



### Results of Topic Selection Process & Next Steps

The nominator, a cerebral palsy clinical researcher, is interested in a new evidence review on Transitional care for People with Cerebral Palsy (CP) to inform current clinical practice for individuals with CP, inform future research efforts and provide a basis for a new guideline.

We identified three review(s) partially covering the scope of the nomination, but not specific to cerebral palsy patients. Therefore, a new review would not be duplicative of an existing product.

Due to the limited impact and value of a new review on this topic, the program will not develop a review at this time. No further activity on this nomination will be undertaken by the Effective Health Care (EHC) Program.

### Topic Brief

**Topic Number and Name:** #0811, Transitional Care for People with Cerebral Palsy

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### Introduction

Cerebral palsy (CP) is a group of disorders that affect a person's ability to move and maintain balance and posture. CP is the most common motor disability in childhood. CDC estimates that an average of 1 in 323 children in the U.S. have CP.<sup>7,8</sup> Classification of CP is based on the main type of movement disorder involved. There are four main types of CP depending on which areas of the brain are affected: spasticity (most common type accounting for 80% of people), dyskinesia, ataxia and mixed.

Cerebral palsy (CP) is caused by abnormal development of the brain or damage to the developing brain that affects a child's ability to control his or her muscles. There are several possible causes of the abnormal development or damage. The majority of CP (85%–90%) is congenital. In many cases, the specific cause is not known. Risk factors for CP include low birthweight, premature birth, multiple births, assisted reproductive technology, infections during pregnancy, kernicterus, maternal conditions such as thyroid disorders, intellectual disabilities and seizures and birth complications including detachment of the placenta, uterine rupture, or problems with the umbilical cord during birth. A small percentage of CP is caused by brain damage that occurs more than 28 days after birth (i.e. *acquired* CP), and usually is associated with

an infection (e.g. meningitis, encephalitis), head injury or cerebrovascular accidents (e.g. thrombotic, hemorrhagic).

The majority of children with CP survive to adulthood. Brooks et al. found that in 2010, the median age at death had increased to 17.1 years.<sup>9</sup> Life expectancies for adolescents and adults were lower for those with more severe limitations in motor function and feeding skills, and decreased with advancing age. In 2005 MEDICAID-enrolled children with CP but without intellectual disability (ID) incurred medical expenditures that were \$15,047 higher than those of control children without CP or ID, while children with CP and co-occurring ID incurred costs that were \$41,664 higher, compared with control children, and \$26,617 more than children with CP but without ID.<sup>10</sup> The estimated lifetime direct and indirect costs in 2003 dollars are expected to total \$11.5 billion for persons with cerebral palsy. Average lifetime costs per person were estimated at \$921,000 for persons with cerebral palsy.<sup>11</sup>

In 2011, the American Academy of Pediatrics (AAP), with the endorsement of the American Academy of Family Physicians (AAFP) and the American College of Physicians (ACP), and the authoring group published a clinical report on health care transition (HCT). The report included a process for transition preparation, planning, tracking, and follow-through for all youth and young adults beginning in early adolescence and continuing into young adulthood.<sup>12</sup> After the publication of the 2011 clinical report, a structured clinical approach with sample tools, called the “Six Core Elements of Health Care Transition,” was developed for all youth.<sup>6</sup> The intended use was by pediatric, family medicine, and med-peds providers to benefit all youth, including those with special needs, as they transition from pediatric to adult-centered health care. The six core elements included: transition policy, transition tracking and monitoring, transition readiness, transition planning, transfer and/or integration into adult-centered care and transition completion and ongoing care with adult clinician. In 2018 this clinical report on HCT was updated and expanded to include more practice-based quality improvement guidance on key elements of transition planning, transfer, and integration into adult care for all youth and young adults.<sup>4</sup>

The National Institute for Health and Care Excellence (NICE) published two guidelines related to care of young adults with CP and HCT. In 2017 “Cerebral palsy in under 25s: assessment and management” was published.<sup>13</sup> This guideline covered diagnosing, assessing and managing cerebral palsy in children and young people from birth up to their 25th birthday. In 2018 “Transition from children's to adults' services for young people using health or social care services” was published.<sup>5</sup> This guideline covered the period before, during and after a young person moves from children's to adults' services.

## **Guiding Questions**

The guiding questions for this nomination are:

1. What is the evidence of the effectiveness of pediatric to adult care transition planning for CP patients?
2. What advanced technology (e.g. telehealth) facilitate the transfer of CP youth to adult care?
3. What are the critical elements of transition of care planning for CP patients such as policies, funding, workforce, payment models?

## **Key Questions and PICOTs**

The key question for this nomination is:

1. What is the comparative effectiveness of different transition care models for people with cerebral palsy moving from pediatric to adult care?

To define the inclusion criteria for the key questions, we specify the population, interventions, comparators, outcomes, timing, setting and study design (PICOTS) of interest (Table 1).

**Table 1.** Key Question and PICOTSS

Key Questions	KQ#1
Population	Individuals up to 18 years old and older with cerebral palsy
Interventions	Care model for transfer from pediatric to adult care
Comparators	Usual care Other care model for transfer from pediatric to adult care
Outcomes	Health outcomes including mental and behavioral Quality of life Function Higher education Independent living Healthcare utilization (ED visit, hospitalizations) Dependent/independent Mobility (GMFCS) Secondary health conditions, disease development Participation, employment, and community engagement
Timing	All
Setting	Outpatient
Study Design	Any trial, longitudinal, observational, cross-sectional

Abbreviations: ED=Emergency Department; GMFCS= Gross Motor Function Classification System

## Methods

To assess topic nomination School-Centered Asthma Programs, #781, for priority for a systematic review or other AHRQ EHC report, we used a modified process based on established criteria. Our assessment is hierarchical in nature, with the findings of our assessment determining the need for further evaluation. Details related to our assessment are provided in Appendix A.

1. Determine the *appropriateness* of the nominated topic for inclusion in the EHC program.
2. Establish the overall *importance* of a potential topic as representing a health or healthcare issue in the United States.
3. Determine the *desirability of new evidence review* by examining whether a new systematic review or other AHRQ product would be duplicative.
4. Assess the *potential impact* a new systematic review or other AHRQ product.
5. Assess whether the *current state of the evidence* allows for a systematic review or other AHRQ product (feasibility).
6. Determine the *potential value* of a new systematic review or other AHRQ product.

### Appropriateness and Importance

We assessed the nomination for appropriateness and importance.

### Desirability of New Review/Duplication

We searched for high-quality, completed or in-process evidence reviews published in the last three years on the key questions of the nomination. See Appendix B for sources searched.

### Impact of a New Evidence Review

The impact of a new evidence review was qualitatively assessed by analyzing the current standard of care, the existence of potential knowledge gaps, and practice variation. We

considered whether it was possible for this review to influence the current state of practice through various dissemination pathways (practice recommendation, clinical guidelines, etc.).

### **Feasibility of a New Evidence Review**

We conducted a literature search in Medline PubMed from 1946 to Nov 2, 2018. See Appendix C for the PubMed search strategy and links to the ClinicalTrials.gov search. We reviewed all 77 identified titles and abstracts for inclusion and classified identified studies by study design to assess the size and scope of a potential evidence review. Thirty-seven were excluded because they did not include a pediatric to adult transition in care intervention.

### **Value**

We assessed the nomination for value. We considered whether or not the clinical, consumer, or policymaking context had the potential to respond with evidence-based change; and if a partner organization would use this evidence review to influence practice.

### **Compilation of Findings**

We constructed a table outlining the selection criteria (Appendix A).

## **Results**

### **Appropriateness and Importance**

The topic is both appropriate and important, based on the prevalence of CP (1 in 323 children), and burden of disease (median age at death had increased to 17.1 years). The optimal transition care model has not been established. Significant practice variation exists. The lifetime direct and indirect costs in 2003 dollars are expected to total \$11.5 billion for persons with cerebral palsy.

### **Desirability of a New Review/Duplication**

A new evidence review would be partly duplicative of an existing product. Six SRs/MAs were identified on transition of care. Three, published 2016, 2016 & 2017 focused on transition in care, but not specifically on CP. The most recent SR included 43 articles including CP patients, but the vast majority of subjects were type 1 diabetes, followed by kidney or liver transplants and juvenile idiopathic arthritis.<sup>3</sup> Study designs were predominantly quasi-experimental (i.e. pre-post population cohorts or retrospective cohorts). Only two RCTs and eight prospective cohort studies were included. See Table 2, Duplication column.

### **Impact of a New Evidence Review**

A new systematic review may have low impact potential given the 2018 AAP Transitions Clinical Report<sup>4</sup>, the 2017 NICE Guideline on Transition from children's to adults' services for young people using health or social care services<sup>5</sup> and the 2014 structured clinical approach "Got Transition."<sup>6</sup> Six core elements of health care transition."<sup>6</sup>

### **Feasibility of a New Evidence Review**

A new technical brief, as opposed to a systematic review is feasible. Thirty nine studies were identified including nineteen surveys<sup>5, 14-31</sup>, eight non-systematic reviews<sup>32-39</sup> and seven uncontrolled cohort studies,<sup>15, 40-45</sup> three cross-sectional,<sup>46-48</sup> three other<sup>49-51</sup> and one active clinical trial<sup>52</sup>. No clinical trials were identified. See Table 2, Feasibility column.

**Table 2.** Key Questions and Results for Duplication and Feasibility

Key Question	Duplication (11/2015-11/2018)	Feasibility (2013 to November 02, 2018)
KQ 1: Comparative effectiveness of different transition care models for people with cerebral palsy	Total number of identified systematic reviews: 3 <sup>1, 2, 3</sup>	<p><u>Size/scope of review</u> Relevant Studies Identified: 39</p> <ul style="list-style-type: none"> <li>• Surveys: 18<sup>14, 16-31</sup></li> <li>• Reviews (non-systematic): 8<sup>32-39</sup></li> <li>• Uncontrolled Longitudinal: 7<sup>15, 40-45</sup></li> <li>• Cross-sectional: 3<sup>46-48</sup></li> <li>• Other<sup>49-51</sup></li> </ul> <p><u>Clinicaltrials.gov</u></p> <ul style="list-style-type: none"> <li>• Recruiting: 0</li> <li>• Active: 1<sup>52</sup></li> <li>• Complete: 0</li> </ul>

Abbreviations: AHRQ=Agency for Healthcare Research and Quality; KQ=Key Question

### Value

The potential for value to partners such American Academy of Pediatrics (AAP), is limited due to recent clinical guidelines based on prior systematic reviews.

### Summary of Findings

- Appropriateness and importance: The topic is both appropriate and important.
- Duplication: A new review would **not** be fully duplicative of an existing product. Three recent systematic reviews, published 2016<sup>1</sup>, 2016<sup>2</sup> & 2017<sup>3</sup> were identified that focused on pediatric to adult transition in care, but not specifically on CP.
- Impact: A new systematic review has **limited** impact potential given three guidelines published on pediatric to adult transition of care in 2014<sup>6</sup>, 2017<sup>5</sup> and 2018<sup>5</sup>.
- Feasibility: A new systematic review is not feasible. The evidence base is likely small and consists of largely uncontrolled studies. A technical brief is feasible.
- Value: The potential for value to partners such AAP is **limited** due to recent clinical guidelines based on prior systematic reviews.

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## Appendix A. Selection Criteria Assessment

Selection Criteria	Assessment
<b>1. Appropriateness</b>	
1a. Does the nomination represent a health care drug, intervention, device, technology, or health care system/setting available (or soon to be available) in the U.S.?	Yes the nomination is focused on the U.S. health care system
1b. Is the nomination a request for a systematic review?	Yes
1c. Is the focus on effectiveness or comparative effectiveness?	Yes
1d. Is the nomination focus supported by a logic model or biologic plausibility? Is it consistent or coherent with what is known about the topic?	Yes
<b>2. Importance</b>	
2a. Represents a significant disease burden; large proportion of the population	Yes based on the prevalence (1 in 323 children), burden of disease (median age at death had increased to 17.1 years)
2b. Is of high public interest; affects health care decision making, outcomes, or costs for a large proportion of the US population or for a vulnerable population	Yes
2c. Represents important uncertainty for decision makers	Yes. Optimal transition care model has not been established. Significant practice variation exists.
2d. Incorporates issues around both clinical benefits and potential clinical harms	Yes
2e. Represents high costs due to common use, high unit costs, or high associated costs to consumers, to patients, to health care systems, or to payers	Yes. The lifetime direct and indirect costs in 2003 dollars are expected to total \$11.5 billion for persons with cerebral palsy.
<b>3. Desirability of a New Evidence Review/Duplication</b>	
3. Would not be redundant (i.e., the proposed topic is not already covered by available or soon-to-be available high-quality systematic review by AHRQ or others)	Yes. A new evidence review would be partly duplicative of an existing product. Three SRs/MAs were identified , published 2016, 2016 & 2017 focused on transition in care, but not specifically on CP.
<b>4. Impact of a New Evidence Review</b>	
4a. Is the standard of care unclear (guidelines not available or guidelines inconsistent, indicating an information gap that may be addressed by a new evidence review)?	No. Recent transition in care guidelines have been published by AAP, NICE and Got Transition.
4b. Is there practice variation (guideline inconsistent with current practice, indicating a potential implementation gap and not best addressed by a new evidence review)?	Yes, practice variation exists with regards to transition care of patients with CP.
<b>5. Primary Research</b>	
5. Effectively utilizes existing research and knowledge by considering: - Adequacy (type and volume) of research for conducting a systematic review - Newly available evidence (particularly for updates or new technologies)	Forty studies were identified: 10 surveys, 8 non-systematic reviews and 7 uncontrolled longitudinal studies. No clinical trials were found. One active study was identified in <i>ClinicalTrials.gov</i> .
<b>6. Value</b>	
6a. The proposed topic exists within a clinical, consumer, or policy-making context that is amenable to evidence-based change	No, the clinical context is not amenable to evidence-based change given the recent clinical guidelines and the gaps in the evidence-base (e.g. lack of controlled studies of transition in care in CP subjects).

<b>Selection Criteria</b>	<b>Assessment</b>
6b. Identified partner who will use the systematic review to influence practice (such as a guideline or recommendation)	No partner was identified who intends to use the SR or technical brief to influence practice.

*Abbreviations: AHRQ=Agency for Healthcare Research and Quality; KQ=Key Question; CP=cerebral palsy*

## Appendix B. Search for Evidence Reviews (Duplication)

Listed below are the sources searched, hierarchically.

<b>Published Reviews</b>
AHRQ: Evidence reports and technology assessments <a href="https://effectivehealthcare.ahrq.gov/">https://effectivehealthcare.ahrq.gov/</a> ; <a href="https://www.ahrq.gov/research/findings/ta/index.html">https://www.ahrq.gov/research/findings/ta/index.html</a> ; <a href="https://www.ahrq.gov/research/findings/evidence-based-reports/search.html">https://www.ahrq.gov/research/findings/evidence-based-reports/search.html</a>
VA Products: PBM, and HSR&D (ESP) publications, and VA/DoD EBCPG Program <a href="https://www.hsrd.research.va.gov/publications/esp/">https://www.hsrd.research.va.gov/publications/esp/</a>
Cochrane Systematic Reviews <a href="http://www.cochranelibrary.com/">http://www.cochranelibrary.com/</a>
HTA (CRD database): Health Technology Assessments <a href="http://www.crd.york.ac.uk/crdweb/">http://www.crd.york.ac.uk/crdweb/</a>
<b>Protocols</b>
AHRQ Products in development <a href="https://effectivehealthcare.ahrq.gov/">https://effectivehealthcare.ahrq.gov/</a>
VA Products in development <a href="https://www.hsrd.research.va.gov/publications/esp/">https://www.hsrd.research.va.gov/publications/esp/</a>
Cochrane Protocols <a href="http://www.cochranelibrary.com/">http://www.cochranelibrary.com/</a>
PROSPERO Database (international prospective register of systematic reviews and protocols) <a href="http://www.crd.york.ac.uk/prospero/">http://www.crd.york.ac.uk/prospero/</a>
<b>PubMed Search w/ SR filter</b>
PubMed <a href="https://www.ncbi.nlm.nih.gov/pubmed/">https://www.ncbi.nlm.nih.gov/pubmed/</a>

## Appendix C. Search Strategy & Results (Feasibility)

### Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations and Daily 1946 to November 02, 2018

Date Searched: November 5, 2018

Searched by: Robin Paynter, MLIS

#	Searches	Results
1	"continuity of patient care"/ or transition to adult care/ or transitional care/	18,979
2	(aging-out or age-out or (care adj3 (model* or plan*)) or transition* or transfer*).ti,ab,kf.	965,698
3	or/1-2	979,958
4	Child/ or Adolescent/ or Child Health Services/ or Adolescent Health Services/	2,634,429
5	(adolescen* or child* or juvenile* or pediatric* or paediatric* or teen* or youth* or "young people").ti,ab,kf.	1,687,606
6	or/4-5	3,283,463
7	adult/ or young adult/	4,751,916
8	adult*.ti,ab,kf.	1,115,251
9	or/7-8	5,415,004
10	Cerebral Palsy/	19,092
11	"cerebral palsy".ti,ab,kf.	20,770
12	or/10-11	25,203
13	3 and 6 and 9 and 12	261
14	(2013* or 2014* or 2015* or 2016* or 2017* or 2018* or 2019*).dp.	6,503,146
15	13 and 14	<b>Overall results 84</b>

16	limit 15 to (adaptive clinical trial or clinical trial, all or clinical trial or controlled clinical trial or equivalence trial or pragmatic clinical trial or randomized controlled trial)	<b>Trial results 5</b>
17	limit 15 to (meta analysis or systematic reviews)	<b>SRs/MAs results 3</b>

**ClinicalTrials.gov**

Date Searched: November 5, 2018

Cerebral Palsy | ( transition\* OR transfer\* OR aging out OR age out OR care model OR care plan )  
= 29 results

One relevant result however *recruitment status = unknown*:  
[LETS Study: A Longitudinal Evaluation of Transition Services \(LETS\)](#) (NCT00975338)