

# Evidence-based Practice Center Technical Brief Protocol

## Project Title: Transitions Care for Children With Special Health Needs

### I. Background and Objectives for the Technical Brief

An effective transition process from a pediatric to an adult health system should ensure continuity of developmental and age-appropriate care. In 2011, the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP) jointly published guideline recommendations based on expert opinion and consensus recommendations for transitioning adolescents into adult care.<sup>1</sup> The 2011 report states that “the goal of a planned health care transition is 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.”<sup>1</sup>

Although examples of transition care models are described, the degree to which strategies meet the objectives of the AAP/AAFP/ACP statement is unclear. Examples of transition models include the use of a separate clinic for transition activities, a phased transfer within a clinical system, and care coordination counselors.<sup>2-5</sup> We anticipate describing these and many more transition care interventions in the Technical Brief.

The process of transitioning to the adult health care system can be particularly fraught for youth with special health needs (CSHN). Potential barriers to successful transition for CSHN include a lack of time and resources to address transition issues, inadequate reimbursement, hesitancy of families and providers to dissolve long-standing therapeutic relationships, and gaps in residency training for both transition processes and medical management of adults with childhood-onset chronic diseases.<sup>6-9</sup> Additionally, CSHN present broader challenges for transition including issues related to insurance, entitlements, guardianship, and eligibility for adult community-based services.<sup>10</sup>

Children with special health care needs are defined by the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”<sup>10</sup>

Healthy People 2010<sup>11</sup> established the goal that all young people with special health care needs will receive the services needed to make necessary transitions to all aspects of adult life, including health care. The AAP states that “optimal health care is achieved when every person at every age receives health care that is medically and developmentally appropriate.”<sup>12</sup>

In 2002, the AAP determined that approximately 500,000 children considered to have special health care needs will transition from pediatric care to adult care annually.<sup>12,13</sup> According to the 2005–2006 National Survey of Children with Special Health Care Needs,<sup>14</sup> less than half of the youth with special health care needs in the United States are receiving needed support and

services for transition from pediatric to adult health care.<sup>15</sup> The proportion is even lower for ethnic minorities and children living in poverty.<sup>16,17</sup> The reliability of these estimates are unclear, due in part to ambiguities regarding the definition and identification of CSHN.

Examples of health care populations that need transition support range widely, including those with chronic illnesses such as diabetes or sickle cell disease and 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. Although they only represent an estimated 13–16 percent of all children, CSHN account for as much as 70 percent of health care expenditures,<sup>13,18,19</sup> and most of these individuals will survive into adulthood as the life expectancy of children with chronic illness has increased dramatically over the last 3 decades.<sup>20,21</sup> These data underscore the importance of implementing effective health care systems, including transition care. Indeed, one of the six core objectives of the Maternal and Child Health Bureau is that “all youth with special health care needs will receive the services necessary to make appropriate transitions to adult health care, work, and independence.”<sup>14</sup>

The relevant literature on this important topic is limited and thus appropriately captured by a Technical Brief rather than a comparative effectiveness review. The most recent systematic review covered the literature from 1986–2010.<sup>22</sup> The authors found very little evidence for effective transition interventions and no evidence involving direct comparisons of transition interventions.<sup>22</sup>

Despite a lack of rigorous research on the topic, as noted above, it is recommended that transition care be a part of the medical home and that it is particularly important for children and adolescents with special health care needs. Thus, programs and descriptive studies have been published, and the comparative literature is growing. Because this type of care is commonly recommended and because there is not an adequate number of studies for a comparative effectiveness review, we will conduct a Technical Brief that will describe the state of the published and unpublished information available on the topic. This Technical Brief will compile information on available programs or approaches for transition care, including a description of the current state of the research, and will identify important gaps in the available research. To accomplish this, the review team will examine the available information from published and grey literature, augmented by structured input from Key Informants to describe existing programs and systems of transition care for youth with special health needs. The report will highlight clinical practice areas that have evaluated strategies for transition care and extract key information (e.g., components, patient characteristics, delivery resources, etc.) that can then be used by other clinical practice areas to build or refine a system for transition care. Finally, the proposed Technical Brief will outline training and barriers, discuss issues of importance to stakeholders, and identify directions for future research.

A thorough and systematic description of transition care programs will inform the successful design, implementation, and dissemination of transition care and will support necessary future research on the effectiveness of transition models. A comprehensive summary of transition care for children with special health needs also will capture contextual issues that will be helpful to providers, health care leaders, policymakers, and patients and their families.

## **II. Guiding Questions**

The definition of CSHN is broad and may encompass many diagnoses and substantial heterogeneity in medical complexity. We propose preliminary Guiding Questions (GQs) that focus specifically on transitions of care from pediatric to adult services (i.e., not child to adolescent, or inpatient to outpatient care) for individuals with chronic (i.e., lifelong) conditions. The need for and the benefits of transition support and planning are well accepted; therefore, the GQs will examine models of care that have been or are being evaluated and can be disseminated and replicated by our end-users. Subquestions may continue to evolve slightly over the course of the research as the researchers gain a deeper understanding of the topic.

### **Draft Guiding Questions**

#### **Question 1. Description of interventions for transitions care**

- a. What is the purpose of transition care and what are the theoretical advantages and disadvantages?
- b. What are the common components of transition care interventions or processes used in clinical practice for children/adolescents with special health care needs?
- c. How do currently used approaches to transitioning health care address the complexity of health issues including comorbidities and the presence of both physical and intellectual/developmental disabilities?

#### **Question 2. Description of the context for implementing transition care**

- a. How widely available are programs or approaches to transition care within the health care setting for children/adolescents with special health care needs?
- b. What are the resources needed to implement transition care?
- c. What are the specific barriers to implementing transition care or processes for children/adolescents with special health care needs?
- d. Who delivers transition interventions and what training is required to implement identified approaches to transition care for children/adolescents with special health care needs?

#### **Question 3. Description of the existing evidence**

- a. What patient groups/clinical conditions are represented in studies on the use and evaluation of transition care for children/adolescents with special health care needs?
- b. What is the length of followup in studies on the use and evaluation of transition care for children/adolescents with special health care needs?
- c. What outcomes are measured in studies on the use and evaluation of transition care for children/adolescents with special health care needs?

#### **Question 4. Issues and future research**

- a. GQ4a: What are the implications (e.g., ethical, privacy, economic) of the current level of diffusion and of further diffusion of transition care for children/adolescents with special health care needs?
- b. GQ4b: What are possible areas of future research for transition care for children/adolescents with special health care needs and which research designs are most appropriate to address these research topics?

### **III. Methods**

The Technical Brief will integrate discussions with Key Informants, a search of the grey literature, and a search of the published literature.

#### **A. Data Collection**

##### **1. Discussions With Key Informants**

Stakeholders help elucidate the decisional dilemmas and are essential for supporting the translation and dissemination of the work. We will engage Key Informants to identify issues related to definitions, clinical areas, population, implementation, resources, and future research. Discussion with Key Informants will inform the content of Technical Brief, particularly GQs 2 and 4.

We searched the Web sites of relevant professional organizations and research and policy groups to identify stakeholders whose work or interests indicate a high likelihood of interest and expertise in the topic. In consultation with the investigative team and the Agency for Healthcare Research and Quality (AHRQ), we assembled a list of individuals representing a clinical, policy, research, and/or advocate perspective for transition care. Following approval by AHRQ of the completed Disclosure of Interest forms for proposed Key Informants, we will conduct discussions with individuals or with a group of Key Informants based on availability and concordance of perspectives.

We will submit strategies and results of indexed and grey literature searches to Key Informants to confirm that we have captured descriptions and evaluations of transition care programs. The Evidence-based Practice Center (EPC) investigators will facilitate the discussions with Key Informants. EPC staff will record, transcribe, and summarize the interviews.

##### **2. Grey Literature Search**

We anticipate that the grey literature is likely to yield model programs and example approaches. Examples of sources of grey literature include the Internet, government Web sites, clinical trial databases, trade publications, and meeting abstracts. The results of the grey literature searches will inform EPC responses to all GQs, particularly GQs 2, 3, and 4.

We will begin with searches of Web sites for relevant not-for-profit organizations and government agencies, including:

- National Center for Medical Home Implementation
- National Initiative for Children's Healthcare Quality
- Family Voices (provides families with tools to make informed decisions)

- Institute for Community Inclusion
- National Collaborative on Workforce and Disability
- National Center for Learning Disabilities (Individuals with Disabilities Education Act resource center)
- National Center for Ease of Use of Community-based Services
- American Academy of Pediatrics Council on Children with Disabilities
- National Health Care Transition Center (Got Transition?)
- Disability.gov

We will also conduct searches of databases that provide coverage of non–peer-reviewed literature (e.g., Lexis-Nexis<sup>®</sup>, ProQuest) and those that cover ongoing health services projects (e.g., NIH RePORTER, HSRProj, ClinicalTrials.gov), as model and project descriptions often appear in these resources. We will also complement this approach with searches of Web sites from relevant professional associations (e.g., the National Association for the Dually Diagnosed) and patient advocate groups (e.g., the Cystic Fibrosis Foundation) that are relevant to the diseases and special needs covered.

Grey literature sources will be instrumental in the identification of innovative transition care models or transition care components being piloted or implemented in unique or local contexts. We will catalogue information on transition care services from individual States and health care systems.

### **3. Published Literature Search**

We will use indexing terms and keywords from grey literature search results to search the published literature for studies that evaluate the programs. A preliminary search strategy is presented in Appendix A. The selection of appropriate databases and all search strategies are vetted by an experienced library scientist who is familiar with all aspects of the Technical Brief protocol. We will review the reference lists of retrieved publications for other potentially relevant publications missed by the search strategies. The search will be updated while the draft brief is being reviewed to identify newly published relevant information. We will incorporate the results from the literature update into the Technical Brief before submission of the final report.

We will use prespecified criteria to screen the full text of the search results for inclusion. We will develop a simple categorization scheme for coding the reasons for exclusion from the report. We will use EndNote<sup>®</sup> (Thomson Reuters, New York, NY) to record and track the disposition of references from the grey literature and published literature searches.

We do not intend to limit by clinical condition, as a primary goal of this review is to identify common characteristics of effective transition support across clinical conditions; however, we plan to review this decision with our Key Informants. We will limit by type of care; we will not seek evidence regarding transition of care within a palliative or hospice situation. We will focus on transitions of care from pediatric to adult services for individuals with lifelong, chronic conditions. We will allow evaluation studies that provide pre-post data but do not have a comparison group, because these are likely to be the majority of studies and at this point in the field may provide clues about where further study should be pursued. The proposed inclusion/exclusion criteria for the evaluation studies are summarized in Table 1.

The results of the indexed literature searches will inform EPC responses to all the GQs, particularly GQs 1 and 3.

**Table 1. Inclusion/exclusion criteria for evaluation studies**

Category	Criteria
Study population	Children with special health care needs
Publication languages	English only
Admissible evidence (study design and other criteria)	<p><u>Admissible designs</u></p> <p>Randomized controlled trials, including wait-list control, cohorts with comparison, pre-post cohort without comparison, stepped wedge designs, case-control, case series, and case reports</p> <p><u>Other criteria</u></p> <ul style="list-style-type: none"> <li>• Original research studies that provide sufficient detail regarding methods and results to enable use and adjustment of the data and results.</li> <li>• Studies must address the following for transitions in care: <ul style="list-style-type: none"> <li>○ Transitions of care from pediatric to adult services.</li> <li>○ Children with special health needs as defined by the American Academy of Pediatrics.</li> <li>○ A. special health need that arises from a chronic physical, developmental, or intellectual condition or disability.</li> </ul> </li> </ul>

## B. Data Organization and Presentation

### 1. Information Management

We will develop forms for data collection to record and summarize the study design, methods, and results from relevant sources. The dimensions necessary to address the GQs are outlined in Table 2. Among other data, we will abstract information on barriers, training needs, variation in practice, and the potential impact of transition care on economic and policy decisions.

**Table 2. Proposed fields for data abstraction**

Field	Specific Data
Study characteristics	<ul style="list-style-type: none"> <li>• Study design</li> <li>• Sample size for eligibility, at recruitment, and at followup</li> </ul>
Population characteristics	<ul style="list-style-type: none"> <li>• Age, race/ethnicity</li> <li>• Disability or health need (e.g., physical, intellectual, developmental)</li> <li>• Clinical disease/diagnosis</li> <li>• Functional limitation or other characteristics that can be stratified</li> </ul>
Intervention characteristics	<ul style="list-style-type: none"> <li>• Type of transition care model</li> <li>• Components of transition care model</li> <li>• Provider type(s)</li> </ul>

Field	Specific Data
	<ul style="list-style-type: none"> <li>• Concurrent or previous interventions</li> </ul>
Comparator	<ul style="list-style-type: none"> <li>• Type of comparator</li> </ul>
Outcomes measured	<ul style="list-style-type: none"> <li>• Patient health outcomes</li> <li>• Satisfaction with care</li> <li>• Cost and resource utilization</li> <li>• Adverse events</li> </ul>
Timing	<ul style="list-style-type: none"> <li>• Length and timing of transition care (including age at initiation and duration)</li> <li>• Timing of outcome measurement</li> </ul>
Setting	<ul style="list-style-type: none"> <li>• Setting of care delivery (e.g., adult, pediatric)</li> <li>• Organizational structure</li> <li>• Geographic location</li> </ul>

## 2. Data Presentation

We will qualitatively summarize the Key Informant interviews and compile information extracted from the published and grey literature search results. We will organize transition care approaches and components that have been evaluated and identify example programs in those categories to present a matrix of commonalities between existing transition care models/programs, as well as approaches that warrant further evaluation. We will identify mismatches between example programs in the grey literature and evaluations from the published literature. We will identify the barriers to adoption and implementation of transition care.

The information on current practice and research will also be presented in the Technical Brief summary tables and text.

## IV. References

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21. Gortmaker SL, Sappenfield W. Chronic childhood disorders: prevalence and impact. *Pediatr Clin North Am*. 1984 Feb;31(1):3-18. PMID: 6366717.
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## **V. Definition of Terms**

Not applicable.

## **VI. Summary of Protocol Amendments**

In the event of protocol amendments, the date of each amendment will be accompanied by a description of the change and the rationale.

## **VII. Key Informants**

Within the Technical Brief process, Key Informants serve as a resource to offer insight into the clinical context of the technology/intervention, how it works, how it is currently used or might be used, and which features may be important from a patient or policy standpoint. They may include clinical experts, patients, manufacturers, researchers, payers, or other perspectives, depending on the technology/intervention in question. Differing viewpoints are expected, and all

statements are crosschecked against available literature and statements from other Key Informants. Information gained from Key Informant interviews is identified as such in the report. Key Informants do not do analysis of any kind nor contribute to the writing of the report and have not reviewed the report, except as given the opportunity to do so through the public review mechanism.

Key Informants must disclose any financial conflicts of interest greater than \$10,000 and any other relevant business or professional conflicts of interest. Because of their unique clinical or content expertise, individuals are invited to serve as Key Informants and those who present with potential conflicts may be retained. The Task Order Officer and the Evidence-based Practice Center (EPC) work to balance, manage, or mitigate any potential conflicts of interest identified.

## **VIII. Peer Reviewers**

Peer Reviewers are invited to provide written comments on the draft report based on their clinical, content, or methodological expertise. Peer review comments on the preliminary draft of the report are considered by the EPC in preparation of the final draft of the report. Peer reviewers do not participate in writing or editing of the final report or other products. The synthesis of the scientific literature presented in the final report does not necessarily represent the views of individual reviewers. The dispositions of the peer review comments are documented and will be published 3 months after the publication of the Evidence Report.

Potential Peer Reviewers must disclose any financial conflicts of interest greater than \$10,000 and any other relevant business or professional conflicts of interest. Invited Peer Reviewers may not have any financial conflict of interest greater than \$10,000. Peer reviewers who disclose potential business or professional conflicts of interest may submit comments on draft reports through the public comment mechanism.

## Appendix A

PubMed search strategy and results

Last updated: 9/05/2013

Search terms	Search results
#1 "Continuity of Patient Care"[mh:noexp] OR "Transition to Adult Care"[mh] OR transition[tiab] OR transitions[tiab] OR transitioning[tiab] OR transitional[tiab]	247658
#2 care[tiab] OR "healthcare"[tiab] OR "Health Services"[mh] OR "Health Services Research"[mh] OR "Health Services Accessibility"[mh] OR "Health Services Needs and Demand"[mh] OR "health services"[tiab] OR "Health Planning"[mh:noexp] OR "Patient Care Planning"[mh] OR "pediatric to adult"[tiab] OR "child to adult"[tiab]	2141964
#3 Adolescent[mh] OR youth[tiab] OR Child[mh] OR pediatric[tiab] OR paediatric[tiab] OR child[tiab] OR children[tiab] OR adolescent[tiab] OR adolescents[tiab] OR adolescence[tiab] OR teen[tiab] OR teens[tiab] OR teenage[tiab] OR teenager[tiab] OR teenagers[tiab] OR "Child Health Services"[mh] OR "Adolescent Health Services"[mh] OR "young people"[tiab]	2594321
#4 Adult[mh] OR adult[tiab] OR adults[tiab] OR adulthood[tiab]	5690952
#5 "Chronic Disease"[mh] OR "special needs"[tiab] OR "special healthcare needs"[tiab] OR "special health care needs"[tiab] OR "special health needs"[tiab] OR "Disabled Children"[mh] OR disability[tiab] OR disabled[tiab] OR "YSHCN"[tiab] OR "CSHCN"[tiab] OR "chronic disease"[tiab] OR "chronic illness"[tiab] OR "chronic diseases"[tiab] OR "Mental Disorders"[mh] OR "mental illness"[tiab] OR "attention deficit"[tiab] OR depression[tiab] OR anxiety[tiab] OR "conduct disorders"[tiab] OR autism[tiab] OR autistic[tiab] OR Asperger[tiab] OR Asperger's[tiab] OR "pervasive development disorders"[tiab] OR "Developmental Disabilities"[mh] OR "developmental delay"[tiab] OR "developmental delays"[tiab] OR "Intellectual Disability"[mh] OR "intellectual disabilities"[tiab] OR "mental retardation"[tiab] OR "mentally retarded"[tiab] OR asthma[mh] OR asthma*[tiab] OR diabetes[tiab] OR diabetic[tiab] OR "Diabetes Mellitus"[mh] OR Epilepsy[mh] OR "seizure disorders"[tiab] OR "seizure disorder"[tiab] OR epilepsy[tiab] OR "Headache Disorders"[mh] OR migraine*[tiab] OR "Brain Injuries"[mh] OR "traumatic brain injury"[tiab] OR "traumatic brain injuries"[tiab] OR concussion*[tiab] OR "Heart Defects, Congenital"[mh] OR "congenital heart disease"[tiab] OR "congenital heart defects"[tiab] OR "Hematologic Diseases"[mh] OR "blood disorders"[tiab] OR "sickle cell"[tiab] OR anemia[tiab] OR "HIV"[tiab] OR "HIV Infections"[mh] OR "Organ Transplantation"[mh] OR "transplant recipients"[tiab] OR "Deafness"[mh] OR "Blindness"[mh] OR deaf[tiab] OR blind[tiab] OR "Cystic Fibrosis"[mh] OR "cystic fibrosis"[tiab] OR "Cerebral Palsy"[mh] OR "cerebral palsy"[tiab] OR "Muscular Dystrophies"[mh] OR "muscular dystrophy"[tiab] OR "Down Syndrome"[mh] OR "Joint Diseases"[mh] OR arthritis[tiab] OR "functional disability"[tiab] OR "functional disabilities"[tiab] OR "Congenital, Hereditary, and Neonatal Diseases and Abnormalities"[mh] OR "congenital disease"[tiab] OR "congenital diseases"[tiab] OR "congenital defects"[tiab] OR "spina bifida"[tiab] OR "Crohn Disease"[tiab] OR Crohn[tiab] OR "Celiac Disease"[mh] OR celiac[tiab] OR "genetic disease"[tiab] OR "genetic disorder"[tiab] OR "genetic disorders"[tiab] OR "genetic diseases"[tiab]	4049292
#6 #1 AND #2 AND #3 AND #4 AND #5 NOT (comment[pt] OR letter[pt] OR editorial[pt] OR news[pt] OR patient education handout[pt] OR legal cases[pt] OR newspaper article[pt] OR news[pt] OR historical article[pt] OR jsubsetk)	1878
#7 #6 AND English[la] AND humans[mh]	1656
#8 #7 AND ("2000/01/01"[dp] : "3000/12/31"[dp])	1373