Matern Child Health J
DOI 10.1007/s10995-013-1371-1

Optimizing Health and Health Care Systems for Children with Special Health Care Needs Using the Life Course Perspective

Christina D. Bethell · Paul W. Newacheck · Amy Fine · Bonnie B. Strickland · Richard C. Antonelli · Cambria L. Wilhelm · Lynda E. Honberg · Nora Wells

Abstract To date, life course research in maternal and child health has largely focused on elucidating fetal and early life influences on adult health and less on promoting the health of children with special health care needs (CSHCN). Consideration of life course theory (LCT) for CSHCN is especially important given their increasing prevalence and comorbidity, their disproportionate vulnerability to weaknesses or instability in the health care system, and the growing evidence linking child and adult health and quality of life. In this commentary we seek to advance the consideration of LCT for CSHCN. We (1) briefly summarize key issues and the importance of a life course approach for CSHCN; (2) present illustrative findings from population-based cross-sectional data that serve to generate hypotheses that can be more rigorously examined when population-based longitudinal data become available; and (3) discuss the application of life course principles as a driving force in the continued implementation and improvement of integrated systems of care for CSHCN.

Keywords Life course · Children · Children with special health care needs · Health care quality · Medical home

Abbreviations

LCT	Life course theory
CSHCN	Children with special health care needs
NSCH	National Survey of Children's Health
NS-CSHCN	National Survey of Children with Special Health Care Needs
EBD	Emotional, behavioral or development problems
MCHB	Maternal and Child Health Bureau
SDBS	Standardized developmental and behavioral screening
DBS	Developmental, behavioral and/or social
IFSP	Individualized Family Services Plan
IEP	Individualized Education Plan

C. D. Bethell (✉) · C. L. Wilhelm
The Child and Adolescent Health Measurement Initiative, Oregon Health and Science University, Portland, OR, USA
e-mail: bethellc@ohsu.edu

C. L. Wilhelm
e-mail: cambria.brown@gmail.com

P. W. Newacheck
Department of Pediatrics, Philip R Lee Institute for Health Policy Studies, University of California, San Francisco, San Francisco, CA, USA
e-mail: paul.newacheck@ucsf.edu

A. Fine
Center for the Study of Social Policy, Washington, DC, USA
e-mail: afinehome@gmail.com

B. B. Strickland · L. E. Honberg
Maternal and Child Health Bureau, Health Resources and Services Administration, Rockville, MD, USA
e-mail: bstrickland@hrsa.gov

L. E. Honberg
e-mail: lhonberg@hrsa.gov

R. C. Antonelli
Division of General Pediatrics, Harvard Medical School, Children's Hospital Boston, Boston, MA, USA
e-mail: richard.antonelli@harvard.edu

N. Wells
Family Voices, Lexington, MA, USA
e-mail: nwells@familyvoices.org

Published online: 08 October 2013

Introduction

The life course perspective, or life course theory (LCT), as described in-depth elsewhere in this issue, seeks to understand the dynamic, emergent and multi-dimensional nature of health and disease patterns across the life span [1–4]. This model has important implications for the design and delivery of health care in the United States. LCT seeks to encourage rethinking existing models of primary care, acute care and chronic illness care [5, 6] to adopt a more explicit focus on promoting and optimizing health across the life span. It emphasizes the real-time and across-time interplay between biology and the social and physical environments.

To date, life course related research in maternal and child health has largely focused on elucidating fetal and early life influences on adult health. Less attention has been given to LCT's role in promoting the health of children with special health care needs (CSHCN). It is well understood that this population of children, by definition, experience chronic health problems which, in turn, may lead to more serious and/or complex adult chronic conditions depending upon how their health needs are addressed in childhood [2, 7–12].

In this commentary we seek to further advance the consideration of LCT for CSHCN by (1) briefly summarizing key questions and the importance of a life course approach for CSHCN; (2) illustrating LCT related analyses and findings based on population-based cross-sectional data to inform research as we await essential longitudinal data sets; and (3) offering conclusions regarding the potential application of life course principles as a driving force in the continued implementation and improvement of integrated systems of care for CSHCN.

Key Issues and Importance of a Life Course Approach for CSHCN

As defined by the federal Maternal and Child Health Bureau (MCHB), CSHCN are those "who have or are at increased risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond those required by children generally" [13]. Children who already have special health care needs (not including the "at risk" group) represent 15–20 % of all US children age 0–17 and nearly 25 % of US families regardless of household income [14]. In population-based contexts, CSHCN are commonly identified using a standardized screener, which selects the subset of all children with chronic conditions who experience ongoing and above routine service needs [14–16].

Life course strategies and policies should promote the optimal health of all children, youth and families across every developmental stage—pre-conception, gestation, early and middle childhood, and transition to adulthood. They also must address children across the range of health risks and needs including CSHCN who currently experience chronic health problems and require ongoing health care and related services. Application of LCT to CSHCN is at an early stage. Although there is a growing body of studies related to the life course of children generally [1, 4, 9, 17, 18], few have addressed life course issues specific to CSHCN. Consequently, much more needs to be done to elucidate the life course experiences of CSHCN, and to understand the wide variations observed in functioning and outcomes of CSHCN even when they experience similar condition diagnoses and other health, psychosocial and economic risks.

To properly assess and promote health potential among CSHCN we must understand the natural course of chronic conditions CSHCN experience and assess opportunities to attenuate risks and promote well-being at both the population and individual child level. It is especially important to avoid a deterministic application of LCT to CSHCN, which could lead to an unfounded acceptance of health disparities by CSHCN status as being inevitable or immutable due to the chronic conditions they experience. Rather than being deterministic, LCT inherently promotes consideration of the unique combination of needs, strengths and risks of each child regardless of diagnoses and seeks to identify and promote the possibilities for enhanced well-being.

At the same time as we avoid a deterministic interpretation of LCT, we also need to better understand how the effects of early life experiences may differ for CSHCN and for subgroups of CSHCN. For instance, how do critical and sensitive periods of the life course affect CSHCN whose developmental trajectories may already vary from the norm? What is the impact of both positive and negative environmental influences on health and well-being across the life course on disparities for those with ongoing health conditions? What, if any, are the cumulative impacts of adverse and protective factors on disparities observed? Finally, how is the life course of CSHCN similar or different from typically developing children in both positive ways (e.g. greater resilience to adversity?) and negative ways that call us to provide additional support to promote the healthy development of CSHCN (e.g. extra support during life transitions?).

Overall, three key observations elucidate the special importance of LCT for CSHCN: (1) the increasing prevalence of CSHCN and the often pronounced health problems, risks, needs and impacts they and their families experience, (2) the disproportionate vulnerability of CSHCN to any weaknesses or instability in the health care systems they

rely on, and (3) the growing evidence linking child and adult health. Each of these is briefly discussed below.

Changing Nature, Prevalence and Severity of Chronic Health Problems Among Children

Studies indicate that the prevalence of childhood chronic conditions severe enough to cause limitations in school or play more than doubled between 1979 and 2009 [19, 20]. With 15–20 % of all children experiencing at least one special health care need and nearly one quarter of US families impacted by these needs, it is critical that we gain a better understanding of the life course trajectory for special needs children and their families, and that we begin to apply new knowledge to optimize their current and potential health and well-being. As a nation we cannot afford to ignore the rapid growth of this population and its impact on individual children, families, school districts, neighborhoods and the workforce; nor can we ignore the ways in which social and environmental factors can shape the capacity of special needs children—by either marginalizing them and leaving needs largely unmet, or by promoting resilience and helping them thrive. The rapid growth in the number of children with emotional, behavioral or development problems (EBD) conditions is particularly distressing given documented gaps in early identification, mental health related services and attention to psychosocial factors and behavioral dimensions of chronic illness [21–25]. More generally, the health care system falls short in addressing the many social, psychosocial and behavioral dimensions of chronic illness [5, 6, 26–28], issues that a life course approach is inherently concerned with addressing [1].

Disproportionate Vulnerability to Weaknesses in the Health Care System

Fewer than 20 % of CSHCN meet the criteria for having access to a high quality system of health services as measured by the MCHB [23, 29–32]. This leaves the majority of CSHCN to experience alarming gaps in the quality of health care they receive. LCT may be especially suited to identifying gaps and helping to guide programs, practices and strategies in policy and practice to help ameliorate these gaps since it (1) inherently orients toward the comprehensive, coordinated and family-centered approach to health care so important for CSHCN; (2) embeds a personalized, holistic and integrated view of health that anticipates needs and impacts over time; and (3) focuses on optimizing health versus treatment of acute episodes [1]. While these system attributes are repeatedly emphasized as essential for the growing numbers of children and adults with chronic conditions [6, 19], they remain, as yet, uncommon in the US health care system.

Health care reform efforts emphasize the development of systems of services and models of care that align with many of the core concepts and goals reflected in the life course perspective. Despite this, many challenges exist. First, the health care system is still best characterized as being dominated by an acute care model, which focuses on diseases and acute episodes of illness. US health care lacks a cross-systems approach with built-in features enabling continuous monitoring, health planning and care coordination, each of which is essential to the effective care of CSHCN. Because of their greater needs, CSHCN are disproportionately impacted by these health care system weaknesses [19, 23, 24, 33]. Existing health care services are not organized in systems that recognize the vital role of families in caring for CSCHN [21–25]. Moreover, the current health care system does not typically account for the long-term impacts of chronic illnesses experienced by many CSHCN—e.g. reduced school performance and social engagement—which impact both the child and family. In efforts to promote health, prevent illness or manage chronic conditions, the predominant system of services often fails to adequately prioritize and address the influence of numerous factors demonstrated to have a substantial impact on health across the life span. These include stress management and the promotion of resilience, enhanced physical activity, healthy eating and the cultivation of stable social and family relationships [34–36].

Growing Evidence Linking Child and Adult Health

In addition to promoting healthy development throughout childhood, life course related research is especially strong in documenting the association between children's health and adult chronic diseases; associations that may be more pronounced for CSHCN. In fact, one-third of adult disability days are attributable to conditions that arose in childhood [34, 35]. Compelling results from other studies, such as the longitudinal Adverse Childhood Events Study [36–38] and those focused on the developmental origins of adult disease, provide evidence regarding (1) the long term impact and cumulative disadvantages set in motion by fetal and early life nutrition and stress, and (2) the often neglected myriad of psychosocial risks experienced in childhood [35, 36]. These studies highlight the potential of programs and policies promoting LCT to dramatically impact the health of the adult population and to possibly reduce the burden of illness and, by extension, the costs of care associated with adult chronic disease.

Illustrative Findings from Population-Based, Cross-Sectional Data

To advance LCT research and translation of LCT evidence into policy and practice for CSHCN, it is essential to have

data that enables investigation into relationships among child health and a range of child, family and environmental risks and protective factors, including performance of the health care system. Longitudinal or panel survey data—available in some countries—would provide the most comprehensive data and convincing evidence. However, the needed longitudinal data do not generally exist in the United States at present. In several years, the National Children's Study will begin providing much needed longitudinal panel data and ideally will collect the full palette of biologic, environmental, psychosocial, health care and other variables required to understand dynamics among the multi-dimensional factors impacting the health of CSHCN across the life course. In the meantime, we have robust cross-sectional data on children 0–17 years of age available in the 2009–2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) and the 2011–2012 National Survey of Children's Health (NSCH). These data permit assessment of the complex associations between the health of CSHCN and a wide range of child, family, community, school and health care system related factors among age-specific cohorts of children.

For this study, we first mapped Fine and Kotelchuck's [1] four conceptual domains for LCT: timeline, timing, environment and equity—to variables available through the NSCH and NS-CSHCN [1]. We then conducted a wide range of analyses to assess the capacity of these data to yield findings relevant to this conceptual framing. Generating associational findings only, this approach is naturally limited. However, we offer it to the LCT research community as having value for both elucidating variability across age cohorts in health and in examining associations with environmental, health care, socioeconomic and related factors known or thought to attenuate or promote the well-being of CSHCN. Optimizing the use of this and similar cross-sectional data can also confirm findings from longitudinal studies based on clinical or local area samples at a population level and can generate hypotheses for more thorough investigation using panel data, such as may emerge from the National Children's Study.

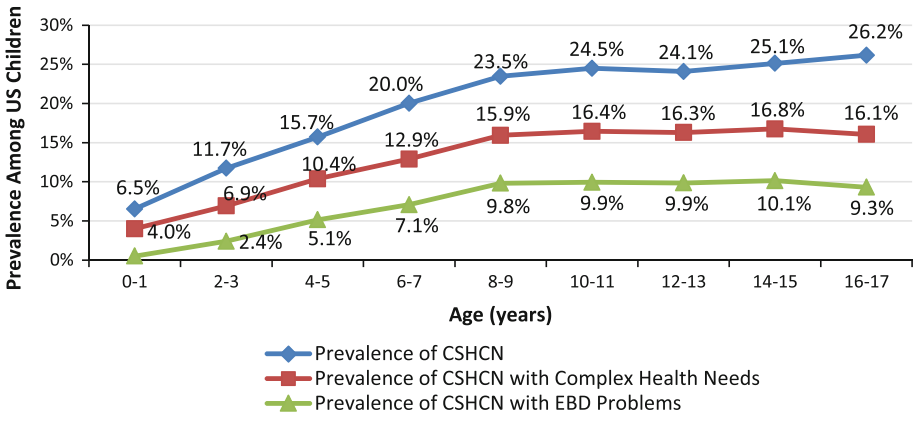
The following sections provide illustrations of findings from these analyses, with an emphasis on data from the 2011 to 2012 NSCH showing population-based variations in (a) CSHCN prevalence and health across age cohorts; (b) the provision of health care services at key points in a child's life; (c) environmental factors such as adverse childhood experiences (ACEs) in the home or community; and (d) socioeconomic disparities and equity in health and health care quality. Construction of all variables included in these analyses are available in publicly accessible codebooks [39] and in various published papers referenced in the Figures shown.

Timeline: Today's Experiences and Exposures Influence Tomorrow's Health

The likelihood that a child will experience a special health care need increases across life stages of childhood and adolescence. Based on the 2011–2012 NSCH, the prevalence of CSHCN among all children increases from 6.5 % for 0–23 month-olds to 26.2 % for 16–17 year olds; generally leveling off after age 8–9. Findings are important to the extent that we know or discover from longitudinal studies that early intervention programs targeted at younger children at risk for developing a special health care need may reduce prevalence of special needs among children as they age. The middle line in Fig. 1 illustrates similar trends for the prevalence of CHSCN experiencing more (vs. less) complex needs and raises questions as to whether this complexity represents the natural course and cumulative impact of illness or lost opportunities to reduce complexity through attention earlier in life. As shown in the bottom line of Fig. 1, a big driver contributing to observed increases in CSHCN prevalence across age groups appears to be increases in the emergence of emotional, behavioral and developmental problems. These are co-occurring with physical conditions for most children with EBD [14, 16, 19, 24]. Prevalence rates of CSHCN with EBD problems range from 0.5 % among 0–23 month olds to 9.3 % among 16–17 year olds; and similarly leveling off after age 8–9. Findings encourage further studies related to how physical problems may contribute to the emergence of EBD problems (and visa versa) and how co-occurring physical and EBD problems interact to impact health trajectories.

Timing: Health Trajectories are Particularly Affected During Critical or Sensitive Periods of Development

Most CSHCN experience the same transition stages as all children do; even if these stages are sometimes reached at older ages for CSHCN whose developmental trajectories are naturally impacted by the health conditions they experience. Two potentially critical stages of focus in LCT are the transition to school and the transition from high school into adulthood. LCT suggests that what happens in each of these transitions, and indeed during school, greatly affects the life course trajectories of all children, including CSHCN. A measure of school readiness for children approaching school age is not yet available in existing population-based data sets in the US. However, the 2011–2012 NSCH does estimate the extent to which children under five who are identified in the survey as being at high risk for developmental, behavioral or social (DBS) delays [using the Parent's Evaluation of Developmental Status (PEDS)-survey version] also have an early intervention (EI) plan [e.g. an Individualized Education Plan



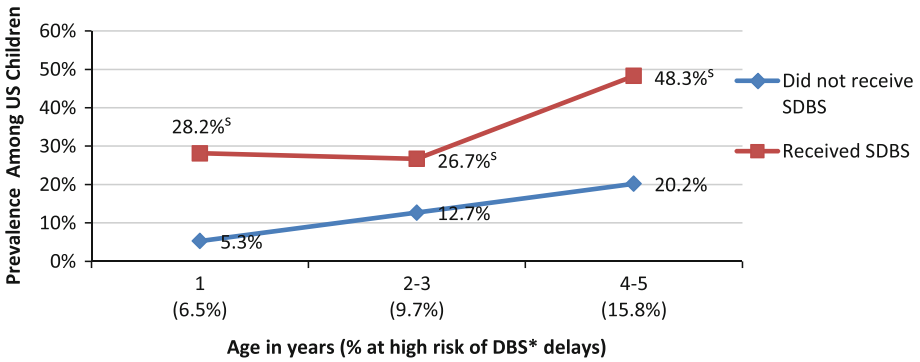


Fig. 1 Prevalence of CSHCN across age groups: by complexity and presence of EBD. *Data source* 2011/2012 NSCH. For more information on the identification of CSHCN using the CSHCN Screener: see references [13, 14, 16]

Fig. 2 Prevalence of young children at high risk for DBS delays who also have an early intervention plan: by whether standardized developmental and behavioral screening (SDBS) occurred in the past 12 months. *Data source* 2011/2012 NSCH. [S]Statistical significance, using Chi square at the $p < 0.05$ level. *For more information on construction of the "high risk for DBS delay" measure and the SDBS measure, see references [39, 40]

(IEP) or an Individualized Family Services Plan (IFSP)], as reported by the parents. Having such a plan is, in turn, known to positively impact school readiness and performance for such at risk children [2, 33, 40]. Figure 2 shows that young children who meet criteria for being at high risk for DBS delays based on the PEDS are much more likely to have an EI plan when data from the NSCH also indicated that they received a screening for developmental and behavioral problems in the past 12 months. Given existing research showing the impact of EI on school success for at risk children, these findings point to a potentially large missed opportunity to promote school readiness through early screening and successful referral and receipt of early intervention services when needed.

Similarly, ensuring youth with special health care needs receive education, support and resources to successfully manage their health needs as they transition out of school and into adulthood is considered to be essential to their continued development and success throughout life [15]. Moreover, learning to manage personal health risks and leveraging personal strengths to promote well-being will contribute to a healthy future workforce and a stronger economy. As illustrated in Fig. 3, services to assist youth with special health care needs in this way may not only be important to their long-term well-being, but also for their families. These findings show that CSHCN age 12–17 who received services to promote successful transition to adulthood are half as likely to have a family who cut back or stopped working because of their child's health needs. These associational findings suggest the need for further study to understand casual pathways between youth transition services and family workforce participation.

Environment: The Broader Community Environment—Biologic, Physical, and Social—Strongly Affects the Capacity to be Healthy

As with all children, the home and community environment impacts the well-being of CSHCN across all stages of childhood growth and development. In particular, ACEs have been demonstrated to have lasting impacts on adult health and often can result in toxic stress that impacts a child's physical health and socio-emotional development [18, 33–38]. ACEs include various forms of family dysfunction such as alcoholism, drug abuse or domestic violence, parental incarceration or death and neighborhood

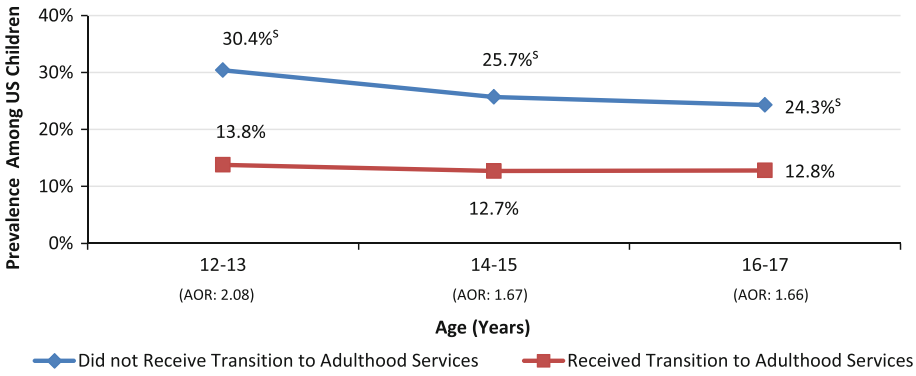


Fig. 3 Prevalence of youth CSHCN whose parents report having to cut back or stop working due to child's health needs, by receipt of transition services (as measured in 2009–2010 NS-CSHCN). *Data source* 2009/2010 NS-CSHCN. [S]Statistical significance, using Chi square at the $p < 0.05$ level. *Adjusted odds ratios (AOR)'s calculated adjusting for sex, race/ethnicity, household income primary household language, family structure and complexity of CSHCN service needs. All AOR's are statistically significant. For more information on construction of variables see references [39, 41]

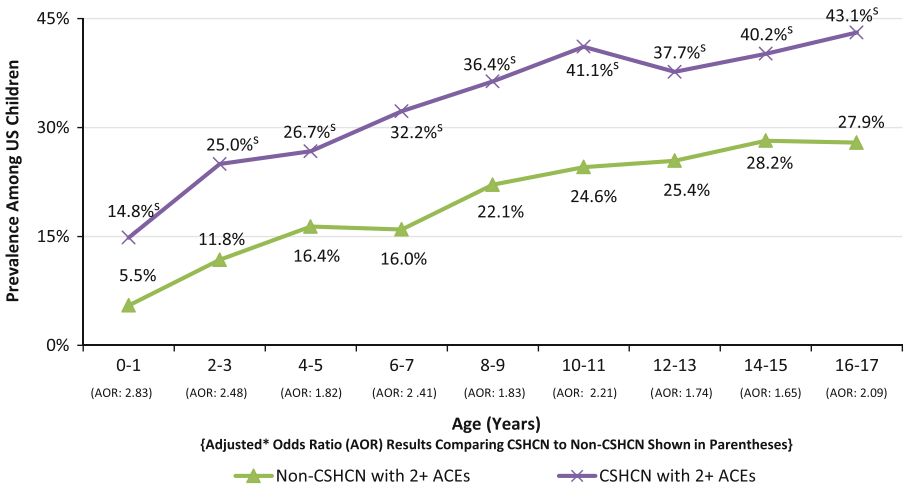


Fig. 4 Prevalence of children with two or more ACEs, by CSHCN status and age. *Data source* 2011/2012 NSCH. [S]Statistical significance, using Chi square at the $p < 0.05$ level. *AOR's calculated adjusting for sex, race/ethnicity, household income and primary household language. All AOR's statistically significant. For more information on the ACEs in the 2011/2012 NSCH, see reference [22]. For more information on construction of variables see reference [39]

violence and racial discrimination [22]. Figure 4 shows that at every age CSHCN are significantly more likely than non-CSHCN to have experienced two or more of the nine ACEs assessed, increasing to 43.1 % for CSHCN age 16–17[1] [20].

In addition to higher rates of ACEs among CSHCN, in Fig. 5 we see that the prevalence of CSHCN with EBD is three to five times greater for children with two or more ACEs. Understanding the causal pathways related to these familial and environmental impacts on the health trajectories and life success of CSHCN is critical for helping the health care system assess, identify and ameliorate risk. These cross-sectional findings show that CSHCN with EBD are more likely to experience ACEs. Additional questions are best answered with longitudinal data sets, such as whether ACEs are directly associated with the biological and related contributors to EBD?

Equity: Inequality in Health Reflects More Than Genetics and Personal Choice

Socioeconomic disparities in health outcomes for all children and for CSHCN are well documented and commonly associated with differential access to societal and institutional resources. Those resources include programs to minimize the occurrence of ACEs and, when ACESs have occurred, programs demonstrated to promote resilience among children and families [42, 43]. Resilience is commonly defined as "adaptive functioning across multiple life domains following significant exposure to adversity" and is associated with improved school engagement and performance, a reduction in risky health behaviors and ultimately better health outcomes [42, 44]. Figure 6 shows that among

[1] The "Adverse Child and Family Experiences Among US Children" measure referenced here is summarized in the "Overview of Adverse Events in Childhood" data brief [20]. ACEs assess include serious financial hardship; divorce; racial discrimination; incarceration of parent; witness violence in the home; victim of violence; alcohol or substance abuse in the home; parent with mental health problems.

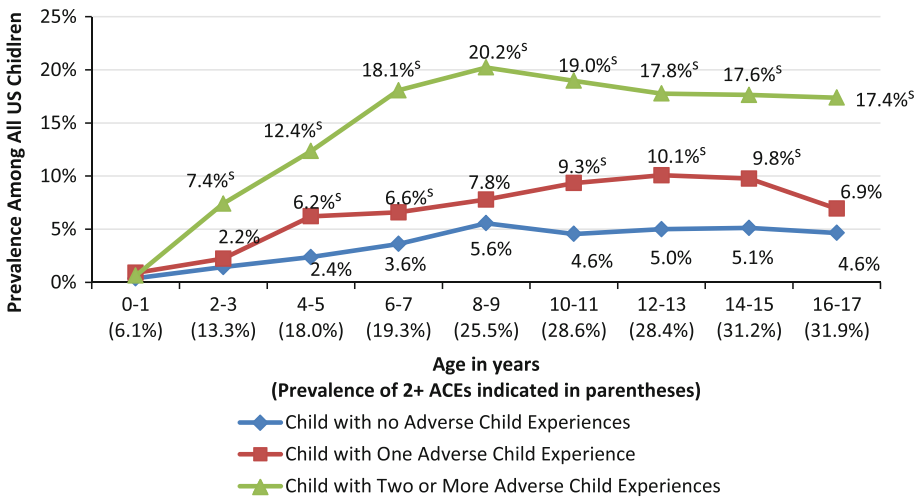


Fig. 5 Prevalence of CSHCN with EBD problems, by number of ACEs and age. *Data source* 2011/2012 NSCH. [S]Statistical significance, using Chi square at the $p < 0.05$ level. For more information on the ACEs in the 2011/2012 NSCH, see reference [22]. For more information on construction of variables see reference [39]

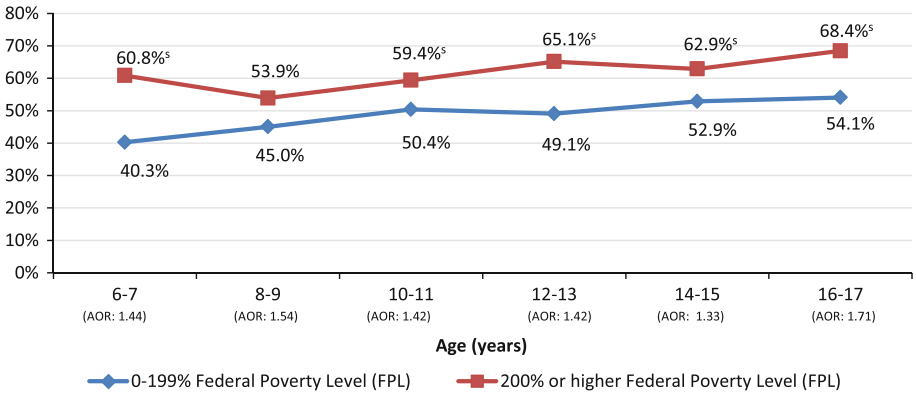


Fig. 6 Among CSHCN with two or more ACEs, prevalence of child resilience status by household income level. *Data source* 2011/2012 NSCH. [S]Statistical significance, using Chi square at the $p < 0.05$ level. *AOR's calculated adjusting for sex, race/ethnicity and primary household language. All AOR's are statistically significant. For more information on measurement of resilience and ACEs measures, see references [22, 39]

school-age CSHCN with two or more ACEs assessed, parent reported resilience of the child (e.g. stays calm and in control when faced with a challenge) is significantly lower for lower income children across all age groups evaluated; with the greatest disparities observed among younger school-age children (age 6–7).

As shown in Fig. 7, resilience is associated with higher levels of school engagement even among CSHCN experiencing multiple adverse events. This suggests a protective effect of resilience for CSHCN, a result that should be confirmed with longitudinal data sources. Evidence from other studies show that resilience can be developed among children regardless of their inherent genetic predisposition or temperament [44, 45]. Together, these results suggest the need for further study of the role of resilience in enhancing the life course of CSHCN.

Access to a high quality system of health and related services is a fundamental prerequisite to equitable health outcomes. Figure 8 shows that at a population level lower income CSHCN are less likely to receive care meeting MCHB's systems of services objectives (illustrated in Fig. 9). Income disparities were significant for each of the 5 age groups over the age of 8 and non-significant for most younger age groups. Even though income mobility is generally low across the life span [46], these cross-sectional findings are limited to determine any cumulative impact of income as it relates to receipt of higher quality health care.

Conclusions on the Application of Life Course Principles to the Implementation and Improvement of Integrated Systems of Care for CSHCN

Many of the principles of primary care set forth by Starfield [47] and others are consistent with LCT. Similarly, the MCHB systems of services model for CSHCN [41, Fig. 9] embodies a life course perspective through its focus on

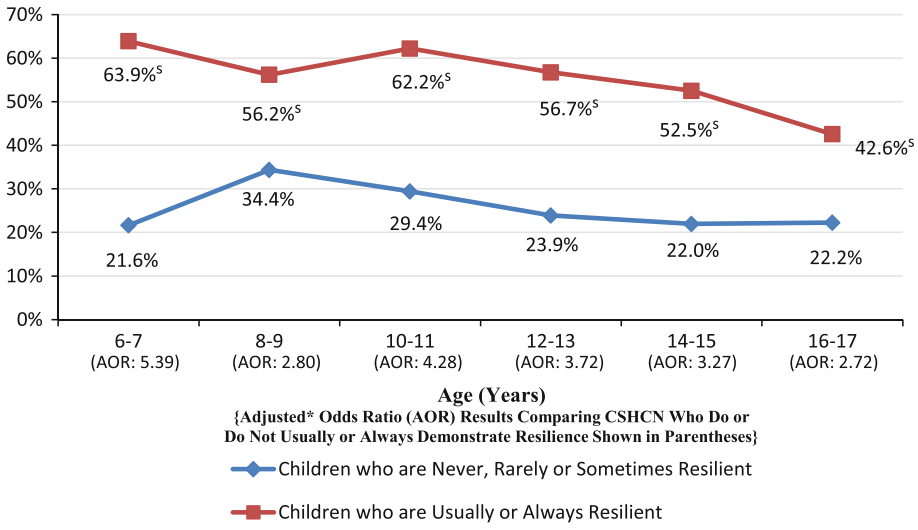


Fig. 7 Prevalence of school engagement among CSHCN with two or more ACEs, by child resilience. *Data source* 2011/2012 NSCH. ^{S}Statistical significance, using Chi square at the $p < 0.05$ level. *AOR calculated adjusting for sex, race/ethnicity and primary household language. All AOR's are statistically significant. For more information on measurement of resilience and school engagement measures, see references [22, 33, 39]

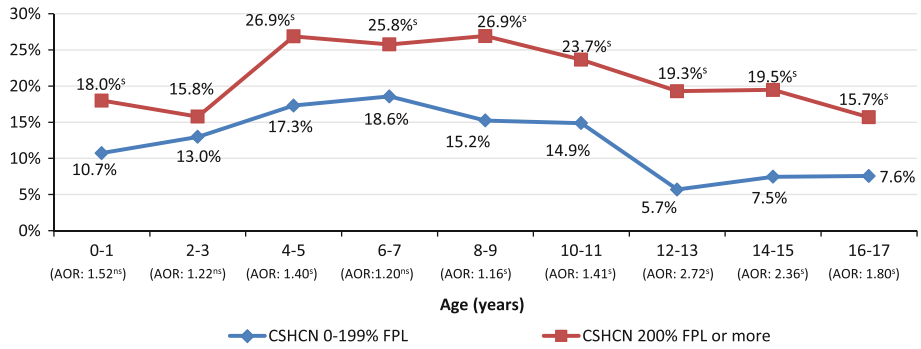


Fig. 8 Prevalence of achieving all MCHB CSHCN systems of services performance measurement criteria: by household income and age. *Data source* 2009–2010 NS-CSHCN. ^{s}Statistical significance using Chi square at the $p < 0.05$ level. AOR adjusted for sex, race/ethnicity, primary household language and complexity of special needs. ^{ns}AOR was not statistically significant. For more information on MCHB Systems of Service Criteria, see Fig. 9 and references [30, 39, 41]

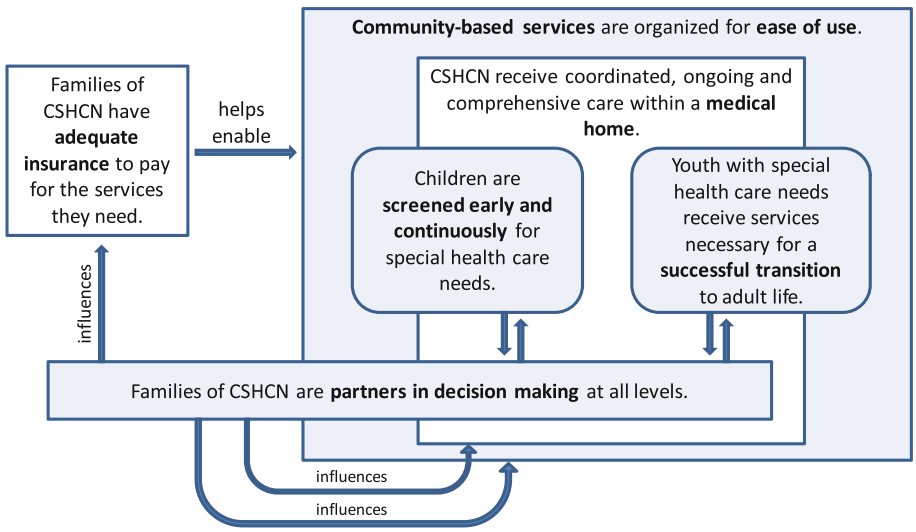


Fig. 9 Maternal and Child Health Bureau CSHCN system of services model

early and periodic screening, presence of a medical home and other system attributes. Conceptually consistent with numerous LCT principles are the more recently deployed Primary Care Medical Home model [5] and emerging Accountable Care Organizations; which are being designed to operate with financial incentives to optimize the health

of both individuals and populations [25, 48]. As initiatives move forward, we anticipate greater attention to the environmental and socioeconomic factors impacting health, and we hope an enhanced focus on early life and childhood. Paying special attention to children with or at risk of chronic conditions can yield both immediate and long-term benefits. These include enhanced health and well-being and reduced impact and severity of chronic conditions in children and in the adults they will become. With average health care expenditures for CSHCN being four times higher than those for other children ($3,392 compared to $856),[2] shorter term health care costs savings may also accrue.

Even though emerging models of health care are highly compatible with a life course perspective it is not clear if they will deliver on their explicit disease prevention, health promotion and disease management goals for all children and CSHCN. Their success is of critical importance to the health of children, adults and the whole population over time. Early studies of these models have demonstrated success primarily based on reductions in acute care events, such as emergency department utilization and hospitalization rates. These findings call for fostering innovation in the provision of chronic care for CSCHS that is aligned with the life course perspective rather than continuing down the road of acute episodic care.

Efforts to develop and implement integrated, comprehensive systems of health care reveal persistent fiscal, organizational and cultural barriers, including common failures in collaboration and information exchange [5, 26–28]. For example, essential to promoting a life course approach is ensuring routine, universal screening for developmental risks and delays, and then linking children at risk to a range of services and supports that go beyond health care. Yet, many medical practices have only minimal information on non-medical services that could help address identified risks. Even when this information is available, limitations of staffing, length of the average visit, and concerns about the quality of non-medical services all mediate against routine referrals beyond the medical system. Similarly, while sharing of information across sectors (health, school and family services) is needed, patient confidentiality restrictions (real and perceived) limit cross-sector communication and joint problem-solving. Further, while a life course approach incorporates the concepts of both risk and protective factors, our existing and even more mature systems of care are heavily tilted toward risk assessment, with a narrower focus on promoting strengths and protective factors, such as stress resilience, family and social connections and healthy behaviors.

Under the untested assumption that emerging health systems will perform functions previously presumed to be under the rubric of public health, recent health care reforms promoted through the Accountable Care Act (ACA) have led to widespread rethinking of the role of public health programs. In this regard, the role of the state Title V Block Grant programs, which play a critical role for CSHCN, may be altered as health care reform is implemented. LCT points to the importance of cross-cutting functions that may be best provided through public health and Title V agencies such as: (1) population and community-based primary care facilitation, services and infrastructure, including promotion of community-wide early screening and follow up; (2) routine and real time population health and system performance data monitoring; (3) fostering and facilitating system learning and partnerships, such as through existing Statewide Quality Improvement Partnerships [49] and (4) optimizing family and community engagement and partnerships at all levels by ensuring use of standards and best practices and support for family and community involvement. Title V programs, which have long focused on infrastructure development and implementation of systems of services model outlined above are potentially ideal partners for these emerging systems and related health care reform efforts.

A life course perspective in maternal and child health, as characterized by Fine and Kotelchuck [1], argues 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 health and well-being". In this way, LCT strikes an optimistic chord for the nearly 25 % of US families who have one or more CSHCN. This is critical since these families experience a range of additional stresses, risks and impacts compared to other families [21–24]. While we wait for results from longitudinal studies we must optimize the data and information we now have to promote the well-being of all children and CSHCN, especially during this unprecedented time of health care reform focused on improving systems of care to optimize health across life for all people.

Conflict of interest The authors have no conflicts of interest to disclose.

[2] Based on an analysis of data from the 2008 Medical Expenditures Panel Survey (MEPS) by the authors. A standard two-part model was used to estimate health expenditures controlling for child's age, sex, race, US geographic region, and family income.

References

1. Fine, A., & Kotelchuck, M. (2010). *Rethinking MCH: The life course model as an organizing framework*. Rockville, MD: U.S. Department of Health and Human Services. Available from http://mchb.hrsa.gov/lifecourse/rethinkingmchlifecourse.pdf.

2. Forrest, C. B., & Riley, A. W. (2004). Childhood origins of adult health: A basis for life-course health policy. *Health Affairs (Millwood), 23*(5), 155–164.
3. Wise, P. H. (2009). Confronting social disparities in child health: A critical appraisal of life-course science and research. *Pediatrics, 124*(Suppl 3), S203–S211.
4. Halfon, N., & Hochstein, M. (2002). Life course health development: An integrated framework for developing health policy, and research. *The Milbank Quarterly, 80*(3), 433–479.
5. Cooley, W. C. (2004). Redefining primary pediatric care for children with special health care needs: The primary care medical home. *Current Opinion in Pediatrics, 16*(6), 689–692.
6. Wagner, E. H., Austin, B. T., David, C., et al. (2001). Improving chronic illness care: Translating evidence into action. *Health Affairs (Millwood), 20*(6), 64–78.
7. Turkel, S., & Pao, M. (2007). Late consequences of pediatric chronic illness. *Psychiatric Clinics of North America, 30*(4), 819–835.
8. Case, A., Fertig, A., & Paxson, C. (2005). The lasting impact of childhood health and circumstance. *Journal of Health Economics, 24*(2), 365–389.
9. Delaney, L., & Smith, J. P. (2012). Childhood health: Trends and consequences over the life course. *Future of Children, 22*(1), 43–63.
10. Elo, I. T., & Preston, S. (1992). Effects of early-life conditions on adult mortality: A review. *Population Index, 58*(2), 186–212.
11. Smith, J. P., & Smith, G. C. (2010). Long-term economic costs of psychological problems during childhood. *Social Science and Medicine, 7*(1), 110–115.
12. Power, C., & Peckham, C. (1990). Childhood morbidity and adulthood ill health. *Journal of Epidemiology and Community Health, 44*(1), 69–74.
13. McPherson, M., Arango, P., Fox, H., et al. (1998). A new definition of children with special health care needs. *Pediatrics, 102*, 137–140.
14. Child and Adolescent Health Measurement Initiative. (2011). *Who are children with special health care needs.* Accessed October 15, 2012, at http://www.childhealthdata.org/docs/nsch-docs/whoarecshcn_revised_07b-pdf.pdf.
15. Park, M. J., Adams, S. H., & Irwin, C. E., Jr. (2011). Health care services and the transition to young adulthood: Challenges and opportunities. *Academic Pediatric, 11*(2), 115–122.
16. Bethell, C. D., Read, D., Blumberg, S. J., et al. (2008). What is the prevalence of children with special health care needs? Toward an understanding of variations in findings and methods across three national surveys. *MCH Journal, 12*(1), 1–14.
17. Power, C., & Hertzman, C. (1997). Social and biological pathways linking early life and adult disease. *British Medical Bulletin, 53*(1), 210–221.
18. Hertzman, C., & Boyce, T. (2010). How experience gets under the skin to create gradients in developmental health. *Annual Review of Public Health, 31*, 329–347.
19. Halfon, N., Houtrow, A., Larson, K., et al. (2012). The changing landscape of disability in childhood. *Future of Children, 22*(1), 13–42.
20. Perrin, J. M., Bloom, S. R., & Gortmaker, S. L. (2007). The increase of childhood chronic conditions in the United States. *The Journal of American Medical Association, 297*(24), 2755–2759.
21. The Child and Adolescent Health Measurement Initiative, & Data Resource Center for Child and Adolescent Health. (2009). Parenting & family life: A national profile, 2007 National Survey of Children's Health. Accessed on October 15, 2012, at http://www.childhealthdata.org/docs/nsch-docs/parent-profile-final-pdf.pdf.
22. Child and Adolescent Health Measurement Initiative, & Data Resource Center for Child and Adolescent Health. Data brief: Overview of adverse child and family experiences, 2011–2012 National Survey of Children's Health. Accessed on May 21, 2013, at http://www.childhealthdata.org/docs/drc/aces-data-brief_version-1-0.pdf?Status=Master.
23. Bethell, C. D., Kogan, M. D., Strickland, B. B., Schor, E. L., Robertson, J., & Newacheck, P. W. (2011). A national and state profile of leading health problems and health care quality for US children: Key insurance disparities and across-state variations. *Academic Pediatrics, 11*(Suppl 3), S22–S33.
24. U.S. Department of Health and Human Services, Health Resources and Services Administration, & Maternal and Child Health Bureau. (2011). *The National Survey of Children's Health 2007: Children with special health care needs in context: A portraits of states and the nation.* Rockville, Maryland: U.S. Department of Health and Human Services. Accessed on October 15, 2012, at http://mchb.hrsa.gov/nsch/07cshcn/.
25. Berry, J. G., Bloom, S., Foley, S., et al. (2010). Health inequity in children and youth with chronic health conditions. *Pediatrics, 126*(Suppl 3), S111–S119.
26. Hirsch, G., Homer, J., Milstein, B., et al. (2012). *Rethink health dynamics: Understanding and influencing local health system change*. Paper presented at 30th international conference of the system dynamics society, July 2012, St. Gallen, Switzerland. Accessed on October 15, 2012, at www.systemdynamics.org.
27. McDaniel, R. R., & Driebe, D. J. (2001). Complexity science and health care management. *Advances in Health Care Management, 2*, 11–36.
28. Kane, R. L., Priester, R., & Totten, A. (2005). *Meeting the challenge of chronic illness*. Baltimore, MD: Johns Hopkins University Press.
29. Child and Adolescent Health Measurement Initiative, & Data Resource Center for Child and Adolescent Health. (2011). CSHCN systems of care core outcomes 2009–2010 NS-CSHCN. Accessed on October 15, 2012, at http://www.childhealthdata.org/action/databriefs#CSHCN.
30. Child and Adolescent Health Measurement Initiative, & Data Resource Center for Child and Adolescent Health. (2011). System of care for CSHCN: CSHCN meeting all age-relevant core outcomes. Accessed October 15, 2012, at http://childhealthdata.org/docs/cshcn/met-all-outcomes.pdf?Status=Master.
31. Child and Adolescent Health Measurement Initiative, & Data Resource Center for Child and Adolescent Health. (2011). Outcome #2: Coordinated, ongoing, comprehensive care within a medical home. Accessed October 15, 2012, at http://childhealthdata.org/docs/cshcn/outcome-2.pdf?Status=Master.
32. Child and Adolescent Health Measurement Initiative, & Data Resource Center for Child and Adolescent Health. (2011). CSHCN systems of care core outcomes 2009–2010 NS-CSHCN findings profiles. Accessed on October 15, 2012, at http://www.childhealthdata.org/action/databriefs#CSHCN.
33. Bethell, C. D., Forrest, C. B., Stumbo, S., et al. (2012). Factors promoting or potentially impeding school success: Disparities and state variations for children with special health care needs. *Maternal and Child Health Journal, 16*(1), S35–S43.
34. Kent, A. L. (2012). Developmental origins of health and adult disease: What should neonatologists/paediatricians be considering about the long-term health of their patients? *Journal of Paediatrics and Child Health, 48*(9), 730–734.
35. Houk, V. N., & Thacker, S. B. (1989). The centers for disease control program to prevent primary and secondary disabilities in the United States. *Public Health Reports, 104*(3), 226–231.
36. *Adverse Childhood Experiences Study* (CDC and Kaiser Permanente, see http://www.ACEstudy.org) *The Damaging Consequences of Violence and Trauma* (see http://www.NASMHPD.org) and *Trauma and Recovery* (J. Herman). Cost data: 2007 Economic Impact Study (PCAA). Chart created by Ann Jennings, PhD. http://www.TheAnnaInstitute.org. Revision April 6, 2010.

37. Felitti, V. J., Anda, R. F., Nordenberg, D., et al. (1998). Relationship of childhood abuse and household dysfunction to many of the leading causes of death in adults: The Adverse Childhood Experiences (ACE) Study. *American Journal of Preventive Medicine, 14*(4), 245–258.
38. Anda, R. F., Felitti, V. J., Bremner, J. D., et al. (2006). The enduring effects of abuse and related adverse experiences in childhood: A convergence of evidence from neurobiology and epidemiology. *European Archives of Psychiatry and Clinical Neuroscience, 256*(3), 174–186.
39. Child and Adolescent Health Measurement Initiative (CAHMI). (2013). 2011–2012 NSCH: Child health indicator and subgroups SPSS codebook, version 1.0. Data Resource Center for Child and Adolescent Health, sponsored by the Maternal and Child Health Bureau. www.childhealthdata.org.
40. Bethell, C., Reuland, C., Schor, E., et al. (2011). Rates of parent-centered developmental screening: Disparities and links to services access. *Pediatrics, 128*(1), 146–155.
41. Strickland, B. B., van Dyck, P. C., Kogan, M. D., et al. (2011). Assessing and ensuring a comprehensive system of services for children with special health care needs: A public health approach. *American Journal of Public Health, 101*(2), 224–231.
42. Hodder, R. K., Daly, J., Freund, M., et al. (2011). A school based resilience intervention to decrease tobacco, alcohol and marijuana use in high school students. *BMC Public Health, 11*, 722.
43. National Institute for Health Care Management Foundation. (2007). Reducing health disparities among children: Strategies and programs for health plans. Retrieved at http://nihcm.org/pdf/HealthDisparitiesFinal.pdf.
44. Shannon, K. E., Beauchaine, T. P., Brenner, S. L., et al. (2007). Familial and temperamental predictors of resilience in children at risk for conduct disorder and depression. *Development and Psychopathology, 19*(3), 701–727.
45. Karatoreos, I. N., & McEwen, B. S. (2013). Annual research review: The neurobiology and physiology of resilience and adaptation across the life course. *Journal of Child Psychology and Psychiatry, 54*(4), 337–347.
46. Leonhardt, D. (2013, July 22). In climbing income ladder location matters. *New York Times*. Accessed on July 25, 2013, at http://www.nytimes.com/2013/07/22/business/in-climbing-income-ladder-location-matters.html?smid=fb-nytimes&WT.z_sma=US_ICI_2013072248.
47. Starfield, B. (2013). Perspective: Refocusing the system. *New England Journal of Medicine, 359*, 20.
48. Patient Protection and Affordable Care Act, Pub. L. No. 111-148 [S]10307]. (2010). Retrieved at http://www.gpo.gov/fdsys/pkg/PLAW-111publ148/pdf/PLAW-111publ148.pdf.
49. Agency for Healthcare Research and Quality Innovations Exchange. (2013). Statewide partnership supports quality improvement in pediatric practices. June 5, 2013. Access July 13, 2013, at http://www.innovations.ahrq.gov/content.aspx?id=3799.