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Introducing Foster Care: Challenges and Opportunities to Reducing Health Disparities

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Introduction to Thinking about Foster Care: Challenges and Opportunities to Reducing Health Disparities

We are pleased to present this issue of *Journal of Applied Research on Children: Informing Policy for Children At Risk (JARC)*, dedicated to children currently and formerly in foster care, as well as children who are struggling, but remain surrounded by hopeful families and home communities. This unique, visionary issue, by Children at Risk and Dr. Chris Greeley, Editor-in-Chief, brings together perspectives from families, medical and behavioral health practitioners, and policy experts who collectively propose potential strategies to improving care of abused and neglected children in the United States.

Improving care of children affected by adversity, particularly children requiring state intervention, is a more urgent issue today than in decades past. The field of epigenetics and its steadily growing intersection with child development suggests strong associations between childhood adversity and subsequent lifespan or multi-generational imprints on health and behavior risks and outcomes. If childhood adversities, such as abuse, neglect, household intimate partner violence, or racism cause disease and poor quality of life across the lifespan, it would mean long-standing “social ills” are in fact public health ills.

Likewise, costs of “societal” struggles can no longer be limited to traditional calculations, such as employment, incarceration, or expenditures on public assistance programs. Instead, regular calculations of the cost of adversities would include acute, chronic, and rehabilitative health and education costs across the life span. As we integrate how epigenetics and childhood adversities affect health and life potential, it may be that society will have to consciously move from viewing early intervention as a mainstay of a *compassionate* society to investing in early intervention as *ethically imperative* for the success of current and future generations.

The theme of this issue dedicated to foster care, therefore, began as a health framework through which to discuss the needs of children and families. That many children who spend time in foster care have disproportionate disease burden, psychotropic prescriptions, and lower socioeconomic attainment is well documented. Understandably, topics surrounding the field of foster care often focus on mental health, trauma-informed care, health insurance coverage, and child welfare intervention. This issue of JARC chose perspectives addressing the growing evidence that childhood adversity affects physical, mental, educational, and developmental outcomes, which have particular meaning for children in

foster care, many of whom experience complex trauma and live in transitional family arrangements.

JARC is unique in offering access to peer-reviewed publications that reach any audience of experts, which is particularly important when discussing the quality of health care in foster care. For example, as communities consider models of care, one potential model is integrated care, which has evidence of impact in select conditions, such as cancer treatment or addiction recovery services. Just as these services bring together medical, mental health, and rehabilitative services, foster care integrated care may need to bring together child protection, legal systems, education, health care, and family caregivers who all influence outcomes for children. Given the broad readership, I hope this issue prompts fresh perspectives and conversations regarding the antecedents and solutions for better systems of care for children affected by diverse adversities, within communities of any size.

Interestingly, assembling health-oriented articles specifically focused on children who have interfaced with child welfare proved challenging. The very factors prompting the topics of interest, namely the unique life and political milieu of children in or at-risk of child welfare intervention, seem to also limit the scope of discussion. Children in foster care have open court cases related to risk factors known to place their well-being at potential risk. These factors are risk factors worthy of study and also render study and open exploration of population level issues difficult. In addition, systems of care are heavily regulated, monitored, and scrutinized, as evident by recent coverage surrounding the highly profiled Texas case, *M.D. vs. Abbott*, ruled upon in 2015 and 2018, similar to other lawsuits filed across the country.

In assembling this issue, we reached out to experts in multiple systems who have found early success in describing or piloting targeted interventions for children in or at-risk of entering foster care. Consistently, families, physicians, mental health trauma experts, child welfare experts, or health systems experts sited challenges to sharing information in publication. As guest editor, I see these challenges falling into three primary themes worthy of further consideration, as they may be limiting our ability to advance the field of foster care and childhood adversity.

1. **Barriers to conducting research aimed to advance the field of foster care:** The fields of foster care, adversity prevention/mitigation, psychological trauma treatment, and child welfare require intensive study to establish evidence-based practice. A well-established method of identifying better practices, treatments, and policies is well-designed, approved, monitored, safe, voluntary, and informed

participation in research. Unfortunately, facilitators for high caliber research seem slow to evolve and limited in foster care.

Cautions to conducting research should be respected. Inarguably, society must categorically prohibit the risk of potentially harmful, targeted intervention for vulnerable populations, particularly during the most vulnerable period in a child's life, separation from parents. Additionally, the legally required, transient nature of foster care can render basic requirements of human subjects research challenging, namely, monitoring intervention outcomes and maintaining updated legal research consent. In an effort, however, to avoid such risks to children in foster care, it may be that agency and institutional policies are limiting the fields of medical and social sciences in discovering necessary advancements in foster care and child welfare practice.

In order to make substantial gains quickly on behalf of thousands of children, regulatory bodies and systems of care will need to relook at equity of current requirements for conducting sound and necessary research. Fortunately in pediatrics, advances in standard of care have led to improved outcomes for children facing similar special health care needs, such as cancer, infectious diseases, orthopedic conditions, and common chronic diseases, such as asthma and diabetes. It would be difficult to assert the same conclusion for children in foster care. Science continues to discover increasing relevance of toxic stress, epigenetics, and the role of nurturing caregiving. Therefore, expanding safe and regulated opportunities to study interventions in foster care is critical to improving life-long outcomes for the over 400,000 U. S. children in foster care, who also meet the definition of children with special health care needs. The potential impact of better interventions and policies to prevent future avoidable, suboptimal outcomes for children affected by complex adversities has long-term individual benefits and perhaps multigenerational impacts. Barriers to research, including lack of standardizations, will likely continue to place this population of children at higher risk of long-term disadvantage by restricting progress and broadening disparities, inadvertently, out of concern to protect them.

Offering every parent, substitute caregiver and child involved with foster care, safe, evidence-based care while in state custody is a shared ethical obligation. Like other special child populations, children in foster care due to abuse and neglect can experience transformative shifts in quality of life as the field advances. Partnering with experts that have successfully tackled similar challenging fields of study may help map safe and effective population level research strategies.

Ultimately, facilitating integrated, cross-disciplinary, safe, approved, local and multi-site research is critical on behalf of the safety and quality of life for children involved with foster care and child welfare systems.

2. **Restrictions to broadly engaging family and caregiver voice:** The fields of patient safety, quality improvement or disease-specific advocacy often involves parents of children or the child himself, who is affected by a particular condition or adverse outcome, to improve systems of care. In contrast, to protect children in foster care, caregivers responsible for the health and safety of children in foster care are legally restricted from identifying or publically speaking on behalf of children in their care. In foster care, not only are licensed caregivers restricted, families of origin are equally in a difficult position to openly disclosing experiences. Parents separated from their children may be working diligently to comply with child welfare reunification requirements while being monitored by child welfare. Disclosing behaviors labeled as stigmatizing or experiences with system challenges may increase their perceived risk for reunification. Approaching children to openly share experiences while they remain in care poses many ethical concerns, as well, without clear direction or resolution. Foster care alumnae have been an effective, powerful voice to bring better understanding and improvements by sharing their unique experiences. Likewise, advocates will have to find ways to also broaden youth representation to those whose disabilities limit open engagement. The need to expand the breath of perspectives to those directly affected by adversity and child welfare systems, with the purpose of improving the system, is a challenge worth solving.
3. **Restrictions to data sharing among systems supporting children in foster care:** Another hallmark of conducting timely, quality improvements and yet, frequently voiced challenge in foster care, is sharing case-based, aggregate, de-identified data with other systems for the purpose of improving services. Descriptive data, data from quality improvement projects, or data outcomes from new policies or pilots present powerful opportunities for discovering new strategies or asking new questions. Unfortunately, due to both perceived risks and current regulations, agencies and contracted providers face restrictions in data sharing. Child welfare, legal systems, health care, and education systems fall under different regulatory authorities, laws, and policies that require strict adherence with risk of stiff penalties for violations. In addition, contract performance requirements, legislative oversight, and general public scrutiny under which publically funded

agencies exist, may deter sharing otherwise promising data, even when allowed. Unfortunately, as with research and family voice, actual and perceived needs for protections and privacy may inadvertently limit the pace of progress.

Systems of care serving children in foster care, or other children who have experienced adversity, serve an overlapping, relatively small, specialized population. Within that lens, data-sharing for quality improvement has tremendous potential. Models exist in numerous industries, which may have application for systems serving families affected by serious adversities. Allowing systems to function within safe, monitored, regulations that support necessary information sharing for quality improvement and safety could help broader, future populations. Finding mechanisms to offer protection to agencies and services providers for purposes of performance improvement could substantially advance the field of recovery health care and child welfare, particularly for children in foster care.

In speaking with experts from across disciplines this past year, I am struck by the creativity, energy, and passion of families and professionals who have dedicated their lives to helping vulnerable children. I am optimistic these three barriers, and other compelling barriers, can be addressed effectively, given the urgency of improving care for children living in foster care today.

On a personal note, the experience of laughing, hoping, and applauding with my patients in foster care forever changed how I see the magic of childhood, the heavy role of parenting, and the beauty of the seemingly mundane moments of family. To my patients, I will share that I have read to them when I read to my own, cut cake for them when they were celebrating at their own dinner tables, and pictured them succeeding somewhere as the seasons changed.

For each child we have met and those we have not, please enjoy the insights and contributions of the authors and parents in this special issue of JARC. It is our hope that this compilation of ideas and views assists families, advocates, policy experts, and system leaders as they continue to improve our community response to our most vulnerable and “at-promise” children.