Technical Brief Disposition of Comments Report

Technical Brief Title: Transition Care for Children With Special Health Needs

Draft available for public comment from December 19, 2013 to January 15, 2014

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Comments to Research Review

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The tables below include the responses by the authors of the review to each comment that was submitted for this draft review. The responses to comments in this disposition report are those of the authors, who are responsible for its contents, and do not necessarily represent the views of the Agency for Healthcare Research and Quality.

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Commentator & Affiliation	Section	Comment	Response
Peer Reviewer 1	General	A basic conceptual problem exists with this document. The concepts of health care transition and transfer are not defined nor distinguished in terms of their application. Throughout the paper, the authors refer incorrectly to transition wherein the appropriate concept to be used is transfer.	We have clarified our operational interpretation of the concept of care transfer by adding to the Background the definition of "transfer" from the 2011 AAP/AAFP/ACP joint recommendations, which note that transfer is a potential component of a successful transition process. We have made revisions to the definition of transition. We note that we use the term "transfer" to describe generally, the point-in-time when a case is transferred from pediatric to adult care. We use the term "transition" to communicate a more comprehensive set of support processes and care that ideally begins before and extend some period of time after the moment of transfer.
Peer Reviewer 1	General	Throughout this paper, the authors refer to health care transition when in essence they have focused their attention related to the event of transfer of care rather than its more comprehensive application to care. Throughout this document, the authors repeatedly refer to the transfer of care as transition. This is not conceptually accurate. The conceptual difference between transition and transfer has been discussed repeatedly in the literature, which is not acknowledged in this document.	Throughout the report we have provided clarity on language and terminology for transfer and transition, and age criteria.
Peer Reviewer 1	General	In some instances, as the authors refer to transfer of care, they also address the need for the adolescent/emerging adult to enroll in another health insurance plan when their eligibility for their pediatric health insurance plan terminates. To a lesser degree, the acquisition of the self-management competencies is referred to; however, the significance of acquiring these competencies needed to manage the daily demands of the treatment regimen is not apparent in this document. There is a brief reference to educational planning as these adolescent progresses through their secondary programs.	We have added text on implications of helping an adolescent manage their care. Additionally, we have added information about patient education and self-management to Guiding Question 1.

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Peer Reviewer 1	General	The comprehensive, interdisciplinary and interagency model of health care transition planning is not evident in this paper. A comprehensive approach to health care transition planning involves the following: a) service referral and coordination with community based transition and adult agencies/organizations such as the high school special education (IEP/504 Plan) and general education programs (504 Plan) ; job development and vocational training programs; postsecondary institutions (university, college, community college); occupational training programs; day programs and so forth.	Although we agree that a comprehensive approach may include referrals, educational, and occupational considerations, the scope of this technical brief was limited to the healthcare setting.
Peer Reviewer 1	General	Additionally, the need for health-related accommodations needed in school, work and community settings need to be addressed as well. These examples have been provided to illustrate the "missing components" that have not been adequately referred to in this document. It would not be expected for the authors to provide this level of depth pertaining to the broad scope of health care transition but it would be expected that the authors would acknowledge that transition involves a comprehensive framework of care.	Thank you. The transition experience in the school, work and community setting is outside of the project scope, but we recognize that these issues are important to this patient population. We include information from identified studies that reference barriers including the challenges related to school and work in Guiding Question 2.
Peer Reviewer 1	General	The authors state that the Six Core Elements of Health Care Transition serve as the organizing framework for this paper. However, it was not readily apparent. The organization of the paper does not align with the framework nor does the format of the guiding questions posed in this document. Lastly, given the fact, the authors chose the Six Core Elements of Health Care Transition as the document-organizing framework, then an Appendix/Table should be included with the listing of the Six Core Elements of HCT. An argument can be made that the Six Core Elements of HCT is an inappropriate framework for the purposes of this document. For example, this paper has addressed variables that are not associated with the Six Core Elements. The Six Core Elements refer to an algorithm, which does not fit with the purpose of this document. In discussing support for an algorithm, then it would be more appropriate to refer to levels of evidence, which are not referred to in this paper.	Our intention was to use the Got Transition rubric as a way to meaningfully organize the information in the report. We have de-emphasized Got Transition throughout the report and clarified how this Technical Brief is using the Got Transition framework.

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Peer Reviewer 1	General	This document reflects a very evident discipline-specific approach, which does not reflect best practices framework of care. Throughout the document, as has been mentioned previously, the focus of the document has been on the transfer of care rather than addressing the broad range of care issues associated with health care transition.	We have commented on the distinction between transfer and transition. We note that most of the research that has been done emphasizes the transfer component of transition, and completion of transfer is a common outcome. Although we attempted to review the state of the literature on the complete transition process, the availability of literature across elements was clearly not consistent and that is reflected in our results.
Peer Reviewer 1	General	This approach strongly reflects a medical centric approach. The terminology used throughout the paper reflects this perspective as well. For example, the term medical is used throughout in instances wherein the term "health" would have been more appropriate. The term "mid-level" providers is used in a portion of the text (lines 13 and 36). Line 41 on page 14 refers to "medical providers" rather than interdisciplinary providers. Line 21, page 14 refers to medical education rather interdisciplinary education.	We have reviewed the use of the terminology, and adjusted from medical to "health" where appropriate.
Peer Reviewer 1	General	Throughout the paper, there were problems with the citations. Here are examples of the problems with inappropriate/incorrect use of citations: a. Page 1, Line 37: References 7 and 8: Very dated and not current b. Page 1: Line 43: Reference 15 is not transition-related c. Page 14, Line 13: In many instances the authors combine varying levels of evidence (i.e.expert opinion, empirical data) d. Page 17, Line 15, reference 107 is about mental health and refers to state level system of care, which is of different entity than what has been described. e. Page 20, Lines 11 to 22 and line 36 refer to different levels of evidence. f. Page 21: In the section entitled Cost and Insurance Programs, there is refer to condition specific conditions (i.e. AIDS, Diabetes, ADHD) which should be specified and may not apply to other diagnostic-specific groups. Again, as has been mentioned previously, there are differing levels of evidence cited throughout this page. g. Page 22, Line 17: Different levels of evidence cited. h. Typos/incorrect reference formatting are evident in the reference list.	a. We have sought more recent data on the life expectancy, but to our knowledge there is no reliable, more recent estimates. We have retained the two references for this statistic: 1) Transition of care provided for adolescents with special health care needs. American Academy of Pediatrics Committee on Children with Disabilities and Committee on Adolescence. Pediatrics. 1996 Dec;98(6 Pt 1):1203-6. PMID: 8951283 and 2) Gortmaker SL, Sappenfield W. Chronic childhood disorders: prevalence and impact. Pediatr Clin North Am. 1984 Feb;31(1):3-18. PMID: 6366717 b. We are unclear about this comment. We have rechecked this citation (reference #15 from the reviewed draft report and now reference #27 in the revised report: Schrander-Stumpel CT, Sinnema M, van den Hout L, et al. Healthcare transition in persons with intellectual disabilities:

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			general issues, the Maastricht model, and Prader-Willi Syndrome. Am J Med Genet C Semin Med Genet. 2007 Aug 15;145C(3):241-7. PMID: 17639594) and believe that it does address transition. c. This is not a comparative effectiveness review or a systematic review. We did not limit the types of evidence that could be reviewed and discussed for Guiding Questions 1, 2, and 4. For Guiding Question 3 we looked only for studies that evaluated a transition program, therefore, used more rigorous limits for eligible study design. d. We believe the cited reference does in fact support the text. Reference #107 in the draft and # in the revised text: Davis M, Geller JL, Hunt B. Within-state availability of transition-to-adulthood services for youths with serious mental health conditions. Psychiatr Serv. 2006 Nov;57(11):1594-9. PMID: 17085607 e. This is not a comparative effectiveness review or a systematic review. We did not limit the types of evidence that could be reviewed and discussed for Guiding Questions 1, 2, and 4. For Guiding Question 3 we looked only for studies that evaluated a transition program, therefore, used more rigorous limits for eligible study design. The technical brief also incorporates input from Key Informants. f. Thank you for your comments. g. This is not a comparative effectiveness review or a systematic review. We did not limit the types of evidence that could be reviewed and discussed for Guiding Questions 1, 2, and 4. For Guiding Question 3 we looked only for studies that evaluated a transition program, therefore, used more rigorous limits for eligible study

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			design. The technical brief also incorporates input from Key Informants. h. We have rechecked the reference list for accuracy and correctness.
Reviewer 2 (TEP)	General	This is well written and provides a reasonable and standard set of analyses and conclusions. However, it does not move beyond conventional wisdom and appears to accept numerous assertions without adequate challenge. For example, the review makes numerous assumptions about the value of specific adolescent health expertise and about the state of adult primary care practice, neither of which are well supported. It points to the core elements of the Got Transition framework without questioning the validity of that framework or its elements or identifying other complementary or differentiating frameworks. Such a more rigorous review would provide greater value to establishing a research agenda.	Our intention was to use the Got Transition rubric as a way to meaningfully organize the information in the report. We have de-emphasized Got Transition throughout the report and clarified how the brief is using the Got Transition framework.
Reviewer 2 (TEP)	General	The review also makes broad statements about how different groups of CSHCN might need different types of transition; however, these statements aren't informed by the literature on categorical vs. non-categorical approaches to CSHCN nor do they clearly identify a number of dimensions that might be useful in approaching transition.	We agree it would be valuable to have data on how to target transition support for children. We note in the future research section: "Documentation of resources could include specific programs such as city based transportation programs available to patients or clinic and institutional resources such as personnel, educational opportunities, and electronic medical record support. Identifying the differences and similarities within successful transition processes could be beneficial to the medical community as individual clinical systems modify components of the transition processes to work within their unique systems."
Peer Reviewer 4	General	I thought that this was an extremely well-written, unbiased appraisal of the literature on transition. I also think that its content is incredibly important and timely; as shown in the report, published perspectives on transition have greatly outpaced actual data collection on interventions to improve the process. The field needs something like this to help clearly illustrate such issues and possible next steps.	Thank you for your comments.
Reviewer 5 (TEP)	General	Very comprehensive summary of the state of transition health care services.	Thank you for your comments.

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Reviewer 6 (TEP)	General	The report is well-written, nicely organized, and addresses the key issues.	Thank you for your comments.
Reviewer 7 (TEP)	General	The authors have done a thoughtful and thorough job with this Technical Brief on a topic with limited literature and limited penetration of improved or "best practices." Granting that the Brief focused on CSHCN, there could have been discussion of the possibility that all youth may benefit from more mindful supports of their transition and transfer from pediatric to adult care. Furthermore, the Brief tends to portray transition in a programmatic framework rather than a process to be incorporated into the general provision of high quality adolescent and young adult care for all in all settings. Dedicated transition programs or clinics will never be a practical solution for a large number of the 500,000 youth with special health care needs who transition to adult care each year. Transition support will need to be built into the general primary and specialty care they receive as adolescents and young adults.	We agree. The reports discussion and findings are set with in the context of what is practical and applicable.
Reviewer 7 (TEP)	General	There could be more attention to the subject of young adults with special health care needs after they have left pediatric care in the sense that their transitions to adult care will not likely be completed. Adult providers will need to be carrying on the work of pediatric providers in terms of preparation, readiness, planning, etc.	Thank you. We have added a comment in Guiding Question 1 to address this point.
Reviewer 7 (TEP)	General	The sequencing of transitions of care in terms of primary care and specialty care is not addressed. Should primary care be transferred to adult providers first and then specialty care or the reverse or does this vary by condition or context; in what instances might primary care be transferred but specialty care remain in a pediatric specialist's hands. How are multiple transitions care (multiple specialists) coordinated and by whom?	It is an interesting question and agree it would be good for future research. We have added a comment in Guiding Question 1 to address this point. “It is worth noting here that while patients cared for by family practitioners may theoretically have the same primary care physician in both childhood and adulthood, these patients may still benefit from a process to help them assume increasing responsibility for their own care as they age and may still need to transfer some of their care from pediatric to adult specialists. There are no empirical data in the literature to guide decisions regarding whether primary care transition and subspecialty care transitions should occur simultaneously or in a sequential fashion.”

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Reviewer 7 (TEP)	General	The children's hospital perspective seems to dominate the Brief instead of one evolving from a focus on primary care and the medical home. The latter was the perspective taken in the 2011 clinical report and the framework developed by GotTransition. This would have communicated the notion that the elements of good transition care are basically the same for youth with and without special health care needs and are grounded in the medical home as part of the process of care.	Thank you for your comments.
Reviewer 7 (TEP)	General	The planning/authoring group appear to be entirely grounded in a tertiary children's hospital setting. The perspective of providers in community based pediatric and adult primary care and adult specialty care, while perhaps present among the key informants, might have helped to inform the planning and execution of the project.	Thank you for your comments. Many children with special healthcare needs are being cared for in tertiary care. Our Key Informants included an adult provider and a community-based pediatric provider.
Reviewer 7 (TEP)	General	The report's use of the US MCHB definition of special health care needs focuses it upon youth with chronic illnesses, disabilities, and mental health issues, but neglects much mention of high risk and vulnerable populations such as young adults emerging from foster care, immigrant populations, homeless young adults, etc who may be at special risk in the transition from pediatric to adult care.	We recognize these as important issues; this brief is focused on the transition process for youth with special health care needs. We have made this clearer in the background and methods sections.
Peer Reviewer 8	General	This is a technical summary of transition programs and guidelines. This is generally well written and extensive. There are some well established transition programs that did not make it to the review, I added some information/programs/articles below.	Thank you for your comments. We have reviewed your suggestion, updated the literature search, and report findings.
Peer Reviewer 9	General	I applaud AHRQ for recognizing the increasing need to address transition care for children with special health needs and commissioning this technical brief.	Thank you
Peer Reviewer 9	General	The report reflects well the pediatric perspective but does not adequately address the adult perspective and issues. To effectively address transition, one needs to fully engage the adult system and study how that system deals with the issue.	We agree there is little information in the literature. We comment in the future research section as well. We did also include an adult provider as a Key Informant to help to capture the adult perspective.
Peer Reviewer 9	General	The report included studies and programs from outside of the United States. It is important to acknowledge that work but one must keep that work in perspective given the differences among the various health care systems. The practices in Canada and UK often are not applicable in the US, particularly given how health care is financed.	We agree and made note about the applicability of these studies.

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Peer Reviewer 10	General	It is critical that the term "transition " is defined at the beginning of the paper - as “the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” (Blum, 1993) (This is, by far, the most often cited definition of health care transition.) "Transition care" could be defined as care that supports a purposeful planned movement..."	We have made revisions to the definition of transition. We note that we use the term “transfer” to describe generally, the point-in-time when a case is transferred from pediatric to adult care. We use the term “transition” to communicate a more comprehensive set of support processes and care that ideally begins before and extend some period of time after the moment of transfer.
Peer Reviewer 10	General	Transfer should be used whenever referring to the move from peds to adult care. In this paper, "transition" is often used when referring to the move to adult care. This leads to confusion ... the reader does not know if the text is referring to "transition care" or to a situation where patients are discharged from peds and referred to adult care with out preparation or support.	We have reviewed the use of the terms transition and transfer and made corrections throughout as appropriate.
Peer Reviewer 10	General	After having read the draft technical report several times, I feel that major changes need to be made if the report is to be of value to organizations in their effort to improve the process of moving youth from pediatric (child-centered) to adult oriented health care providers, programs and facilities.	We have substantially revised the report.
Peer Reviewer 10	General	As discussed more specifically below, this report provides a limited and sometimes mistaken description of the state of the science of “transition care” (AKA health care transition [HCT]); a limited and sometimes mistaken description of strategies, approaches and mechanisms currently used to improve the process of moving YSHCN from child-centered to adult oriented care; a limited and sometimes mistaken analysis of the implications of various transition approaches/programs; and presents a framework (Got Transition) that is appropriate for understanding and assessing a limited range of transition-related approached/programs. As a result, this technical brief does little to help stakeholders to grasp the critical issues that impact the health care transition process and to guide future research in the field.	There are different definitions and we recognize that we will not be consistent with the range of definitions.
Peer Reviewer 10	General	The 2011 Clinical Report - Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home which provides an transition process algorithm makes a major contribution to the HCT literature. It provides a broad framework for describing and assessing the clinical patient-focused components of transition care. However it does not provide guidance on what patient behaviors, knowledge, beliefs and attitudes etc. are most important to assess and change (to assure that the patient is ready to move to adult care); nor does the report provide a framework for designing, implementing and evaluating specific approaches for bring about “needed” change.	Thank you. The 2011 Clinical Report is included as a reference.

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Peer Reviewer 10	General	Further, the literature has identified a number of forces and factors that appear to impact the adoption and implementation of promising transition practices by health care systems and institutions. The limited capacity of adult health care professionals and systems to provide developmentally appropriate, acceptable, and evidence-based clinical care is a major issue; a young adult cannot successfully move to adult care if there are no willing, interested and clinically competent physicians and support systems. The AAP clinical report does not provide a framework for addressing these “systems” issues; and assessing the utility of specific strategies and approaches.	We concur and touch on some of these important forces in the future research section, noting that adult providers are an essential component to the transition process. We found little data on how individual health care systems affect transition. To be useful, evaluations of transition care programs should specify the type of systems in which the transition was performed and the resources or tools necessary to implement the program.
Peer Reviewer 10	General	A major problem with this report is the “sloppy” use of the term “transition”. As it discussed in many HCT articles, it is critical that the term "transition” and “transfer” are not used interchangeably. Transition should be used when referring to activities that promote “the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems” (Blum, 1993) (This is, by far, the most often cited definition of health care transition.) "Transition care" could be defined as care that supports a purposeful planned movement..."	Throughout the report we have provided clarity on language and terminology for transfer and transition
Peer Reviewer 10	General	Transfer is an event (not a process). It should be used whenever referring to a patient or patient population leaving (being discharged from, aging out of) pediatrics (child-oriented care, the child health care system) and starting to receive health care from adult-oriented health care professionals, facilities and programs. (It is of note that significant proportions of patients “drop out” of care after they are discharged from Pediatrics, and then receive health care only through an Emergency Department for a period of time; and may never be fully integrated into the adult system of primary and specialty care). Therefor it should not be assumed that “leaving pediatrics” is synonymous with “transfer”. This failure to use these terms carefully can lead to confusion; and is discussed later, under Background and GQ1a	Throughout the report we have provided clarity on language and terminology for transfer and transition

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Peer Reviewer 10	General	This technical report includes information about transition programs and transition approaches. I would like to see a greater emphasis on “transition approaches”. I believe that distinct transition programs can be of great benefit to CYSHCN, but that a limited number of facilities will develop and fund such programs. I believe that a much greater number of CYSHCN (and their families) would receive needed transition-related supports if pediatric and adult primary and specialty care providers would integrate “promising transition practices” into their everyday clinical interactions with CYSHCN.	We attempted to identify and summarize transition care for CSHCNs as it is described in the published and grey literature. Ideally, common approaches or practices would emerge from the summary and descriptions within the report. We describe and organize the report using “programs” to not advocate a specific package. We agree that patients may be more likely to receive needed services if adult and specialty care providers integrated promising practices. We include a description of transition components (Guiding Quesiton1) that could be readily adopted without implementation of a formal transition program.
Peer Reviewer 10	General	Cooley’s six elements or components of health care transition provide an excellent example of approaches that can be integrated into standard clinical practice. These elements are identified as a viable framework for structuring future research – and it is recommended that investigators describe their interventions with the Got Transition rubric.	We agree.

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Peer Reviewer 10	General	The focus of this report is on identifying and describing programs and approaches; and presenting evidence regarding the effectiveness of specific patient-focused practices; i.e. what approaches are of potential benefit to patients. However, the report does not a more basic question: what strategies and mechanisms are effective training health care professionals to incorporate "transition-related" approaches into their everyday clinical practice. The use of the term "Program" implies that transition related services are separate and different from the activities that primary and specialty care professionals can engage in as part of their care. This technical report focuses on "transition programs" – This may be because staff at AHRQ and or those developing the report have the expectation that transition-related services and supports are generally provided to CYSHCN through a defined program or service.	We have attempted to emphasize strategies over programs throughout the revised text and as noted above, we describe existing transition care reported in the published and grey literature. Ideally, common approaches or practices would emerge from the summary and descriptions within the report. We organize the report using "programs" but agree that patients may be more likely to receive needed services if adult and specialty care providers integrated promising practices. We include a description of transition components (Guiding Quesiton1) that could be readily adopted without implementation of a formal transition program. The report authors did not assume that transition care for CSHCNs is provided only through defined program or service.
Peer Reviewer 10	General	Aside from information on the availability of specific transition programs or plans, the proportion of youth with special health care needs who are given information and assistance with transition (either within the context of a transition program or through their pediatric provider) is low.	We agree. Thank you for your comments.
Peer Reviewer 10	General	"while some HCT-related tasks are distinct, such as developing a written transition plan or identifying adult providers, most clinical activities that promote readiness for the eventual move out of pediatrics are integral to providing developmentally appropriate care. These include promoting a patient's self-management knowledge and skills, and meeting with adolescent patients individually for part of the medical visit."	Thank you for your comments.
Peer Reviewer 10	General	I also note that the limited adoption of "transition related behaviors" in the clinical setting may be "the result of physicians seeing HCT as a new, distinct task that is being added to the many clinical activities that must be carried out during time-limited medical visits with adolescents. This perception that HCT is a new and separate service may be, in part, an unintended con- sequence of efforts to draw attention to the issue and change physician behaviors through promulgation of HCT guidelines, consensus statements, and clinical reports."	Thank you for your comments.

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Peer Reviewer 10	General	Also the letters associated with the 3 questions should be the same as the letter used on page 2. (a,b,c; not m, n, o)	Yes, thank you. This was an error in the list formatting. We have corrected this in the final report.
Reviewer 11 (TEP)	General	Very comprehensive report on an area that needs much more attention. The number of children with special health care needs is increasing, yet policy, practice and funding streams have not kept up with this demand. There is clearly no one size fits all solution for the wide range of special health care needs in this category, and much more research and work is needed, as evidenced by this report.	Thank you for your comments.
Peer Reviewer 12	General	This is a much needed and well-written report that summarizes the lack of relevant literature that evaluates programs and processes for transition to adult care for Children with Special Health Care Needs (CSHCN). The methodical approach provided through the structure of a Technical Brief supports the comprehensive nature of the review, and underscores the paucity of quality in this research field. The authors are to be commended for a comprehensive and well thought-out report.	We appreciate your feedback.
Peer Reviewer 13	General	There should be clear definitions up front about transition care, transition readiness, etc. There were times when it seemed that transition care referred to care outside pediatrics and other times when it seemed transition care took place in the pediatric setting. Please define transition readiness and other relevant terms like transfer (See Schwartz et al papers on transition readiness).	We have attempted to add more definitions as appropriate. The term “transfer” is generally used to describe the point-in-time when a case is transferred from pediatric to adult care while the term “transition” is used to communicate a more comprehensive set of support processes and care that ideally begin well before and extend some period of time after the moment of transfer.
Peer Reviewer 13	General	The inclusion of English speaking papers outside the US should be discussed. What are the implications of including papers from outside the US with different health care systems? What is the associated bias of English only?	We agree and have addressed in the Summary and Implications section. We note that “Interpretation of information from evaluation studies of transition care published in English from countries other than the United States must consider differences in the structure and financing of healthcare systems across countries.”

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Peer Reviewer 13	General	More should be said about transition registries. What should they include? How to track? What are examples?	Little information is available at this time, but this an area for future research. We suspect that decisions about what to track would be disease-dependent. We have expanded the text on registries in Guiding Question 1.
Peer Reviewer 13	General	The importance of behavioral health issues such as adolescent health harming behaviors, family conflict, non adherence, etc were well stated. However, the role of behavioral health (psychology and psychiatry) in transition care was not discussed.	We agree that the role of behavioral health in transition care is key, and is not discussed well in the literature. We have added this point to Future Directions (Guiding Question 4): "Behavioral health care is important in the transition process to provide support and services to address coping with chronic medical diseases and treatment, non-adherence, and psychological effects of their chronic disease. Few studies have addressed this aspect of transition care. Studies evaluating the role of behavioral health within the transition process will be critical."
Peer Reviewer 13	General	Role of culture and SES is not well articulated	We agree that is missing in the literature.
Peer Reviewer 13	General	The limitations of measures (materials) was not discussed. No measure has been well validated and there is little data on measures other than the TRAQ and a few others. Also, most measures are limited to measuring skills and/or knowledge. Other aspects and barriers of the process are not assessed, nor are the perspectives of multiple stakeholders	We agree these data are missing from the literature at this point.
Reviewer 2 (TEP)	Background	The start of the background raises questions for me about pediatrics as a specialty per se -- why are age cut offs required at all? Is it appropriate for all to have pediatric primary care vs. general practitioner approaches? It suggests there may follow evidence comparing transition issues for children followed in family practice/FNP settings vs. peds to adult care settings. This could likely be avoided by stating up front that this review is only focused on CYSHCN.	We have made this clearer by stating that the review is focused on youth.
Reviewer 2 (TEP)	Background	The issue of transition is accentuated in the frequent focus on the importance of adolescent expertise. To me, this raises the potential for yet another set of transitions in providers, so seems odd in this report.	We are not endorsing adolescent providers, but adolescent expertise.

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Reviewer 2 (TEP)	Background	The notes about racial and economic differences in transition would be strengthened by brief inclusion of actual data.	We have strengthened this section with quantitative data from relevant research.
Reviewer 2 (TEP)	Background	The listing of the core elements is important, but at the level they are reported they are so vague as to be uninformative.	We have added a brief description of the six core elements to the Background.
Reviewer 2 (TEP)	Background	They also do not really appear to be a research framework--they are identified as concrete actions and steps to be taken, with tools for each. A research framework might better be viewed with these elements as one dimension in a matrix, and the attributes of a desired transition in the other.	We tried to use this as an organizing framework. We have made changes to help clarify this.
Reviewer 2 (TEP)	Background	Also, the Got Transition elements note strongly that each need apply to both adult and pediatric settings…actions are required in each. This is not conveyed in the report.	We have added clarification in the text under Guiding Question 1b.
Sharadha Kulamani	Background	Nowadays chidren due to their eating habits face lots of psychological problems. For eg in India children suffer from malnutrition and they also face the same psychological problems. Our ecosystem is not balanced trough out the world. In some places nature gives a lot and in some places very less.	Thank you for your comments.
Shilpa Amin	Background	Thank you for the opportunity to comment. A well-written background and report (kudos to the lead investigator (s) and team) on selecting this topic as an extension and continuum of their previously established evidence work in the area of developmental disabilities and transition of care.	Thank you for your comments.
Shilpa Amin	Background	Might consider incorporating some reference to the ACA legislation and to legislative activities in progress that are examining transitions of care in pediatric populations with the advent of PCMH.	We have added discussion of the Affordable Care Act to the Background of the technical brief.
Peer Reviewer 4	Background	I was surprised that "Got Transition" was used as a framework for such an empirical piece. This website actually does not seem very data driven (for example, if you look at their "research" list, it's mainly citations that were excluded from this report). I think it would be helpful to perhaps give a more neutral presentation of this resource and/or more rationale for its centrality in the report. For example, there is a comment to this end on p 41 which seems a little late.	Added text under Guiding Question 1 better describing the quality improvement methodology of Got Transition and comment emphasizing need for continued evidence-based research.

Commentator & Affiliation	Section	Comment	Response
Reviewer 5 (TEP)	Background	So we have continue to use "500,000 children in the US with special health care needs transition to adult care annually" (line 33) This number is over 10 years old and I have got to believe the number has increased significantly. I am not sure where to get the correct number but if you can't get a current number than reference that as "in 2002 (or whatever the date that it was referenced) there were 500,000 children..."	We have complemented this statistic with more recent estimates from the National Alliance to Advance Adolescent Health: The National Alliance to Advance Adolescent Health estimates that chronic health conditions affect approximately 25% of the 18 million US young adults aged 18 to 21 who should be transitioning to adult-centered health care.
Reviewer 6 (TEP)	Background	Excellent background:	Thank you.
Reviewer 6 (TEP)	Background	Page 1, line 11: I recommend adding the works (or something to that effect) in capitals below: "...create discomfort and challenges for other pediatric patients and their families AS WELL AS FOR ADULT PATIENTS..."	Thank you, we have added this text.
Reviewer 7 (TEP)	Background	Good background review generally. The literature review might have been enriched somewhat by touching the adult transitions of care literature (Coleman and others). This literature focuses on transitions from hospital to home or to nursing home, etc., but it tends to support the Six Core Elements in endorsing preparation, planning, coordination, communication with tested tools that may have application in the pediatric to adult care transition. The adult literature also articulates the important notion of clinical responsibility for the patient resting with the "sending entity" until care is firmly established in the receiving entity. Transitioning young adults following their "final visit" to their pediatrician are sometimes unclear who to call with problems or prescription renewals, etc. prior to their first appointment on the adult side - this can be a period of months	We recognize this is an important issue; this brief is focused on the transition process for youth. We have made this clearer in the background and methods sections.
Reviewer 7 (TEP)	Background	Transition care examples are generally referred to as "programs" throughout the Brief, which conveys the impression that transition care is an add-on to other clinical care rather than embedded in it. While "transition programs" do exist, mostly in children's hospitals, they can only address the needs of a relatively small number of transitioning youth.	We changed to transition care and transition processes as appropriate throughout the document.
Peer Reviewer 8	Background	There should be 1 sentence in the abstract that states that poor outcomes have been associated with the transition period, and hence why this review is necessary. Just because people age and need to transfer doesn't justify the need of transition programs. This is done in the section, GQ1, but should be noted earlier.	We have moved the data about health impact of poor transitions to the background section to further emphasize the significances of improving healthcare transitions for children with special healthcare needs.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer 8	Background	Similarly in the background, there should be a brief summary paragraph on the current state of transitions/problems and a summary of poor transitions and outcomes. Currently, outcomes are buried in the report. There is data that supports why addressing transitioning is important (Lotstein, CF foundation, recent diabetes literature, adolescents utilizing EDs rather than primary care, associations with continuity of care and poor health outcomes). It's not just about prevalence, nor age cutoffs, but the increased morbidity and mortality that occurs during this period. I think it's important for an AHRQ report to indicate the poor outcomes attributed to poor transitions and why these interventions are necessary. One can argue that, just because you're not counseled on transitions, doesn't justify the costs of implementing a program if it doesn't pertain to long-term outcomes. I agree with the first paragraph, with letting people know there is no age cut off. I do think it's important to indicate the "so what", as a naive reader may think "Well, just boot these attached young adults from your clinic… problem solved".	We have added a description of outcomes to the Background section. We recognize that there are a host of challenges and poor outcomes associated with poorly planned transition that has been described in the literature, including increased morbidity, poor health outcomes, and reduced quality of life.
Peer Reviewer 8	Background	I agree that the authors acknowledge "….individuals with developmental disabilities that are associated with a host of challenges ranging from higher risks of specific health outcomes to the need for special support in navigating the health care system." I don't consider the higher risk of health outcomes as a challenge, rather a poor outcome. The challenges are poor navigation, developmental stage of the patient, health literacy, provider knowledge, system integration and a host of other factors already well described in the literature are issues which then potentially lead to poor health outcomes. Unfortunately, as the authors note, data investigating what specific domains/process targets are related to improved outcomes is limited and is why we need to develop the evidence as to what processes improve transition outcomes in this population. Even implementation of the GotTransition recommendations may not lead to improved clinical outcomes.	We agree we need more evidence.
Peer Reviewer 8	Background	There is a distinction between the transition process and transfer process, and that should be clearly defined at the beginning of the report. The Blum definition of "purposeful and planned movement the definition of transition" is often widely cited as the definition of "transition". This is as compared to transfer. Transition of care tends to have the domain of the youth, family and provider and is done over a prolonged period of time. As written the work muddies the difference between transfer programs from a pediatric to adult provider and transition programs with elements of transfer. It does not discuss the purposeful and planned movement from pediatric to adult health systems. This would also help capture the mechanisms of how each program was designed. Some programs are transfer-based, some are more transition preparedness based. While there is a header of "transition and transfer" the work doesn't make the distinction clear.	We have included an operational definition for transfer in the Background of the Brief.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer 9	Background	The authors need to state clearer that 18 years of age traditionally has been a time of change in the various systems, including health care. At a minimum, parents do not have access to the youth's records without the youth's permission. So it's not so arbitrary as it sounds on line 8, page 1 and it's not just moving from a pediatrician to an internist. Transitioning cannot be seen as just transferring from a pediatric to an adult practice (one who sees a family physician may never had to change practice) but must be seen as moving from a pediatric system to an adult system. Also, increasingly, children's hospitals have instituted age cut-offs. So there are structural barriers for young adults	Reframed the statement to indicate that 18 is the age of majority and this is the age at which parents may lose access to their children's records.
Peer Reviewer 9	Background	I suggest establishing a broader rationale, not just viewing this at the clinical level but also at the population level. First, there's a need to acknowledge the vulnerabililty of the population of youth and young adults in accessing the needed health care services, particularly those with special health care needs. Then one can establish the need by noting the increasingly number of youth and young adults with special health care needs and the need to assist them in managing their own health, realizing their full potential of achieving independence, higher education, and employment and their contribution to society. More need to be said about the health care transformation, the need to improve quality of care, health experiences while controlling costs and how the attention to reform is increasing attention on the transition issue with the need to improve services and resource allocation.	We agree that this is broader issue. The scope of this technical brief is healthcare system.
Peer Reviewer 10	Background	One example, page 1, 4th paragraph. Report states "Currently, around 500,000 children in the United States with special health care needs transition to adult care annually" This should say " 500,000 children in the United States with special health care needs age out of the pediatric system"… May youth are lost to follow – drop out of care when discharged from peds. As written, this could be interpreted as indicating the 500000 are transitioned (receive transition care)	We have added discussion of recent data about the number of youth who reach transition age to complement this statistic about the number of youth who transition.
Peer Reviewer 10	Background	A serious omission in the background section is a discussion of why transition services are necessary. (It is my experience that many health organization leaders – especially those in the adult system do not understand why transition-related services and supports should be provided to youth with chronic health conditions.)	We have added data in the Background to illustrate some of the poor health outcomes associated with failed or ineffective transition from pediatric to adult care.
Peer Reviewer 10	Background	The background section appears to me to be a fairly random compilation of phrases pulled from the background section of other articles and reports.	We have made significant revisions to the Background.
Peer Reviewer 10	Background	It does help the reader gain an understanding why transition services are a critical component of high-quality care for YSHCN.	Thank you for your comments.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer 10	Background	Brumfield & Lansbury (2004, Disabil Rehabil) (reference 62 in the technical report) includes a brief, but very informative description of transition (as an educational and therapeutic process) and discussion of why transition services are a necessary component of quality care for youth and young adults with chronic health conditions. Quotes and paraphrase from the article is below. It is currently well recognized that young adults, when developmentally ready, should receive their health care in adult-oriented settings.2 – 4 This 'transition' by the client with CF from a paediatric to adult health care setting involves the change in care as part of a planned, purposeful process which is an educational and therapeutic process.5, 6 Transition is necessary due to the great differences between paediatric and adult models of care. Rosen described the focus of care in a paediatric setting as being on growth and development, whereas in an adult setting it monitors the progression of illness.7 He also emphasized that while paediatricians tend to communicate with parents and other family members, the adult system communicates directly with the patient. In the adult care system, patients are empowered more with information, and have greater expectations placed on them.7 It is necessary that these differences exist, in order that care be appropriate for both children and adults. By instigating transition programmes, the change can be made gradual so increasing the comfort of patients and lessening the risk of associated complications.	Thank you for your comments and sharing the text from the cited publication. As you note, we cited the publication (Brumfield K, Lansbury G. Experiences of adolescents with cystic fibrosis during their transition from paediatric to adult health care: a qualitative study of young Australian adults. Disabil Rehabil. 2004 Feb 18;26(4):223-34. PMID: 15164956) in the report in Guiding Question 1a. We have made significant changes to the background section of the report to describe the need for transition.
Peer Reviewer 10	Background	Also, as background from one of my grant proposals: "Adult oriented health care providers expect their patients to be autonomous and able to negotiate the health care system with little or no help from their physicians. Thus, in order to be ready to receive care from the adult health care system, young adults must be capable of carrying a broad range of tasks and activities that include: making appointments and showing up on time for medical visits; providing a medical history, giving detailed information about their current symptoms; actively participating in medical decision making; following through on referrals; filling prescriptions and taking medications as directed and otherwise adhering to the physicians course of treatment; and having health insurance or otherwise being able to pay for needed care1. 2"	Thank you. We have noted that we purposefully confined the scope of the report to transition in health care, with the understanding that the provision of clinical services is a part of a comprehensive evaluation of successful transition that would likely include educational, psychosocial, and occupational supports, to name a few. However, in several instances throughout the report, we have added text that is consistent with the information you shared from your grant proposal. In Guiding Question 1b: "It is worth noting here that while patients cared for by family practitioners may theoretically have the same primary care physician in both childhood and adulthood, these patients may still benefit from a process to help them assume increasing

Commentator & Affiliation	Section	Comment	Response
			responsibility for their own care as they age and may still need to transfer some of their care from pediatric to adult specialists." And "Second, youth and family report a need for education about the differences between pediatric and adult care and may receive ongoing anticipatory guidance regarding what to expect from adult specialty care as well as instruction for navigating the system of entitlements, such as Medicaid and Supplemental Security Income." In the section on Transition Preparation we note: "In the absence of rigorously tested transition readiness tools, use of behavior theories, such as the transtheoretical model and stages of change, to assess patient readiness has been suggested. The five stages of change in the transtheoretical model are precontemplation, contemplation, preparation, action, and maintenance and can describe transition from a patient who has not yet considered transition to the adult health care system through a patient that fully accepts responsibility for his/her health."
Peer Reviewer 10	Background	The background section should also include a discussion of the consequences of not providing transition care on youth/patients, families, health care professionals and health care systems.	We have added data in the Background to illustrate some of the poor health outcomes associated with failed or ineffective transition from pediatric to adult care.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer 10	Background	On page 1 (background) second paragraph, the authors make an error when presenting information from the 2002 consensus statement. The technical brief says that the consensus statement was published in 2011 (and references a 2011 secondary source) and describes "the purpose of transition care as to "maximize lifelong functioning and well-being…[thereby] ensuring that high-quality, developmentally appropriate health care services are available in an uninterrupted manner as the person moves from adolescence to adulthood."1 The word "thereby" was inserted by the technical brief authors, as shown by the [ ]. , This change to the original text alters the meaning of the quoted section – and result in an illogical statement. Further, the consensus statement talks about the GOAL (desired result) of transition, not the purpose (reason why something is done).	We have corrected to: The goal of transition in healthcare for young adults with special healthcare needs is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate healthcare services that continue uninterrupted as the individual moves from adolescence to adulthood' from the 2002 consensus statement.
Peer Reviewer 10	Background	The two sections of the consensus statement that describe the GOAL are as follows: "The goal of transition in health care for young adults with special health care needs is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood." "The goal is to maximize lifelong functioning and potential through the provision of high- quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood."	We have corrected to: The goal of transition in healthcare for young adults with special healthcare needs is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate healthcare services that continue uninterrupted as the individual moves from adolescence to adulthood' from the 2002 consensus statement.
Peer Reviewer 10	Background	The referenced 2011 Cooley article, which refers to the 2002 consensus statement also talks about the goal (not purpose) of health care transition. Cooley notes that a high quality transition process includes ensuring that health care is uninterrupted as the person moves to adulthood.	We have corrected this and noted that the 2011 reference reaffirms the 2002 consensus statement.
Peer Reviewer 10	Background	There should be a separate and clearly labeled section that answers each of the 3 questions separately:	The subquestions are identified in parentheses at the end level 2 heading for the Guiding Questions components. Correcting the error in list level (from m, n, o to a, b, c) will remedy this confusion.
Reviewer 11 (TEP)	Background	The background does a very good job of laying out the challenges in this area. The background summarized the clinical challenges and needs for new policies and practices in health care as it relates to youth with special health care needs and their families.	Thank you for your comments.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer 12	Background	This section provides the relevant background information for the report that ensues and summarizes the work to date in this field, appropriately pointing out policy documents and the Got Transition elements that have been articulated by the AAP, AAFP, and ACP. This section also provides the rationale for the report and underscores the great number of CSHCN who transition annually. I would suggest that since the 6 Core Elements of Health Care Transition (from Got Transition) form the basic framework for much of this report, it would be very nice to see these elements spelled out and expanded beyond the very cursory listing on page 2 (line 25). Couldn't a table with the elements and explanations of their components be included as an appendix for this document? I had to go to the www.gottransition.org website to track them down so I could more fully understand them.	Thank you for your comments. The Got Transition six core elements is cited and available online. We have included a more detailed description of the framework's six core elements.
Reviewer 2 (TEP)	Background-Guiding Questions	For question 1c, the report simply indicates that patients with cognitive difficulties might not be well served. It is not clear if the authors reviewed the literature on developmental disabilities, which is distinct from the literature on CYSHCN and may be informative.	The last sentence under Guiding Question 1c was misleading. It has been removed from the text.
Reviewer 2 (TEP)	Background-Guiding Questions	The review also makes assumptions that adult care settings may not be well suited, or may be less well suited that pediatrics, but no evidence is provided.	We have removed this sentence from the disadvantages text.
Reviewer 2 (TEP)	Background-Guiding Questions	Issues of duration of follow up are not addressed.	We agree this is missing in the literature. We have included information about length of follow-up for studies of transitions of care for CSHCN in Tables 3, 4, and 5 for Guiding Question 3.
Peer Reviewer 4	Background-Guiding Questions	These were outstanding!	We appreciate your comments.
Reviewer 5 (TEP)	Background-Guiding Questions	So I believe your questions were sufficient and comprehensive as the paper captured how I present the issue myself	Thank you.

Commentator & Affiliation	Section	Comment	Response
Reviewer 7 (TEP)	Background-Guiding Questions	As mentioned the guiding questions take a mostly pediatric perspective. They don't seem to distinguish the transfer of primary care from the transfer of specialty care or get at the ways in which to sequence the two.	We intended to report on children. We did not find information about the timing of primary and specialty care. We have added to the text for Guiding Question 4 (future directions): "No research has identified an optimal timing of transfer when multiple provider specialties are involved in an individual patient's care. Therefore, no data are available to guide which service should transfer first during the transition process." In Guiding Question 1 we noted, "Current practice involves a range from simple transfer of care from pediatric to adult settings that occurs at a set time-point to a well-planned and coordinated transition of care that occurs over time and encompasses elements both before and after the anticipated transfer of care.72-74" In Guiding Question 1c we state: "Our Key Informants noted that while all adolescents with a chronic condition would need some sort of transition support, their diversity in terms of conditions and complexity affects what is needed and where." Key Informants also stated that care plans be in place at the time of transfer (as noted in Guiding Question 2b)
Reviewer 7 (TEP)	Background-Guiding Questions	Overall the guiding questions are appropriate for the topic.	Thank you.
Reviewer 7 (TEP)	Background-Guiding Questions	In line 57 on page 9 - American Association of Family Practitioners should be American Academy of Family Physicians. Generally individuals in this specialty preferred to be called family physicians rather than family practitioners these days (check for other instances in the text).	This has been corrected. Thank you.

Commentator & Affiliation	Section	Comment	Response
Reviewer 7 (TEP)		Line 16 on page 11 - pediatric care is characterized as "generally centered around a medical home, including care coordinating with specialists" in contrast to adult care. The reality is that in both pediatric and adult care the medical home model remains aspirational at best in terms of penetration. Though progress is occurring, because of more incentives and interest, there may be more adult primary care practices nationally that have functionalities of a medical home. This sentence may need restating.	We have removed this sentence from the text.
Reviewer 7 (TEP)	Background-Guiding Questions	Line 54 and 55 on page 11 - GotTransition has been supported by cooperative agreements of the US Maternal and Child Health Bureau, first with the Center for Medical Home Improvement and now with the National Alliance to Advance Adolescent Health.	We have added this association to the text under Guiding Question 1.
Peer Reviewer 8	Background-Guiding Questions	The questions posed by the authors are appropriate to the field.	Thank you.
Peer Reviewer 9	Background-Guiding Questions	One needs to include the components of transition care in the adult system.	Thank you.
Peer Reviewer 10	Background-Guiding Questions	I feel that the report might be clearer if Question 1a was changed to “What are the goals of transition care and …” and the term “purpose” (when referring to transition care, be changed to “goals”. This might help the authors organize materials under Question 1; and more clearly and consistently distinguish between content related to Q1a, Q1b, and Q1c	We have revised from “purpose” to “goals” for clarity.
Peer Reviewer 12	Background – Guiding Questions	The guiding questions are appropriate to the topic at hand and are modified as needed for this population and topic.	Thank you.
Peer Reviewer 12	Background – Guiding Questions	It would have been nice to see the list of Key Informants to help me in evaluating this Technical Brief, but perhaps it is a policy to not include them at the review stage? I didn't see anything in the guidance provided that explained why their names weren't included.	The reviewer is correct; it is the EPC Program policy to not include the names of Key Informants in the draft report. The names of Key Informants are in the final report.
Peer Reviewer 12	Background – Guiding Questions	One other note: in subsequent lists of the Guiding Questions, the sub-bullets continued the lettering after "l" starting with "m" on page 9. I suspect this is an error of the automatic formatting that Microsoft Word often performs, but it did make it confusing to follow.	This has been corrected.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer 1	Methods	The references cited for this report were generated from one search engine, PubMed. It would be relevant to this document to access additional search engines such as CINAHL and PsychINFO.	During peer review, we updated the results of the literature search and conducted a separate search in CINAHL. In our initial testing of search strategies and databases, retrieval from PsycInfo was duplicative.
Peer Reviewer 1	Methods	There are noteworthy articles that are missing from this review. For example, a special issue of the International Journal of Pediatric and Adolescent Health on health care transitions published in 2010. None of the articles from that issue are cited in this document and there are relevant studies to be included in this document.	We used hand searching to identify papers from this and other journal titles. We screened articles from the 2010 Journal of Pediatric and Adolescent Health and included one of these in the report.
Peer Reviewer 1	Methods	Discussion with Key Informants: This section lacks important information about the process. There is no information provided as to the Key Informants who participated in the process. The authors did not provide information about the following: a) number of Key Informants who participated; b) background information about the participants (discipline/years of experience/affiliation in terms of clinical/academic setting); and c) the process used to select Key Informants. The authors did not provide information about the procedures used in eliciting input from the Key Informants. There are several questions that need to be addressed in this document: Did Key Informants meet together as a group? Were Key Informants interviewed individually? How often did Key Informants meet? Were Key Informants interviewed more than once? In addition, questions remain as to the development of the interview process used to elicit input from the Key Informants as this information is missing in the document.	We have added information to describe the Key Informant interview process and supplied additional details about Key Informants.
Peer Reviewer 1	Methods	The author do not specific the procedure that was employed to access the grey literature.	We have added information to the methods section and reference the appendices for additional details on the findings form the gray literature.
Reviewer 2 (TEP)	Methods	The methods are well described.	We appreciate your feedback.
Reviewer 2 (TEP)	Methods	The table of admissible designs seems to suggest the all the listed studies are subsets of RCT's---I think this is a punctuation issue.	This has been corrected.
Sharadha Kulamani	Methods	In order to solve this type of nature we humans should bring the ecosystem under one roof not dividing in case of race, religion, community, and country. Than everything will be available for everyone and we can shape the future men and women i.e. today's children.	Thank you for your comments.

Commentator & Affiliation	Section	Comment	Response
Marcia Kaminker	Methods	How many key informants were interviewed?	We held a conference call with four Key Informants and received written feedback from one. We have added information to the methods description to make this clearer.
Peer Reviewer 4	Methods	It would be helpful to include much more detail about the Key Informants. For example, how many were included and how were they engaged? I think especially given the interdisciplinary nature of the topic, it is very important to describe what specific fields the Key Informants represent and their involvement in transition as clinicians or researchers or both.	We held a conference call with four Key Informants and received written feedback from one. We have added information to the methods description to make this clearer.
Reviewer 5 (TEP)	Methods	Very concise and informative on how you did the research. As a key informant, it would of been interesting to see the summary of what everyone had said during the discussions. Maybe a summary table but of course that won't have been in the method section.	The summary of Key Informant discussions are distributed to participants but are not published as part of the review.
Reviewer 6 (TEP)	Methods	No comments. Well-described.	Thank you.
Reviewer 7 (TEP)	Methods	The methods are clearly described and reflect the state of knowledge, current research, and the literature on this topic. As mentioned, elements of the adult literature might have been missed if the search terms included items such as "children with special health care needs."	Thank you. We have added statements in the Introductory sections to re-emphasize that this report was focused on the literature in youth.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer 8	Methods	The methods seem appropriate, though the authors missed several consensus statements, and I'm not sure how that occurred given the search criteria and paneling.	We have reviewed our database of literature and have identified and added five consensus statements on transition. 1) Bell et al., Adolescent transition to adult care in sold organ transplantation: a consensus conference report. American Society of Transplantation, Pediatric Committee. (2008) 2) Rosen et al., Transition to adult health care for adolescents and young adults with chronic conditions. Society for Adolescent Medicine. (2003) 3) Sable et al., Best practices in managing transition to adulthood for adolescents with congenital heart disease: the transition process and medical and psychosocial issues. American Heart Association. (2011) 4) Sullivan et al., Primary care of adults with developmental disabilities. Canadian Consensus Guidelines, Colloquium on Guidelines for the Primary Health Care of Adults with Developmental Disabilities (2011) 5) Van Riper et al., Position of the American Dietetic Association: providing nutrition services for people with developmental disabilities and special health care needs. American Dietetic Association. (2010)
Peer Reviewer 8	Methods	Appendix D: In looking at your exclusion criteria, what do you define as “original research” There were quite a few primary data collection studies and analyses of national surveys that were excluded as “not original research”. I would have placed these as X-6 “original research, not answering a guiding question”. The ones that are labeled as X-6 “original research, not answering a guiding question” were mostly expert opinion papers. Did the authors get this category label switched?	Yes, the coding for the labels was incorrect. X-5 should be “original research not answering a guiding question” and X-6 should be “not original research and not answering a guiding question”. We have made the edit to the Appendix. Thank you for this keen discernment.
Peer Reviewer 8	Methods	Appendix C-3: There were two specific society consensus/policy papers that should be included.	Thank you. We have added these to our list in C-3.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer 9	Methods	While the authors indicated the type of individuals they interviewed, they did not indicate the number of individuals.	We have added this information to the description of Key Informants section in the Methods chapter.
Peer Reviewer 9	Methods	It is unclear if interviews were conducted with youth, young adults, and/or parents. It would be a major gap if their opinions were not captured.	We conducted discussions with advocacy group representatives, as well as healthcare providers, researchers and policy makers.
Peer Reviewer 9	Methods	The subject matter was well researched and the published literature search included major publications. I found the summary of grey literature useful, particularly the categorization of the resources. However, I don't understand how the search did not reveal some important resources including those from MDA, AUCD, American College of Medical Genetics ACT sheets on transition, Nemours, New England Genetics Collaborative Transition toolkit (http://newenglandconsortium.org/for-families/transition-toolkit/printable-transtiion-toolkits).	We did not intend to capture all relevant Transition literature and grey literature for this particular report. We used multiple strategies to locate and identify transition literature and resources and screened more than 2000 items. We are sensitive to the fact that some things were missed. We are appreciative of your and others efforts to notify us of specific citations that were missed; we have added these to the appropriate sections within the report.
Reviewer 11 (TEP)	Methods	This area did describe the engagement with the key informants, and provided an outline of how they were identified and their backgrounds of clinical, policy, research and advocacy perspectives.	Thank you.
Peer Reviewer 12	Methods	I thought the process used and the resources accessed were appropriate. The survey of key informants, published literature, and "grey" (why is it "grey" literature and not "gray"??) Literature was appropriate and comprehensive. Again, I can't evaluate the qualifications of the key informants since I don't know who they were. I note that appendices A, B, and D further flesh out the methodology. It is rigorous, systematic, and thorough.	We have corrected from “grey” to “gray”.
Peer Reviewer 12	Methods	Related comment: In appendix C-1, the summary of grey literature, the headings for the table were unclear. For example, what is meant by "Government"? Does this mean funded by the government, sponsored by the government, or something else? Federal or state government? The bullets did not appear to consistently indicate any of these possibilities, so I was left confused.	We have inserted a description of the coding and definitions we used to categorize the resources, “Data Coding and Definitions for Table C-1”. We reviewed the “Government” column of Table C-1 and elected to remove this column because the information does not add value and as the commentator notes, the categorization is inconsistent. Furthermore, Table C-2 provides a more comprehensive list of U.S. Federal and State-level resources.

Commentator & Affiliation	Section	Comment	Response
Reviewer 2 (TEP)	Findings	Comments on the findings are noted in the general comment section, above.	Thank you.
Reviewer 2 (TEP)	Findings	The listing of advantages highlights access to sub specialists, but the literature emphasizes both primary care and subspecialty care.	We have edited this section to emphasize advantage of providing ongoing care both to primary care providers as well as subspecialist providers
Reviewer 2 (TEP)	Findings	The emphasis on education (especially of adult provides) in specific conditions may not be appropriate. Education about a condition that a provider may never see or see only rarely is unlikely to be valued or recalled. A more appropriate recommendation is to make on demand support and access to information and consultation available. (page 19).	For clarity, we have added the statement "In cases where training the adult providers is not feasible, or the specific condition that a patient presents with is too rare to warrant training, the availability of consultation with experts in specific childhood-onset conditions may increase adult providers' willingness to provide care to transitioning youth with special health care needs."
Reviewer 2 (TEP)	Findings	A sharper differentiation on transition issues addressing autonomy and pragmatics (e.g., insurance) from issues of clinical management and interpersonal care seems warranted. The issues in organization of services, planning and execution may be quite different.	We have revised and reorganized section and statements within the report to improve the distinction between the concepts.
Reviewer 2 (TEP)	Findings	On page 21, the comment about individual vs. multidisciplinary care being different in adult and pediatric settings ignores the major emphasis on medical home in adult settings.	We have removed this sentence from the text.
Reviewer 2 (TEP)	Findings	The review of evidence is quite helpful and well done.	Thank you for your comments.
Reviewer 2 (TEP)	Findings	The emphasis on "objective" measures (as opposed to valid and reliable measures) is not well supported. Many of the reports do include "objective" measures such as HgbA1c values.	Thank you. We have added text to Guiding Question 3 to address this comment.
Reviewer 2 (TEP)	Findings	The section on patient specific information requires further explication. Is "controlling" for differences in patient and system characteristics the appropriate strategy? I suspect there will be substantial interaction.	We have revised this section and noted "In addition, the hypothesis that children with different diseases may require different transition processes requires further investigation since no study has evaluated the efficacy of disease specific versus general transition processes in a comparative manner."

Commentator & Affiliation	Section	Comment	Response
Reviewer 2 (TEP)	Findings	The section on educational research mixes patient and provider education, and focuses on whether education takes place vs. effective mechanisms to improve care and outcomes.	As this is part of the “Future Research” section it does not outline effective mechanisms. We have separated the statements on provider and patient education.
Peer Reviewer 4	Findings	Overall, I thought that the findings were clearly presented and comprehensive.	We appreciate your comments.
Peer Reviewer 4	Findings	The barriers (starting on p 21) were presented in a piecemeal fashion. It might be helpful, with an eye towards intervention, if some of these were linked together.	We have re-organized the “Barriers to Implementation and Transition” section.
Peer Reviewer 4	Findings	The section on personnel (p 24) felt unfocused. It might be helpful to discuss broadly what areas of expertise are needed during transition. Given the issues presented, it seems like experts in disease specific concerns (physicians, nurses), adolescent/young adult development, psychosocial considerations and case management are all essential while there might be other personnel recommended for specific presentations (e.g. a pharmacist, dietitian).	We have added the statement, “In cases where training the adult providers is not feasible, or the specific condition that a patient presents with is too rare to warrant training, the availability of consultation with experts in specific childhood-onset conditions may increase adult providers’ willingness to provide care to transitioning youth with special health care needs.”
Peer Reviewer 4	Findings	Finally, I was surprised to see little information about parents in the report.	We have added reference under Guiding Question 1 regarding value of continued family involvement.
Reviewer 5 (TEP)	Findings	On page 13 under transition registry "practices can maintain transition registries" Do you want to reference that this practice is part of the global practice of medical home that transition should be a part of?	Thank you. We have added text and cited, “Clinical Report – Supporting the health Care Transition From Adolescence to Adulthood in the Medical Home”
Reviewer 5 (TEP)	Findings	Also on the same page (line 15/16) list "capacity building” I thought this also meant the need to increase the number of adult health care providers willing to accept this population of patients. I am now questioning my use of the phrase as that is what I use it for.	We agree that this terminology is confusing and have deleted it from the text.

Commentator & Affiliation	Section	Comment	Response
Reviewer 5 (TEP)	Findings	Throughout the documentation the use of cognitive impairment/delay/limitations is mentioned although there is also mention of intellectual disabilities such as on page 12 line 9/10 and developmental disabilities on page 37/38 page 14. When I see cognitive impairment I think of an elder with a stroke. Usually children are referred to as having IDD or intellectual and/or developmental disability. Putting on my medicine cap I think of cognitive impairment more as someone who had a stroke or accident and may get better. Not sure if you want to make it more consistent across the paper. You might want to consult your development folks on the proper terminology to use.	We have reviewed the terms and changed from “cognitive impairment” to “intellectual disability”.
Reviewer 6 (TEP)	Findings	Typo on page 9, line 57: It is the American ACADEMY of Family Physicians (not "Association")	This has been corrected. Thank you.
Reviewer 6 (TEP)	Findings	Page 15, Table 2: consider adding clinical decision support systems (to the Checklists item) that remind clinical teams about sequential steps for transition planning .	We have added text under Guiding Question 1b. We think this is a very forward-thinking and important idea, though we do not have any references that specifically discuss it. We have added this to the bullet list of descriptions in Checklists item as suggested by the reviewer.
Reviewer 6 (TEP)	Findings	Page 22, line 47: minor edit suggested. Suggest simplify, "...more of the burden of responsibility on the individual" to, "...place more responsibility on the individual..."	We have corrected as suggested.
Reviewer 6 (TEP)	Findings	Page 24, lines 43-46: What about a comment about the challenges of implementing such a team-based model outside of health systems; the challenge of robust transition teams in independent practices due to the lack of a business model (i.e., sufficient payment to offset the costs of the additional resources needed)?	We have added the statement, “Indeed, it should be noted that there may be substantial resource barriers to implement team-based care in independent practices, so practicality of this type of approach should also be studied.”
Reviewer 6 (TEP)	Findings	Page 25, lines 3-5: understand the reason why HIPAA is included in this list, but in a section highlighting the deficiencies in the clinical knowledge of adult health providers, leading with HIPAA as an example of training modules (i.e., instead of a clinically relevant one) seems a bit odd.	In the section, “What additional training is necessary”, we have revised to place the clinically relevant examples before the HIPAA example.
Reviewer 7 (TEP)	Findings	The findings are clearly portrayed and seem to proceed from the methods in a logical manner.	Thank you.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer 8	Findings	Disadvantages on page 10. Potential disadvantages to improving transition include cost of system changes, loss of revenue for children's hospitals (especially if congenital cardiovascular cases are moved from pediatrics to adult hospitals), potential poor outcomes by transferring patients to providers who may not be trained in disease specific generalized care.	Thank you. We have added this information to the section, "Disadvantages"
Peer Reviewer 8	Findings	Line 17 page 9, got transition probably shouldn't be a superscript.	Thank you, this was a typographical error that has been corrected.
Peer Reviewer 8	Findings	In discussing differences in pediatric care, one can mention that pediatrics is family centered, but adult medicine is moving towards patient centered care (that doesn't really involve families, rather forces engagement with patient). In doing the right thing for adult patients, it has caused problems in pediatrics.	We added the following statement, "In particular, increasing emphasis on patient-centeredness in adult care, in which patients are expected to work in partnership with their clinicians to make medical decisions, may paradoxically cause undue stress on individuals with special health care needs especially as they transition."
Peer Reviewer 8	Findings	In describing barriers (pg 23) There are differences in resources between pediatrics and adult medicine. Philanthropic donations, differences in funding streams allow for programs to be generated that may or may not be evidence based, but have significant resources for patients (transition programs, multi-specialty disease specific programs). This is more prevalent in pediatrics, but is fiscally unsustainable in the adult medicine world. Adult medicine doesn't have specialty programs that can generate the same level of resources as pediatric institutions, the exception being the CF programs because of the CF foundation, and a few other niche programs. This may be a challenge/barrier.	Thank you for the comment
Peer Reviewer 8	Findings	We still lack research on what is normative development for chronic disease management. That is, when should a child know how to use an inhaler? When should a child know how to measure their insulin and inject themselves? Until we know what is normal and expected, it's difficult to generate training and assessment.	Thank you for your comments.
Peer Reviewer 8	Findings	Page 25. In addition to Medicaid, age out of Title V services may have greater impact for those with severe medical needs that require durable medical equipment. There is no "title V equivalent" in adult medicine.	We address this issue in the "Summary and Implications" section.
Peer Reviewer 9	Findings	Please correct the statement on page 11, line 54. Got Transition is the name of The National Alliance to Advance Adolescent Health's transition initiative/center, which is funded by the US Maternal and Child Health Bureau.	Thank you. This has been corrected.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer 9	Findings	Research on use of technology is important. The role of social media and telehealth in particular. Also, there needs to be better research and measurement on the experiences of the youth, young adults, parents, and providers.	We have commented on use of technologies for transition in the "Transition Registry", "Transition Completion" sections of Guiding Question 1b and in the "Future Research" section.
Peer Reviewer 10	Findings	[GQ1- Purpose of Transition Care] This section needs to be reorganized. It is confusing to start this section with data on #'s and survival rates, and a vague description of the limitations of current transition services. It should start with a clear statement about the goal s of transition care.	The section has been reorganized. We have moved this information to later in the section.
Peer Reviewer 10	Findings	The section "What is the purpose of transition care and what are the theoretical advantages and disadvantages?" should not include any information about the common components (which is the focus of question b).	Thank you for your comments. We have reviewed the content of this section to ensure that the information is consistent with the heading.
Peer Reviewer 10	Findings	This is an example of content that lacks clarity; and combines 2 separate ideas into one sentence. "Unfortunately, health care delivery systems that support optimal transition from pediatric to adult providers have not kept pace with this growing population, and abrupt transfers from pediatric to adult health care fail to meet the needs of this population"	We have revised and this sentence and separated the ideas into distinct sentences. We now state "When transition involves only an abrupt care transfer, patients may be put at risk of getting "lost in the system"…" We also have a new paragraph in this section describing the increasing number of children and youth with special health care needs living into adulthood.
Peer Reviewer 10	Findings	The phrase "that support optimal transition from pediatric to adult providers" is a misleading modifier of "health care delivery systems" should be deleted. I think the authors tried to paraphrase content from an article/report and, in doing so produced "Unfortunately, health care delivery systems that support optimal transition from pediatric to adult providers have not kept pace with this growing population, and abrupt transfers from pediatric to adult health care fail to meet the needs of this population".38, 39	We have deleted the statement and revised the section to now state "When transition involves only an abrupt care transfer, patients may be put at risk of getting "lost in the system or experiencing decreased access to care, both of which may be associated with poorer long-term health outcomes, impaired function, and high-cost emergency care." We also have added a paragraph in this section describing the increasing number of children and youth with special health care needs living into adulthood.
Peer Reviewer 10	Findings	[in GQ1, Purpose of Transition] "unfortunately" is not a term to be used in an objective technical report.	We have deleted the word "unfortunately".

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer 10	Findings	As noted above, cited articles assert that the Goal of health care transition is to optimize quality of life, etc. [in GQ1, Purpose of Transition] "The purpose of transition care is to optimize the quality of life and future potential of youth with special health care needs by ensuring continued access to and appropriate use of clinical care.1, 23, 43-49"	Thank you for your comments.
Peer Reviewer 10	Findings	This first sentence should be broader – and serve as an introduction to the many, related goals and objectives of transition services and supports. I recommend that the more concrete patient centered functional goals (improve patients communication, decision making and self- care skills) be presented before the broader, long term goal of optimizing future potential. (Skill building is a key component of transitional programs and services).	This has been revised to now read "The provision of high quality transition care for youth with special health care needs should optimize the patient's quality of life and ensure continued access to and appropriate use of clinical care. More specifically, the American Academy of Pediatrics (AAP) suggests that good transition care follow the principles of the medical home. Transition care should be coordinated, comprehensive, individualized, culturally competent, and patient-centered. The AAP also recommends that the transition program promote skills in communication, decision-making, assertiveness, and self-care to enhance a sense of control and independence of health care for youth."
Peer Reviewer 10	Findings	Discussion of model programs (page 17, line 10) does not belong in this section – This content addresses Question b (common components of transition care interventions or processes used in clinical practice for children/adolescents with special health care needs?)	The statement you refer to is a summary from the Key Informant Interviews; the statement summarizes the panel's comments on the purpose of transition.
Peer Reviewer 10	Findings	[In GQ1a, "Advantages"] what is a "proposed advantage" Maybe "Benefits" is a better term than "advantages". Maybe "potential benefits" of transition "services and supports" rather than programs. This section is supposed to address the potential benefits of transition services and supports, even if they are not provided through a "program"	We have revised to "proposed benefits" as suggested.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer 10	Findings	[In GQ1a, "Advantages"] the use of the term "Program" implies that transition related services are separate and different from the activities that primary and specialty care professionals can engage in as part of their care.	The statement has been revised. We have revised from, "Proposed advantages of purposeful transition through organized programs are that they provide youth with access to subspecialists for ongoing care, promote competence in disease management, foster independence, social, and emotional development through teaching self-advocacy and communication skills, and allow for a sense of security for support of long-term health care planning and life goals." To "Proposed benefits of purposeful transition care are that it provides youth with ongoing access to primary care and subspecialist care, promotes competence in disease management, fosters independence, social, and emotional development through teaching self-advocacy and communication skills, and allows for a sense of security for support of long-term health care planning and life goals."
Peer Reviewer 10	Findings	[In GQ1a, "Advantages"] the following "advantage" is not directly related to benefit derived from a transition program or approach. Rather is speaks to the advantage of transferring pediatric patients "early enough". An example of seeing "transfer" as "transition care" : "advantage of transitioning is that eventually, as patients age, they will need additional targeted care for issues related to adulthood and aging. Adult providers are better suited to address adult issues such as pregnancy and comorbidities associated with adult lifestyle and ongoing aging, so establishing care early enough for them to follow the patient through adulthood may be helpful.58, 59"	We have revised the paragraph to clarify and we inserted the sentence, "When addressing the advantages of transition care, benefits of the actual transfer of care to an adult provider must be considered."
Peer Reviewer 10	Findings	[In GQ1a, "Disadvantages"] "There is general agreement in the literature and among key informants that the advantages of a well-planned, tailored transition approach are many" belongs in advantages, not disadvantages. Rather: There is general agreement in the literature and among key informants that and that a poorly planned, unsupported transition of care from the pediatric to adult setting for individuals with special health needs can result in poor health outcomes.	Thank you. We have deleted the statement.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer 10	Findings	[In GQ1a, "Disadvantages"] The term "TRANSFER" should be used here, rather than transition: "Certain populations may be at increased risk for adverse or worsening outcomes following a transition in care."	We agree and have made the recommended changes.
Peer Reviewer 10	Findings	[In GQ1a, "Disadvantages"] The term "TRANSFER" or "the move from pediatric to adult care" should be used here, rather than transition. This is NOT a disadvantage of "a planned purposive process" for moving from pediatrics to adult care: "An inherent disadvantage of transition care includes a change in the health care provider and a move away from a familiar pediatric setting."	We agree and have made the recommended changes.
Peer Reviewer 10	Findings	Again, the term "TRANSFER" or "the move from pediatric to adult care" should be used here, rather than transition. This information is from an article that studied the impact of the move to adult care; it was not a study of the impact of a transition program or transition services. NOT a disadvantage of using "a planned purposive process" to move patients from pediatrics to adult care: "As illustrated in a study published in 2011 that assessed the transition experiences and medical outcomes of a cohort of individuals with HIV acquired in childhood, the transition to adult care was more difficult than expected, and youth reported feelings of abandonment and sadness with the loss of patient-provider relationship after transfer to adult health care. Almost one half of the participants who transitioned to adult care (19/42) reported problems with medication adherence. This study also reported that CD4 counts trended downward from pre- to post-transition.64"	We agree and have made the recommended changes.
Peer Reviewer 10	Findings	All of the items listed as disadvantages are examples of how the author's failure to understand the difference between transition and transfer results in an inaccurate conclusion. The examples listed above are not disadvantages of providing transition services; but rather are examples of the consequences of not providing transition services	We agree and regret that we were not more deliberate about the use of the terms transition and transfer. The commenters point is well taken.
Peer Reviewer 10	Findings	[GQ1 Components of Care, models of care] Primary care model – no mention is made of transition related services and supports. Does this model address more than care coordination? Cooley's Got Transition model is a primary care model (where the PCP promotes patient autonomy and decision making, etc.). However the authors fail to clearly identify it as such in this section.	We have added information to address this comment and the sentence now reads, "The most common practice models are: a primary care model where the general practitioner provides ongoing medical care and implements and/or utilizes transition related services and supports"
Peer Reviewer 10	Findings	[GQ1 Components of Care, models of care] Did the authors rely on secondary sources to conclude that the three models cites were the "most common" ways in which transition services and supports are provided to youth?	We have inserted the relevant references.

Commentator & Affiliation	Section	Comment	Response
Reviewer 11 (TEP)	Findings	This section contains very helpful information about the transition intervention and its context. The identification does need to be corrected. Under Findings, under each Guiding Question, the sub questions need to be clearly marked a, b, c... Instead, they were incorrectly marked beginning with an m and this made the outline somewhat confusing at first. With that correction made, the information is clearly identified and outlined.	Thank you. We have corrected the lettering for the Guiding Question sub-questions.
Peer Reviewer 12	Findings	This is the critical section of the report, and is well-stated and clearly organized. This is a very good summary of the relevant findings from the variety of sources including published literature. The section is organized based on the Guiding Questions and the 6 Core Elements from Got Transition, and I think this is a good strategy. (Again, I would have loved to see these elements spelled out/explained in one concise location!). I was impressed by the information provided in section GQ2c on Barriers to Implementation of Transition Care and appalled by the dearth of provider training in child onset conditions;	Thank you.
Peer Reviewer 12	Findings	page 23, line 44 comments that "more than half of pediatric neurologists were unable to find adult neurologists wiling to care for patients with severe disabilities." Moreover, the review of the evidence provided in section GQ3a was even more appalling; of only 21 studies in 23 publications was there even an attempt to evaluate the approaches to provide transition care, 8 dealt diabetes care (where at least one quasi-objective measure, the HbA1c level is available), and only one dealt with physical disabilities. I did not see a single study that addressed cognitive or behavioral disabilities including autism. This is unbelievable given the burden of care and high prevalence of these conditions! This point was made several times in the report but is worth calling out. In addition, the need for family-centered care, the lack of insurance coverage, the lack of natural history data for many of these conditions, and the lack of well-defined outcome measures were also highlighted as issues.	Thank you for your comments.
Peer Reviewer 12	Findings	There is inconsistency in the use of AAFP and SAHM (see pages 9-10 where AAFP is improperly defined and page 14 (line 52) where SAHM is misnamed the Society of Adolescent Medicine.	We have corrected to “American Academy of Family Physicians” and we have corrected use of Society for Adolescent Medicine and the Society for Adolescent Health and Medicine.
Peer Reviewer 12	Findings	Page 10, line 57: Need to indicate that drops in CD4 counts correlate with worsening of HIV disease for those who may not know these nuances of HIV.	We have revised the sentence to “. This study also reported that CD4 counts trended downward, clinically indicating worsening disease status, from pre- to post-transfer.”

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer 12	Findings	Page 12, line 51: Pamphlets may be portable and cost-effective, but in this day of social media and a savvy adolescent population, they seem outdated. I was pleased to see references to other forms of educational materials such as cell phone apps, internet sites, and text messaging, among others, called out on page 20 (line 32).	Thank you.
Peer Reviewer 12	Findings	Page 35, line 43: the issue of poor reimbursement is one that could be highlighted more strongly. I believe that until we demonstrate that transition care is cost-effective, there will be no traction (or adequate reimbursement) for its widespread adoption. Our health-care system is unfortunately driven by economic factors, and I think this element needs to be emphasized.	We agree and appreciate your comments.
Peer Reviewer 12	Findings	Minor point: page 28, last box in last column: what's a "YAC"?	We have spelled out the acronym.
Peer Reviewer 1	Summary & Implications	As stated at the beginning of this critique, the authors did not adequately distinguish the differences between health care transition and transfer of care.	We have clarified the “transition” and “transfer” in first paragraph of Guiding Question 1a. We have added a sentence to the background addressing the difference between transition and transfer of healthcare. “These recommendations also differentiate between healthcare transition and provider transfer, noting that transfer to an adult clinician may be one component of a successful transition process if dictated by the specific needs of an individual.”
Peer Reviewer 1	Summary & Implications	This implications section is narrowly focused on the transition issues concerning adolescents and emerging adults and their families. The authors focus on transfer of care and the acquisition of self-management knowledge and skills, which is certainly important but does not comprehensively address the range of their needs during this period. The preponderance of narrative in this section addresses service-related and provider issues.	We have revised this section, summarizing the findings from the evaluation studies.
Reviewer 2 (TEP)	Summary & Implications	The implications section also suffers from broad generalizations about adult care, the role of insurance and the impact of disadvantage on transition.	We have made significant revisions to this section and the “Next Steps” section to comment on the role of insurance.
Reviewer 2 (TEP)	Summary & Implications	The importance of defining a standard set or framework for outcome assessment of transition should be stated even more forcefully.	We have addressed this issue in the revised “Summary and Implications” text.

Commentator & Affiliation	Section	Comment	Response
Reviewer 2 (TEP)	Summary & Implications	In addition, as noted in my general comments above, the dimensions that CYSHCN that can affect transition are many; studies might examine how transition differs and how it is similar.	We agree, these and other important issues should inform a future research agenda.
Reviewer 2 (TEP)	Summary & Implications	The emphasis on QI research is outstanding. Providing a reference to a standard text would be good, as would a slightly expanded description of how such methods could apply.	We have added a reference to a basic text on quality improvement research designs to the section describing recommendations for study designs in future research.
Reviewer 2 (TEP)	Summary & Implications	Similarly, the review of technology is very superficial. There are some additional studies of technology and transition that could be cited.	We have added text and a reference on technology and transition
Peer Reviewer 4	Summary & Implications	The summary starting on p 36 of "Areas for Future Research" was very concise and helpful. I thought that it tied together the document very well. I might add more of this material to the specific "Summary and Implications" and "Next Steps" sections.	Thank you. We have added comments to the “Summary and Implications” and “Next Steps” sections.
Reviewer 5 (TEP)	Summary & Implications	I am wondering if this isn’t the place to say that the transition care supports the medical home concept, a concept that in itself is needing more validation. The "got transition" was built on the medical home concept.	We have addressed this concept in the revised “Summary and Implications” text.
Reviewer 5 (TEP)	Summary & Implications	What was most revealing to me was the paper cited the same 21 articles that I use to discuss transition research.	We are happy to hear that our retrieval and screening is consistent with the methods of other reviewers.
Reviewer 6 (TEP)	Summary & Implications	Nicely written; succinct.	Thank you.
Reviewer 7 (TEP)	Summary & Implications	The brief summary probably reflects the state of the science on this topic at this time.	Correct, that was the objective of this technical brief.
Reviewer 7 (TEP)	Summary & Implications	The summary again fails to frame transition care as grounded in a set of steps needed by all youth and young adults on which may be superimposed additional specialized elements for specific chronic conditions or populations.	We have addressed this issue in the revised “Summary and Implications” text.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer 8	Summary & Implications	GotTransition 6 core elements are not a program evaluation framework nor a research framework, but recommendations may be a target for outcome measures. Is that what the authors suggest? Are they suggesting that GotTransition 6 core elements should be outcome or process measures for program evaluations? If that is the case, there are many other transition domains that are not included in the 6-core elements which may have importance in transitions that are not measured. General implementation theories (ecological frameworks, individual theories, etc.) would be applicable for transitions because of the difference in systems that various practices reside. Also the recommendations in GotTransition are not unique; the various consensus statements also go over the elements of transition. Almost every transition program process fall under some domain (education, transition readiness, care coordination, measures etc.). Given the expenditure, and lack of outcomes, it may be difficult to justify certain elements that GotTransition covers. For example, generating a registry may not be feasible for some practices, and may not be necessary. Rather, there may be other ways for practices to ensure that elements of transition are performed uniformly that do not require a registry. Next steps may be studies of various modalities, or systems, which may allow for “preparedness”, "transition coordination", "transfer coordination" or “emergency care” to occur.	Our intention was to use the Got Transition rubric as a way to meaningfully organize the information in the report. We have de-emphasized Got Transition throughout the report and clarified how the brief is using the Got Transition framework.
Peer Reviewer 9	Summary & Implications	The GotTransition framework was designed to serve as a framework for quality improvement not health services research	Our intention was to use the Got Transition rubric as a way to meaningfully organize the information in the report. We have de-emphasized Got Transition throughout the report and clarified how the brief is using the Got Transition framework.
Peer Reviewer 9	Summary & Implications	I would have like the authors to have affirmed the need for the health care system to address more uniformly transition for children with special health care needs while acknowledging the varying needs of the various populations.	We have addressed this issue in the revised “Summary and Implications” text.
Reviewer 11 (TEP)	Summary & Implications	This section does address key decisional uncertainties by pointing out that the field lacks even a consistent and accepted way of measuring transition success. Starting with development of that measurement and building to establish consistent goals will be a first step so that a body of literature can be build to change policy and practice.	Thank you for your comments.
Peer Reviewer 12	Summary & Implications	One minor point: Typo on page 41, line 17--should be "clinic" not "clinical".	This has been corrected.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer 13	Summary & Implications	There is a need (implications section) to understand elements of transition readiness/transition care that are universal and elements that are disease specific.	We have addressed this issue in the revised “Next Steps” text: “An important consideration going forward is recognizing that while the health care system as a whole should more uniformly address transition needs for children with special health care needs, the specific implementations will reflect the substantial heterogeneity of this population…..This heterogeneity and implications for approaches to transition care could form an important basis for research, including identifying predictors of successful transition as well as assessing the appropriateness of common elements of transition care for different conditions and identifying which elements should be different.”
Peer Reviewer 1	Next Steps	This section is limited in scope and could be more fully developed.	We have made significant revisions to this section.
Reviewer 2 (TEP)	Next Steps	It would help if the authors were more explicit about how the got transition rubric could be used for framing research; if there were more specific ideas about outcome measures; and about the role of the ACA and its expansion on transition.	We have made significant revisions to the Next Steps section and addressed these important issues.
Peer Reviewer 4	Next Steps	Again, the emphasis on "Got Transition" did not feel convincing and perhaps even diluted the scientific tone of the report. But, the statement about investigators needing to agree on a rubric does make great sense (it seems like there have been far too many attempts at coming up with rubrics/models rather than acting on agreed upon ideas). I might suggest mentioning this earlier as part of the rationale for drawing from "Got Transition." It's not "Got Transition" per se but the need to move forward with a set of guiding principles that seems to be the framework for this report if I am understanding right.	This sentiment is now reflected in the section revisions.
Reviewer 5 (TEP)	Next Steps	Maybe transition success will have to be measured by quality improvement methodology and not by rigorous randomized controlled trials. Head to head would not be tolerated if one patient got the information and others left out "in the dark" to navigate on their own. The Got Transition principles lend themselves well to quality improvement projects.	Thank you. We have comments on the role of Quality improvement research in the “Areas for Future Research” section.

Commentator & Affiliation	Section	Comment	Response
Reviewer 6 (TEP)	Next Steps	Nicely written; succinct.	Thank you for your comments.
Reviewer 7 (TEP)	Next Steps	This section should comment again (as the authors did earlier) on the importance of engaging adult providers and adult health systems researchers.	Thank you, this is now addressed in the Future Research section: "Traditionally, transition efforts and transition research has been led by pediatric providers even though adult providers are an essential component to the transition process. Future research should include both pediatric and adult researchers."
Peer Reviewer 8	Next Steps	Unfortunately, many intervention studies, in general, follow no framework at all. This has been noted in the SQUIRE guidelines for quality improvement reporting. I do not recommend the next steps of research to emphasize the principles of the 6 core elements, as it is a clinical guideline (like the other consensus statements), but it is not a research framework, nor an implementation sciences framework. They are more of an action item, which may or may not be useful to a practice. I do agree with the authors that we require assessment of the various transition domains they noted in their review (e.g. assessing transition readiness, developmental need). Emphasizing that researchers need to be explicit about what transition domain they are investigating, then mentioning that GotTransition is one such clinical framework may be useful. I also think that recommendations from the other consensus statements should also be studied as whether or not these best practices improve health outcomes or quality of care delivery. I appreciate the authors trying to find a unifying framework, but having a more theoretically or evidence based program evaluation framework would be ideal. Recommending that we require further work on generating such research rubric would then be appropriate.	Our intention was to use the Got Transition rubric as a way to meaningfully organize the information in the report. We have de-emphasized Got Transition throughout the report and clarified how the brief is using the Got Transition framework.
Peer Reviewer 9	Next Steps	There currently exists a transition research community and the development of a consortium.	We have added information about the consortium.
Reviewer 11 (TEP)	Next Steps	The Next Steps section provides some very concrete important issues and a proposed framework for that including development of a consistent way of measuring transition success, development of consistent goals and even a rubric for synthesizing literature. Another key area pointed out here is research on the costs and resources needed.	We appreciate your comments.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer 12	Next Steps	This section was remarkably similar to Summary and Implications. I would like to see more specific "next steps" articulated that some of the research funding agencies could use in developing funding announcements or research programs to address transitions. After singing the praises of Got Transition throughout this document, the recommendation that investigators use this rubric "or another agreed upon rubric" when describing their interventions seemed a bit wishy-washy. This is an opportunity to really articulate a vision for this field, so I was disappointed that it didn't do more to propose a framework for moving forward.	We have made significant revisions to this section.
Reviewer 2 (TEP)	General-Clarity and usability	The report is clear and well organized and it can help inform future research. A crisper analysis of the current frameworks, current system and population would help more.	Thank you for your comments. We have made substantial revisions to the report.
Peer Reviewer 4	General-Clarity and Usability	Overall, I thought that the report was very well structured and organized. The appendices were excellent too. I thought that the "Areas for Future Research" section was a major strength in the document and could be used as a blueprint for future undertakings.	Thank you for your comments.
Reviewer 5 (TEP)	General-Clarity and Usability	I felt the summary was very good. The Next Steps or conclusion could develop bullet points on future research and needs more expansion. Those bullet points could start with the idea of using "Got Transition" principles as the "rubric" and that further research centers itself around these concepts. Doing quality improvement projects using the SQUIRE guidelines for quality improvement reporting. Using existing tools to broaden our knowledge about the patient's experience with transition e.g. National Survey of Children with Special Health Care Needs. Questions can be expanded on transition such as "did you use a transition tool" I also like the idea of cost effective medicine research and that could be expanded. These are just some ideas.	Thank you for your suggestions.
Reviewer 6 (TEP)	General-Clarity and Usability	The report is nicely structured; headings and subheadings make sense.	Thank you
Reviewer 7 (TEP)	General-Clarity and Usability	The report is readable and logically organized. The structure is laid out in the Abstract and then followed in the narrative. It seems to follow a more or less standard format. There is so much needed in the way of research especially around measures that demonstrate good transition outcomes and in turn provide an evidence base for good transition practices - this Brief would seem to provide a good beginning.	Thank you.

Commentator & Affiliation	Section	Comment	Response
Reviewer 7 (TEP)	General-Clarity and Usability	However, it is key that two points are made clear: 1) good transition care practices should proceed from good transition care for all youth/young adults rather than flowing in the other direction; 2) young adults in general are a special population needing special processes of care (including continued transition care) on the part of adult health care providers; the transition to adulthood in all of its aspects including health will continue for most youth well into the twenties and well beyond the transfer of care from pediatrics.	Thank you for your comments.
Peer Reviewer 8	General-Clarity and Usability	Generally this is well written and well organized. I would suggest being explicit about the various domains of research that need to be explored in the next steps.	Thank you. We have expanded the points in the Next Steps Section.
Peer Reviewer 8	General-Clarity and Usability	There is a paucity of process measures and outcomes research in transitions of care, and the authors articulate this well in their review.	Thank you for your comments.
Peer Reviewer 9	General-Clarity and Usability	I would have found the report more useful if the authors had identified and described the various models in existence (GQ1). Utilize matrix beginning on page 27. Model specific rather than condition specific. One perhaps then can apply the GotTransition framework to those models. It would be worthwhile to view how these models have addressed GQ2, what are the gaps. I'm not sure what information I gained, for example, with the examination of length of follow-up and outcomes measure except there are many diabetes transition studies and they all do it differently. I do commend the authors for all the good information.	We have reported on the information that was available in published studies and from gray literature sources.
Reviewer 11 (TEP)	General – Clarity and Usability	Except for the minor problems mentioned under the Findings, the report is well structured and organized. The conclusions are definitely clear about the lack of work in this area.	Thank you.
Peer Reviewer 12	General – Clarity and Usability	Yes, I think the report is very well-written and clearly organized. I think it has the potential to inform future research and I hope it will inspire the research community to adopt more rigorous standards and develop more robust outcome measures to address the identified gaps in transition research.	Thank you.
Peer Reviewer 12	General – Clarity and Usability	Related to this point, in appendix E, it would be nice to know the source of funding for the clinical trials cited. I know that this is generally available in clinicaltrials.gov, but it would be helpful to include this in the table as well. In order to make the case for further research in this area, I would like to know which agencies/foundations/etc are currently funding these studies, even if not terribly rigorous (or perhaps moreso!).	Thank you. We have added the information when it was reported.