American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN®

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June 13, 2018
Kathleen McHugh
United States Department of Health and Human Services
Administration for Children and Families
Director
Policy Division
330 C Street SW
Washington DC, 20024

Dear Ms. McHugh:

On behalf of the American Academy of Pediatrics (AAP), a non-profit professional organization of 66,000 primary care pediatricians, pediatric medical sub-specialists, and pediatric surgical specialists dedicated to the health, safety and well-being of infants, children, adolescents, and young adults, we appreciate the opportunity to provide input on the Administration for Children and Families' (ACF) Advanced Notice of Proposed Rulemaking (ANPR) requesting input on streamlining the 2016 final rule to update the Adoption and Foster Care Analysis and Reporting System (AFCARS). The AAP does not believe that further changes to the 2016 final rule are necessary and opposes the Administration's proposed delay of the 2016 final rule because it will negatively affect ACF's ability to address the health needs of vulnerable children in foster care. We strongly urge you to move forward with implementation of the 2016 final rule without delay.

Children in foster care experience disproportionate exposure to trauma and, as a result, often have complex health, including medical, developmental, educational, and behavioral and mental health, needs. Access to coordinated, high-quality, and trauma-informed health care is essential to ensuring that children in foster care receive the health services they need to thrive. Safety, permanency, and the well-being of children in foster care are three key precepts that inform the work of ACF, state child welfare agencies, and professionals serving children in foster care, including pediatricians. A thorough understanding of a child's health status and the work of professionals to promote child health play a critical role in advancing those three precepts. Well-being remains the most complex to define, measure and improve. For this reason, we strongly supported the 2016 final rule for updating AFCARS in a way that begins to engage some of the factors of well-being, including health.

Quality child welfare data collection is crucial to the improvement of children's health and well-being. As state and local child welfare agencies look to improve the overall health of the children in their care, effective and robust data collection tools are increasingly necessary. AFCARS offers states a critical tool to conduct this important work. The health-related elements within the 2016 AFCARS final rule lend themselves to the improved coordination of the health and social services necessary to support the safety, permanency, and well-being of children in out-of-home care. Ongoing trends in child welfare data improvement, including ACF's work to transition the Statewide Automated Child Welfare Information System to the Comprehensive Child Welfare Information System, underscore the importance of ensuring the collection of child welfare and health data to improve child outcomes. As an additional example, Ohio has created a data portal, IDENTITY, which links electronic health record with child welfare data to improve communication between health care providers and the child welfare system. This new portal will also support the state's ability to meet AFCARS reporting requirements more efficiently. These ongoing trends point to the critical importance of collecting quality data through AFCARS to support improved child health and wellbeing.

AFCARS plays a key role in tracking the experience of children in foster care and the success of implementation of federal child welfare law at the state level. The AAP supports the 2016 final rule as an important improvement to AFCARS, particularly the expansion of the Children's Bureau's ability to collect and analyze information about the health of children in foster care and the health services they receive. In addition, the update created important new data elements and structures to examine the extent to which states are complying with the health-related requirements of federal law, particularly the Health Oversight and Coordination Plan (HOCP) requirements in Fostering Connections. AAP also applauds ACF for expanding the perspective of AFCARS to allow for longitudinal and cohort analysis, which will improve providers' ability to help children in foster care.

ACF has implemented several landmark updates to federal child welfare law in the nearly twenty years prior to the last update to AFCARS in 2016. This includes major updates to the requirements for the provision and oversight of health services for children in foster care, such as those made under the Fostering Connections to Success and Increasing Adoptions Act of 2008 (P.L. 110-351), the Child and Family Services Improvement and Innovation Act (P.L. 112-34), and the Preventing Sex Trafficking and Strengthening Families Act (P.L. 113-183). ACF is now also starting to implement the recently enacted *Family First Prevention Services Act* (P.L. 115-123), which will also help improve the health and well-being of children in foster care. Policymakers, advocates, and service providers have worked collaboratively to develop improvements to the child welfare system that improve the health and well-being of children in foster care. It is important that the update of AFCARS facilitate robust examination of the implementation of these policies to support ongoing quality improvement. We urge ACF not to rescind the progress made towards better data collection of the health information of children in foster care represented by the 2016 final rule.

We encourage ACF to retain and implement the 2016 final rule without delay. With increasing numbers of children entering foster care because of the opioid epidemic and the associated traumas that come with that, it is critical that states and ACF collect useful data that support improved access to care for vulnerable children. This delay will perpetuate outdated and inefficient data systems that inhibit the ability of child welfare agencies to ensure children receive coordinated, high-quality, and efficient care. This delay would be a significant obstacle

in the advancement of children's health for those within the foster care system, and we strongly oppose any delay of the 2016 rule implementation.

These comments: 1) outline AAP's feedback to the overall proposal to delay and update the AFCARS final rule; 2) highlight the importance of key AAP-supported AFCARS provisions; and 3) provide specific responses to questions that ACF raises in the ANPR.

Role of 2016 Final Rule in Ensuring Effective Implementation of Health Oversight and Coordination Plans

Central to the importance of the 2016 final AFCARS rule is its role in assessing states work to oversee and coordinate health services for children in foster care. *Fostering Connections* requires states to include Health Oversight and Coordination Plans (HOCP) as part of their five-year Child and Family Service Plans (CFSPs). The AAP remains concerned about the issue of states' fidelity to the HOCP provisions of their CFSPs. HOCPs have the potential to serve as critical avenues to continually improve health outcomes for children in foster care. However, they cannot serve this function without effective implementation at the state level, which depends upon federal guidance, technical assistance, and oversight. The most recently available evidence indicates that there is still significant room for progress in this area.

HOCPs must include: initial and follow-up health screenings; how children's health needs identified through screenings are monitored and treated; how children's medical information is updated and shared via electronic medical records; how the state ensures continuity of health services and establishes medical homes for every child in foster care; how the state conducts oversight of prescription medicines; how the state actively consults with physicians and professionals in determining appropriate medical treatment for children in foster care; whether the state has a transition plan that meets the health care needs of children aging out of foster care; and what steps a state is taking to monitor and treat emotional trauma associated with a child's maltreatment and placement in foster care.

Because ACF has not yet implemented updates to AFCARS that reflect the provisions of *Fostering Connections*, ACF does not currently have the necessary data to assess state implementation of these provisions. We strongly support the collection of the information needed to assess state progress in implementing HOCPs, and commended ACF for including these updates in the 2016 AFCARS final rule. We had also urged ACF to include in AFCARS data elements that measure not just screenings but each aspect of state HOCPs highlighted above to ensure the Children's Bureau has the data needed to examine HOCP implementation during Child and Family Service Reviews (CFSR).

Absent implementation of the 2016 final rule, ACF will not have the necessary tools available to determine whether states are meeting the provisions in their HOCPs. These are vital data that are key to improving the wellbeing of children in foster care. We strongly oppose ACF's proposal to delay, and potentially reduce, the scope of the 2016 AFCARS final rule. We urge you to implement the final rule as promulgated without delay. The following are responses to the individual questions of the ANPR. AAP did not weigh in on the Indian Child Welfare Act (ICWA) elements during the notice and comment period for the development of the 2016 final

rule, so these comments do not include a response to Question 2, which is specific to the ICWA elements.

ANPR Question #1: Identify the data elements, non-ICWA related, that are overly burdensome for state and tribal title IV-E agencies and explain why.

The AAP does not believe that the 2016 AFCARS final rule was overly burdensome. The 2016 final rule was a significant compromise, which left out many important data elements AAP proposed such as: whether a child was born in the U.S.; sources of state assistance in a child's living arrangement; immunization data; the mental health services a child in foster care receives, including whether they are evidence-based and trauma-informed, what their treatment plan is, and the frequency of the services; whether an adoption is open or closed; whether a child is receiving dental care; the extent to which foster parents have completed evidence-based trauma-informed training; and tracking of child health outcomes associated with a child's physical and mental health diagnoses.

Although ACF did not include these important elements, AAP still supported the 2016 final rule because of the importance of the data elements the rule would add to AFCARS. The following are vital data elements in the 2016 final rule that AAP strongly supports. We urge you to implement the 2016 final rule without delay, and offer these highlighted data elements as illustrative of the critical importance of the rule's role in promoting improved health for vulnerable children in out-of-home care.

§ 1355.43 (b): Data Reporting Requirements: Out-of-home data file elements

The AAP supports the 2016 final rule that allows for the longitudinal and cohort analysis of AFCARS data. This is a critically important element that enables the review of a child's experience including health status and health services they have received. This information would support ACF's work to ensure child health and wellbeing as well as promote improved outcomes.

§ 1355. 44(b)(11)(ii) Out-of-Home Care Data File Elements: Date of Health Assessment

The AAP supports the inclusion of the 2016 final rule element that notes the date of a child's health assessment within AFCARS. This information is important for assessing access to care for a significant portion of the foster care population at the state and national level. This is an important aspect of measuring a state's compliance with its HOCP. We greatly appreciate the inclusion of health assessment dates in the 2016 final rule, which provide a baseline understanding of the health of children entering the child welfare system.

Within this element, we had strongly recommended the inclusion and use of the *Fostering Health* standards for health care for children in foster care. *Fostering Health* is a set of practice standards designed specifically for the health needs of children in foster care. An AAP multidisciplinary panel of experts developed these standards, which establish a three-stage health assessment process that occurs over the first 2-3 months after a child's removal from their family and placement in foster care. Under *Fostering Health*, the initial health screening should occur within 24 hours of removal and is ideally conducted by the pediatrician servicing the child's medical home or a pediatric specialist in child welfare, with a possible extension of up to 72 hours. We also suggested that AFCARS collect data for each screening, not just the most recent, to provide a more holistic outlook on the health of the children entering this system. This data

collection can provide more comprehensive information on a child's health, such as the medications a child is taking. We believe the 2016 final rule strikes an appropriate balance.

The inclusion of the date of a child's health assessment is particularly important given the nationwide increase in parental substance use disorders, which has resulted in more children entering the foster care system with significant trauma. Children can manifest this trauma by developing various physical, developmental, educational and mental health conditions. By having a greater understanding of how this trauma is affecting these children, children can receive needed services sooner and better heal from the trauma that they have experienced.

§1355.44 (b) (12): Out-of-Home Care Data File Elements: Timely Health Assessment

The AAP strongly supports this element from the 2016 final rule. Timeliness of health assessment is critical to ensuring that child welfare agencies can appropriately identify health needs such as trauma-related behavioral challenges and developmental delay. We had originally recommended that ACF assess if children in foster care are receiving Early and Periodic Screening, Diagnostic and Treatment (EPSDT) services under Medicaid, if eligible.

We also recommended that ACF clarify within AFCARS the definition of health assessment. Currently, there is too much variability within state child welfare agencies' definitions of health assessment, encouraging inconsistency on their content and timing. We recommended basing it on the AAP's *Fostering Health* standards. We also suggested, to ensure the consistent collection and reporting of AFCARS data, that ACF provide guidance to states and child welfare professionals as to the difference between a health screening and a health evaluation. A health screening is not a full preventive visit. The clarification of these two elements would facilitate a greater amount of consistency within the data AFCARS collects.

§1355.44(b)(13) Out-of-Home Care Data File Elements: Physical Health, Developmental, Behavioral, or Mental Health Conditions

The AAP supports the inclusion of this element and urges its retention. This element helps to further detail important health data about the children entering the foster care system. We are also in strong support of ACF's option to maintain this file over time and not overwrite a child's previous data for every entry. This is essential for providers to revisit diagnoses over time based on the needs of the child, and equally helps to gather longitudinal information on a child's diagnoses to create an accurate view of their health history.

The AAP greatly appreciated the inclusion of specific mental health disorders as individual health diagnoses in the 2016 final rule. These individual elements would allow for providers to develop more specific treatment plans for children with these conditions, in a timelier manner. We also recommended the inclusion of initial mental health screenings at entry into the foster care system, and within 30 days a full mental health evaluation including a trauma assessment by a trauma-informed pediatric mental health professional. Many of the children entering foster care have been exposed to significant levels of trauma and multiple adverse childhood experiences. These assessments provide a better understanding of children's trauma history and what services they need to heal. This is an important item to monitor given that *Fostering Connections* mandates that states have established plans for steps to monitor and treat the emotional trauma associated with a child's maltreatment and placement in foster care. Evidence shows that

addressing childhood trauma sooner improves children's lifelong health and wellbeing, and can reduce future health care costs associated with the long-term sequelae of trauma.

This element is vital to ensuring the health and wellbeing of children in foster care. By recording in detail, the health conditions of children in foster care, health care providers can better assess their health status. This will allow for a better analysis of the improvements necessary in health service delivery for this population.

§ 1355.44(b)(14): School Enrollment/ §1355.44(b)(15): Educational Level/ §1355.44(b)(16): Educational Stability

The AAP supported these school-related elements in the 2016 final rule as they have important health implications. These data are important for assessing the educational experiences of children in foster care. While we greatly appreciated the inclusion of this element, we had also suggested the inclusion of a truancy element to determine the number of school days that a child misses, as a further measure of educational stability. We had suggested that this also include the reasons for said misses, including, but not limited to, suspension and expulsion.

The AAP also suggested the addition of fields to capture information on child development and early childhood education. In addition to capturing information from kindergarten onward, early childhood development, which plays a critical role in health and school readiness, has important implications for ensuring the appropriate oversight and coordination of health services for children in foster care. The development that takes place in a child's pre-kindergarten years is formative and especially significant if that child enters foster care during that time.

§1355.44(b)(18): Special Education

The AAP supported the inclusion of this data element in the 2016 final rule. This element would assess the number of children in foster care with special education needs. Within this element we suggested the addition of an element aimed at assessment of the reception of services by children in foster care, as indicated in their 504 or Individualized Education Plans (IEP).

With that addition, this element would further improve service coordination for children with special health care needs, further increasing the potential for collaborative inter-agency efforts as a means of improving the well-being of children in foster care.

§1355.44(b) (19): Prior Adoption; §1355.44(b)(20) (i-ii): Prior Guardianship

The AAP also supported the data collection elements regarding prior adoptions and/or guardianships in the 2016 final rule. The inclusion of these elements would provide further insight into the nature of prior adoptions and guardianships for these children now entering the foster care system. Every change of caregiver disrupts attachment and is traumatizing for a child. By including intercountry adoptions as well as reasons for the dissolution of these relationships, ACF and state child welfare agencies can gain a better understanding of the supports needed by adoptive families and guardians. This understanding can potentially lead to better support services for children and families, particularly for treatment of behavioral and mental health issues.

§1355.44(b)(21) (i-xiii): Child Financial and Medical Assistance

The AAP applauded the inclusion of this element in the 2016 final rule and its subsequent descriptive individual elements denoting type of assistance, particularly the inclusion of state and tribal child financial and medical assistance. These fields would provide a more robust analysis of all such assistance a child is receiving, with important implications for their medical coverage. This would improve efficiency in caring for children by ensuring efficient service delivery and financing.

§1355.44 (d) (7): Victim of sex trafficking prior to entering foster care/ §1355.44 (d) (8): Victim of Sex Trafficking while in Foster Care

The AAP strongly supported the inclusion of this information to review implementation and effectiveness of P.L. 113-183 in the 2016 final rule. We previously suggested adding categories to identify any health and mental health services a child receives as a result of their sex trafficking, in order to determine what states are doing in an effort to support these identified child sex trafficking victims. We also suggested that ACF provide more clarity in terms of those who are victims during the time that they run away from foster care. This collection of data can prove to be an enormous resource in combatting such a traumatic experience as sex trafficking and also identify youth at risk of pregnancy and sexually transmitted infections and more extensive medical evaluation.

§1355.44(d) (4): Environment at Removal

The AAP also supported this element in the 2016 final rule. We also greatly appreciated the inclusion of homelessness as a subcategory within the "Other" selection. Understanding the home life of children entering foster care would provide insight into the types of supports and services they and their caregivers may need.

§1355.44(d) (6): Child and Family Circumstance at Removal

The AAP strongly supported this section of elements in the 2016 final rule. We particularly supported the addition of the categories ""psychological or emotional abuse", "medical neglect", "domestic violence", "diagnosed condition", "inadequate access to mental health services", and "inadequate access to medical services" as categories. We supported the differentiation made between prenatal exposure to substances and childhood exposure, which is important within the context of the ongoing opioid crisis. We also supported the inclusion of categories that highlight and capture those children that have entered out-of-home care due to the immigration status of their birth parents. In addition to these categories, we suggested the inclusion of a category meant to denote those children that are placed into the foster care system due to the status as an "unaccompanied minor immigrant".

The relevance of these elements ties in directly with those regarding the environment at removal. Given the environmental circumstances at removal, certain familial circumstances may be present as well, which in turn would necessitate pertinent family support services. Understanding the family ecology from which the child came can help health care providers better meet a child's health needs and help promote familial healing.

§1355.44(e): Living Arrangement and Provider Information

The AAP supported this element in the 2016 final rule. We appreciated the incorporation of additional differentiation among living arrangements and providers, and suggested the inclusion of "skilled nursing facility" as an additional living arrangement category.

Given the newly enacted *Family First Prevention Services Act*, these data could support ACF's understanding of children's placement settings, which is important context for the oversight of IV-E financed prevention services.

§1355.44 (b) (23-25): Sibling Information

The AAP supported these elements in the 2016 final rule. These data are important for capturing the number and type of siblings that a child entering foster care has. The inclusion of the element detailing the foster care status of those siblings is also critical. We had also urged ACF to collect information on the extent to which children have ongoing interactions with extended family members. This sustained connection to a child's birth family can help to alleviate the traumatic experience that is removal and placement into out-of-home care. It can also help in allowing for a kinship placement to take place in the future, as well as potentially improving the connection with the birth parent on their path back to reunification.

§1355.44(f) (1): Permanency Plan

The AAP fully supported the 2016 final rule's planned collection of permanency plan information within AFCARS. For those children with permanency plans targeting reunification, the collection of information regarding visitation frequency and the nature of the visit is crucial.

§1355.44 (f) (5): Juvenile Justice

The AAP fully supported this element of the 2016 final rule and its ability to examine the overlap of children in the Child Welfare and Juvenile Justice systems. This examination could be used on the national level to determine how the intersection of Title IV-E dollars serve children in both systems and how best to improve their health and wellbeing.

§1355.44(f) (6-7): Caseworker Visit Information

We also supported this element of the 2016 final rule and suggested gathering information on parental visits similar to the permanency plan element. Where reunification is the goal, birth parent contact is crucial. It serves as an impetus for the parent to meet the necessary requirements for reunification, as well as a comfort to the child experiencing the trauma of removal from their parent. Along with this information, we suggested the information on the visits include anything outside of routine supervision, such as Parent Child Interaction Therapy (PCIT), Child Parent Psychotherapy (CPP), Visitation Coaching, and Parents as Teachers (PAT). Pediatricians play an important role in assessing the impact of visitation on children, in supporting appropriate visitation for a child's developmental and legal status, and in advocating for changes when indicated, whether that be for an increase or reduction, change in venue or supervision or services.

§1355.44 (f) (8): Transition Planning

The AAP supported the transition plan elements within the 2016 final rule, particularly those related to health. We suggested a more deliberate inclusion of health data elements into this field,

to further encourage the healing of the children transitioning out of the foster care system. This should include discussions with a child's caseworker on their eligibility for Medicaid. We also suggested the addition of an item focused on whether a child's health coverage and treatment information are coordinated with a child's medical home during the transition. Health practitioners play an important role in providing developmentally appropriate advice and support for youth and families during transitions, linkages to ongoing primary and subspecialty care, prescriptions for medications and health education.

ANPR Question #3: Please provide specific recommendations on which data elements in the regulation to retain that are important to understanding and assessing the foster care population at the national level. Also, provide a rationale for your suggestions that may include its reference to monitor compliance with the title IV-B and IV-E programs or another strong justification for using the data at the national level.

As outlined above, the health-related elements of the 2016 final rule are vital to monitoring compliance with the Title IV programs, and particularly the HOCPs states develop pursuant to Title IV-B. Individual case review has proven insufficient for this purpose, as demonstrated by the significant barriers to the operationalization of the health screening element of state HOCPs.

The March 2015 U.S. Department of Health and Human Services (HHS) Office of the Inspector General (OIG) Report "Not All Children in Foster Care Who Were Enrolled in Medicaid Received Required Health Screenings"[1] examined the provision of initial health screenings to children in foster care in four states: California, Illinois, New York, and Texas. The report found that in those four states, nearly one-third of children in foster care enrolled in Medicaid did not receive at least one health screening, and over one-quarter received at least one screening late. The provision of initial and follow-up health screenings is one required element for state HOCPs under *Fostering Connections*, so this finding by the OIG provides cause for concern and likely points to issues implementing other aspects of *Fostering Connections*.

National level data related to child health and wellbeing are critical to ensuring the effective provision, coordination, and oversight of health services for children in foster care. These data are also critical for identifying and addressing potential barriers to children accessing needed care. The AAP strongly supports the collection of national level data in the 2016 final rule, and particularly the elements identified in our response to Question 1.

ANPR Question #4: Please provide specific suggestions to simplify data elements to facilitate the consistent collection and reporting of AFCARS data. Also, provide a rationale for each suggestion and how the simplification would still yield pertinent data.

We believe the 2016 final rule strikes an effective compromise that has already effectively balanced the need for administrative simplicity with the need for actionable data that can support the work of ensuring the safety, permanency, and wellbeing of children in out-of-home care. As we note in our response above to Question 1, there were numerous elements AAP suggested for inclusion which ACF declined to incorporate into the 2016 final rule. We believe that the 2016 final rule as written balances the necessary interests and achieves the goals of AFCARS. In addition, the decades-long ongoing delay of an update to AFCARS has itself contributed to inefficiencies in child welfare data systems and a lack of information states need to manage their

[1] See https://oig.hhs.gov/oei/reports/oei-07-13-00460.pdf

programs and ACF needs to monitor their compliance with federal child welfare law. The continued delay of the implementation of the 2016 final rule creates significant administrative burden within ACF by limiting the agency's ability to ensure the effective implementation of federal laws designed to, among other things, ensure vulnerable children in foster care have access to needed health services.

ANPR Question #5: Please provide specific recommendations on which data elements in the regulation to remove because they would not yield reliable national information about children involved with the child welfare system or are not needed for monitoring the Title IV-B and IV-E programs. Please be specific in identifying the data elements and provide a rationale for why this information would not be reliable or is not necessary.

The 2016 final rule is an effective compromise that includes critical data ACF will need to monitor the Title IV-B and IV-E programs. We do not recommend the removal of data elements from the final rule. The AAP opposes the ongoing delay of the 2016 final rule, and we urge ACF to implement it as written without delay.

Conclusion

The AAP greatly appreciates the major improvements already made to AFCARS. We strongly encourage the reinstatement of the 2016 final rule immediately. Concurrently, we strongly oppose any potential delay to the implementation of this rule as well as a scaling back of the elements listed in the rule. The updates ACF has included are a significant improvement over the previous system, and we look forward to working with you to continue to promote the health and well-being of children in foster care. If you have any questions please do not hesitate to contact Zach Laris in our Washington, D.C. office at 202/347-8600 or zlaris@aap.org.

Sincerely,

Colleen A. Kraft, MD, FAAP
President

CAK/me