: Proposed § 457.450 provides States with helpful "safe harbor" coverage options they can adopt without expensive and time-consuming actuarial analyses. However, unclear language clouds subsections (a) and (b). These provisions authorize States to provide, through separate child health programs, benefits like those furnished through Medicaid. The regulatory language does not make explicit that Medicaid benefits for children (as opposed to those for adults) may be covered as "Secretary-approved" without triggering any need for actuarial review.

The touchstone should not be Medicaid benefits for adults. Children and adults have very different health needs. A benefits package developed explicitly to meet adults' needs may exclude services essential to children, such as frequent check-ups for newborns and preventive dental care. Adult benefit packages are developed based on financial trade-offs that simply do not apply to children, as the most expensive categories of care for adults involve chronic conditions, like heart disease, that rarely occur in children. The following graphs from the Children's Defense Fund (http://www.childrensdefense.org/health_needsbase.html) illustrate the starkly different health care needs of children and adults:

Common chronic health problems, children vs. working-age adults



Common short-term health problems, children vs. working-age adults



Source: National Center for Health Statistics, 1995 National Health Survey. Calculations by Children's Defense Fund, 1/98. Children are under age 18 and adults are ages 18 to 64.

The proposed rule, which permits States to define SCHIP benefits package by copying Medicaid benefits for adults, not only is medically inappropriate for children, it threatens to undermine Medicaid's current EPSDT package. If SCHIP children receive only adult Medicaid benefits, it will become more confusing and difficult to continue covering richer and more developmentally appropriate benefits for Medicaid children. The

purpose of the SCHIP statute was to improve children's access to health care, not to undermine essential health coverage for the roughly one in four American children covered by Medicaid before adoption of SCHIP.

A State's Medicaid benefits for adults can be narrower than any benchmark package. A State Medicaid program can deny adults 31 different services that it guarantees to children,[2] including even such essential health care as prescription drugs, wheelchairs and other durable medical equipment and long-term care for children. The evident purpose of the proposed "safe harbor" examples of Secretary-approved coverage is to eliminate needless actuarial analyses of benefits packages that are sure to qualify as benchmark-equivalent. For example, expediting approval of a benefits package that includes all benchmark benefits and others as well eliminates pointless administrative burdens on States without cutting essential health care. However, the current version of the regulation instead may deny children such necessary care by authorizing benefits packages that could be worse than benchmark coverage, benchmark-equivalent coverage and existing comprehensive State health coverage.

In authorizing benchmark-equivalent coverage, Congress limited State flexibility with actuarial value provisions that establish a floor below which State benefit packages may not go. Congress sought to prevent States from reducing the overall level of coverage below that provided by benchmark commercial plans. The proposed rule instead permits States with limited Medicaid benefits for adults to avoid this actuarial review and give children fewer overall benefits than are provided by benchmark commercial plans. The regulation should be revised to forbid such an end-run around the minimum benefits test devised by Congress.

We recommend revising this regulation to give States the option to use, without actuarial analysis, their Medicaid benefits packages developed specifically with children in mind. Not only does this approach meet children's distinct medical needs, it offers administrative advantages permitting States to integrate their general Medicaid and separate child health programs. With the same benefits, the same health plans can be used, and outreach and application systems can be simplified and integrated. The President has made clear the importance of covering the greatest possible number of uninsured children through such measures as simplifying outreach and enrollment systems. That goal is best served by clarifying and consolidating subsections (a) and (b) of § 457.450 as noted above.

28. 42 C.F.R. § 457.490 - Delivery and utilization control systems

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[2] *See* http://www.hcfa.gov/medicaid/mcdsta95.htm.

- We support the regulatory language of § 457.490, as well as explanatory language in the preamble.

Rationale: The preamble contains useful language about utilization review:

> Utilization control systems are administrative mechanisms designed to ensure that children use only health care that is appropriate, medically necessary and approved by the State or its subcontractor.... The State should describe its plan for review, coordination, and implementation of utilization controls... in order to assure that necessary care is delivered in a cost-effective and efficient manner.

64 Fed. Reg. 60910. This and the corresponding regulatory language in § 457.490 set out a helpful framework that encourages States to ensure that utilization controls limit costs without denying essential health care to children.

29. 42 C.F.R. § 457.495 - Grievances and appeals

- The proposed rule rightfully applies procedural safeguards to any "reduction or denial of services." However, appeals and grievances should be available when children's health care services are completely terminated, not just when they are denied beforehand or reduced. The regulation should be amended to explicitly provide that procedural safeguards also apply to "termination" of services.

- For additional comments on grievances and appeals, see § 457.95.

Rationale: The regulation must be amended to explicitly include "termination of services" for consistency and to ensure protection of due process rights. For example, § 457.365 permits appeals and grievances for "denial, suspension or termination" of eligibility (emphasis supplied). Without similar language covering terminations of services, § 457.495 could easily be construed to deny appeal rights when, for example, a managed care plan seeks an overly rapid hospital discharge of a seriously ill child.

In § 457.480(b)(4), the proposed rule acknowledges the harm that can be done through premature termination of services. That section applies to SCHIP newborns the minimum hospital stay requirements of the Newborns and Mothers Health Protection Act. That same recognition should give children appeal and grievance rights when services are terminated. Children can be harmed by termination of a service no less than by its denial or reduction.

Without this clarification, § 457.495 has paradoxical results:

(1) Appeal rights are properly granted when a parent wants a new service for a child, even without any medical justification. By contrast, after treatment for a child has begun based on a determination of medical necessity by a medical professional, the service can be terminated without any appeal rights.
(2) Appeal rights are granted when a service is reduced, and a child therefore has some ongoing care. However, if that same service is terminated and the child loses all care, the child has no appeal rights. Not only is this distinction hard to justify on its own terms, it creates a perverse incentive to minimize appeals through outright terminations rather than reductions in services a child currently receives.

In part, the proposed grievance and appeal procedures are intended to safeguard the constitutional due process rights of SCHIP children. These rights are based on the Fourteenth Amendment's recognition of a protected "property" interest in the receipt of statutorily-provided benefits that can be essential to survival. Goldberg v. Kelly, 397 US 254, 262-64 (1970). It is hard to see why a child's "property" interest in termination of a service that is currently being provided is any less than such an interest in either (a) a reduction of the identical service or (b) the provision of a new service never before received. If anything, termination of a current service is even more likely to deprive a child of "the very means by which to live while he waits," 397 US at 264-65, for an ultimate determination of the need for the service.[3]

Subpart E - State Plan Requirements: Beneficiary Financial Responsibilities

30. 42 C.F.R. § 457.505 - General State plan requirements

- We support proposed § 457.505 requiring States to describe the cost sharing features of its SCHIP program in the State plan. We are particularly pleased that HCFA is requiring States to include the methods it will use to inform the public about the various charges. We also strongly support the language of §§ 457.505(c)(1-3) stating that "[a] procedure that primarily relies on a refund given by the State for overpayment b a beneficiary is not an acceptable procedure.

31. 42 C.F.R. § 457.510 - Premiums, enrollment fees, or similar fees: State plan requirements

[3]Later sections of these comments dealing with Part I explain the need for "aid paid pending" safeguards that give children continued eligibility and services pending a hearing about the appropriateness of a proposed reduction or termination.

- HCFA should amend § 457.510(d) to require that State plans include a description of the disenrollment protections established pursuant to § 457.570, in addition to the consequences for a beneficiary who does not pay a charge**.**

Rationale: Section § 457.570 requires States to establish a process that gives beneficiaries reasonable notice of an opportunity to pay past due premiums, copayments, coinsurance, deductions or similar fees prior to disenrollment (or, we would add other adverse action). However, nothing in the regulation currently requires States to describe these processes in the State SCHIP plan.

- HCFA should amend § 457.510(e) to require that in describing the methodology used to ensure that total cost sharing liability for a beneficiary's family does not exceed the cumulative cost sharing maximums, the State must explain how the State calculates total income for each family, and how the State will prevent charges over the cumulative cost sharing maximums.

Rationale: As drafted, § 457.510(e) provides only that the State describe the methodology used to ensure that the total cost sharing liability for a beneficiary's family does not exceed the cumulative cost sharing maximums. The preamble states that the methodology *must* explain how the State calculates total income for each family, and how the State will prevent charges over the cumulative cost sharing maximum. This obligatory language should be incorporated into the regulation.

- States should be required to develop a tracking or accounting mechanism to monitor when families have attained the cumulative cost sharing maximum.

Rationale: Although HCFA recommends in the preamble that States develop a tracking mechanism to monitor when families have attained the cumulative cost sharing maximum, we believe that States can and should be required to develop such mechanism. This is preferable and more reliable than the shoe box methodology, and lessens the burden on low-income families. We are particularly concerned about the need to develop reliable tracking mechanisms for families with children with chronic and disabling conditions who are most likely to reach the cumulative maximums.

32. 42 C.F.R. § 457.515 - Co-payments, coinsurance and deductibles

- We support the language of § 457.515(f) providing that enrollees will not be held liable for additional costs, beyond the copayment amounts specified in the State plan, that are associated with emergency services provided in an out-of-network facility and that the State may not charge different co-pay amounts for out-of-network services.

- We urge HCFA to add a provision making clear that an enrollee may not be denied emergency services based on the inability to make a co-payment, regardless of whether the provider is in or outside of the network. We also urge HCFA to include in the preamble a discussion of the obligations of emergency services providers under the Emergency Treatment and Active Labor Act (EMTALA).

Rationale: We are concerned that provisions allowing for co-payments for emergency services may be misconstrued by States and providers. Under EMTALA, a Medicare-certified hospital that operates an emergency room must provide emergency treatment and stabilization services without regard to the patient's ability to pay. Therefore, the inability to make a co-payment, when the enrollee is seeking emergency treatment should never be a bar to receiving treatment.

33. 42 C.F.R. § 457.520 - Cost sharing for well-baby and well-child care

- We strongly support provisions prohibiting the imposition of cost-sharing for well-baby and well-child care.

34. 42 C.F.R. § 457.525 - Public schedule

- We support the proposed requirements of § 457.525.

- We strongly urge HCFA to require that the public schedule also contain information about an enrollee's rights with respect to cost sharing, including the right to receive notice, to make past due payments and other protections established by the State in § 457.570.

35. 42 C.F.R. § 457.550 - Restriction on the frequency of cost sharing charges on targeted low-income children in families at or below 150 percent of the FPL.

- For clarity, amend § 457.550(b) as follows: <u>Any copayment that the State imposes under a fee for service system may not exceed $5.00 per visit, regardless of the number of services furnished during one visit.</u>

Rationale: Currently, § 457.550(b) provides that the State plan may not impose more than one co-payment for multiple services furnished during one office visit. Since § 457.555(a)(2) imposes a $5.00 per visit cap on co-payments under a managed care system, we assume § 457.550(b) applies only to fee-for service programs. The rule, as drafted, however, does not provide any guidance as to how the co-payment is to be

calculated. Since we assume that the provider will seek the highest allowable co-payment, for clarity, the rule should simply state that $5.00 is the maximum allowable per visit.

36. 42 C.F.R. § 457.555 - Maximum allowable cost sharing for families between 101 to 150 percent of FPL.

- While establishing cost sharing for managed care is not prohibited, it should not be encouraged. We urge HCFA to include language in the preamble to underscore that the philosophy and structure of managed delivery systems makes cost-sharing as a utilization control mechanism unnecessary.

- We urge HCFA to encourage States to set lower maximum allowable cost-sharing amounts for institutional services than those permitted in the proposed rule at § 457.555(b).

37. 42 C.F.R. § 457.560 - Cumulative cost sharing maximum

- We strongly support the 2.5% cap for families with incomes below 150% FPL.

38. 42 C.F.R. § 457.565 - Grievance and appeals

- We support the requirement that States must provide enrollees in a separate SCHIP program the right to file grievance and appeals for disenrollment from the program due to failure to pay cost sharing. However, as noted below, we believe HCFA must do more to articulate the protections available to consumers who fail to pay cost sharing or to comply with other requirements of the program.

39. 42 C.F.R. § 457.570 - Disenrollment protections

- We fully support inclusion of requirements relating to disenrollment protections for enrollees who have failed to pay cost sharing. However, we do not believe that the proposed rule goes far enough to establish standards for an adequate system to protect children enrolled in SCHIP.

- At minimum, HCFA should articulate minimum standards to protect children from disenrollment *and other sanctions* due to a failure to pay cost sharing. Such standards should include:

  (1) a clear definition of what constitutes reasonable notice;
  (2) a requirement that only the State (and not the provider) may disenroll a child or impose any other sanction for failure to pay cost sharing;

(3) that the burden of proving a family failed to pay cost sharing is on the State;
(4) that disenrollment can only be effected after all reasonable steps have been undertaken to avoid disenrollment;
(5) that the failure to pay a cost sharing requirement should trigger a review of the family's income and payment history to determine whether the family has reached the cumulative maximum, is subject to a lower maximum due to a change in income or the child has become eligible for Medicaid;
(6) that families should be offered the opportunity to establish a re-payment plan;
(7) that families cannot be subjected to penalties or interest for past due payments; and
(8) that a child may not be subject to a lock out period for failure to pay a premium.

Subpart G - Strategic Planning, Reporting and Evaluation

40. 42 C.F.R. § 457.710 - State plan requirements: strategic objectives and performance goals

- The Secretary should take the lead by specifying a minimum set of national strategic objectives related to increasing the extent of creditable health coverage among targeted low-income children and other low-income children. Among strategic objectives of national significance are:

  (1) the need to reduce and/or eliminate racial and ethnic disparities in children's health insurance coverage;
  (2) the need to reduce and/or eliminate barriers to health coverage for children with disabilities;
  (3) the need to reduce "stigma" and barriers to access in Medicaid, the single largest insurance program for low-income children; and
  (4) the need to ensure that the goal of increasing coverage for uninsured children does not supplant or overshadow the importance of ensuring that coverage results in the provision of quality care and improves health outcomes.

Rationale: Although the SCHIP program is built on a commitment to State flexibility, the federal government must still play a role to ensure that the SCHIP program supports and enhances national standards and strategic goals. The Secretary must use her authority to guide State implementation toward compatible strategic objectives.

- The Secretary should designate a core set of performance goals that relate to national strategic objectives, designate performance measurements and standards that relate to the performance goals and require that all States collect and report the data and information in a standardized format.

- The Secretary should ensure that any designated measures or standards are publicly available.

Rationale: The Secretary is authorized to monitor and evaluate the implementation of SCHIP programs. Pursuant to Section 2107(b), States are required to collect, maintain and furnish reports to the Secretary "at the times and in the standardized format the Secretary may require in order to enable the Secretary to monitor State program administration and compliance and to evaluate and compare the effectiveness of State plans. . . . " As drafted, however, the proposed rules allow States unfettered discretion to establish their own performance goals and measurements and to develop methodologies to assure the quality and appropriateness of care. We are concerned that absent a requirement that States report a common set of measures, the regulations risk supplying information that is meaningless and can not be used to evaluate or compare the effectiveness of State plans.

We do not endorse use of a particular set of performance measures such as HEDIS because HEDIS measures are not publicly available, and therefore, we can not evaluate whether they relate sufficiently to strategic objectives that are appropriate to the SCHIP program. For example, we believe it is very important that SCHIP monitoring focus on minority populations and children with special needs. We also believe it is important to understand whether children in SCHIP remain enrolled over time or are subject to the kind of "churning" that occurs in the Medicaid program. Without having had the opportunity to evaluate HEDIS measures, we simply lack sufficient information to conclude that they would be appropriate for use as a tool to monitor State implementation of SCHIP.

Nevertheless, because so much extraordinary work has been done to identify criteria for children's health care needs, we believe that a core set of measures, customized to fit the strategic goals of SCHIP and the specific populations served, can be readily identified and designated for use by all States.

41. 42 C.F.R. § 457.720 - State plan requirement: State assurance regarding data collection, records and reports

- See comment regarding 42 C.F.R. § 457.710.

42. 42 C.F.R. § 457.730 - State Plan Requirements: State Annual Reports and Evaluation

- HCFA should require States to use a designated framework for submitting annual reports and evaluations.

- HCFA should obtain input from advocates and other stakeholders regarding the format and content of the framework prior to finalizing the draft and making a designation. HCFA can do this easily by posting the document on its website.

Rationale: The preamble makes clear that HCFA has been working with States and the National Academy of State Health Policy to develop an "optional model framework" for the State evaluation and annual report due on March 31, 2000. The proposed rule, however, does not reference this document; it merely requires that a State plan describe the State's strategy for submission of the annual report and evaluation. Again, we are concerned that failing to mandate that States use a standardized reporting format will mean that information submitted to the Secretary to be used for evaluation and comparison will be meaningless. We therefore strongly urge HCFA to amend the rule to require States to use a reporting format designated by the Secretary. To ensure that HCFA has the flexibility to update its form, we are not recommending that the rule identify a specific format. Further, as HCFA has already moved ahead to develop a standardized (but optional) format, we urge HCFA to obtain the input of consumers and advocates before the format is used. Consumers and advocates will view the form from a unique perspective and are likely to be able to suggest improvements and modifications that are different than those offered by States.

43. 42 C.F.R. § 457.735 - State plan requirement: State assurance of the quality and appropriateness of care

- While we support the requirement of assurances for access and quality, the rule does not go far enough to ensure that State strategies are adequate. We strongly recommend that, at a minimum, HCFA establish quality standards with respect to those areas designated in the rule and identify the methodologies for monitoring those standards in the rule itself. In particular, we recommend annual application of a standardized survey of children's physical, mental and social health. HCFA should require (not merely encourage) States to describe how they will ensure that children have access to pediatricians and other health care providers with expertise in meeting the health care needs of children.

- HCFA should amend § 457.735(b) as follows: HCFA should amend § 457.735(b) as follows: States must assure appropriate and timely procedures to monitor and treat enrollees with complex, ~~and~~ serious or chronic medical conditions (including

symptoms), including access to appropriate pediatric, adolescent and other specialists and specialty care centers and must assure that children with complex, serious or chronic medical conditions receive no lower quality of care than received by children with special health care needs served by the State's programs under title V of the Social Security Act.

Rationale: Again, we strongly believe that HCFA must set standards for State quality strategies. This means not only setting the actual standards for quality but designating the methodologies for monitoring those standards. We also strongly believe that requiring States to assure adequate and appropriate access to pediatricians and other health care providers with expertise in meeting the health care needs of children is a necessary requirement of any State quality strategy for a program that is designed solely to meet the needs of children. It is equally important that children with chronic, serious or complex conditions also have access to appropriate pediatric, adolescent and other specialists who are knowledgeable about the special needs of children. Considerable scientific consensus exists that "children are not little adults." Experience under Medicaid and title V of the Social Security Act with children with complex, serious or chronic medical conditions has demonstrated that the availability of appropriate specialists and specialty care centers for children is essential for quality assurance. For instance, most State title V programs set standards for specialty care centers serving children with sickle cell anemia, spina bifida, neuromuscular diseases, and other medical conditions so that children receive coordinated care and be followed by a team of pediatric specialists with experience with the child's medical condition. The quality assurance standards which protect children with special health care needs also should protect children covered by the State Children's Health Program.

44. C.F.R. § 457.740 - State expenditure and statistical reports

- We support the reporting requirements and methodology but strongly urge HCFA to add the following to the quarterly statistical reporting requirements:

  (1) race, ethnicity and primary language spoken of SCHIP enrollees;
  (2) sex of SCHIP enrollees;
  (3) number of children disenrolled for any reason and reasons for disenrollment; and
  (4) number of children identified during the screening process as Medicaid eligible and the number of children enrolled in Medicaid.

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- In § 457.740(c), HCFA should require that the annual, unduplicated count of children enrolled in Medicaid, separate child health program and the Medicaid expansion, also be reported by race, ethnicity, primary language and sex.

Rationale: Collecting and reporting data establishing the race, ethnicity and primary language of children enrolled in SCHIP is widely supported by health professionals and providers, as well as immigration, health, child and civil rights advocacy organizations. (*See* Exhibit A, NHELP letter to Secretary Shalala, dated December 29, 1999). Minority children face the highest risk of being without access to health insurance and health care. In order to understand how and if SCHIP is meeting the needs of uninsured minority children, it is critical that HCFA mandate that States collect and report data that identifies the race, ethnicity and primary language of children enrolled in SCHIP. Collection and reporting of data regarding the race, ethnicity and primary language of SCHIP enrollees is also needed to ensure compliance with Title VI of the Civil Rights Act of 1964. It also will assist the Department to meets its goal of eradicating racial and ethnic disparities in health care by the year 2010.

Data should also be collected on the sex of enrollees. In addition, HCFA should require States to track and report data on disenrollments, as well as data that will help monitor the effectiveness of State "screen and enroll" methodologies.

45. 42 C.F.R. § 457.750 - Annual reports

- We support the collection of this information and would recommend that these reports be posted via the Internet.

- We also recommend that States be required to collect and report:

  (1) grievances, complaints or problems reported related to enrollment, access, and quality of care as a means of measuring consumer satisfaction;
  (2) progress in addressing barriers to access experienced by minority children;
  (3) cultural competency measures;
  (4) continuity of care between plans, providers or programs;
  (5) special attention to underserved or under-identified populations, i.e. homeless children; and
  (6) systemic integration with schools and other community groups.

46. 42 C.F.R. § 457.760 - State evaluations

- We support the proposed categories of evaluation, but recommend more frequent reporting and evaluation.

- In addition to the recommended reporting with respect to proposed § 457.750, we recommend that the optional requirement to report on SCHIP's effect on children and their families by the identified demographic factors become a mandatory requirement. Specifically, § 457.760((c)(1) should require that description and

analysis of the characteristics of the children assisted in the program include race, ethnicity, primary language and sex.

Subpart H - Substitution of Coverage

47. 42 C.F.R. § 457.805 - State plan requirements: private coverage substitution

- Generally, we support the regulation's basic approach, as amplified by the preamble, to defer to State judgments about substitution that favor children's coverage, remaining open to new empirical findings.

Rationale: We believe that HCFA's approach is consistent with the literature on substitution, which overall suggests that the problem may have been exaggerated. *See* Dubay, Expansions in Public Health Insurance and Crowd-Out: What the Evidence Says (Kaiser Family Foundation October 1999). The proposed approach also acknowledges that many key substitution issues, such as the appeal of Medicaid vs. private coverage, vary dramatically from State to State. *See* Weill, The New Child Health Insurance Program: A Carefully Crafted Compromise (Kaiser Family Foundation October 1999) p. 7.

- We support § 457.810 establishing stricter standards when public dollars are funneled through employer-sponsored plans.

Rationale: Use of employer-sponsored group health plans truly involves extraordinary risks of wholesale substitution. As many commentators have noted, an employee's decision to accept State subsidies is much more appealing if it involves continued use of the employer's health plan. Compared to leaving employer coverage for a separate, explicitly public program, a choice to accept public subsidies for employer coverage is far less stigmatizing, much less disruptive of existing family patterns of seeking health care, and easier for the employee administratively. *See* Weill, supra, page 11; Dubay, supra, page 5; Feder, et al., The Difference Different Proposals Make: Comparing Proposals to Expand Health Insurance (Kaiser Family Foundation October 1999).

Above all, one of the most effective safeguards against widespread substitution is employer ignorance of changing public benefit rules. Matters far more basic to a health insurance purchaser's role are unknown to a shockingly large percentage of employers. *See, e.g.*, Levitt, et al., Employer Health Benefits 1999 (Kaiser Family Foundation 1999), Exhibit 5.11, showing that most employers (e.g., 87% of small employers) have never heard of NCQA accreditation for health plans. Put simply, competitive market pressures and rising health costs, not changing Medicaid and SCHIP coverage rules, drive

reductions in employer subsidies for health coverage. The safeguard of employer ignorance ends when the employer is contacted by a State agency and becomes a partner in purchasing SCHIP coverage.

A slower and more cautious approach with respect to employer-sponsored plans also makes sense for reasons unrelated to substitution. Such caution makes it easier to accomplish the challenging operational goal of ensuring that employer-sponsored coverage meets the SCHIP statute's requirements for cost-sharing and benefits.

- We strongly recommend limiting States' discretion to use fears about substitution as an excuse to deny health coverage for uninsured children. Accordingly, outside the context of employer-sponsored plans, final regulations should bar waiting periods that either:

  (1) impose disproportionate harm on children through continuing beyond six months or denying coverage (except where an employee voluntarily drops employment-based coverage without any change in circumstances) for pregnant women, children with disabilities, or children with preexisting conditions under HIPAA; or
  (2) deny SCHIP benefits to children who lack employer coverage for reasons unrelated to SCHIP (e.g., the child was recently adopted, the parents lost or changed jobs, COBRA coverage expired, a parent died, the family moved outside the area served by the employer's health plan, the employer required increased payments that were unaffordable to the family, etc.).

Subpart I - Program Integrity and Beneficiary Protections

48. 42 C.F.R. § 457.910 - State program administration

- In § 457.910(b), add the following new subsection:

  (3) the use or disclosure of information concerning applicants, recipients or services are restricted to purposes directly connected with the administration of the plan.

Rationale: Although the proposed rule at § 457.990 addresses medical records privacy and privacy and confidentiality of electronic data transmissions, nothing in the proposed rule addresses the need to safeguard administrative information that is collected by State SCHIP programs including eligibility applications, case files, and other administrative

data. It is particularly important to explicitly require that States safeguard such information because of concerns that information about recipients, including data regarding national race, ethnicity and primary language, may be misused.

49. 42 C.F.R. § 457.925 - Preliminary investigation

- To ensure timeliness, we suggest that HCFA specify that the State must undertake a preliminary investigation within a reasonable time not to exceed 60 days.

50. 42 C.F.R. § 457.930 - Full investigation, resolution, and reporting requirements

- We suggest that HCFA specify that State must have *written* procedures for investigating and resolving suspected and apparent instances of fraud and abuse.

51. 42 C.F.R. § 457.955 - Conditions necessary to contract as a Managed Care Entity

- As a condition precedent to being qualified as an MCE contractor, § 457.955(d) provides that the State may inspect, evaluate and audit MCEs at any time, as necessary, in instances where the State determines that there is a reasonable possibility of fraudulent and abusive activity. This provision should also apply to any provider under contract to provide SCHIP services.

52. 42 C.F.R. § 457.960 - Reporting changes in eligibility and redetermining eligibility

- HCFA should provide guidance to States regarding how the redetermination process should be conducted. States should not be permitted to request a re-application or require that enrollees provide information that is not needed to complete the eligibility determination. States also must be required to give the enrollee adequate time to respond to any request for additional information.

- If a SCHIP enrolled child has become eligible for Medicaid, the State must provide assurances and describe in their State plan how the child will be enrolled in Medicaid without experiencing a break in coverage.

53. 42 C.F.R. § 457.970 - Eligibility and income verification

- The rule should explicitly state that State eligibility and income verification processes must be designed to minimize barriers and facilitate SCHIP enrollment. The rule should also explicitly state that States may use self-declaration of income and assets.

Rationale: The preamble states that "[w]e propose that States have flexibility to determine these documentation and verification requirements, and can use self-declaration of income and assets." (64 Fed. Reg. 60927). However, the regulation only explicitly addresses State flexibility. Flexibility could be interpreted to allow States to design and implement eligibility and verification requirements that serve as barriers to enrollment.

- We urge HCFA to restate or reference its guidance letters of January 1998 and September 1998 in the preamble.

Rationale: HCFA's guidance letters of January 1998 and September 1998 provided helpful and detailed guidance to States to streamline and simplify SCHIP eligibility and verification procedures.

- We urge HCFA to delete § 457.965(d) providing that "[t]he State may terminate the eligibility of an applicant or beneficiary for 'good cause.'"

Rationale: We are deeply troubled by a rule that would authorize States to terminate the health insurance coverage for a child due to the conduct or misconduct of a parent/caretaker. Even TANF rules prohibit States from terminating a child's Medicaid coverage as a result of the parent's failure to comply with program requirements. *See* 42 U.S.C. § 1396u-1(b)(3)(B). Using the example that is provided in the preamble, if a parent has committed fraud by providing false information, then the State, pursuant to SCHIP program integrity rules, should investigate and refer the case for prosecution as appropriate.

- If § 457.970 is not deleted in its entirely, we strongly urge HCFA to revise its definition of "good cause" in § 457.970(d)(1) and to add additional safeguards. Specifically:

  (1) Prohibited terminations -- No child may be terminated from SCHIP due to:
  (a) the conduct of misconduct of a parent/caretaker; or
  (b) the failure of a parent/caretaker to provide verification or documentation of information unless:
  (i) in the absence of the information, a determination of eligibility or continued eligibility cannot be made;
  (ii) the information is not available from any alternative source; and
  (iii) the State has complied with Section 2 below.
  (2) Procedure for establishing "good cause." -- Before initiating a termination for "good cause," the State must:
  (a) notify the family, in writing, of the specific items or requirements that

must be provided and the reason why the information is needed;
(b) offer assistance to the child or family, including any reasonable accommodations that may be required under Title VI of the Civil Rights Act or the Americans with Disabilities Act; and
(c) provide a reasonable opportunity to comply with any request which shall not be less than 60 days.

- We support the requirement in § 457.970(d)(2) that beneficiaries terminated for good cause receive notice. However, HCFA must make clear that:

  (1) the notice must be provided in advance of the actual date of termination.
  (2) the State must provide a reasonable opportunity for the beneficiary to cure the defect or appeal the decision prior to the date of termination.
  (3) if a timely appeal has been filed ,benefits continue until the appeal has been decided.

Rationale: See comments on grievance and appeals at § 457.985.

54. 42 C.F.R. § 457.975 - Redetermination intervals in cases of suspected enrollment fraud

- Delete § 457.975.

Rationale: This rule would allow States broad discretion to increase the frequency of redeterminations for all or targeted groups of beneficiaries based on generalized suspicions of enrollment fraud. We believe this rule opens the door for abuse. We are particularly concerned about how this rule could be used to justify increased scrutiny of racial and ethnic minorities. Furthermore, the proposed program integrity rules including §§ 457.925 and 457.930, give States adequate tools to investigate and prosecute suspected fraud. Therefore, this rule is unnecessary.

55. 42 C.F.R. § 457.985 - Enrollee rights to file grievances and appeals

- We applaud HCFA's inclusion of §457.995 (g) and §457.985 establishing a grievance and appeals process for children enrolled in separate State SCHIP programs. However, we believe that significant changes to the proposed language are needed to accomplish this important objective.

- HCFA should ensure that the terms grievance and appeal are defined and employed consistently across all of its programs -- particularly Medicaid and SCHIP.

Rationale: The use of these terms -- grievance and appeal -- varies tremendously across federal and State governments and within the private sector. It is critical that HCFA take the lead in establishing clear and consistent definitions for each of these terms so that States have guidance regarding their responsibilities and beneficiaries are able to understand their rights. See below for comments regarding the use of the term "complaint."

- HCFA should reorganize the grievance and appeal sections of the regulation into a more logical format. Specifically, all of the information on grievances and appeals should be in a single subpart with cross references where appropriate.

Rationale: In general, the grievance and appeal requirements are confusing because they are addressed in several different parts of the proposed rule, terms are used inconsistently, and the requirements are unclear. For example, the right to file a grievance and the right to notice of the right to file a grievance when eligibility is denied, suspended or terminated are addressed in three sections:

> § 457.365: The State must provide enrollees in separate child health programs with an opportunity to file grievance and appeals for denial, suspension, or termination of eligibility in accordance with 457.985.
> § 457.985: State and its participating providers must give applicants and enrollees written notice of their right to file grievances and appeals in cases where the State or its contractors take actions to deny, suspend or terminate eligibility.
> § 457.995: States and their participating contractors must ensure the family's right to file grievances and appeals by notifying beneficiaries of this right and by having written procedures in place to afford applicants and enrollees the right to file grievances [and appeals?] in cases where action is taken to -- deny, suspend or terminate eligibility in accordance with §457.365.

In addition to the confusion stemming from the language inconsistencies (e.g., "participating contractors" vs. "participating providers"; "grievances" vs. "grievances and appeals"), it is confusing to the reader to have the same issue addressed in several different sections.

- We strongly support the language in § 457.985(a) which requires that, in addition to the State, the "participating providers" provide applicants and enrollees written notice of their right to file grievances and appeals.

Rationale: It is important that applicants and enrollees have access to information about their grievance and appeal rights at the points of direct contact -- which is most often a provider. Therefore, it is important that HCFA place the responsibility of providing notice on both the State and the providers.

- HCFA should clarify that for States that have implemented Medicaid expansions, applicants and recipients are entitled to all of the Medicaid protections.

Rationale: As currently drafted, this important distinction is not clear in the regulation text or the preamble. For example, the preamble states that "we encourage States to use the grievance procedures as described in part , [sic] subpart E regarding fair hearings for Medicaid applicants and recipients, and the Medicaid grievance and appeal procedures for Medicaid managed care entities, which were set forth in the Medicaid Managed Care proposed rule (63 FR 52022)." This preamble language could easily be interpreted to mean that States have a choice as to whether the Medicaid grievance and fair hearing rules apply "for Medicaid applicants and recipients" under SCHIP. It is important that HCFA's message is clear -- if a State expands Medicaid eligibility under SCHIP, then all of the Medicaid fair hearing and grievance protections remain intact.

- HCFA should require States to use their Medicaid grievance and fair hearing process for eligibility and disenrollment determinations rather than deferring to internal appeals or State specific insurance practices. For other issues, the State could choose between the Medicaid and the State insurance practices, as provided in the proposed rule.

Rationale: It is inappropriate to route appeals regarding eligibility determinations (denials, suspensions, terminations and delays) and disenrollment issues into the internal plan/contractor appeals process or an external review process that has been established to evaluate utilization decisions made by an insurer or managed care plan. Internal and external reviewers are not only not competent to address these issues, they would be quickly overburdened by the task. As a public insurance program, SCHIP monitoring and enforcement will most closely resemble Medicaid and therefore, it is the most logical place to put these type of appeals.

- If the State does not use the Medicaid procedures, HCFA should outline the basic requirements that must be addressed by the State's chosen system. These requirements should specify, at a minimum,

  (1) the content of the written notice;
  (2) circumstances for continued benefits;
  (3) processing of grievances and fair hearings including exhaustion requirements;
  (4) the beneficiaries' rights and responsibilities during the grievance and fair hearing;
  (5) standards for conduct of the hearing; and
  (6) time frames for expedited and final resolution of grievances and appeals.

Rationale: If a State does not use its Medicaid fair hearing process, the rules lack sufficient clarity and specificity to ensure that consumers will be accorded adequate due process protection in the contemplated grievance and appeal system.

- HCFA should permit applicants and enrollees to file grievances and appeals on the grounds that eligibility determinations or requests for covered services were limited or delayed.

Rationale: Limitation and delay of eligibility determinations or services can function as a denial in many instances and they therefore should be included as a grounds for filing grievances and appeals. A long-standing Medicaid Act provision guarantees a fair hearing "to any individual whose claim for medical assistance . . . is denied or not acted upon with reasonable promptness." 42 U.S.C. § 1396a(a)(3). *See also* Goldberg v. Kelly, 397 U.S. 245 (1970). Limitation and delay of services were included as grounds for grievance and appeal under the proposed Medicaid managed care rule and should be included in the SCHIP rule as well. The same due process protections should be incorporated in this regulation for SCHIP applicants and beneficiaries.

- HCFA should specifically address situations where the services are reduced, limited, delayed, terminated or denied in whole or in part.

Rationale: In § 457.985(a)(3), enrollees have a right to receive written notice of their right to file grievances and appeals in cases where the State or its contractors take action to "[r]educe or deny services provided for in the benefit package." Enrollees should also receive notice when services are terminated. In addition, beneficiaries need to know that their right to file a grievance or appeal exists even if only a portion of the service was affected. For example, if the beneficiary requests 12 hours of home health care and the MCO approves only 6 hours, many MCOs claim that the service request was approved. However a denial, limitation or reduction in services has occurred because the beneficiary did not get coverage of the entire service that was requested.

- HCFA should require that, in all instances, the grievance and appeal system must be designed to provide beneficiaries with a single point of entry so that, regardless of the subject matter, beneficiaries file their grievance or appeal with a single State entity. The single State agency would then be responsible for assigning it to the appropriate reviewing authority.

Rationale: NHELP offered the same comment to the proposed Medicaid managed care regulation and the same rationale holds true for SCHIP. We believe that it is imperative that the federal and State governments take responsibility for ensuring that consumers have meaningful access to a hearing and appeals system. Given that different decisions may be subject to different treatment, it is critical that HCFA require States to establish a

single point of entry and to assume the responsible for ensuing that appeals are properly routed. Establishing a single point of entry assures that all grievances and appeals with be logged in one place. Central logging makes the grievance and appeal process more accountable to State monitors and consumers. The log also serves to start the clock on the required time limitations for resolving grievances. Most importantly, central logging provides assurances that consumers' grievances will not languish in a Gordian Knot of never-ending internal grievance processes - a frequent problem when consumers are encouraged or required to use internal grievance procedures to resolve problems.

- Prohibit States from requiring exhaustion of internal plan processes. If HCFA does not prohibit such a requirement, it must include adequate safeguards so that plans do not benefit from delay at the enrollees expense. Specifically, HCFA must require that States set strict timetables for review and determination, assure aid continuing pending determination and provide for expedited review when the failure to authorize a required level of treatment or provide or continue a service jeopardizes the enrollee's health.

Rationale: We strongly oppose requiring enrollees to exhaust internal plan grievance processes. Our general experience is that these processes merely serve to delay final resolution. In a managed care environment, such delay almost always enures to the benefit of the plan which gets paid whether the care is provided or not. For an enrollee with a serious or chronic health problem, requiring exhaustion means that needed treatment is not attainable. Therefore, the price of exhaustion is often the enrollee's health. We are especially concerned about allowing States to require exhaustion of internal plan processes in a program that has been designed specifically to address the health needs of children. Delay in treating a child may mean that a reversible condition becomes a chronic, lifelong problem.

- HCFA should delete § 457.985(d) that provides that the "State and its contractors must have in place a meaningful process for reviewing and resolving complaints that are submitted outside of the grievance and appeals procedures as part of the quality assurance process."

Rationale: Similar to the proposed Medicaid managed care regulation, the proposed SCHIP rule includes general requirements relating to "complaints that are submitted outside the grievance and appeals procedures." However, the term "complaint" is not defined, and it is not clear what type of problem constitutes a complaint that would end up "outside" the grievance and appeals procedures. It is also unclear who would be responsible for making such a determination, and what would happen should the plan decide that a consumer's grievance is really only a "complaint" or vice versa. While a plan may not want a complaint to be part of the formal grievance and appeal system for administrative reasons or because high numbers of grievances will reflect badly on the

plan, a formal and structured system would protect the consumer and the plan better than would an informal "complaint" procedure. We recognize that managed care plans need to have the flexibility to resolve minor concerns or misunderstanding without relying on a structured grievance and appeal procedure, and indeed, managed care plans already have "consumer relations" or "customer service" systems in place to address such concerns. However, the regulation should not sanction the development or utilization of "complaint" systems that fall outside of the grievance and appeals system. To do so only interjects confusion and complexity.

- **L** We support requiring compliance with the requirements in § 457.985(e) to provide beneficiary access to information related to actions which could be subject to grievance or appeal.

Rationale: These access requirements are drawn directly from the regulations governing the Medicare+Choice program and are also incorporated by reference into the proposed Medicaid managed care regulations. We strongly support providing beneficiaries with access to this critical information.

- **L** If States opt not to use their existing Medicaid fair hearing process, HCFA should include minimum standards to ensure that:

  (1) appeals and determinations are timely;
  (2) decisions are made by an impartial hearing officer or person;
  (3) hearings are held at reasonable times and places;
  (4) beneficiaries have the right to:

    (a) timely review their files and other applicable information necessary to prepare for the hearing;
    (b) be represented or represent oneself; and
    (c) present testimony and evidence

Rationale: The rule fails to provide sufficient guidance and safeguards in the event States opt not to use their Medicaid fair hearing system.

56. 42 C.F.R. § 457.990 - Privacy protections

- ***L*** We strongly support the inclusion of the Medicaid privacy protections for SCHIP beneficiaries and the listed contract requirements regarding information protection and access for beneficiaries.

- **L** We recommend that HCFA explain in the preamble language how these privacy protections interact with the privacy standards proposed in October 1999 and the

security standards proposed in August 1998 when all of the proposed rules are finalized. We believe it is extremely important that all of the protections are harmonized so that the legal interpretations of State and contractor obligations are not unnecessarily confusing..

57. 42 C.F.R. § 457.995 - Overview of beneficiary rights

- HCFA should either (1) consolidate all of the sections that relate to beneficiary protections in one or two sections or (2) leave the protections in different parts of the proposed rule, ensure that the protections are consistent with the Consumer Bill of Rights and Responsibilities, and provide a summary of the protections in the preamble only. We would support either approach.

Rationale: While we strongly support HCFA's attempt to address the Consumer Bill of Rights and Responsibilities, the rule does not incorporate the rights and requirements in a coherent and logical fashion. § 457.995 is merely summarizing requirements found in other sections of the rule, it seems redundant and at times, inconsistent. For example, § 457.110(b) provides that information provided to beneficiaries must be "accurate" and "easily understood" and that the information must be "made available to applicants and beneficiaries in a timely manner." This "overview" section provides a blanket requirement that "information must be accurate and easily understood and provide assistance to families in making informed health care decisions." (*See* § 457.995(a)(4)). These two provisions address similar issues but include slightly different requirements. These inconsistencies are difficult to reconcile and therefore could result in inappropriate interpretations by States, courts and beneficiaries.

- HCFA must reconcile the substantive requirements in other sections of the regulations with the information requirements in §457.995(a).

Rationale: The overview provides that information may be provided to beneficiaries either individually or through public notice. However, the substantive requirements cited only require public notice (*see* §§ 457.65 and 457.525) -- there is no discussion of providing individual notice as an alternative to public notice. § 457.65 relates to the public notice requirements for changing benefits, eligibility and cost-sharing; it states that prior to any change, "public notice of the proposed change [must be provided] in a form and manner provided under applicable State law." § 457.525 relates to the public schedule requirements and only states that the public schedule must be made available to a stated list of individuals and groups, including "the general public." Neither section permits individual notice to serve as a substitute for public notice.

- The regulation should have separate requirements for public notice/schedule and for individual notices.

Rationale: A public schedule should not be a substitute for providing important information about benefits, eligibility and cost-sharing to individuals.

- The information provided to beneficiaries and applicants should address specific procedures and access to specialists for enrollees with complex and serious medical conditions.

Rationale: The proposed rule requires States to assure that enrollees have appropriate and timely procedures to monitor and treat enrollees with complex and serious medical conditions including access to specialists, but does not explicitly provide a right to information about these procedures.

- HCFA should correct the citations referred to in § 457.995(a)(3).

Rationale: This section of the regulation incorrectly refers to §§ 457.360(d) and 457.360(e) -- neither of these provisions exist. The first reference was probably intended to refer to the requirements in § 457.360(c) regarding providing full and complete information on the Medicaid program. The second reference was probably intended to refer to the requirements in § 457.361(b) and (c) regarding the SCHIP program.

- As stated above, we strongly support the language in § 457.985(a) which requires that, in addition to the State, the "participating providers" provide applicants and enrollees written notice of their right to file grievances and appeals.

Rationale: It is important that applicants and enrollees have access to information about their grievance and appeal rights at the points of direct contact -- which is most often a provider.

- HCFA should reconcile § 457.995(b) regarding choice of providers with the substantive requirements cited in the regulation.

Rationale: The first requirement identified is that States must provide "assistance in making health care decisions" and cross references § 457.110. The substantive requirement in § 457.110, however, is more narrow than this "summary" statement. Section § 457.110 requires States to "provide assistance to [families of targeted low-income children] in making informed health care decisions <u>about their health plans, professionals, and facilities</u>." If HCFA elects to keep an "overview" section in the regulation that is intended to simply restate requirements in other sections, the language and requirements must be much more carefully coordinated.

- HCFA should separate the two substantive issues raised § 457.995(4)(b) and address them both individually.

Rationale: This section raises two issues -- providing beneficiaries with assistance in making health care decisions and developing procedures for monitoring and treating beneficiaries with complex conditions, including ensuring access to specialists. These two issues are quite distinct.

- The provision relating to "assistance" should also include a reference to "application assistance" in 457.361(a) and to translation services. We suggest the following revision:

(b) Application and enrollment assistance:

(1) States must afford families a reasonable opportunity to complete the application process and must offer assistance to families in understanding and completing applications, including the provision of free translation services, and in obtaining any required documentation, in accordance with § 457.361(a).

(2) States must provide assistance to families of targeted low-income children in making informed health care decisions about their health plans, professionals, and facilities in accordance with § 457.110

(c) Procedures relating to enrollees with complex and serious medical conditions: States must assure appropriate and timely procedures to monitor and treat enrollees with complex and serious medical conditions, including access to specialists, in accordance with § 457.735.

Rationale: In order for the "overview" to be comprehensive, it should include all of the beneficiary protections related to each particular subheading. There is no reason why "application assistance" should be excluded from the overview.

- We recommend that HCFA include the following additional beneficiary rights:

(1) Provider network adequacy: States must provide that plans have sufficient numbers and types of providers and that providers are accessible to enrollees to ensure access to access to all covered services without delay;
(2) Out of network access: If provider network capacity is inadequate to provide medically necessary care, than the States must ensure that consumers are allowed to go out-of-network at no greater cost than if the services were provided within the plan.
(4) Women's health specialists: States must ensure female adolescents who are SCHIP enrollees have access to qualified women's health specialists.
(5) Transitional care - States must ensure that an enrollee who is undergoing a course of treatment for a chronic or disabling condition … at the time he or she involuntarily changes health plans or at a time when a provider is terminated by a

plan for other than cause should be able to see his or her current specialty providers for up to 90 days.

Rationale: These recommendations are consistent with the Consumers Bill of Rights.

- HCFA should divide § 457.995(c) regarding access to emergency services into two separate subsections: "access" and "cost-sharing for emergency services."

Rationale: This section addresses much more than "access to emergency services." If the purpose of the overview section is to summarize and highlight the beneficiary protections, it is important that HCFA provide a clear and consistent message with respect to quality and appropriateness of care.

- Section 457.995(d) regarding participation in treatment decisions should clarify that enrollees have the right to refuse treatment.

- We support the requirement that States prohibit gag rules and establish principles for disclosure of physician financial arrangements that could affect treatment decisions in §457.985(e)).

- We support §457.995(e) regarding respect and nondiscrimination.

- In § 457.995(f), we recommend the following language: "States must ensure the confidentiality of a beneficiary's health information and provide beneficiaries access to medical records ~~only~~ in accordance with applicable ~~federal and State~~ law (§ 457.990)"

Rationale: This proposed formulation is awkward in that it excludes confidentiality protections and access rights afforded by other laws, such as local or tribal laws, as well as industry practices that are more protective of confidentiality and provide greater access to health information.

Subpart J - Allowable Waivers: General Provisions

58. 42 C.F.R. § 457.1005 - Waiver for cost-effective coverage through a community-based health delivery system

- § 457.1005(b)(1) should be amended to incorporate by reference the cost-sharing protections in Subpart E and the various beneficiary protections provided in other subparts of the proposed rule (and summarized in § 457.995).

Rationale: We are concerned that children that receive care in a community-based health delivery system will not benefit from the important consumer protections provided in this regulation. States should not be permitted to utilize these waivers as a means of circumventing the protections that are afforded to other SCHIP applicants and enrollees.

- "Health services initiatives" (§ 457.1005(d)(1)) should be defined in the regulation and discussed in the preamble. We suggest that HCFA adopt the definition used in the August 6, 1998 guidance letter to State Health Officials from HRSA and HCFA. Specifically: Health services initiatives are:

  > activities that protect the public health, protect the health of individuals or improve or promote a State's capacity to deliver public health services and/or strengthens resources needed to meet public health goals.

Rationale: "Health services initiatives" are neither defined nor discussed in the regulation or in the preamble.

- In the preamble, HCFA should make clear that all immigrant children, regardless of their status or date of entry, can participate in, and benefit from, Health Services Initiatives. Health services initiatives such as health education activities, school health programs, and direct services such as newborn screening and lead testing can be targeted to low-income, immigrant communities including temporary communities of migrant or seasonal farm workers.

59. 42 C.F.R. § 457.1010 - Waiver for purchase of family coverage

- We fully support giving States flexibility to improve and expand coverage for low-income families. However, before granting a family coverage waiver under Title XXI, HCFA should ensure that States have utilized their options for expanding health coverage to lower-income adults in non-Title XXI funded programs.

Rationale: As HCFA notes in "Supporting Families in Transition," before expanding coverage under Title XXI, States will need to implement a Medicaid expansion under Section 1931 to avoid an anomalous result in which higher income families are covered under SCHIP, but parents of lower-income children lack coverage. .

- At this time, HCFA should not define "family" for purposes of this subpart.

Rationale: This term may be defined differently across States, employers, and insurers. Unless HCFA is willing to define the term broadly enough to include all of the categories of individuals that are included in other definitions (e.g., domestic partners, adopted children)

then the agency should leave the definition to the States' discretion. Once HCFA has reviewed a wide range of proposals, it could revise the regulations to include a definition if necessary.

Subpart K - Expanded Coverage of Children Under Medicaid and Medicaid Expansions

60. 42 C.F.R. § 435.229 - Optional targeted low-income children

- HCFA should not cross-reference the definition of "targeted low-income child" provided in § 457.310(a) but rather define it independently for Medicaid expansion programs.

Rationale: The proposed regulation incorporates by reference the definition of "targeted low-income child" provided for separate State SCHIP programs. This definition is not appropriate for Medicaid expansions in several respects. For example, the definition permits eligibility to be limited by geographic region -- this type of limitation is not consistent with Medicaid policy, as is stated in the preamble language. An independent definition should be developed that is consistent with both the SCHIP definition in § 457.310(a) as well as Medicaid law and policy.

61. 42 C.F.R. § 435.1102 - General rules

- We support HCFA's decision to require statewide availability of presumptive eligibility in those States that choose to offer this option.

- We disagree with HCFA's decision to restrict the States' ability to require qualified entities to utilize spenddowns and disregards in establishing presumptive eligibility. HCFA should allow States to develop their eligibility standards independently.

Rationale: A State may be able to develop simplified worksheets that qualified entities can use that account for some disregards or spenddowns that are relatively straightforward. HCFA should not presume that States and qualified entities are incapable of developing simplified systems that are consistent with the policy goals of presumptive eligibility.

- While we support HCFA's requirement that qualified entities provide written information to the child's custodian regarding eligibility or denial, we disagree with HCFA's proposal not to require a notice of termination. When a State has not received a Medicaid application prior to the expiration of a presumptive eligibility period, the State should be required to send an expiration notice to the child's family as well as information on how to apply for Medicaid and another application.

Rationale: It is important that the parent or custodian receive the written information initially, but this single contact does not constitute adequate notice. A separate notice before the child is terminated is a relatively simple tool that States can use to increase access for children -- it may serve as a reminder or it may alert parents that the application that they submitted was not processed accurately. This notice is particularly important if the State places limits on the number of times that a child may become presumptively eligible.

- We support HCFA's decision to require States to make all services available to presumptively eligible children.

- We support HCFA's policy to waive MEQC eligibility errors resulting from the coverage of children under new eligibility groups added by PRWORA and BBA.

Exhibit A: Letter to Shalala re: data
Exhibit B: Letter from Cade to Region