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Developmental Care for Hospitalized Infants With Complex Congenital Heart Disease: A Science Advisory From the American Heart Association

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ABSTRACT: Developmental disorders, disabilities, and delays are a common outcome for individuals with complex congenital heart disease, yet targeting early factors influencing these conditions after birth and during the neonatal hospitalization for cardiac surgery remains a critical need. The purpose of this science advisory is to (1) describe the burden of developmental disorders, disabilities, and delays for infants with complex congenital heart disease, (2) define the potential health and neurodevelopmental benefits of developmental care for infants with complex congenital heart disease, and (3) identify critical gaps in research aimed at evaluating developmental care interventions to improve neurodevelopmental outcomes in complex congenital heart disease. This call to action targets research scientists, clinicians, policymakers, government agencies, advocacy groups, and health care organization leadership to support funding and hospital-based infrastructure for developmental care in the complex congenital heart disease population. Prioritization of research on and implementation of developmental care interventions in this population should be a major focus in the next decade.

Key Words: AHA Scientific Statements ■ congenital heart disease ■ developmental care ■ family-centered care ■ infant ■ neurodevelopment

Developmental disorders and disabilities encompass a broad range of developmental delays or abnormalities and are increasingly recognized as a common outcome in congenital heart disease,[1] particularly for those most at-risk infants with complex congenital heart disease who require surgical intervention early in life. Importantly, the combined outcomes of developmental disorders and disabilities, including academic difficulties, behavioral abnormalities, and physical limitations, represent the single most common morbidity affecting the quality of life in survivors with complex congenital heart disease, surpassing the rates of late mortality, severe exercise impairment, unplanned reoperations, bacterial endocarditis, or significant arrhythmias.[2] Infants with complex congenital heart disease are at risk for developmental disorders and disabilities caused by both biological and environmental risk factors.[3] Despite growing attention by the scientific community, research has explained only one-third of the variance in developmental disorders and disabilities through biological and medical variables, which are largely nonmodifiable.[3,4] Previous American Heart Association scientific statements[1] have highlighted the importance of outpatient evaluation of child neurodevelopment; however, early experiences on the vulnerable infant brain are known to have lifelong implications.[5,6] Therefore, identifying and targeting early factors influencing developmental disorders and disabilities in complex congenital heart disease remain critical needs.

Developmental care for infants is an approach that individualizes care by observing and interpreting the infant's behavior and thus modifying the environment and caregiving to meet the developmentally appropriate expectations of the infant's brain. This approach has been shown in premature infants to maximize neurological development and reduce long-term developmental disorders and disabilities.[7] Developmental care also should be individualized to meet the needs of families regardless of racial, ethnic, cultural, religious, socioeconomic, or language backgrounds. Developmental care in the complex congenital heart disease population incorporates a unique understanding of complex congenital heart disease and its physiological, mental, behavioral, and emotional effects on infants and their families.[8] Most studies in which developmental care was examined in newborn intensive care units have excluded infants born with complex congenital heart disease[9]; thus, developmental care may require adaptation for full-term infants with complex congenital heart disease.[8] Infants with complex congenital heart disease hospitalized immediately after birth are particularly vulnerable to the interruption of normal developmental processes, offering a critical developmental window for intervention. As surgical options for children with complex congenital heart disease expanded in the 1980s and 1990s, many children's hospitals created separate pediatric cardiac intensive care units or separate sections within other intensive care units to care for infants with complex congenital heart disease.[10] At that time, the focus of clinical care and research was primarily dedicated to infant survival, and the risks of developmental disorders and disabilities were unknown. Health care professionals were not trained on developmental care practices, and units were not built with the resources or infrastructure to support developmental care. Despite calls for a paradigm shift in clinical practice in the early 2010s to include developmental care,[11] variation in practice and barriers to developmental care have persisted over the past decade.[12–15] The purpose of this advisory is to (1) briefly describe the burden of developmental disorders and disabilities for infants with complex congenital heart disease, (2) define the potential health and neurodevelopment benefits of developmental care for infants with complex congenital heart disease, and (3) identify critical gaps in research aimed at evaluating developmental care interventions to improve neurodevelopmental outcomes in complex congenital heart disease.

BURDEN OF DEVELOPMENTAL DISORDERS, DISABILITIES, AND DELAYS

The burden of developmental disorders and disabilities in complex congenital heart disease has been well-documented.[1,16–18] Children with complex congenital heart disease have developmental disorders and disabilities that extend far beyond modest decreases in intelligence quotient and impact multiple domains, persisting through adolescence, such as executive function, attention, memory, visual–spatial skills, language, motor function, and behavior (Table 1).[1,19–27] These neurodevelopmental impairments translate into lower educational achievement, the need for remedial academic services, and diminished quality of life.[28–31] We now recognize that developmental disorders and disabilities in children with complex congenital heart disease follow white matter injury and compromised brain maturation (dysmaturation) that evolves over time.[32,33] These findings suggest consideration of both brain injury and impaired brain maturation in developmental disorders and disabilities across the life course.[34] Developing early interventions to promote brain maturation, mitigate risk factors, and change the trajectory of neurodevelopment are now urgent research priorities.[35]

COMPONENTS OF DEVELOPMENTAL CARE: HEALTH AND NEURODEVELOPMENTAL BENEFITS

Developmental care is an overarching term that incorporates a constellation of interventions that can be integrated across the continuum of care (Figure 1).[8] We highlight essential developmental care domains and their application in the care of infants with complex congenital heart disease and their families below.

Parents as Primary Caregivers

A cornerstone of developmental care is that it is family centered and focused on supporting the infant within the context of the family unit.[8] Parents are the infant's primary caregivers and central figures for decision making.[36] Provision of developmental care asserts that there is a proactive, relational partnership between health care professionals and parents to support active engagement in their infant's care, beyond visitation and participation.[8] Parents must receive support to positively and safely interact with their infant to promote development.[37] The experience of an infant's complex congenital heart disease diagnosis, subsequent hospitalization and interventions, immersion in a foreign environment, and alterations in parental role are tremendously stressful for parents.[38] These experiences place parents at high risk for anxiety, depression, and posttraumatic stress that may interfere with parenting and family functioning and lead to or exacerbate existing developmental disorders and disabilities.[39] Families with a lower socioeconomic status or non-English speaking are at particularly high risk.[40]

Table 1. Developmental Concerns for Children and Young Adults With Complex Congenital Heart Disease[1,13]

Domain	Described delays and deficits
Cognition	Intelligence quotient Processing speed
Attention	Sustained and divided attention Conflict monitoring Alertness and vigilance
Executive function	Inhibitory control Organization and planning Working memory Problem solving Cognitive flexibility and decision making
Speech and language	Speech articulation, phonation, oral-motor coordination Pragmatics, fluency, phonological awareness, and sentence formulation
Visuospatial processing	Visual perceptual reasoning and processing Visuomotor integration and visuoperception
Memory	Visual and verbal memory
Motor	Fine motor (control, speed, and dexterity) Motor competence Manual dexterity and visual–spatial–motor integration Strength, balance, and endurance
Academic achievement	Special education and remedial services Academic challenges and learning disabilities
Social cognition and adjustment	Social functioning and social communication Theory of mind
Emotional and behavioral functioning	Internalizing (anxiety, depression, and social withdrawal) Externalizing (hyperactivity, aggression, oppositional behavior) Attention deficit/hyperactivity disorder Psychosocial functioning Emotional regulation
Adaptive skills	Conceptual and social skills Functional independence Practical daily living skills (self-care, community use, home living, leisure, and self-direction) Psychosexual development Effective disease management Oral feeding and oral-motor coordination
Quality of life	Physical and psychosocial Emotional, behavioral, and daily functioning

Cue-Based Family-Centered Care

Individualization through cue-based care is another core component of developmental care and includes reading the infant's behavior (attention, state, autonomic, and motor systems) and altering the environment and caregiving to support infant brain expectations.[7,8] Provision of care to premature infants often elicits stress responses.[41] Frequent activation of stress response systems in premature infants results in reductions of frontal and parietal brain volumes, reduced white matter maturation, and epigenetic changes.[42,43] Attenuating repeated stress responses through cue-based care has the potential to mitigate developmental disorders and disabilities in complex congenital heart disease by preventing adverse stress-related changes in the brain. Timing, clustering, and pacing of caregiving based on infant behavioral assessment, including sleep–wake cycles, allows the infant periods of undisturbed time for rest and sleep, which is strongly related to neurodevelopmental outcomes in premature infants.[44]

Support of infant feeding also requires recognition of infant behavior through cue-based care.[45] Infants with complex congenital heart disease frequently experience feeding interruptions because of invasive procedures, clinical status changes, hemodynamic instability with risk of poor mesenteric perfusion, use of sedatives and analgesics, and the noxious hospital environment.[46] Infants with complex congenital heart disease often lack the attention, oromotor skills, and endurance required to sustain oral feeding and are at increased risk for complications that influence feeding outcomes such as vocal cord paralysis, diaphragmatic paresis, noninvasive positive pressure ventilation, poor intestinal perfusion, and oral aversion.[46] Feeding challenges in complex congenital heart disease can result in high levels of parental stress.[47] Cue-based feeding is a developmentally supportive strategy that may mitigate parental stress and improve feeding outcomes such as demonstrating safe oral feeding and growth. In addition to attending to infant cues, developmentally supportive feeding may be further supported by including use of human milk, because this has been shown in premature infants to improve neurodevelopmental outcomes.[48,49]

Reducing Environmental Stress and Pain

The infant's environment influences brain growth, neurodevelopment, sensory awareness, and autonomic stability.[5] The experience of sound, light, touch, temperature, parent presence, and caregiving in the newborn intensive care unit has long-term impact on infant cognition, executive functioning, and neurobehavior.[6] Positive sounds and touch, such as a mother's voice and skin-to-skin care, improve cardiopulmonary responses, autonomic stability, and sleep in extremely premature infants.[50] Newborn intensive care units provide developmentally supportive experiences such as reduced sound, ambient lighting, and increased parental touch. Infants with complex congenital heart disease are often admitted to units that care for children of all ages, and physical renovations or innovative approaches may be needed to meet environmental standards for newborn care.[51]

Undertreated pain results in increased sensitivity to future pain experiences, altered stress reactivity, along with long-term mood and behavior disorders.[52] Although the use of medications to treat moderate to severe pain is warranted,[53] developmental care

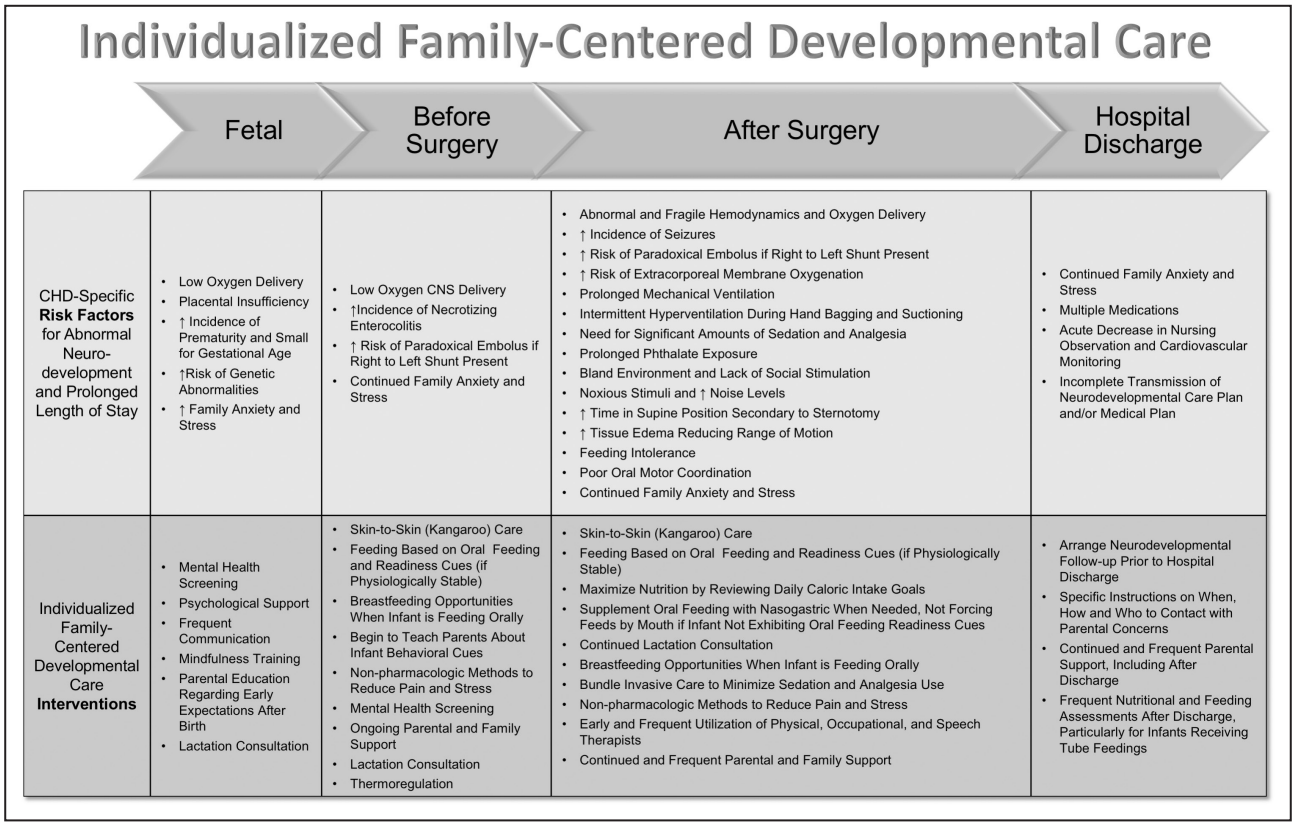

Figure 1. Individualized family-centered developmental care.
CHD indicates congenital heart disease; and CNS, central nervous system. Modified from Lisanti et al[8] with permission from Wolters Kluwer Health, Inc. © 2019. The Creative Commons license does not apply to this content. Use of the material in any format is prohibited without written permission from the publisher, Wiley, on behalf of the American Heart Association, Inc.

integrates the use of nonpharmacological interventions such as breastfeeding, closeness with family, and nonnutritive sucking to prevent and reduce infant pain. These interventions demonstrate varying degrees of efficacy in reducing procedure-related pain in hospitalized infants.[54] There are a few small, single-center studies that report analgesic effects of skin-to-skin care, massage, and containment via facilitated tucking in infants with complex congenital heart disease.[55–57]

Positioning and Motor Support

Motor impairments are common in complex congenital heart disease and may be exacerbated by longer intubation and prolonged hospital length of stay.[58] Musculoskeletal development requires adequate nutrition, proper infant positioning, and movement to prevent immobility-related developmental disorders and disabilities. Developmentally supportive positioning uses the 4 principles of flexion, containment, alignment, and comfort,[59] and promotes development of fine and gross motor skills, self-calming, energy conservation, proper head shape, and sleep hygiene.[58] Awake prone positioning is a crucial component for development of head control and upper body strength, which are the building blocks for later developmental skills such as sitting, crawling, and fine motor skills.[60] Safety and feasibility of early physical therapy, passive range of motion, and awake prone positioning (tummy time) even early after sternotomy have been demonstrated, with improvements in motor outcomes.[61–63]

CRITICAL GAPS IN RESEARCH

Research evaluating the impact of developmental care interventions on brain maturation, developmental disorders and disabilities, and parent mental health is needed. Given the variability of outcomes even within relatively homogenous types of complex congenital heart disease, large multisite studies are needed. As outlined in the preceding sections, developmental care interventions that mitigate developmental disorders and disabilities in other populations but have not been well studied in complex congenital heart disease include parent caregiving during infant hospitalization, cue-based care, pain

management, environmental stress reduction, therapeutic positioning and motor support, developmentally supportive feeding and nutrition, and use of human milk. Compared with premature newborns, infants with complex congenital heart disease have markedly different homeostasis challenges, length of stay, and clinical trajectories.[8] Additionally, parents of infants with complex congenital heart disease may have differing needs than parents of premature infants. Wherle and colleagues recently found that although children with congenital heart disease undergoing cardiopulmonary bypass surgery and children born preterm share an overall risk for neurodevelopmental impairments, these impairments manifest in different domains. Despite this, children with congenital heart disease receive fewer therapies, indicating a lack of awareness of the neurodevelopmental burden these children face.[64] Therefore, specific approaches to developmental care may be warranted in infants with complex congenital heart disease and their families and should be developed and tested systematically. Although we highlight potential directions for developmental care research in Table 2 and briefly describe major priorities below, we acknowledge many others exist beyond the scope of this article.

Measurement of the infant stress response is a critical component of describing physiological response to the environment and, importantly, examining the effects of future interventions. Knowledge of how the infant responds physiologically to the environment will enable development of interventions supportive of optimal physiologic regulation. Studies should include stress biomarkers such as heart rate variability or cortisol.[55,65] Large-scale studies are critically needed to understand relationships between age, type of surgical intervention, and patterns of stress response using objective biomarkers.

One type of intervention, skin-to-skin care, has demonstrated positive effects on infants with complex congenital heart disease and their parents. Skin-to-skin care is associated with lower maternal self-reported anxiety, lower maternal cortisol levels, and improved attachment to their infant.[66] Infant effects include enhanced physiologic stability and reductions in pain,[55] and improved cognitive and autonomic function.[67] Although these positive effects found in complex congenital heart disease were consistent with research findings in the premature infant population, multisite studies with subjects representing more diverse communities are warranted.

Systematic evaluation of cue-based caregiving, specifically feeding and its impact on growth and feeding outcomes, is needed. Additionally, human milk is the ideal nutrition for infants with complex congenital heart disease.[68] Research is needed to address barriers to the provision of human milk via maternal direct breastfeeding or pumping or via donor milk to increase the frequency of human milk administration. Significant gaps remain in our understanding of the best practices to measure and promote gross motor development in infants with complex congenital heart disease. Most studies of motor development in infants with complex congenital heart disease are in the outpatient setting and many months after hospitalization and fail to capture the impact of the hospital environment. Furthermore, no studies have considered the importance of early caregiving experiences during hospitalization in fostering parenting engagement, which may support motor development at home.

Interventions to improve parent mental health and infant neurodevelopment are needed. Unfortunately, although there is growing evidence of the profound impact of social determinants of health on developmental disorders and disabilities for children with chronic illness, data within the complex congenital heart disease population are limited.[69] Parental education level, financial and job stability, social support systems, mental health, exposure to systemic racism, and access to the health care system may all affect the effectiveness of developmental care interventions, particularly those that are family centered. Strategies to address these systemic inequities must be a part of any research endeavor if the goal is to impact all patients.[70]

RESEARCH ENGAGEMENT, INFRASTRUCTURE, AND RESOURCES FOR DEVELOPMENTAL CARE

Patient engagement in research leads to better outcomes by ensuring that studies focus on patient-identified priorities with the principles of inclusiveness, support, mutual respect, and codesign of interventions (eg, Canada's Strategy for Patient Oriented Research, United Kingdom Standards for Public Involvement, and Patient-Centered Outcomes Research Institute). The primary patient-partners with personal experience of developmental disorders and disabilities in complex congenital heart disease are children and adults with complex congenital heart disease and their parents, and they should be engaged as proactive partners at each stage of the research process.

Without current evidence of the impact of specific developmental care practices on outcomes in children with complex congenital heart disease, determining practice standards and establishing universal and consistent resources remains challenging. With

Table 2. Suggested Research to Address Critical Gaps

Developmental care goal	Developmental care interventions needing research in complex congenital heart disease
General	
Promote brain maturation and prevent brain injury.	• Evaluate effect of parent mental health support, infant pain control, decreasing stress, and controlling environmental stimulation on brain maturation and infant behavior. • Design and implement randomized control trials using brain imaging in infancy and later childhood to evaluate potential changes to brain function and structure following developmental care.
Enhance precision in measurement of infant stress using biomarkers.	• Describe infant behavior and stress responses for infants with complex congenital heart disease using biomarkers, such as heart rate variability and cortisol, and their relationship to developmental disorders and disabilities outcomes. • Define the impact of developmental care interventions on infant stress reactivity.
Promote enhanced medical management while in the hospital.	• Evaluate impact of developmental care on short-term medical outcomes such as days on assistive breathing, days on tube feeding, incidence of stroke or seizure, weight gain, length of intensive care unit and hospital stay.
Promote developmental care across institutions.	• Evaluate developmental care in multicenter, diverse populations to identify needed system supports and possible barriers to implementation. • Develop, implement, and evaluate developmental care curriculum into health care professional orientation and continuing education. • Develop and implement electronic medical record documentation that reflects implementation of developmental care practices.
Promote health equity and reduce disparities in developmental outcomes.	• Evaluate the extent of disparities existing in the provision of developmental care in units caring for infants with complex congenital heart disease. • Develop, test, and implement developmental care interventions in underrepresented populations, tailoring interventions as needed to address inequities and any other barriers to developmental care implementation.
Promote long-term development and increased quality of life.	• Design and implement longitudinal studies evaluating impact of developmental care on long-term physiology, development, executive functioning, school achievement, and mental health using standardized measures throughout childhood and into adulthood.
Parents as primary caregivers	
Promote parental engagement in care.	• Evaluate impact of parental engagement interventions on parent mental health outcomes. • Evaluate impact of parental engagement (eg, skin-to-skin care, feeding, close contact) on infant behavior and developmental outcomes. • Develop and implement parent resources that promote ongoing developmental care and the importance of neurodevelopment follow-up.
Cue-based family-centered care	
Promote cue-based care by staff and parents.	• Evaluate staff and parent knowledge of reading infant cues. • Evaluate the impact of teaching parents to understand infant cues on feeding and neurodevelopmental outcomes • Assess effect of cue-based care on infant stress response. • Evaluate effect of cue-based interventions and stress response on brain maturation and developmental outcomes.
Promote oral feeding and the development of oral-motor skills.	• Identify developmental care interventions to reduce complications associated with oral aversion and poor oral motor skills. • Assess effect of cue-based feeding on infant feeding outcomes and oral motor skill development. • Design and evaluate interventions to support parents as their infant's primary provider of nutrition and the impact on parental stress, infant weight gain, and infant feeding.
Promote developmentally supportive nutrition and somatic growth.	• Test interventions to support the administration of human milk. • Assess the dose effect of human milk and direct breastfeeding on long-term neurodevelopmental outcomes. • Assess overall developmental care interventions on infant somatic growth and neurodevelopment.
Promote health of the family unit.	• Evaluate the effect of developmental care on family health outcomes including parental mental health, sibling well-being, and family functioning over time.
Reducing environmental stress and pain	
Provide positive visual and auditory interaction while minimizing excess environmental stimuli.	• Assess sound levels and evaluate interventions to reduce sound. • Test cycled lighting interventions to promote sleep and circadian rhythm development. • Evaluate the impact of visual and auditory stimuli on the behavior of infants with complex congenital heart disease.

(*Continued*)

Table 2. (Continued)

Developmental care goal	Developmental care interventions needing research in complex congenital heart disease
Optimize comfort and pain control through nonpharmacologic options to reduce the adverse effects of pharmacotherapy.	• Evaluate nonpharmacologic interventions (eg, nonnutritive sucking, swaddling, containment, holding and rocking, human touch) on pain control, mobility, and infant behavior. • Identify effective combinations of pharmacologic and nonpharmacologic strategies in infants to reduce polypharmacy, oversedation, and withdrawal.
Positioning and motor support	
Promote musculoskeletal development.	• Identify the effectiveness of developmental supports and therapeutic positioning including holding, hands to midline, and awake prone positioning on motor skill development.

established benefits in other populations, however, appropriate care improvements should not be restrained while waiting for rigorous complex congenital heart disease–specific trials. Many cardiac centers have implemented developmental care programs based on available infrastructure, lessons learned from newborn intensive care unit colleagues, and collaboration with other institutions.[13] With increasing lack of equipoise, the possibility of withholding a developmental care intervention for a control group becomes unethical. There are opportunities to study the addition of specific components of developmental care to local standards of care. However, this can occur only if current documentation practices of developmental care are dramatically improved.[14]

Financial support is required for developmental care including education and training of multidisciplinary staff, organizational structure, dedicated staff time, core measures for testing and evaluation, resources for implementation, and design of the physical space.[71] Formalized developmental care programs, such as the Newborn Individualized Developmental Care and Assessment Program, have been validated in premature infant populations and shown to improve long-term outcomes, decrease medical complications, and decrease length of hospital stay, which provide significant cost savings to the institution.[5–7,72] Programs such as these do require an initial cost for training. The implications of lifelong cost savings through improved developmental trajectories in complex congenital heart disease need to be understood and warrant investigation and investment by funding agencies.

Currently, developmental care is not routinely budgeted for or integrated into most pediatric cardiac programs.[12,13,15] Resources allocated to developmental care and infrastructure vary across programs.[13] Major challenges to implementing developmental care in units caring for infants with complex congenital heart disease include lack of funding, time, staff, and support for education.[12,15] Developmental evaluations and interventions are not consistently reimbursed through third-party payers; many programs pursue philanthropic support to provide these services.[73] Research-based funding for large trials to implement developmental care will be invaluable to demonstrate effectiveness and cost savings to secure future institutional financial investments.

Significant gaps remain in our understanding of the best practices to improve neurodevelopmental and psychosocial outcomes for individuals with complex congenital heart disease and their families. This call to action targets research scientists, clinicians, policymakers, government agencies, advocacy groups, and health care organization leadership to support funding and hospital-based infrastructure for developmental care in the complex congenital heart disease population. Prioritization of research on and implementation of developmental care interventions in the complex congenital heart disease population should be a major focus in the next decade.

ARTICLE INFORMATION

The American Heart Association makes every effort to avoid any actual or potential conflicts of interest that may arise as a result of an outside relationship or a personal, professional, or business interest of a member of the writing panel. Specifically, all members of the writing group are required to complete and submit a Disclosure Questionnaire showing all such relationships that might be perceived as real or potential conflicts of interest.

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Writing Group Disclosures

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This table represents the relationships of writing group members that may be perceived as actual or reasonably perceived conflicts of interest as reported on the Disclosure Questionnaire, which all members of the writing group are required to complete and submit. A relationship is considered to be "significant" if (a) the person receives $5000 or more during any 12-month period, or 5% or more of the person's gross income; or (b) the person owns 5% or more of the voting stock or share of the entity, or owns $5000 or more of the fair market value of the entity. A relationship is considered to be "modest" if it is less than "significant" under the preceding definition.

*Modest.

†Significant.

Reviewer Disclosures

Reviewer	Employment	Research grant	Other research support	Speakers' bureau/ honoraria	Expert witness	Ownership interest	Consultant/ advisory board	Other
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Marcie Meador	Baylor Texas Children's Hospital	None	None	None	None	None	None	None
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*Modest.

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