

## Report

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# Promoting Children's Long-Term Health and Functioning:

## Applying a Life Course Approach to Pediatric Care for Children with Special Health Care Needs



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## Abstract

**L**ife Course Theory (LCT) refers to a growing scientific literature that enhances understanding of health and disease patterns across the life span and across populations. The life course perspective takes into account variations in timing, timeline, environment and equity in experiences and exposures across individuals and populations—and examines the impact on health throughout life.

Life course science has been embraced by health researchers, public health agencies, health policy experts, health care providers and leading academics in the U.S. and abroad. However, the translation of LCT to actual pediatric practice and systems has been slow to take hold in any organized way, reflecting a kind of “developmental delay” in making life course practice a reality in pediatric care—for the special needs population, as well as for the general pediatric population. There is a big gap between designing individual strategies or interventions that reflect a life course perspective and undertaking a life course redesign of a pediatric practice. Promoting life course implementation in pediatric care for children with special health care needs (CSHCN) requires a life course implementation framework specifically designed by and for this constituency, with the goal of helping pediatric practices define and become life course practice settings. As a first step in moving toward such a framework, key themes identified through a literature review and interviews were consolidated into six action areas for pediatric practices.

### Action Areas for Pediatric Practices

- Enhance early identification and timely interventions.
- Target transitions throughout life.
- Strengthen the family context—reduce stress, build resilience and agency.
- Link children and families to needed community services and supports.
- Monitor the status of CSHCN as a sub-population within the pediatric practice and take action to assure equity in care and experience.
- Focus on functional status.

Together, these six action areas form the core of an initial implementation framework—a starting point for pediatric practices that seek to provide a life course approach to care for children with special health needs. This framework will be of greatest value if it can initiate a broad consensus process across multiple stakeholders, with the goal of further defining what it means to be a “life course pediatric practice” for the care of CSHCN and their families.

## Introduction

Over the past decade, a growing scientific literature has developed that enhances understanding of health and disease patterns across the life span and across populations. This new life course science has been embraced by health researchers, public health agencies, health policy experts, health care providers and leading academics in the U.S. and abroad.

Many health institutions and agencies, including the American Academy of Pediatrics,<sup>1,2</sup> U.S. Maternal and Child Health Bureau, Health Resources and Services Administration,<sup>3</sup> Centers for Disease Control,<sup>4</sup> Institute of Medicine, and the National Academy of Sciences,<sup>5,6</sup> have begun to explore how a life course approach can be applied at the policy and systems levels to improve the health trajectories of individuals and communities. Implementation of the life course perspective in pediatric health care settings has received far less attention, however, and this is especially the case with regard to care for children with special health care needs (CSHCN)—that is, those “who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition.”<sup>7</sup>

This report is predicated on two starting assumptions: (1) that the application of life course science has the potential to transform health and health care across the population, and (2) that CSHCN—by virtue of their greater reliance on medical care and the chronic nature of their conditions—are among those who have the most to gain from that potential transformation. Grounded in these assumptions, this study was designed to determine the current status and future promise of applying life course theory (LCT) to pediatric care for special needs children: where is the field now, where does it need to go, and how does it get there?

The findings, starting points and recommendations that follow are based on several sources: a literature review conducted by the Child and Adolescent Health Measurement Initiative in 2012-2013; key informant interviews with national experts in maternal and child health, LCT, pediatrics and systems of care for CSHCN; interviews with parents of CSHCN; findings from focus group discussions with families of CSHCN; and interviews with exemplary practices and programs. An additional source of information was a review of transcripts from parent focus groups as well as provider interviews that were conducted by another study supported by the Lucile Packard Foundation for Children's Health.<sup>8</sup>

1 Braveman, P. and Barclay, C., *Health Disparities Beginning in Childhood: A Life-Course Perspective*. Pediatrics November 2009; 124: Supplement 3 S163-S175; doi:10.1542/peds.2009-1100D.

2 DC Baltimore Research Center on Child Health Disparities Writing Group, *Starting Early: A Life Course Perspective on Child Health Disparities – Research Recommendations*. Pediatrics November 2009; 124:S257-S261.

3 Fine, A. and Kotelchuck, M., *Rethinking MCH: The Life Course Model as an Organizing Framework*. 2010; <http://www.hrsa.gov/ourstories/mchb75th/images/rethinkingmch.pdf>

4 Swanson, M. and Bolen, J., *CDC's Life Course Model for Children and Young Adults with Chronic Conditions* (Episode 2). Webinar Series Sponsored by AAIDD and AAHD: The Unique Role of CDC's Division of Human Development and Disability, Centers for Disease Control and Prevention, November 29, 2011.

5 Committee on Evaluation of Children's Health; Board on Children, Youth, and Families; Division of Behavioral and Social Sciences and Education; National Research Council and Institute of Medicine. *Children's Health, the Nation's Wealth: Assessing and Improving Child Health*. Washington, DC: National Academies Press; 2004.

6 Shonkoff, J. P. and Phillips, D.A., (eds.), *From Neurons to Neighborhoods: The Science of Early Childhood Development*. Washington, National Academy Press. November 29, 2011.

7 McPherson, M., Arango, P., Fox, H., Lauver, C., McManus, M., Newacheck, P.W., Perrin, J.M., Shonkoff, J.P., Strickland, B. A new definition of children with special health care needs. Pediatrics. 1998; 102:137-140.

8 Hughes, D. Reflections and Responses: Six Model for Understanding How Families Experience the System of Care for Children with Special Health Care Needs. Lucile Packard Foundation for Children's Health, November 2014.

## Life Course Theory: A Conceptual Framework for Maternal and Child Health

Within the federal government, the Maternal and Child Health Bureau (MCHB) has taken a lead role in focusing on the implications of life course theory (LCT) for women, children and families. In 2010, MCHB developed a life course conceptual framework to help guide the Bureau’s strategic planning for its work with maternal and child health programs and agencies across the states. The MCHB paper—*Rethinking MCH: The Life Course Model as an Organizing Framework*<sup>9</sup>—provided the initial conceptual framing for this review of life course and CSHCN.

Briefly, *Rethinking MCH* identifies four broad concepts that are fundamental to understanding and applying LCT:

- *Timeline* – Today’s experiences and exposures influence tomorrow’s health.
- *Timing* – Health trajectories are particularly affected during critical or sensitive periods of development.
- *Environment* – The broader environment—biologic, physical and social—strongly affects the capacity to be healthy. This concept incorporates stress (including cumulative stress), as well as risk and protective factors.
- *Equity* – Disparities in health across populations reflect more than genetics and personal choice (i.e., population disparities reflect the interplay of multiple factors, applied unequally at the individual, clinical, community systems and societal levels).

Of particular relevance to CSHCN, the MCHB conceptual framework notes that “the development of health over a lifetime is an interactive process, combining genes, environments and behaviors” and concludes that “throughout life and at all stages, even for those whose trajectories seem limited, risk factors can be reduced and protective factors enhanced, to improve current and subsequent

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health and well-being.” Thus, LCT and its key concepts are important ones for CSHCN and their families, their health care providers and all who wish to maximize individual achievement and social contribution of these children.

The MCHB framework has been well-received by the maternal and child health community, offering a succinct, simplified and understandable introduction to life course concepts and providing a launching point to help a broad range of public health and clinical care providers grapple with potential applications for their own clinical and population health services.

While the MCHB framework does not go so far as to describe specific programs, resources or activities that can be implemented by pediatric practices, it notes that LCT “greatly expands the opportunities (and some would say, the obligations) for intervention to include a much broader set of venues and partners, over a much longer timeline, and it suggests the need to rethink and revise

9 Fine and Kottelchuck. Op cit. <http://mchb.hrsa.gov/lifecourse/rethinkingmchlifecourse.pdf>

some of the current strategies.” More specifically, the conceptual framework suggests the need to refocus both clinical and population health strategies to:

- Place greater emphasis on multiple determinants of health.
- Incorporate earlier detection of risks as well as early and timely interventions.
- Promote factors that protect against disease and disability and reduce factors that place children at increased risk of poor health and development.
- Shift from discrete and episodic services to developing integrated, multi-sector service systems that build health across the lifespan.
- Complement the dominant medical approach that focuses on individual diseases, conditions or body systems, with a whole-person, whole-family, whole-community systems approach.

These suggestions take the field a step closer to implementation; however, the translation of LCT to actual pediatric practice and systems has been slow to take hold in any organized way—for the special needs population, as well as for the general pediatric population—reflecting the inherent difficulties of moving from broad theory to concrete action, particularly when potential changes in culture, practice, financing and partnerships may be involved.

By reporting on current status of the adoption of life course-oriented care, providing a starting framework for action and offering recommendations for next steps, it is hoped that this report will serve as a catalyst to help parents, pediatric care providers, community leaders and policymakers jump-start the process of translating theory into action so that pediatric care for CSHCN can truly benefit from and further inform life course science.



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# Current Interface between Life Course Theory and Children with Special Health Care Needs

## What's in the Literature?

The literature review looked for articles that *explicitly* address the application of life course concepts to pediatric health care for children with special health care needs (CSHCN). A search of two databases—Medline and Google Scholar—identified a limited number of publications with a reference to both life course and CSHCN, and even fewer focused on the *application* of life course theory or perspective to care for special needs children and their families.

While many life course-focused publications emphasize the importance of childhood and its various developmental stages, discussion of life course influences—such as adverse childhood experiences, social determinants of health, risk and protective factors, and critical and sensitive periods—is most often oriented toward the impact on *adult* health and economic outcomes. To the extent that interventions are discussed it is generally within the context of primary prevention—that is, preventing the occurrence of chronic conditions. In short, there is very little focus in the life course literature on the special needs pediatric population and even less within that literature on interventions to optimize the trajectories of CSHCN (including little or no focus on secondary or tertiary prevention), many of whose lives are shortened or otherwise limited by their health problems.

At the same time, several themes of note emerge from the existing literature. Perhaps most important for this discussion is the concept of “agency,” which is very much part of the psychology life course literature. Several articles emphasize the importance of parent agency—that is, the ability of parents to take positive action as it relates to their special needs child and to their own lives. The concept of agency—for parents and for special needs children and youth—has not been a primary focus of the medical and public health literature on life course, and deserves more attention. A related concept is the impact on the family of raising a special needs child, and the importance of helping families address stressors proactively and in real time. Also of note is the need for longitudinal data on CSHCN, so that there is a better baseline on life experiences, health outcomes and trajectories of special needs populations from birth through adulthood and on the differential impact of interventions for this population. A final finding is that we are in the early stages of applying life course concepts to both pediatric practice and community systems.

A limitation of the review is that it focused on articles that explicitly mention both life course and CSHCN (or related search terms for the broad population of children with or at risk of disabilities and/or chronic conditions). This could limit findings in at least two ways: it did not pick up articles that might highlight the intersection of life course and a single disease or disorder; nor did it identify articles that might touch on key life course concepts as they apply to CSHCN, but do not explicitly identify those concepts within a life course frame as the concept remains new.



## Findings from Key Informant Interviews

The key informant interviews with national experts on LCT, pediatric care and systems of care for CSHCN confirmed that there has been relatively little direct reference to the population of CSHCN and their families in the literature or broader discourse on life course, and that at the practice level there is no clear set of life course implementation guidelines or models. However, the key informants also described an evolving understanding of the relationship between life course science and CSHCN.

Initially, when the maternal and child health community embraced life course concepts in the late 1990s and early 2000s, much of the literature was deterministic in tone, focusing on the earliest onset of chronic conditions, with little attention to interventions that might ameliorate the impact of that early onset.<sup>10</sup> Understandably, many parents and advocates for special needs children felt left out or pushed out of life course framing in a period when others in the MCH community were embracing it. Were young children diagnosed with chronic conditions considered “failures” from the life course perspective? Did life course science hold any promise for CSHCN and their families, or was this yet another example of marginalizing the special needs population?

**The difficulty for pediatricians lies not in understanding life course principles but rather in figuring out how to implement those principles within a clinical setting**

Despite these initial reactions, special needs families, advocates and professionals have come together with the federal MCHB to grapple with the implications of life course, adding their perspectives to the evolving definition and understanding of its principles and applications. For example, within MCHB, comments from the Division of Services for Children with Special Health Needs (DSCSHN) helped shape the Bureau's life course framework. In addition, the DSCSHN convened meetings to discuss how LCT might apply to special needs populations and to track the relationship between life course principles and MCHB's national agenda to facilitate the development of community-based “systems of services” for special needs children and their families.<sup>11,12</sup> At a meeting convened by MCHB in 2011, participants concluded that the core outcomes for the MCHB system of services were consistent with the core concepts outlined in the MCH life course framework and that next steps would include further exploration of this interface.

Current thinking about the interface between life course framing and the CSHCN system of services is still in the formative stage. There is a need to better understand where there are gaps, where the two are related and where not; and there is a need for better translation down to the practice level—for both the life course framework and the “system of services” model. With regard

<sup>10</sup> This finding is similar to a critique by Paul Wise in his article “Confronting social disparities in child health: a critical appraisal of life course science and research,” in a 2009 *Pediatrics Supplement* downloaded from: [http://pediatrics.aappublications.org/content/124/Supplement\\_3/S203.full.html](http://pediatrics.aappublications.org/content/124/Supplement_3/S203.full.html) on November 21, 2014.

<sup>11</sup> HRSA/MCHB. “Achieving & Measuring Success: A National Agenda for Children with Special Health Care Needs” downloaded from: <http://www.mchb.hrsa.gov/programs/specialneeds/achievementsuccess.html> on September 14, 2014.

<sup>12</sup> The MCHB “system of services” core outcomes include: 1) All children with special health care needs will receive coordinated ongoing comprehensive care within a medical home. 2) All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need. 3) All children will be screened early and continuously for special health care needs. 4) Services for children with special health care needs and their families will be organized in ways that families can use them easily. 5) Families of children with special health care needs will partner in decision-making at all levels, and will be satisfied with the services they receive. 6) All youth with special health care needs will receive the services necessary to make appropriate transitions to adult health care, work, and independence.

to life course framing, the difficulty for pediatricians lies not in understanding life course principles but rather in figuring out how to implement those principles within a clinical setting. Like most conceptual frameworks, the MCHB framework is at the “40,000 foot level”—the concepts are big and potential applications very broad, making it difficult to get a handle on where to start—especially in the clinical setting.

**Life course can help us move from *being the condition* to *living with the condition***

One potential conflict or difficulty for clinical care providers is that the life course focus on broader, population-based, social determinants of health can further exacerbate frustrations with the limitations of clinical care settings and the pediatric care visit. As one key informant noted,

“Within current clinical care systems there are few incentives to move pediatric practices toward the kind of high-performing health care systems that truly embrace a life course perspective. For example, there are weak incentives toward population health; quality incentives focus on individualized care; and clinical care training programs do not deal with population health management.”

On the other hand, another key informant painted this picture of the potential application of life course to care for special needs children: “As currently conceived, the life course perspective is very relevant to those who are at risk. Thinking forward to broader applications, life course means maximizing opportunities. We need to take kids where they are and maximize everything they have. The really bright piece is that life course can help us view kids on a continuum—well-adjusted, resilient, etc.—no boxes. Life course can help us move from *being the condition* to *living with the condition*.”

## Potential Application of Life Course in Pediatric Care: What Would It Look Like?

To begin fleshing out the potential application of life course science to pediatric care for CSHCN, key informants (including national experts and parent interviewees) were asked to comment on the core concepts of *timing and timeline*, *environment* and *equity* plus the concept of *agency*: how might these ideas (and the science behind them) apply to special needs children and their families, and how could pediatric care providers act on these concepts in their practice? Transcripts from parent focus groups were also reviewed to identify examples of how the concepts might apply and the role of pediatric practices in addressing each. Finally, interviewees were asked to think broadly—beyond the MCHB core concepts—and identify additional ways in which a life course perspective might be applied to pediatric care for CSHCN. Several consistent themes emerge regarding the potential application of life course concepts to special needs children and their families. These are summarized below and grouped by the MCHB core concepts.

### Timing and Timeline

These concepts—reflecting the impact of early and critically timed exposures and experiences—are a natural fit for CSHCN. Within the clinical setting, pediatricians can translate the concepts into a *focus on early identification and timely intervention*. As one interviewee noted, “Earlier interventions make a huge difference in the life course of children with special needs—for example, children with autism.” Another pointed out, “Parents say, ‘If only I’d heard about this or that program two years ago....’ The question for life course is how do we act in a way that is proactive and sensitive?” Among the suggestions for action: “Solutions need to start at hospital discharge. One approach could be to develop a rigorous hospital social worker discharge protocol.” This interviewee noted the importance for discharge planning to include connecting the family to Social Security Income and other services and assuring that the parents are well-trained to care for their child’s medical condition. One recent example of a potential framework for discharge planning outlines a set of activities throughout the hospitalization of a child from admission to discharge.<sup>13</sup> Developed by Jay G. Berry and colleagues, this framework serves as a way to inform health care professionals about key elements of discharge planning, including guidelines, regulations, planning tools, quality improvement and research.

A second theme related to timing and timeline is that of *transitions throughout life—both predictable and inflective*. Normal, predictable life course transitions are often highly stressful for CSHCN and their families. Because they can be anticipated, these transitions could be addressed proactively. As one interviewee noted: “We have natural spots for anticipatory guidance, for example: ages 3-5, the mid-late elementary school years, transition to high school, transition to adulthood. We can pick up kids at these points and have an opportunity to help. These are natural screening opportunities, but we don’t have responses ready.” This interviewee suggested that pediatric practices schedule additional visits or check-ins with the family during predictable transition points to assess and

<sup>13</sup> Berry, J.G., Blaine, K., Rogers, J., et al. A framework of pediatric hospital discharge care informed by legislation, research, and practice [published online August 25, 2014]. *JAMA Pediatr*. doi:10.1001/jamapediatrics.2014.891.

address the need for additional supports: “Practices could use electronic medical records (EMR) flags at key transition periods, similar to Bright Futures flags.”

While some life course transitions are predictable, for CSHCN many transitions are not: their condition might flare up without warning, requiring hospitalization or a change in interventions and resulting in a change in functional status, which may or may not be temporary. The health care system must be prepared to address both types of transition—not only for the child but also for the family.

## Environment

It is useful to think about environmental influences at three levels: *family, community and societal*.

### *Family Environments*

Family interactions and family circumstances are critical in shaping the trajectories of all children, especially CSHCN. From a life course perspective, pediatric care provides a unique opportunity to focus on the family context, not only seeing families as shared decision-makers, but also recognizing families as the primary caregivers and care coordinators, and—as one key informant suggested—working with and supporting families so that they “become the intervention”—that is, the families are able to provide the kind of day-to-day intensive support, structure, skill development and nurturing their child needs to reach her/his full potential.

With these family roles in mind, pediatric health care providers can take action by recognizing and addressing family stress and supporting family resilience and agency (including that of the child and adolescent with special needs). Particularly important is the need to recognize and respond to the stresses of raising a special needs child. As noted by one interviewee, “We need strategies for helping physicians be more aware of stresses on families.” Another interviewee suggested, “Develop an intake form for families asking about stress related to taking care of their special needs child. This could include questions about employment adversity, time off from work and problems that lead to children not getting to school when they ought to. Start with the kinds of issues addressed by the Medical-Legal Partnership<sup>14</sup> and then add questions on special stressors for families related to disability and chronic conditions—the kinds of issues addressed by disability rights advocates.”

For special needs youth, another interviewee pointed out the need to “help these kids have more resiliency, more control in various parts of their lives... support social development for adolescents... consider group activities, group pediatric care.” Finally, a key informant advocated for home visits as integral to pediatric care for special needs children: “Without a home visit [the pediatric practice] is missing part of the clinical picture. These visits could be reimbursed. This is an example of the clinical side moving into [the families’] social world.”

### *Community Environments*

The life course perspective tells us that health is also shaped by the community environments in which children live, including a broad array of services and supports—both formal and informal.

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<sup>14</sup> The Medical-Legal Partnership connects clinics and other health care settings to legal expertise in order to help patients obtain services and supports to which they are entitled, and to address other legal barriers to health and well-being. For more information, contact the National Center for Medical-Legal Partnership: <http://medical-legalpartnership.org/>.

Pediatric health care providers can act on this life course concept by *better connecting families to a full range of needed community services and supports*—not only direct services for the child, but also resources to address the family's broader needs—financial, emotional, logistical and more.

The interviewees noted the need for better linkage, while also recognizing the difficulty of bringing all the pieces together for and with families, even among those practices that are well-established medical homes. As one key informant put it, “The concept of the medical home starts to address the complex needs of CSHCN and their families, but medical homes must be organized to better link families to community services and supports beyond health care.” Another noted, “The medical home can't do this alone. What can advance collaboration between primary care and specialty care, behavioral health and housing advocacy? For me, integration will be essential.” And finally, an interviewee spelled out the barriers faced by pediatric practices. “Connecting to other services and systems is a capacity and reimbursement issue: whose role is it and how does it get done? The thoughtful pediatricians recognize that it needs to be done.”

Fortunately, innovative and “early adopter” pediatric practices across the country are finding ways to collaborate with other stakeholders in their communities to implement strategies that better link children and families to needed services and supports. For example, Help Me Grow<sup>15</sup> (first developed by Connecticut Children's Medical Center in Hartford) is a national initiative that works through state affiliates to help pediatric practices and other early childhood service providers link children and their families to a broad range of needed developmental services and supports. The Medical-Legal Partnership<sup>16</sup>—a national initiative with local affiliates (first developed at Boston Medical Center)—connects pediatric health care providers with legal experts to help families access needed community services and supports and/or remove barriers that impede health. And, as identified by Early Childhood-LINC—a Learning and Innovation Network for Communities (co-sponsored by the Center for the Study of Social Policy and the Children's Services Council of Palm Beach County, FL)—there are exemplary early childhood systems building initiatives in cities and counties nationwide that work to seamlessly integrate services and supports for children and families, including linkage to and from pediatric health care.<sup>17</sup>

### *Societal Environment*

At the societal level, many CSHCN and their families are socially isolated and feel marginalized, potentially leading to or exacerbating emotional, behavioral and chronic physical health problems. In life course parlance, long-term marginalization is a form of continuous background stress leading to adverse health outcomes and diminished well-being. Chronic marginalization, like chronic discrimination, can have a toxic effect on the developing child and family—in both the short and long run. At the societal level there is a need for more inclusive policy, program and service strategies to address these issues. As one interviewee noted, “It would be useful to think about the special needs population as a socio-economic group—they do not have access to the community, jobs and more.” And from another informant: “We don't think about what a community system can do for people with disabilities. Keep asking about disability. It should be a universal world.”

15 For more information, contact the Help Me Grow National Center: <http://www.helpmegrownational.org/>.

16 For more information, contact the National Center for Medical-Legal Partnership: <http://medical-legalpartnership.org/>.

17 For more information on exemplary early childhood systems building initiatives, contact Early Childhood-LINC (a Learning and Innovation Network for Communities) at the Center for the Study of Social Policy: <http://www.cssp.org/reform/early-childhood/early-childhood-linc>

While these examples focus on societal/systemic responses to marginalization, pediatric practices can take action by addressing the stress of marginalization. For example, one key informant noted, “Look at participation in school, bullying/being bullied, and friends. There are not big differences when CSHCN are young, but they become more pronounced as kids get older. These are findings that if we had paid a fraction of attention to them, it would have made a difference.” Clinicians should anticipate increased bullying. They can raise this issue, provide an opening for discussion at clinical visits and, ideally, link the child or youth to ongoing support sessions in the community.

## Equity

Equity involves eliminating disparities that are based on unequal and unfair opportunities, treatment, exposures and environments. The core concept of equity reflects the unique public health perspective on life course—that is, a perspective grounded in population health, including a focus on identifying and addressing disparities in opportunities and outcomes across population groups.

Equity issues arise both within the special needs population and when comparing CSHCN to typically developing children. Race/ethnicity and poverty play a critical role in our society. Among CSHCN, for example, minority children are more likely than their white counterparts to be hospitalized.<sup>18</sup> In addition, poor and minority children are over-represented among children with disabilities (i.e., CSHCN with functional limitations). There are also disparities by type of condition, age of diagnosis and institutional setting. For instance, as compared to other CSHCN, children with disabilities have more unmet service needs and are less likely to receive care from a medical home.<sup>19</sup>

When asked about applying the concept of equity to pediatric care for CSHCN, interviewees again focused particular attention on the themes of marginalization and inclusion of special needs children, pointing to the need for health care providers to be attentive to these issues. Pediatric practices can act on these particular equity issues by making sure that their own policies and practices are inclusive, help families feel welcome, and do not inadvertently marginalize CSHCN.

On a very practical and concrete level, inadvertent marginalization within health care settings can result in missed services, including fewer well-child visits, or missed opportunities for anticipatory guidance, as well as missed opportunities to pick up on potential social/emotional issues related to marginalization in other venues. Suggestions from the interviewees include making sure the physical environment of the practice is easy to navigate for special needs patients and their families; scheduling behaviorally disruptive children at the beginning of clinic hours or allowing them to wait outside; and perhaps most important, getting to know the child and family, and building a positive relationship with them as individuals.

One area of concern is whether special needs children receive the benefits of well-child care, including continuous screening for developmental, behavioral, social and other needs; timely

**Innovative pediatric practices across the country are finding ways to implement strategies that better link children and families to needed services and supports**

18 Newacheck, P.W., Hung, Y.Y., Wright, K.K. Racial and ethnic disparities in access to care for children with special health care needs. *Ambul Pediatr.* 2002 July-Aug;2(4):247-54.

19 Houtrow, A.J., Okumura, M.J., Hilton, J.F., Rehm, R.S. Profiling health and health related services for children with special health care needs with and without disabilities. *Acad Pediatr.* 2011 November; 11(6):508-516. doi:10.1016/j.acap.2011.08.004



immunizations; and developmentally appropriate anticipatory guidance on topics such as obesity prevention and sexuality. As described by a key informant, “CSHCN need the same health promotion and prevention activities as other children; but in practice children with complex medical needs often miss out. Past a certain age, these pieces just don’t get done.” A suggested solution: “Pediatric care providers need to make sure that CSHCN have regularly scheduled well-child visits that use the normal protocol and timeline for well-child visits and are adjusted as needed. These visits may need to be modified and may take longer, but they are needed.” Obesity prevention is one example of a health promotion and prevention activity that may be overlooked for CSHCN. Yet, obesity prevention is particularly important for children with physical and/or metabolic problems that make it more difficult for them to reverse excess weight gain. Similarly, clinicians may be tempted to skip sexuality discussions with adolescents with developmental delays, despite the fact that these youth are particularly vulnerable to sexual abuse and assault, and need special anticipatory guidance as they move through puberty.

## Additional Topics

Life course is about putting all the pieces together to help individuals and populations reach their full potential. In keeping with this perspective, the interviewees noted the importance of focusing on the development and maturation of the “whole child.” This concept was most often expressed

**One area of concern is whether special needs children receive the benefits of well-child care**

as going beyond an individual’s diagnosis to a focus on function—that is, attaining the highest levels of functioning and quality of life a child might achieve. One of the most compelling examples of how a focus on function can shift life course trajectories for the special needs population is the change in outcomes for children and adults with Down syndrome over the past 50 years. Individuals with Down syndrome now live longer, healthier, more productive and socially connected lives than ever before, with much of the change resulting from a change in expectations and a focus on improving functional status on multiple levels. Currently, similar shifts to a functional focus for

children with autism show promising results. For example, one interviewee reported that as a result of a new intervention program—which provides support and training for early, continuous, day-to-day interventions implemented by families—many of the behaviors usually associated with autism never arise in children diagnosed with autism spectrum disorders.



## What's Needed: A Life Course Implementation Framework for Pediatric Practices

The themes and findings identified in this review are instructive in several ways:

- First, it is clear that the MCHB/public health conceptual framework—with its broad focus on timing, timeline, environment and equity—does not translate immediately into an actionable agenda for pediatric practices for typical children, let alone CSHCN. Something more is needed.
- While pediatric care providers may understand and even embrace life course science, translating life course concepts into clinical care is currently a matter of individual interpretation. There are no guidelines for implementing any of the core concepts in pediatric care.
- Although respondents speculated on how practices might address individual life course concepts with a specific approach or action, none commented on how individual strategies might be woven together in an organized and systemic fashion to develop a “life course practice setting.”
- There is, of course, a big gap between designing individual strategies or interventions that reflect a life course perspective and undertaking a life course redesign of pediatric care. There is a need to jump-start this process, starting with a more comprehensive life course implementation framework.

**One of the most compelling examples of how a focus on function can shift life course trajectories for the special needs population is the change in outcomes for children and adults with Down syndrome over the past 50 years**

Table A outlines a proposed implementation framework specifically designed to help pediatric practices define and become life course practice settings for special needs children. This initial framework (1) incorporates a concise set of core action areas reflecting key life course concepts or principles; (2) provides a series of concrete steps that practices could take; and (3) provides a cross-walk of selected guidance, guidelines and tools for each action area so that pediatric practices do not have to reinvent these and so that the life course framework can be cross-walked with other, complementary frameworks for care.

The proposed six life course action areas are derived from key themes identified during this study. Together, these form the core of the proposed life course implementation framework:

- Enhance early identification and intervention.
- Target predictable life transitions, and respond to unanticipated transitions with an eye toward future functioning and health.
- Strengthen the family—reduce stress, build resilience and agency.
- Routinely link children and families to needed community services and supports.

- Monitor the status of CSHCN as a sub-population within the pediatric practice and take action to assure equity in care and experience.
- Focus on functional status and quality of life.

The potential action steps are examples only, and are not meant to be exhaustive. Similarly, the references to guidance and guidelines are a starting set, to be further developed over time. The goal of this proposed framework is to provide a concise, understandable and actionable starting point that can be reviewed, refined, tested and improved by multiple stakeholders at a variety of levels. Future experience and research will no doubt identify additional actions and guidance for pediatric practice.

**Table A: Life Course Care for Children with Special Health Care Needs: An Implementation Framework for Pediatric Practices**

Core Action Areas	Potential Action Steps	Guidance, Guidelines and Toolkits of Note
<p><b>Enhance early identification and timely interventions.</b></p>	<ul style="list-style-type: none"> <li>● Provide universal, early and continuous screening and surveillance for all children in the practice, including those already identified with special needs.</li> <li>● Move from a default position of “wait and see” to a proactive response to identified risks and concerns.</li> <li>● Recognize parents’ inherent strength and willingness to do whatever it takes to help their child thrive. Don’t “protect” families from the information they need to move to appropriate interventions in a timely manner.</li> <li>● Anticipate adverse outcomes and address them proactively.</li> </ul>	<ul style="list-style-type: none"> <li>● AAP Policy Statement: Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening. <i>Pediatrics</i>. 2006; 118(1):405-420. Reaffirmed December 2009</li> </ul>

Core Action Areas	Potential Action Steps	Guidance, Guidelines and Toolkits of Note
<p><b>Target transitions throughout life.</b></p>	<ul style="list-style-type: none"> <li>● Identify predictable critical transition points for CSHCN—e.g., transition from hospital to home, transition to a new school/ grade level, and transition from pediatric care to adult care.</li> <li>● Flag these transitions in the EMR/chart, and institute a practice-wide plan to proactively provide additional support, guidance and linkage to resources for the child and family during these times, as needed.</li> <li>● Don't discount interventions as simple as asking or stating: "How's it going?", "How can I help you?", or "I will help you get help with transitioning home with your child." Parents value this form of support.</li> <li>● For children with recurrent hospitalizations, partner with the family and school to help the child stay abreast of classroom assignments—thus easing the transition back to school.</li> </ul>	<ul style="list-style-type: none"> <li>● AAP Clinical Report: Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home. American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, Transitions Clinical Report Authoring Group. <i>Pediatrics</i> Vol. 128 No. 1 July 1, 2011. pp. 182-200. (doi: 10.1542/peds.2011-0969)</li> <li>● 6 Core Elements of Health Care Transition 2.0. Contact <i>Got Transition</i>: <a href="http://www.gottransition.org/providers/index.cfm">http://www.gottransition.org/providers/index.cfm</a></li> </ul>

Core Action Areas	Potential Action Steps	Guidance, Guidelines and Toolkits of Note
<p><b>Focus on family context—stress, resilience and agency.</b></p>	<ul style="list-style-type: none"> <li>● Incorporate regular surveillance and screening for signs and symptoms of family stress and stressors, as well as parents' capacity to address these factors.</li> <li>● Incorporate family-to-family peer support into the practice—through staffing or through contracting with a family resource center.</li> <li>● Give parents encouragement and “permission” to take care of their own health and well-being: e.g., “This isn’t easy. You’re doing a good job.” “You will feel isolated. Get out and about. Your child needs you to do this.”</li> <li>● Connect parents to stress reduction resources such as mindfulness-based stress reduction classes.</li> <li>● Involve the child/youth in decision-making, recognizing that the child’s ability will change over time. Also recognize that parents will shift in their abilities to cope with their child’s diagnosis/condition and provide supports accordingly.</li> </ul>	<ul style="list-style-type: none"> <li>● Healthy Steps for Young Children - Screening Questions on Adult Risk and Protective Factors: <a href="http://healthysteps.org/for-medical-practices-and-other-organizations/how-to-become-a-healthy-steps-site/healthy-steps-component-service-delivery/">http://healthysteps.org/for-medical-practices-and-other-organizations/how-to-become-a-healthy-steps-site/healthy-steps-component-service-delivery/</a></li> <li>● AAP Clinical Report: Parent-Provider-Community Partnerships: Optimizing Outcomes for Children With Disabilities. Nancy A. Murphy, MD, Paul S. Carbone, MD, the Council on Children With Disabilities. <i>Pediatrics</i> Vol. 128 No. 4 October 1, 2011, pp. 795-802, (doi: 10.1542/peds.2011-1467)</li> <li>● Achieving a shared plan of care for children and youth with special health care needs. <i>LPFCH</i>: <a href="http://lpfch-cshcn.org/publications/research-reports/achieving-a-shared-plan-of-care-with-children-and-youth-with-special-health-care-needs/">http://lpfch-cshcn.org/publications/research-reports/achieving-a-shared-plan-of-care-with-children-and-youth-with-special-health-care-needs/</a></li> </ul>

Core Action Areas	Potential Action Steps	Guidance, Guidelines and Toolkits of Note
<p><b>Link children and families to needed community services and supports.</b></p>	<ul style="list-style-type: none"> <li>● Routinely monitor CSHCN and their families regarding their need for community services and supports.</li> <li>● Identify a primary contact within the practice to provide referrals, supports and care coordination that go beyond traditional physical health care services.</li> <li>● Identify key community resources, especially “shared utilities”—such as Help Me Grow, a local family resource center, Medical-Legal Partnership for Health—and develop a working relationship with those that can serve as a hub for further connection.</li> </ul>	<ul style="list-style-type: none"> <li>● Medical-Legal Partnership. To find MLP sites or start your own partnership: <a href="http://medical-legalpartnership.org/">http://medical-legalpartnership.org/</a></li> <li>● Help Me Grow National Center. To find sites or start your own state affiliate: <a href="http://www.helpmegrownational.org/">http://www.helpmegrownational.org/</a></li> <li>● See also AAP Clinical Report: Parent-Provider-Community Partnerships. (cite above)</li> </ul>

Core Action Areas	Potential Action Steps	Guidance, Guidelines and Toolkits of Note
<p><b>Monitor the status of CSHCN as a sub-population within the pediatric practice and take action to assure equity in care and experience.</b></p>	<ul style="list-style-type: none"> <li>● Develop a way to flag charts of CSHCN and routinely conduct chart reviews comparing the status on key indicators for CSHCN vs others in the practice. Include monitoring of status of immunizations and other well-child care, as well patient satisfaction responses.</li> <li>● Schedule regular well-child visits for CSHCN using the normal protocols and timeline for well-child care and then adjust as needed, providing developmentally appropriate anticipatory guidance.</li> <li>● Make sure the physical environment of the practice is easy to navigate for special needs patients and their families.</li> <li>● Create a welcoming and accommodating environment for the special needs child: Allow children with disruptive behavior to wait outside until they can be seen, or schedule their visits at the beginning of the day. Ask how things are going at home, at school and in the community.</li> </ul>	<ul style="list-style-type: none"> <li>● Bright Futures <a href="http://bright-futures.aap.org/">http://bright-futures.aap.org/</a></li> <li>● Practicing Comprehensive Care: A Physician's Operations Manual for Implementing a Medical Home for Children with Special Health Care Needs. Silva TJ, Sofis LA, Palfrey JS. 2000. Boston, MA: Institute for Community Inclusion, Boston. <a href="https://www.communityinclusion.org/pdf/compcare.pdf">https://www.communityinclusion.org/pdf/compcare.pdf</a></li> </ul>

Core Action Areas	Potential Action Steps	Guidance, Guidelines and Toolkits of Note
<p><b>Focus on functional status.</b></p>	<ul style="list-style-type: none"> <li>● Recognize that functioning is fluid across the life course and use checklists for function as a guide to care.</li> <li>● Incorporate the use of planning tools to help the family and child focus on the whole child/person and future planning, especially at times of transition.</li> <li>● Routinely monitor and update plans, especially around transition periods.</li> </ul>	<ul style="list-style-type: none"> <li>● Towards a Common Language for Functioning, Disability and Health <a href="http://www.who.int/classifications/icf/training/icfbeginners-guide.pdf">http://www.who.int/classifications/icf/training/icfbeginners-guide.pdf</a></li> <li>● See ICF Checklist Version 2.1a for Clinician International Classification of Functioning, Disability and Health. <a href="http://www.who.int/classifications/icf/icfchecklist.pdf">http://www.who.int/classifications/icf/icfchecklist.pdf</a></li> </ul>



## Recommendations for Next Steps

While individual pediatric practices might want to explore this framework and implement one or more action steps, the framework will be of greatest value if it can serve as a catalyst for a broad consensus process across multiple stakeholders, with the goal of further defining what it means to be a “life course pediatric practice” for the care of CSHCN and their families. Accomplishing this work will require a coordinated national strategy undertaken by a variety of stakeholders, including but not limited to: funders, policymakers, national associations, professional societies, parent/consumer organizations and federal agencies. The steps in this process would include:

- ***Convene a national panel of experts to review and revise the proposed implementation framework.***

This exercise could be convened by one or several national agencies or organizations that are significantly engaged in work focused on pediatric health care, services for CSHCN and/or life course science. Potential convening entities might include, among others: American Academy of Pediatrics, Association of Maternal and Child Health Programs, Family Voices, and Health Resources and Services Administration/Maternal and Child Health Bureau.

- ***Pilot use of the implementation framework in a selected set of pediatric health care settings to assess feasibility and acceptability among health care providers and families. Revise and refine the framework and any supporting materials based on pilot results.***
- ***Convene an expert panel to develop quality indicators for each key action area and pilot their use.***

This work could be undertaken by health services researchers in a variety of settings in conjunction with an expert panel convened to develop and refine measures and a quality improvement facilitator such as the National Child Health Quality Institute to assist with implementation.

- ***Reach out to accrediting organizations and regulatory agencies to explore and promote the use of the most promising life course quality measures.***
- ***Disseminate the results of these activities to a wide range of researchers, practitioners, program developers and policymakers working to improve the life course of CSHCN and their families.***

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## Conclusion

This review was undertaken based on two assumptions: that life course science has the potential to transform medical care and that CSHCN have much to gain from the application of life course concepts and principles in pediatric practice. While there is potential to translate life course science into practice, thus far the application of life course concepts in rethinking and redesigning pediatric care for CSHCN has been neither systematic nor widespread. The development of an implementation framework could be a first step in defining what it means to be a “life course pediatric practice” for the care of CSHCN and their families. The proposed framework is intended as a starting point for a broad consensus process that will fully realize the potential of life course science to transform care and lives.

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14. For more information, contact the Help Me Grow National Center: <http://www.helpmegrownational.org/>.
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