The Need for Primary Care Medical Homes for Children in Foster Care

White Paper | July 2016

Author(s) and affiliation(s): Karla A. Lawson, PhD, MPH, Director of The Dell Children's Trauma and Injury Research Center; Amy Brandes, Licensed foster parent & Manager of Perinatal & NICU Nutrition for Seton Healthcare Family.

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Executive Summary

Child maltreatment is a significant public health problem in the United States with millions of children investigated for maltreatment annually and hundreds of thousands of children in out-of-home foster care placement. These children have increased rates of chronic mental and physical health challenges as well as lifelong health effects following maltreatment. Health care before entry into foster care has often been fragmented and inconsistent. The American Academy of Pediatrics (AAP) recommends children and adolescents in foster care utilize a medical home model for children with complex health care needs. Data supports their utility in multiple populations, though specific foster care medical homes have not been systematically evaluated in the literature. The AAP and other organizations make recommendations regarding their use, including providing a multitude of services and consistent delivery of care. These recommendations are clearly focused on mitigating the complexity of caring for children and adolescents in foster care.

Introducing the Problem

Child maltreatment is a significant public health concern in the United States. The World Health Organization defines maltreatment as "all forms of physical and/or emotional ill-treatment, sexual abuse, neglect and exploitation, resulting in actual or potential harm to a child's health, survival, development or dignity" (2016). Over three million U.S. children were investigated for child maltreatment in 2013, with 679,000 children substantiated as victims (U.S. Department of Health and Human Services, 2015). Of these, almost 80% were experiencing neglect while 18% were victims of physical abuse and 9% victims of sexual abuse. Following investigation for child maltreatment or for other reasons, 240,000 children were newly placed in foster care and a total of 641,000 children spent at least some amount of time in the foster care system in 2013 (Child Trends, 2015). The majority of children and adolescents in foster care will remain in placement for longer than one year with more than 20% remaining in foster care placements for more than three years (Szilagyi et al., 2015).

The Medical Needs of Children and Adolescents in Foster Care

Children and adolescents in foster care placement have a higher rate of medical issues prior to system entry, maintain increased risk within the system, and develop poor health outcomes after transition. 30% to 90% of children entering the foster care system are estimated to have at least one physical health problem, special health care need, or chronic health condition (Chernoff et al., 1994, Leslie et al., 2005, Ringeisen et al., 2008, Stein et al., 2013). There have been a number of studies looking at the heightened health care needs of these children. Studies have highlighted increased rates of post-traumatic stress disorder (PTSD), other mental health issues with increased prescription of psychotropic medication, reproductive health risk in adolescents including increased rates of teen pregnancy and sexually transmitted diseases, chronic physical conditions, and dental issues (Blatt et al., 1997, Szilagyi et al., 2015). In addition to these children and adolescents having higher rates of health issues as they enter foster care,

they are also more likely to have additional health care needs after placement. The risk of continued child abuse and neglect can remain within the foster care placement and vigilance for these children and adolescents is warranted. In addition, the need for mental health services is imperative to the medical treatment for children in foster care not only due to previous abuse and neglect, but also secondary to transitioning into foster care itself and/or movement between foster care placements. Therapies should be evidence-based and trauma-informed, such as parent-child interaction therapy (PCIT) and trauma-focused cognitive behavioral therapy (TF-CBT). Health outcomes post-foster care transition are also of concern for this population, with studies showing persistent mental health issues in more than half of the population, chronic physical health issues in a substantial percentage of transitioned youth, as well as social factors such as unemployment and poverty leading to lack of health insurance coverage and access to care (Felitti et al., 1998, Reilly, 2003, Szilagyi et al., 2015, Campbell et al., 2016).

In addition to those conditions suffered by children entering, currently being served by, or recently transitioned from the foster care system, there are chronic health outcomes associated with child maltreatment. There are considerable detrimental effects of child maltreatment on the child, family, and society. Data from the Adverse Childhood Experiences (ACE) Study, one of the largest studies to specifically investigate the latent effects of child maltreatment and other types of childhood trauma on health, illuminates this concern (Felitti et al., 1998, Campbell et al., 2016). A large body of scientific literature has emerged utilizing and replicating data collected in the ACE Study. In the original study, almost 10,000 adults were questioned regarding the presence of adverse experiences during their childhood (Felitti et al., 1998). The number and types of these reported experiences were then correlated with poor health outcomes. The study found a significant relationship between the number of adverse events suffered as a child with risky adult health behaviors and disease. Alcoholism, drug abuse, and mental illness were four to twelve times more likely in those experiencing four or more types of adverse events in their childhood. Similar findings were true for smoking and sexual health related factors. A smaller but significant relationship was also found between adverse events and lack of physical activity and obesity in this population. In addition to its relationship to health risk factors, these adverse events were also related to adult-onset chronic disease presence including heart disease, cancer, chronic lung disease, skeletal fractures and liver disease (Felitti et al., 1998). Recent and exciting scientific work is seeking to establish a causal connection between child maltreatment and health and well-being later in life. This work is focusing on the effect of adverse events on epigenetic changes and subsequent changes in gene expression that may point to a direct causal relationship between adverse experiences of the child and poor health throughout the life cycle, illuminating the need for early and consistent intervention.

Coordination of Care and the Medical Home Model

With the increased health risks of children entering the foster care system, increased negative sequela secondary to maltreatment, lifelong detrimental health effects, and limitations in access to care for those in foster care, it is imperative to determine a coordinated care model to deliver timely and appropriate physical and mental health care to these children. The majority of children remain in the foster care system for more than one year and many enter the system having limited consistent health care before entry (Simms, 1989, Leslie et al., 2005). The American Academy of Pediatrics, in their technical report on health care issues for children and adolescents in foster care, point to integrated models of care including both physical and mental health via a medical home model as a promising way to fulfill the health care needs of this vulnerable population (Szilagyi et al., 2015).

There have been few studies investigating the efficacy of the medical home model for foster care children and youth, though empirical data would suggest the medical home model to be optimal for maximizing care for this population. In 1997 Steven Blatt and his co-authors published on a comprehensive, multidisciplinary approach to health care for children in foster care (Blatt et al., 1997). Their work highlighted the need for comprehensive care for children in out-of-home placement including the need for general pediatrics, psychology, and educational assessment, as well as strong collaborations with state health services, child protective services (CPS), and child abuse assessment teams. Though data on clinical

and behavioral outcomes after clinic participation were not presented, findings did mirror other studies in showing increased health care needs for this population. Mark Simms reported in 1989 about a medical home model for pre-school aged children in foster care (Simms, 1989). The goal of this medical home clinic was to identify children in need of services, especially those related to educational or therapeutic interventions, and to coordinate care with multiple community agencies for the child's needs as well as to determine any problems with the foster care placement. These were in addition to the typical health assessments needed for this age group, though the clinic did not provide primary pediatric care for these children. This study also identified the need for increase in assessment of health related issues for this vulnerable population and the need for developmental intervention, with over 60% of children showing delay in language development, fine motor delay, gross motor delay and/or cognitive delay. This study did not supply any outcome data for the children related to their use of the comprehensive multidisciplinary clinic or make comparisons to any other model of care delivery.

Though outcome data and comparison-based studies are not available for the evaluation of medical homes for children and youth in foster care, data does exist for the use of the medical home model for other complex health care needs. Studies on this model for health care delivery have shown a decrease in emergency room visits as well as hospitalization rates for children with complex health care needs (Lafata et al., 2002, Homer et al., 2005 & 2008, Cooley et al., 2009). In addition, the medical home model shows promise for the general population of pediatric patients, with increased parental report of favorable health in children who are followed by a medical home as compared to those who are not, as well as increase in preventative medical visits and decrease in sick visits (Long et al., 2012).

Though research is clearly needed in the field of foster care medical home evaluation, empirical data does point to the utility and need for such programs. There are a number of concerns in coordinating care for children in the foster care system that can be mitigated using a medical home model to provide consistent care for the children in out-of-home placement.

Concerns Regarding Coordination of Health Care for Children in Foster Care

- Need for mental health screening and treatment
- Need for continued child maltreatment surveillance and intervention
- High risk population with increased rates of chronic, undiagnosed, or under-treated illness
- Transient nature of population
- Need for developmental and educational support and intervention
- Increased time needed for evaluation
- Discordance with authority for consent and treatment
- Lack of consistent and complete health information history
- Need for communication with multiple collaborators including child protective services, advocates, sub-specialty providers, and both foster care and biological parents
- Prior lack of preventive services
- High hospitalization rates

Medical Home Recommendations

The American Academy of Pediatrics points to integrated models of care, including both physical and mental health via a medical home model, as a promising way to fulfill the health care needs of this vulnerable population and makes global statements regarding the description of these institutions (Szilagyi et al., 2015, 1134): A medical home for a child or teenager in foster care ideally offers "high-quality, comprehensive, coordinated health care that is continuous over time, compassionate, culturally competent, family centered, and child focused."

The AAP also makes recommendations regarding the composition and activities of the medical home for children and adolescents in foster care. They base most recommendations on the premise of seeing this population "early and often" with prescribed time frames for initial health screening after system entry, full physical, mental and education health assessment visits, as well as follow-up and preventative services visits (1135). Medical homes are recommended to include pediatric practitioners, mental health practitioners, education experts, as well as CPS liaisons and other ancillary staffing. Other

organizations such as Superior HealthPlan have developed recommendations for the development of Foster Care Centers of Excellence (FCCOE). These recommendations mirror those by the AAP and include interaction with CPS, communication with both birth and foster parents, promotion of health and wellness through prevention programming, primary care visit schedules to promote seeing patients early and often, collaboration with child abuse pediatrics and surveillance for child maltreatment, mental health screening and coordination of treatment, educational and developmental screening and coordination of intervention, training for consent issues, and collaboration with sub-specialty physicians in children with more complex health needs. These programs are required or recommended to include a number of health care providers to participate in the care of these children and adolescents, including primary care physicians, child abuse physicians, other sub-specialty physicians, mental health care professionals, speech and language pathologists, special education experts, physical and occupational therapists, therapists, dietitians and social workers.

Conclusion

The medical home for children and adolescents with special and complex healthcare needs is recommended by the AAP based on literature showing beneficial effects in certain populations. Empirically, this model is recommended for the health care needs of children and adolescents in foster care. There are a number of barriers to the comprehensive medical care of children in foster care including lack of consistent past care, lack of medical history, issues around medical consent, high rates of chronic mental and physical health issues, lack of past preventative care, as well as increased need for communication with both outside institutions like child protective services and sub-specialty physicians. Many of these issues could be mitigated via the utilization of a medical home for children and adolescents in foster care. The AAP and other groups have recommended the composition and services provided by a medical home model for these children to include primary mental and physical health care, collaboration with child abuse pediatrics and surveillance for child maltreatment, educational and developmental screening and coordination of intervention, and collaboration with sub-specialty physicians.

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