Webinar Series: Health Care Transition & Title V Care Coordination Initiatives

A five-part Webinar Series featuring examples of best practices among state Title V agencies, tools and resources, and problem-solving strategies.

Session 1 · Starting A Transition Improvement Process Using the Six Core Elements of Health Care Transition

- Overview of Health Care Transition Baseline Results from Title V Care Coordination (CC) Programs
- Forming a HCT quality improvement team with CC team and youth/young adults/parents
- Defining HCT pilot population, timeline, measures of success
- Selecting HCT core elements and delineating roles of CC program and YSHCN providers

Click here to view webinar recording on YouTube

MATERIALS INCLUDE:
- Care Coordination Webinar 1 Slides: Starting a Transition Process
- Baseline Assessment of HCT in Title V Programs
- Current Assessment of HCT in Care Coordination Programs
- Six Core Elements Side by Side Handout
- HCT Clinical Report 2011
- Gabriel et al 2017 Article

Got Transition is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) (U39MC25729).

Health Care Transition & Title V Care Coordination Initiatives: Webinar Series

Webinar #1 | February 28, 2018

STARTING A TRANSITION IMPROVEMENT PROCESS USING THE SIX CORE ELEMENTS

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Got Transition's Webinar Series Goals

- Support state Title V implementation and measurement of health care transition (HCT) in care coordination programs
- Guide care coordination improvements by sequentially building on the evidence-informed Six Core Elements
- Share promising practices from state Title V-supported care coordination programs
- 5-session webinar series on HCT and care coordination
- The webinars and handouts will be available following each session at www.gottransition.org

Webinar #1: Objectives

At the conclusion of Webinar 1, attendees will be able to…

- Discuss HCT clinical foundations & evidence of effectiveness
- Discuss HCT measurement options & results from the National Survey of Children's Health
- Discuss Title V care coordination baseline results on implementing Six Core Elements of HCT
- Have an approach to initiate a HCT pilot to achieve measurable improvements in Six Core Elements

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Webinar #1 Handouts

1. Webinar #1 Slideshow
2. Supporting HCT from Adolescence to Adulthood in Medical Home (AAP/AAFP/ACP Clinical Report)
3. Side-by-Side Version of Six Core Elements HCT
4. Baseline Assessment of HCT Implementation in Title V Care Coordination Programs (Got Transition Report)
5. Current Assessment of HCT Activities in Care Coordination Programs (customized Got Transition tool)

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Opening Remarks

Susan Chacon, MSW

AMCHP, President

New Mexico Title V CSHCN Director

HCT Clinical Foundations

2011 AAP/AAFP/ACP HCT Clinical Report

- Update, expected in coming months
- Expert opinion/consensus recommendations
- Algorithm for standardizing HCT process

Six Core Elements of HCT

- Aligned with Clinical Report
- Define basic components of HCT support with linked tools and measurement resources

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HCT Clinical Foundations

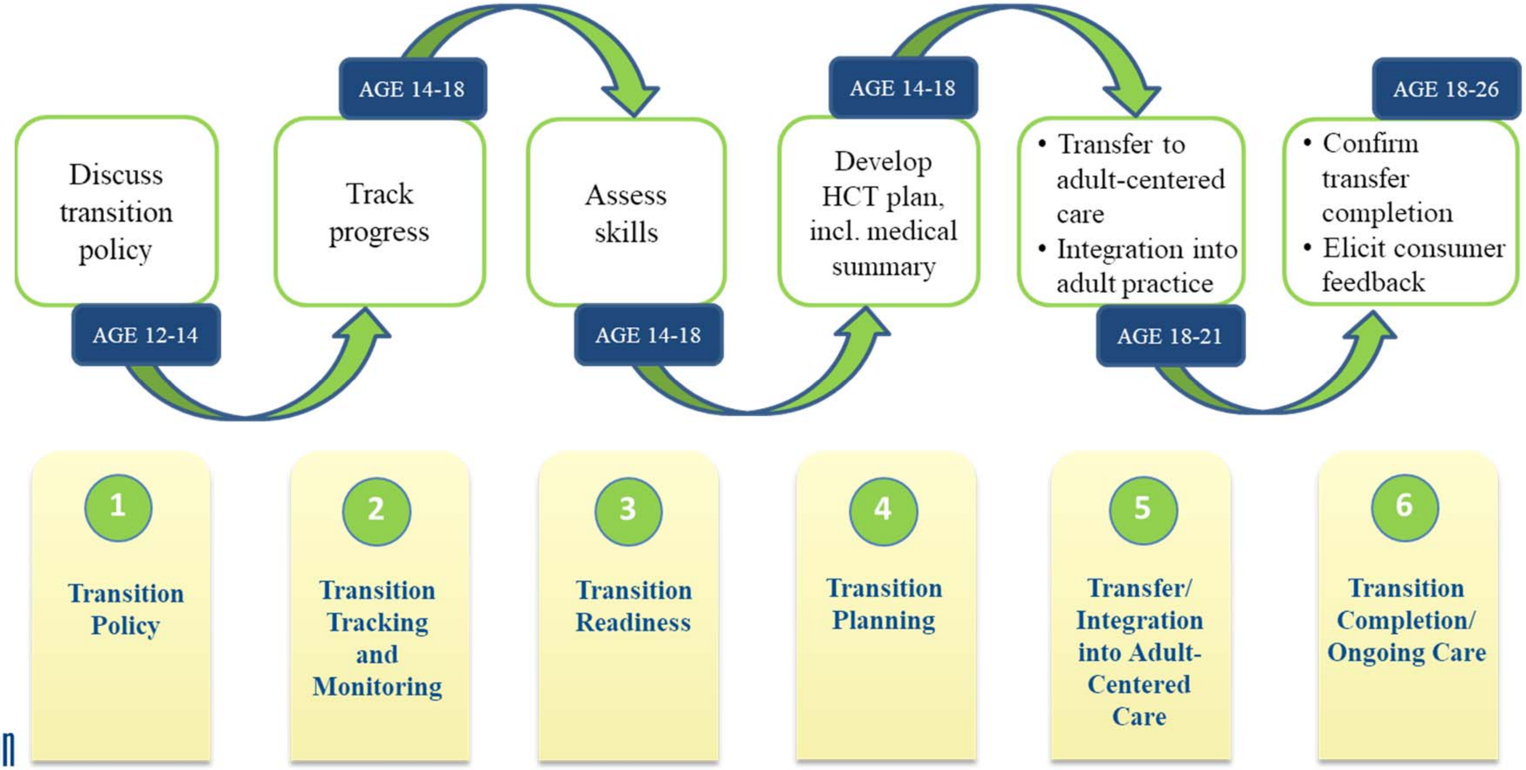
AAP/AAFP/ACP Clinical Report on HCT (Handout)

Age 12	Youth and family aware of transition policy
Age 14	Health care transition planning initiated
Age 16	Preparation of youth and parents for adult approach to care and discussion of preferences and timing for transfer to adult health care
Age 18	Transition to adult approach to care
Age 18-22	Transfer of care to adult medical home and specialists with transfer package

- In 2011, Clinical Report on Transition published as joint policy by AAP/AAFP/ACP
- Targets all youth, beginning at age 12
- Algorithmic structure with:
  - ➢ Branching for youth with special health care needs
  - ➢ Application to primary and specialty practices
- Extends through transfer and establishment of care to adult medical home and adult specialists
- Clinical Report recently renewed by the AAP

HCT Clinical Foundations

Six Core Elements of HCT: Transitioning Youth to an Adult Provider (Handout)



Discuss transition policy

AGE 12-14

AGE 14-18

Track progress

Assess skills

AGE 14-18

AGE 14-18

Develop HCT plan, incl. medical summary

- Transfer to adult-centered care
- Integration into adult practice

AGE 18-21

AGE 18-26

- Confirm transfer completion
- Elicit consumer feedback

1 **Transition Policy**

2 **Transition Tracking and Monitoring**

3 **Transition Readiness**

4 **Transition Planning**

5 **Transfer/ Integration into Adult-Centered Care**

6 **Transition Completion/ Ongoing Care**

Systematic Evidence Review of Structured HCT Interventions

Article:

Outcome Evidence for Structured Pediatric to Adult Health Care Transition Interventions:
A Systematic Review

by Gabriel et al. *Journal of Pediatrics*. 2017.

Click here for Gabriel article

Systematic Evidence Review of Structured HCT Interventions

Statistically Significant Positive Impacts:

Population Health

- Adherence to care
- Patient-reported health & quality of life
- Self care skills – disease specific knowledge, self-management of medications, higher transition readiness scores, carrying important information

Experience of Care

- Satisfaction – with transition, with transfer, with life and health goals, helpfulness of tools, autonomy, time alone with provider

Utilization and Costs of Care

- Service utilization - increase in adult visit rates; reductions in ER visits and hospitalizations, decrease in time between last pediatric and first adult visit
- Improved process of care
- Costs of care seldom examined

HCT Performance Measurement for YSHCN

Two Important Sources

1. National Survey of Children's Health (NSCH)
2. Current Assessment of HCT Activities in Care Coordination Programs

HCT Performance Measurement for YSHCN

National Survey of Children's Health

- Conducted annually
- Parent survey of youth ages 12 through 17 (with and without special needs)
- HCT Questions:
  - Chance to speak with the MD or health care provider (HCP) privately at last preventive visit
  - MD/HCP actively worked with youth to gain skills to manage health care
  - MD/HCP actively worked with youth to understand changes in health care that happen at age 18 (e.g., privacy, consent)
  - MD/HCP talked about eventually seeing doctors or other HCPs who treat adults
- Only 17% of YSHCN met national transition measure
- State results available at www.childhealthdata.org

HCT Performance Measurement for YSHCN

Current Assessment of HCT Activities in Care Coordination Programs (Handout)

- Customized from Got Transition's Current Assessment of HCT Activities
- A qualitative self-assessment that provides a snapshot of how far along CC program is with implementing Six Core Elements
- The self assessment scores CC program's level of implementation related to 7 HCT elements
- Conducted in May 2017, to be repeated in May 2018 by Got Transition
- 27 of 32 states that selected HCT as national performance measure responded

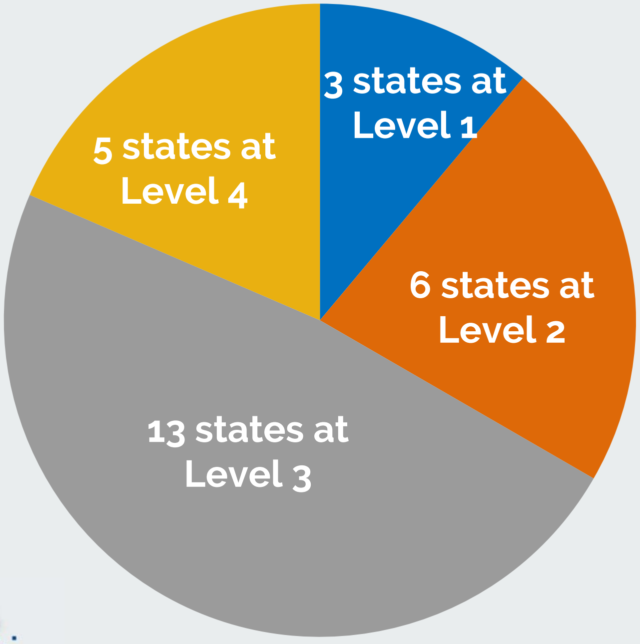
2017 Baseline Assessment of HCT Implementation in Title V Care Coordination (CC) Programs: Results (Handout)

1. Transition Policy
2. Transition Tracking
3. Transition Readiness
4. Transition Planning
5. Transfer of Care
6. Transition Completion
7. Youth and Family Engagement

Baseline Assessment: Results

TRANSITION POLICY

Average Level: 2.7



Level 1: CC program has no uniform approach or written policy shared with YSHCN and families.

Level 2: CCs follow a similar, but not a written policy that it shares with YSHCN and families on HCT.

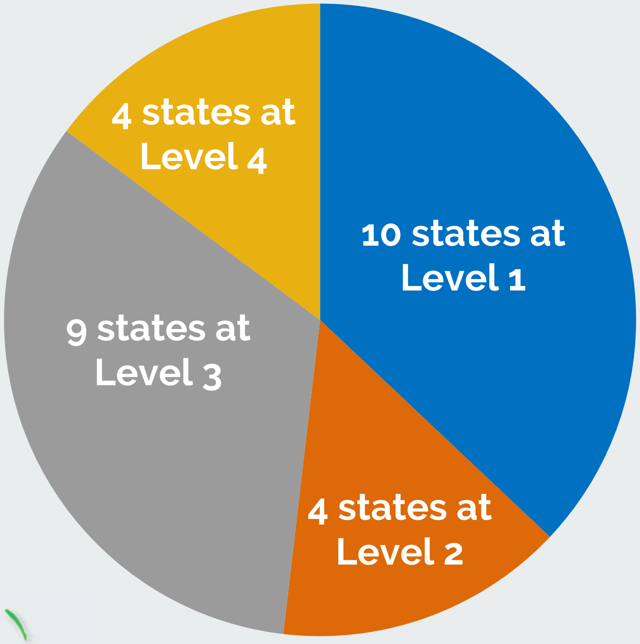
Level 3: The CC program has a written HCT policy that describes its HCT approach, legal changes that take place in privacy and consent at age 18, and the age when Title V eligibility ends. The HCT policy is not consistently shared with youth and families.

Level 4: CC program has written HCT policy describing its HCT approach, legal changes that take place in privacy and consent at age 18, and age when Title V eligibility ends. CCs consistently share and discuss HCT policy with all YSHCN and families beginning at ages 12-14. Policy is publicly posted and used by all CCs.

Baseline Assessment: Results

TRANSITION TRACKING

Average Level: 2.3



Level 1: CCs vary in the identification of transition-age YSHCN, but most wait close to the age of transfer to prepare youth for HCT.

Level 2: CCs use patient records to document certain relevant HCT information (e.g., adult doctor information, date of transfer to adult doctor).

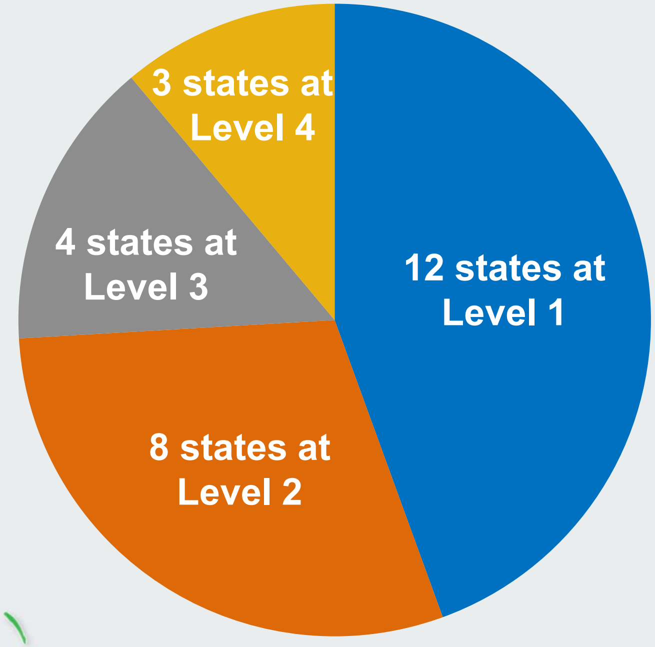
Level 3: The CC program uses an individual transition flow sheet or registry for identifying and tracking a subset of transition-age YSHCN, ages 14 and older, as they complete some but not all of the Six Core Elements of HCT.

Level 4: The CC program uses an individual transition flow sheet or registry for identifying and tracking all transition-age YSHCN, ages 14 and older, as they progress/complete all of the Six Core Elements of HCT, using an EHR if possible.

Baseline Assessment: Results

TRANSITION READINESS

Average Level: 1.9



Level 1: CCs vary in whether they assess HCT readiness/self-care skills.

Level 2: CCs assess HCT readiness/self-care skills, but do not consistently use a HCT readiness assessment tool.

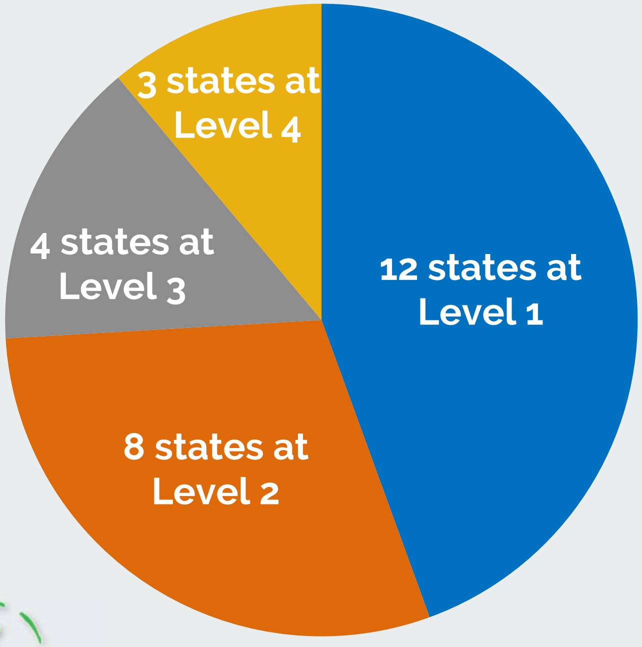
Level 3: CCs assess HCT readiness/self-care skills using a HCT readiness/self-care skill assessment tool.

Level 4: CCs consistently assess and re-assess each year HCT readiness/self-care skills beginning at ages 14 to 16, using a transition readiness/self-care assessment tool.

Baseline Assessment: Results

TRANSITION PLANNING

Average Level: 1.9



Level 1: CCs vary in whether they include goals and action steps related to HCT in the plan of care for YSHCN.

Level 2: CCs consistently include goals and action steps related to HCT for YSHCN, but vary in addressing privacy and consent changes that take place at age 18 and, if needed, decision-making supports for adult-focused health care.

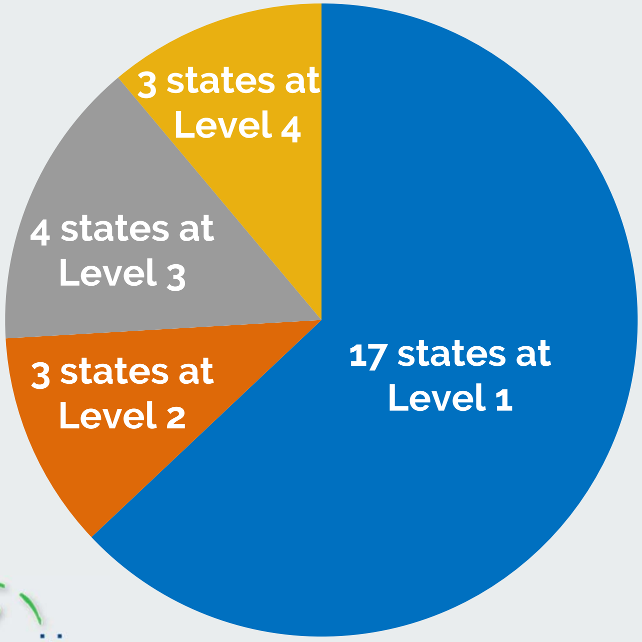
Level 3: CCs consistently include goals and action steps related to HCT for YSHCN based on the results from a HCT readiness/self-care assessment tool. CCs consistently address privacy and consent changes that take place at age 18 and, if needed, decision-making supports for adult-focused health care. This plan of care is regularly updated.

Level 4: The care coordination program has incorporated HCT into its plan of care template for all YSHCN. CCs consistently include YSHCN goals and action steps related to HCT based on results from HCT readiness/ self-care assessment tool. CCs consistently address privacy and consent changes that take place at age 18 and, if needed, decision-making supports for adult-focused health care. This plan of care is regularly updated and shared with YSHCN and families.

Baseline Assessment: Results

TRANSFER OF CARE

Average Level: 1.7



Level 1: CCs vary in whether they give YSHCN and families a list of adult providers. They rarely share plans of care with HCT information to adult providers for their transitioning YSHCN.

Level 2: CCs consistently give YSHCN and families a list of adult providers and share the plan of care, including HCT information to the adult provider(s) for transitioning YSHCN.

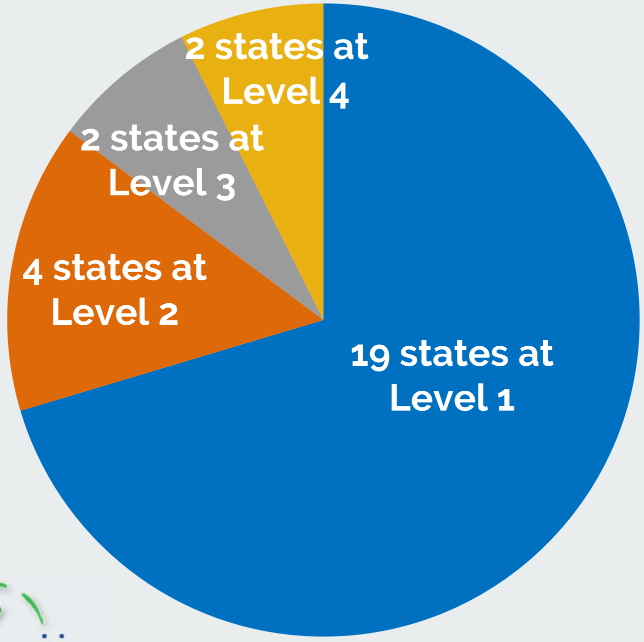
Level 3: The CC program is actively involved in outreach to identify potential adult providers for transitioning YSHCN. Care coordinators share the plan of care with HCT information to the adult provider(s) for their transitioning YSHCN.

Level 4: The CC program is actively involved in outreach to identify potential adult providers for transitioning YSHCN. CCs consistently share the plan of care with HCT information for YSHCN transferring to the adult provider(s). In addition, care coordinators routinely communicate with adult providers to ensure information was received and transfer was completed.

Baseline Assessment: Results

TRANSITION COMPLETION

Average Level: 1.5



Level 1: CCs vary in whether they follow-up with YSHCN and parents/caregivers to provide feedback about the HCT support provided by the CC program.

Level 2: CCs consistently encourage YSHCN and parents/caregivers to provide feedback about the HCT support provided by the care coordination program, but do not use a specific HCT feedback survey.

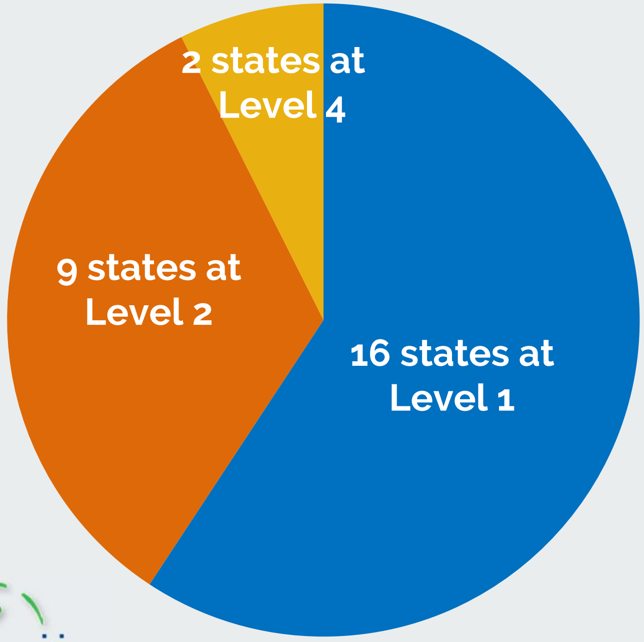
Level 3: CCs consistently obtain feedback from YSHCN and parents/caregivers using a HCT feedback survey.

Level 4: The CC program uses the results from its HCT feedback survey as part of its transition performance measurement for the Title V block grant reporting.

Baseline Assessment: Results

YOUTH & FAMILY ENGAGEMENT

Average Level: 1.6



Level 1: The CC program offers general information about HCT to YSHCN and parents/caregivers, but has limited involvement of YSHCN and parents/caregivers in Title V HCT program development and evaluation.

Level 2: The CC program, in addition to its HCT education efforts with YSHCN and parents/caregivers, has trained YSHCN and parents leaders about the Six Core Elements of HCT.

Level 3: The CC program offers HCT education to YSHCN and parents/caregivers, has trained YSHCN and parent leaders about the Six Core Elements, and involves them in Title V program development and evaluation on HCT.

Level 4: The CC program offers HCT education to YSHCN and parents/caregivers and involves YSHCN/parent HCT leaders, knowledgeable about the Six Core Elements in statewide efforts to advance HCT improvements.

What to do? Where to start?

Starting a HCT Pilot to Achieve Measurable Improvements

Goal:
Maximize HCT supports for YSHCN by increasing Title V CC implementation of Six Core Elements

Use qualitive improvement (QI) methods:

- Gain leadership support
- Form HCT QI improvement team
- Create AIM statement/definition of success
- Clarify measurement
- Specify activities/actions needed for HCT improvement
- Test change (plan, do, study, act/PDSA cycle)
- Implement pilot

Leadership Support and QI Team

Obtain senior Title V leadership support for HCT improvement process

Form HCT QI Team:

- Leaders with enough authority to test and implement change (including CC managers, both pediatric and adult clinicians, and office staff)
- Family and YSHCN
- Day-to-day leader who understands CC operations and effects of changes and works effectively with others
- Administrative expert who can assist with tracking progress and information system updates/EMR modifications
- HCT QI sponsor (e.g., CYSHCN director) with connection to senior management and can overcome barriers of team (involved not as a regular team member, but to review/learn about progress)

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Aim Statement Example

Aim: By May 2018, 80% of youth (with selected conditions), ages 14-21, will complete a standardized Transition Readiness Assessment, and their transition skill needs will be incorporated into a plan of care that is jointly developed with YSHCN and families.

- This aim intends to reach Level 3 on Transition Readiness and Transition Planning core elements
- Aim could focus on other core elements
- Aim should include date, population, target, and specific HCT element(s)
- Important to align aim statement with what success should look like and to reach a specific level of HCT implementation

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Ways to Measure Aim Statement

Aim: By May 2018, 80% of youth (with selected conditions), ages 14-21, will complete a standardized Transition Readiness Assessment, and their transition skill needs will be incorporated into a plan of care that is jointly developed with YSHCN and families.

1. **Transition Registry (of population group ages 14-21)**
   - Name, DOB, Age
   - Transition Readiness Assessment administered (date)
   - Plan of Care with HCT skill action steps (date)
2. **Current Assessment of HCT Activities in CC programs**
   - Baseline collected in May 2017
   - To be repeated in May 2018 by Got Transition

Activities Needed for HCT Improvement

1. Select pilot population
2. Select/customize Transition Readiness Assessment (RA) tools involving CCs and youth and families (Got Transition, ACP, TRAQ)
3. Decide at what age RA to be given
4. Decide if youth/parent will complete RA on their own or CC will administer RA with youth/parent

Activities Needed for HCT Improvement (continued)

5. Decide how RA skill needs and action steps will be jointly identified with youth/parents
6. Clarify roles in terms of who will provide needed self-care education (CC, clinician, family depending on skill needed)
7. Decide how identified RA skills and action steps will be included in plan of care
8. Decide how often to repeat RA and offer self-care education
9. Decide how CC program will track date when YSHCN received RA and plan of care was updated with HCT skill needs and action steps

Testing HCT Activities Using PDSA Cycles

Transition Readiness Assessment

- Pilot with small group of youth (e.g., from different age groups, conditions/ complexities, family backgrounds). What questions or words were problematic? Were important questions missing? Is the reading level/language appropriate?
- Pilot using different processes to administer RA by YSHCN on their own or by CCs/clinician office
- Pilot using different processes to provide self-care education

Transition Plan

- Pilot within small group of YSHCN (e.g., from different age groups, conditions/ complexity, family backgrounds)
- Pilot updating plan of care with CCs

Tracking

- Pilot tracking method with CC and administrative staff

Refine and Re-test

Implementing Changes That Will Result in HCT Improvement

Aim: By May 2018, 80% of youth (with selected conditions), ages 14-21, will complete a standardized Transition Readiness Assessment, and their transition skill needs will be incorporated into a plan of care that is jointly developed with YSHCN and Families.

- After testing changes on small scale and refining, HCT change process is ready for implementation to broader pilot population.
- Consider a planned launch with education for CCs.
- Measure progress from tracking method(s) and provide ongoing feedback to CCs and senior leadership.
- Keep track of lessons learned, including sequencing of tasks, effective ways of working with youth and families, etc.

Lessons Learned in Implementing Six Core Elements Pilots

- Choose your pilot wisely. Rest of CC program is watching. Try not to transition the most complex patients until HCT processes are in place.
- Without leadership support and continued buy-in, sustainability is impossible.
- Outline measurement strategies up front so that everyone knows what “success looks like.”
- Success in implementing Six Core Elements is about putting a fail-safe process in place that is integrated into routine CC functions. It is not about hiring a CC to make it all happen.
- Clear delineation of the distinctive and collaborative roles of CCs and pediatric and adult clinicians in HCT process is important.
- HCT progress is rewarding and youth and families appreciate and benefit from these recommended HCT supports!

Got Transition aims to improve transition from pediatric to adult health care through the use of new and innovative strategies for health professionals and youth and families.

News & Announcements

Are you ready to transition to adult health care?

New Got Transition Webinar Series
Registration is open for Got Transition's new webinar series, "Health Care Transition & Title V Care Coordination Initiatives." more>

AAP Transition ECHO
The American Academy of Pediatrics Transition ECHO offers a standardized curriculum on health care transition more>

New Transition of Care Video Series for Neurology
The Child Neurology Foundation has released a new Transition of Care Video Series that shares the journeys of patients transitioning to adult neurologists and showcases perspectives of national transition experts. more>

Health Care Providers

Find out about how to implement health care transition quality improvement in your practice or plan using the new Six Core Elements of Health Care Transition (2.0). Download accompanying clinical resources and measurement tools for use in any setting.

Customize the Six Core Elements of Health Care Transition to meet your patients'

Youth & Families

Hear what young adult and parent experts have to say about common transition questions and discover new resources to make this process work easier.

Turning 18: What it Means for Your Health

Researchers & Policymakers

Find new transition policy developments, research and measurement approaches, and federal and state transition initiatives.

NEW Got Transition Webinar Series

Questions?

- About writing a HCT Aim statement?
- About selecting HCT activities to achieve improvement?
- About measuring HCT improvement?
- About CC baseline results?
- About clinical foundations?

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Upcoming Title V Care Coordination Webinars

Transition Preparation
March 28, 3-4 pm ET

Transfer to Adult Care
April 26, 3-4 pm ET

Integration into Adult Care
May 31, 3-4 pm ET

Youth, Young Adult, & Parent Engagement
June 28, 3-4 pm ET

To register, please visit Got Transition's website under News & Announcements (www.gottransition.org)

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Thank You!

WEBSITE
www.gottransition.org
See link to new transition news and articles and download the *Six Core Elements 2.0* packages to start making HCT quality improvements in your practice

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REPORT – NO.4
OCTOBER 2017

Baseline Assessment of Health Care Transition Implementation in Title V Care Coordination Programs

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This report presents a current snapshot of Title V care coordination program implementation of the Six Core Elements of Health Care Transition,[1] the evidence-driven approach that is aligned with the AAP/AAFP/ACP Clinical Report on Transition.[2] This approach to health care transition (HCT) involves 1) developing a transition policy, 2) establishing a process to identify and track transitioning youth, 3) regularly assessing their self-care skills, 4) developing a plan of care that incorporates transition readiness goals and prepares youth for an adult model of care, 5) assisting in the identification and transfer to adult providers with current medical information, and 6) following up to ensure transfer completion. Using quality improvement methods with active engagement of youth and parents and participation of both pediatric and adult clinicians, the Six Core Elements can be implemented in care coordination programs as well as in primary and specialty or behavioral care practices, health plans, and hospitals.

Since many state Title V programs either fund or are involved in statewide care coordination efforts for youth with special health care needs (YSHCN), Got Transition conducted this assessment as a starting point from which to support state Title V programs in their efforts to implement evidence-informed transition strategies and measure progress and impact. In 2016, 32 states, including the District of Columbia, as well as Puerto Rico, Virgin Islands, Guam, Federated States of Micronesia, and Marshall Islands, selected the HCT measure as a focus in the youth with special health care needs (YSHCN) population domain.[3]

This report summarizes the baseline assessment scores for implementation of the Six Core Elements in state Title V care coordination programs. It also describes an upcoming webinar series on how to implement HCT in care coordination programs. Additional reports on state Title V HCT efforts can be found at www.gottransition.org.[3-5]

METHODS

This baseline assessment of HCT activities in care coordination programs was conducted in May 2017. It was sent to the 32 state Title V programs that selected HCT as their national performance measure. A total of 28 states completed the online self-assessment, for a response rate of 88%. Among these 28 states, 20 directly fund care coordination programs, and eight are involved in statewide care coordination efforts for YSHCN. An additional two states were excluded from this analysis because they do not fund or participate in statewide care coordination efforts. Two states did not respond to the survey; the survey was not sent to the U.S. territories.

To obtain consistent information regarding implementation of the Six Core Elements, Got Transition's Current Assessment of HCT Activities was customized for care coordination programs. States were asked to have their care coordination staff complete this self-assessment. To provide a baseline of Six Core Elements implementation as well as of youth and family engagement, states ranked their level of progress along a continuum from level 1 (basic) to level 4 (comprehensive). Each level is defined by a brief narrative description. Each state received a total score, which could range from 7 (all six core elements and youth and family engagement at level 1) to 28 (all six core elements and youth and family engagement at level 4). See Appendix 1 for the HCT self-assessment tool for state Title V care coordination programs. Participating states also received an individualized transition report, which allows each state to compare its scores with the national averages.

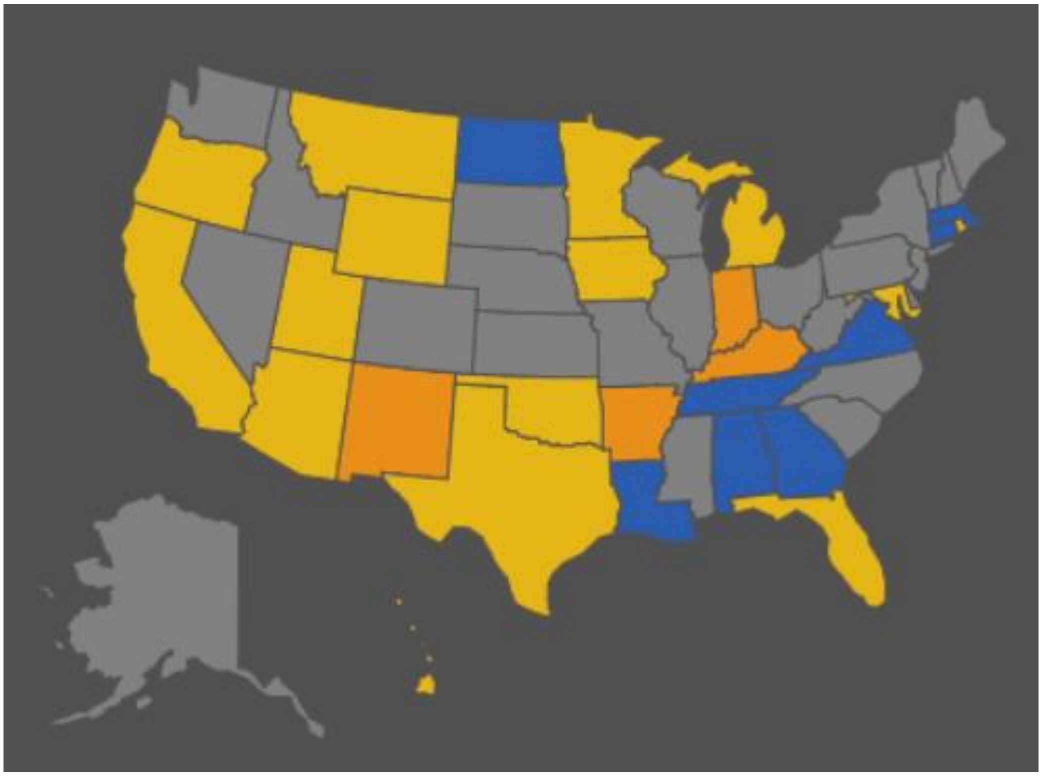
RESULTS

There was wide variation in HCT implementation within care coordination programs for YSHCN among the 28 state respondents, as shown in Figure 1. Overall state scores ranged from a low of 7 to a high of 28, with 15 states scoring between 7 and 12 (out of a potential of 28). Despite the wide variability, this baseline assessment revealed that more than half of state Title V care coordination programs are at level 1 or level 2 for each of the HCT Six Core Elements. More than a quarter of state respondents scored between 13 and 19, with a few of the core elements at level 3 or level 4. Five states – Arkansas, District of Columbia, Indiana, Kentucky, and New Mexico – scored the highest – between 20 and 28. Figure 1 displays the distribution of total scores among state respondents. Table 1 shows that in general states had higher average levels on transition policy and lower levels on transition completion. Figure 2 displays the number of states reporting their level of HCT implementation for each of the Six Core Elements and shows that all had progressively lower scores for transfer of care, transition completion, and youth and family engagement.

CONCLUSIONS AND NEXT STEPS

State Title V programs that selected HCT as their national performance measures, with some exceptions, are in the early phases of incorporating the Six Core Elements of HCT into their care coordination programs. To support continued progress in implementing evidence-driven transition approaches, Got Transition is offering a webinar series beginning in January, on the topics listed in Table 2. These webinars will feature examples of best practices among state Title V Agencies, tools and resources, and problem-solving strategies. State-specific HCT baseline assessment reports have been sent to each state that responded to the survey to allow them to benchmark their results against these national averages. Got Transition plans to conduct this same assessment one year following the initial assessment to track state progress, which can be reported by states in their Title V block grant applications.

Figure 1. Baseline HCT Assessment Scores in State Title V Care Coordination Programs, 2017



Score Range *(lowest possible 7, highest possible 28)*	**State**	**Key**
7-12	AZ, CA, FL, HI, IA, MD, MI, MN, MT, OK, OR, RI, TX, UT, WY	🟨
13-19	AL, CT, GA, LA, MA, ND, TN, VA	🟦
20-28	AR, DC, IN, KY, NM	🟧
N/A*	Not part of analysis	⬜

** 2 states did not have a care coordination program (WI, NY); 2 states who chose transition as a Title V NPM did not respond (IL, NJ); 18 states did not choose transition as a Title V NPM.*

Table 1. Average Levels and Number of States by Level of Implementation of Six Core Elements, 2017

Six Core Elements	**Average Level** 1 (basic) to 4 (comprehensive)	**# of States at Level 1 or 2**	**# of States at Level 3 or 4**
Transition Policy	2.8	9	19
Transition Tracking	2.3	15	13
Transition Readiness	1.9	21	7
Transition Planning	1.9	21	7
Transfer of Care	1.8	20	8
Transition Completion	1.5	24	4
Youth and Family Engagement	1.5	26	2

Figure 2. Number of States Reporting Specific Levels of Implementation of Six Core Elements, 2017

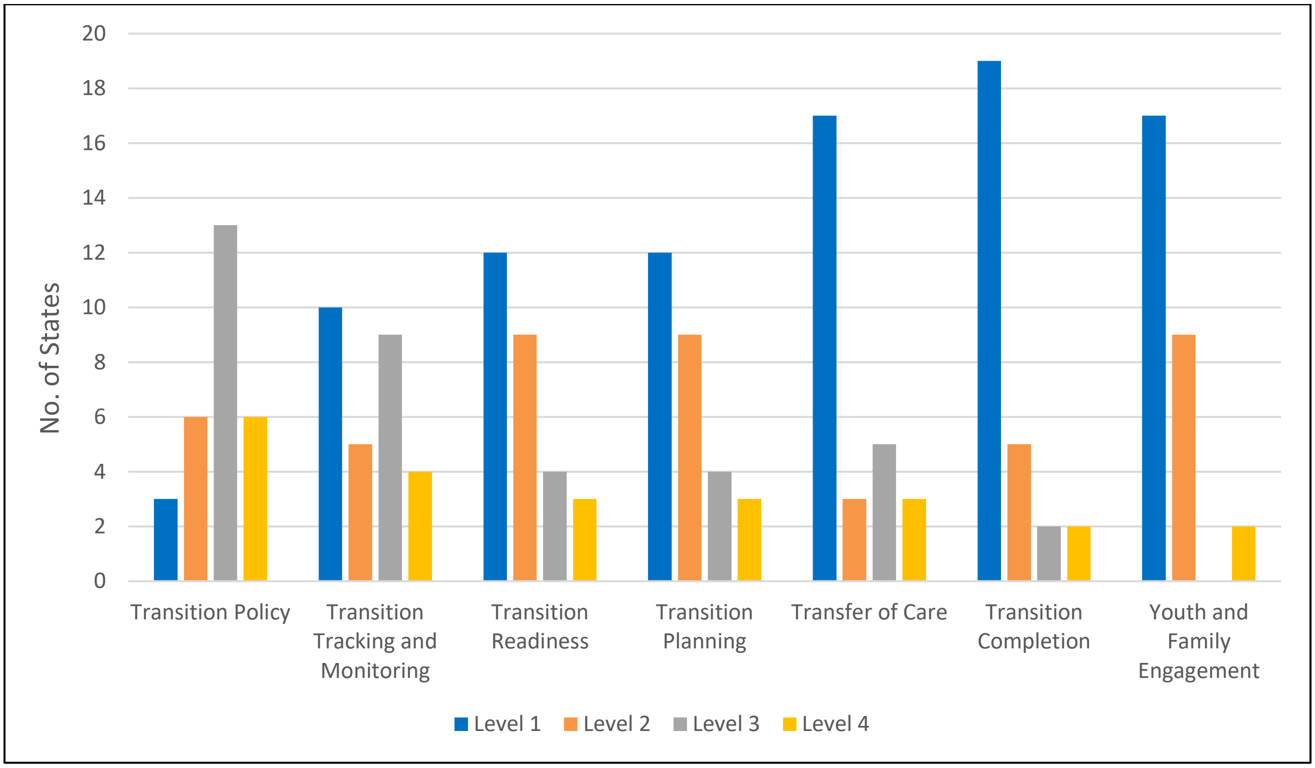


Table 2. Got Transition Webinar Series
Health Care Transition Implementation in Title V Care Coordination Programs

Starting in January 2018

Session 1	**Starting A Transition Improvement Process Using the Six Core Elements of Health Care Transition**
	• Review of Six Core Elements and overview of Title V HCT assessment results • Forming a HCT quality improvement team with youth/young adults/parents • Defining HCT pilot population, timeline, measures of success • Selecting HCT core elements and delineating roles of care coordination program and YSHCN providers
Session 2	**Transition Preparation**
	• Identifying key components of HCT policy that families/youth want to know • Customizing transition readiness assessment (RA) • Piloting and disseminating HCT policy and RA • Incorporating RA skill needs into plan of care and educating youth and families on needed skills • Preparing medical summary and emergency care plan with youth and families and their providers
Session 3	**Transfer to Adult Care**
	• Identifying willing adult primary and specialty providers • Sequencing plans for transferring young adults with multiple providers • Identifying ways to support adult practices (consultation, care coordination) • Preparing transfer package and communicating with pediatric and adult practices
Session 4	**Integration into Adult Care**
	• Ensuring welcome and orientation FAQs from the adult practice to transferring young adults and pediatric practice • Facilitating initial appointment to adult doctor, including confirmation of receipt of transfer package • Supporting adult practice with assistance in linking to adult disability resources
Session 5	**Youth/Young Adult and Parent Engagement**
	• Identifying youth/young adults/parents to participate in Title V HCT initiatives • Providing transition education and training and mentoring opportunities • Eliciting consumer feedback with HCT care coordination process • Building youth/young adult/parent leadership roles on HCT within state Title V programs

APPENDIX 1: Assessment of Health Care Transition Activities

1. Transition Policy

- ☐ *Level 1*. The care coordination program has no uniform approach or written policy that it shares with YSHCN and families on HCT.
- ☐ *Level 2*. Care coordinators follow a similar, but not a written policy that it shares with YSHCN and families on HCT.
- ☐ *Level 3*. The care coordination program has a written HCT policy that describes its HCT approach, legal changes that take place in privacy and consent at age 18, and the age when Title V eligibility ends. The HCT policy is not consistently shared with youth and families.
- ☐ *Level 4*. The care coordination program has a written HCT policy that describes its HCT approach, legal changes that take place in privacy and consent at age 18, and the age when Title V eligibility ends. Care coordinators consistently share and discuss the HCT policy with all YSHCN and families beginning at ages 12 to 14. The policy is publicly posted and used by all care coordinators.

2. Transition Tracking and Monitoring

- ☐ *Level 1*. Care coordinators vary in the identification of transition-age YSHCN, but most wait close to the age of transfer to prepare youth for HCT.
- ☐ *Level 2*. Care coordinators use patient records to document certain relevant HCT information (e.g., adult doctor information, date of transfer to adult doctor).
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- ☐ *Level 3*. Care coordinators assess HCT readiness/self-care skills using a HCT readiness/self-care skill assessment tool.
- ☐ *Level 4*. Care coordinators consistently assess and re-assess each year HCT readiness/self-care skills beginning at ages 14 to 16, using a transition readiness/self-care assessment tool.

4. Transition Planning

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- ☐ *Level 2*. Care coordinators consistently include goals and action steps related to HCT for YSHCN, but vary in addressing privacy and consent changes that take place at age 18 and, if needed, decision-making supports for adult-focused health care.
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- ☐ *Level 4*. The care coordination program has incorporated HCT into its plan of care template for all YSHCN. Care coordinators consistently include YSHCN goals and action steps related to HCT based on the results from a HCT readiness/self-care assessment tool. Care coordinators consistently address privacy and consent changes that take place at age 18 and, if needed, decision-making supports for adult-focused health care. This plan of care is regularly updated and shared with YSHCN and families.

5. **Transfer of Care**
   - ☐ *Level 1*. Care coordinators vary in whether they give YSHCN and families a list of adult providers. They rarely share plans of care with HCT information to adult providers for their transitioning YSHCN.
   - ☐ *Level 2*. Care coordinators consistently give YSHCN and families a list of adult providers and share the plan of care, including HCT information to the adult provider(s) for transitioning YSHCN.
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   - ☐ *Level 1*. Care coordinators vary in whether they follow-up with YSHCN and parents/caregivers about the HCT support provided by the care coordination program.
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   - ☐ *Level 4*. The care coordination program uses the results from its HCT experience survey as part of its transition performance measurement for the Title V block grant reporting.

7. **Youth and Family Engagement**
   - ☐ *Level 1*. The care coordination program offers general information about HCT to YSHCN and parents/caregivers, but has limited involvement of YSHCN and parents/caregivers in Title V HCT program development and evaluation.
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CURRENT ASSESSMENT OF HEALTH CARE TRANSITION ACTIVITIES IN CARE COORDINATION PROGRAMS

1. Transition Policy

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5. Transfer of Care

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Adapted by Got Transition from the Current Assessment of Health Care Transition Implementation, a measurement tool used to monitor implementation of the Six Core Elements of Health Care Transition.

Side-by-Side Version
Six Core Elements of Health Care Transition 2.0

The *Six Core Elements of Health Care Transition 2.0* are intended for use by pediatric, family medicine, med-peds, and internal medicine practices to assist youth and young adults as they transition to adult-centered care. They are aligned with the AAP/AAFP/ACP Clinical Report on Transition.[i] Sample clinical tools and measurement resources are available for quality improvement purposes at **www.GotTransition.org** ■

Transitioning Youth to Adult Health Care Providers (Pediatric, Family Medicine, and Med-Peds Providers)	**Transitioning to an Adult Approach to Health Care Without Changing Providers** (Family Medicine and Med-Peds Providers)	**Integrating Young Adults into Adult Health Care** (Internal Medicine, Family Medicine, and Med-Peds Providers)
1. Transition Policy • Develop a transition policy/statement with input from youth and families that describes the practice's approach to transition, including privacy and consent information. • Educate all staff about the practice's approach to transition, the policy/statement, the *Six Core Elements,* and distinct roles of the youth, family, and pediatric and adult health care team in the transition process, taking into account cultural preferences. • Post policy and share/discuss with youth and families, beginning at age 12 to 14, and regularly review as part of ongoing care.	**1. Transition Policy** • Develop a transition policy/statement with input from youth/young adults and families that describes the practice's approach to transitioning to an adult approach to care at 18, including privacy and consent information. • Educate all staff about the practice's approach to transition, the policy/statement, the *Six Core Elements,* and distinct roles of the youth, family, and health care team in the transition process, taking into account cultural preferences. • Post policy and share/discuss with youth and families, beginning at age 12 to 14, and regularly review as part of ongoing care.	**1. Young Adult Transition and Care Policy** • Develop a transition policy/statement with input from young adults that describes the practice's approach to accepting and partnering with new young adults, including privacy and consent information. • Educate all staff about the practice's approach to transition, the policy/statement, the *Six Core Elements* and distinct roles of the young adult, family, and pediatric and adult health care team in the transition process, taking into account cultural preferences. • Post policy and share/discuss with young adults at first visit and regularly review as part of ongoing care.
2. Transition Tracking and Monitoring • Establish criteria and process for identifying transitioning youth and enter their data into a registry. • Utilize individual flow sheet or registry to track youth's transition progress with the *Six Core Elements.* • Incorporate the *Six Core Elements* into clinical care process, using EHR if possible.	**2. Transition Tracking and Monitoring** • Establish criteria and process for identifying transitioning youth/young adults and enter their data into a registry. • Utilize individual flow sheet or registry to track youth/young adults' transition progress with the *Six Core Elements.* • Incorporate the *Six Core Elements* into clinical care process, using EHR if possible.	**2. Young Adult Tracking and Monitoring** • Establish criteria and process for identifying transitioning young adults until age 26 and enter their data into a registry. • Utilize individual flow sheet or registry to track young adults' completion of the *Six Core Elements.* • Incorporate the *Six Core Elements* into clinical care process, using EHR if possible.
3. Transition Readiness • Conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth and parent/caregiver their needs and goals in self-care. • Jointly develop goals and prioritized actions with youth and parent/caregiver, and document regularly in a plan of care.	**3. Transition Readiness** • Conduct regular transition readiness assessments, beginning at age 14, to identify and discuss with youth and parent/caregiver their needs and goals in self-care. • Jointly develop goals and prioritized actions with youth and parent/caregiver, and document regularly in a plan of care.	**3. Transition Readiness/Orientation to Adult Practice** • Identify and list adult providers within your practice interested in caring for young adults. • Establish a process to welcome and orient new young adults into practice, including a description of available services. • Provide youth-friendly online or written information about the practice and offer a "get-acquainted" appointment, if feasible.

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[i] American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians. Transitions Clinical Report Authoring Group. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics.* 2011; 128:182.

Continued »

■ Got Transition™ is a program of The National Alliance to Advance Adolescent Health supported by U39MC25729 HRSA/MCHB ■ www.GotTransition.org

Side-by-Side Version (continued)

Six Core Elements of Health Care Transition 2.0

Transitioning Youth to Adult Health Care Providers (Pediatric, Family Medicine, and Med-Peds Providers)	**Transitioning to an Adult Approach to Health Care Without Changing Providers** (Family Medicine and Med-Peds Providers)	**Integrating Young Adults into Adult Health Care** (Internal Medicine, Family Medicine, and Med-Peds Providers)
4. Transition Planning • Develop and regularly update the plan of care, including readiness assessment findings, goals and prioritized actions, medical summary and emergency care plan, and, if needed, a condition fact sheet and legal documents. • Prepare youth and parent/caregiver for adult approach to care at age 18, including legal changes in decision-making and privacy and consent, self-advocacy, and access to information. • Determine level of need for decision-making supports for youth with intellectual challenges and make referrals to legal resources. • Plan with youth/parent/caregiver for optimal timing of transfer. If both primary and subspecialty care are involved, discuss optimal timing for each. • Obtain consent from youth/guardian for release of medical information. • Assist youth in identifying an adult provider and communicate with selected provider about pending transfer of care. • Provide linkages to insurance resources, self-care management information, and culturally appropriate community supports.	**4. Transition Planning/Integration into Adult Approach to Care** • Develop and regularly update a plan of care, including readiness assessment findings, goals and prioritized actions, medical summary and emergency care plan, and, if needed, legal documents. • Prepare youth and parent/caregiver for adult approach to care at age 18, including legal changes in decision-making and privacy and consent, self-advocacy, and access to information. • Determine of need for decision-making supports for youth with intellectual challenges and make referrals to legal resources. • Plan with youth and parent/caregiver for optimal timing of transfer from pediatric to adult specialty care • Obtain consent from youth/guardian for release of medical information. • Provide linkages to insurance resources, self-care management information, and culturally appropriate community supports.	**4. Transition Planning/Integration into Adult Practice** • Communicate with young adult's pediatric provider(s) and arrange for consultation assistance, if needed. • Prior to first visit, ensure receipt of transfer package (final transition readiness assessment, plan of care with transition goals and pending actions, medical summary and emergency care plan, and, if needed, legal documents, condition fact sheet, and additional provider records.) • Make pre-visit appointment reminder call welcoming new young adult and identifying any special needs and preferences. • Provide linkages to insurance resources, self-care management information, and culturally appropriate community supports.
5. Transfer of Care • Confirm date of first adult provider appointment. • Transfer young adult when his/her condition is stable. • Complete transfer package, including final transition readiness assessment, plan of care with transition goals and pending actions, medical summary and emergency care plan, and, if needed, legal documents, condition fact sheet, and additional provider records. • Prepare letter with transfer package, send to adult practice, and confirm adult practice's receipt of transfer package. • Confirm with adult provider the pediatric provider's responsibility for care until young adult is seen in adult setting.	**5. Transfer to Adult Approach to Care** • Address any concerns that young adult has about transferring to adult approach to care. Clarify adult approach to care, including shared decision-making, privacy and consent, access to information, adherence to care, and preferred methods of communication, including attending to health literacy needs. • Conduct self-care assessment (transition readiness assessment) if not recently completed and discuss needed self-care skills. • Review young adult's health priorities as part of ongoing plan of care. • Continue to update and share portable medical summary and emergency care plan.	**5. Transfer of Care/Initial Visit** • Prepare for initial visit by reviewing transfer package with appropriate team members. • Address any concerns that young adult has about transferring to adult approach to care. Clarify approach to adult care, including shared decision-making, privacy and consent, access to information, adherence to care, and preferred methods of communication, including attending to health literacy needs. • Conduct self-care assessment (transition readiness assessment) if not recently completed and discuss the young adult's needs and goals in self-care. • Review young adult's health priorities as part of their plan of care. • Update and share portable medical summary and emergency care plan.
6. Transfer Completion • Contact young adult and parent/caregiver 3 to 6 months after last pediatric visit to confirm transfer of responsibilities to adult practice and elicit feedback on experience with transition process. • Communicate with adult practice confirming completion of transfer and offer consultation assistance, as needed. • Build ongoing and collaborative partnerships with adult primary and specialty care providers.	**6. Transfer Completion/Ongoing Care** • Assist young adult to connect with adult specialists and other support services, as needed. • Continue with ongoing care management tailored to each young adult. • Elicit feedback from young adult to assess experience with adult health care. • Build ongoing and collaborative partnerships with specialty care providers.	**6. Transfer Completion/Ongoing Care** • Communicate with pediatric practice confirming transfer into adult practice and consult with pediatric provider(s), as needed. • Assist young adult to connect with adult specialists and other support services, as needed. • Continue with ongoing care management tailored to each young adult. • Elicit feedback from young adult to assess experience with adult health care. • Build ongoing and collaborative partnerships with pediatric primary and specialty care providers.

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Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home

American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, Transitions Clinical Report Authoring Group

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DOI: 10.1542/peds.2011-0969

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Guidance for the Clinician in
Rendering Pediatric Care

Clinical Report—Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home

abstract

Optimal health care is achieved when each person, at every age, receives medically and developmentally appropriate care. The goal of a planned health care transition is to maximize lifelong functioning and well-being for all youth, including those who have special health care needs and those who do not. This process includes ensuring that high-quality, developmentally appropriate health care services are available in an uninterrupted manner as the person moves from adolescence to adulthood. A well-timed transition from child- to adult-oriented health care is specific to each person and ideally occurs between the ages of 18 and 21 years. Coordination of patient, family, and provider responsibilities enables youth to optimize their ability to assume adult roles and activities. This clinical report represents expert opinion and consensus on the practice-based implementation of transition for all youth beginning in early adolescence. It provides a structure for training and continuing education to further understanding of the nature of adolescent transition and how best to support it. Primary care physicians, nurse practitioners, and physician assistants, as well as medical subspecialists, are encouraged to adopt these materials and make this process specific to their settings and populations. *Pediatrics* 2011;128:182–200

1. INTRODUCTION AND METHODOLOGY

With reasonable biological certainty, most adolescents transition to adulthood. There is much less certainty about the manner in which health care professionals support this transition. Transition planning, when present at all, can be inexplicit, incomplete, or late, and when necessary, the transfer of care to an adult medical home and to adult medical subspecialists involves more of a drift away from pediatric care rather than a clearly planned and executed handoff. In 2002, a consensus statement coauthored by the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP)-American Society of Internal Medicine was published, stating the importance of supporting and facilitating the transition of adolescents with special health care needs* into adulthood.[1] This statement represented the shared perspectives of health care professionals, families, youth, researchers,

AMERICAN ACADEMY OF PEDIATRICS, AMERICAN ACADEMY OF FAMILY PHYSICIANS, AND AMERICAN COLLEGE OF PHYSICIANS, TRANSITIONS CLINICAL REPORT AUTHORING GROUP

KEY WORDS

health care transition, youth transition, medical home, children with special health care needs, primary care, adolescent health, quality improvement

ABBREVIATIONS

AAP—American Academy of Pediatrics
MCHB—Maternal and Child Health Bureau
CCM—chronic condition management
EHR—electronic health record

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*The Maternal and Child Health Bureau (MCHB) defines children and youth with special health care needs as "[t]hose 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."[21]

and policy-makers. It provided foundational guidance for health care processes that include health care planning and information exchange, for professional education and certification, and for insurance and payment reform. Its conclusions and critical steps remain widely accepted standards that have informed the development of pilot projects, model practices, and national initiatives to improve support for transitioning youth. The US Department of Health and Human Service's Maternal and Child Health Bureau (MCHB) has been instrumental in promoting the importance of seamless, effective, and comprehensive services for all youth and families during this major life transition.[2]

After nearly a decade of effort, widespread implementation of health transition supports as a basic standard of high-quality care has not been realized. To date, only limited progress can be documented in the achievement of the consensus statement's 6 critical steps. Although 2 National Surveys of Children With Special Health Care Needs indicate improvements between 2001 and 2006, there has been only limited achievement of national health policy goals related to transition.[3,4] Outcomes-related research efforts have, so far, failed to fully address the transition needs of adolescents with or without chronic conditions.[5] A recent national survey revealed that pediatricians remain poorly informed about the conclusions of the consensus statement and that most pediatric practices neither initiate transition planning early in adolescence nor offer transition-support services, which have been found to be critical for ensuring a smooth transition to the adult health care model.[6] The survey authors noted that "gaps in transition support are due in part to limited staff training; lack of an identified staff person responsible for transition; financial barriers; and anxiety on the part of pediatricians, adolescents, and their parents about planning for their future health care."[7] Other authors have cited the lack of developmentally appropriate tools for assessing child and family readiness for transition as a barrier to transition.[8,9]

The result is that many pediatricians, youth, and families have found a limited availability of adult providers with whom to arrange a smooth transition of care.[10–14] In addition, evidence indicates that many adult providers feel unprepared to care for young adults with complex chronic conditions. In some cases, there is no identified adult primary care or specialty provider to whom care can be transitioned. Lack of time, adequate payment, and training have been cited as major barriers to transition.[15] Workforce shortages exist and are anticipated to worsen for physicians and other health professionals providing care for adults of all ages. In the face of an aging population that needs care, these shortages may be an obstacle to the delivery of primary care to more young adults with or without special health care needs.[16]

Family physicians caring for youth note that no transfer of primary care will be needed; nevertheless, there is a need to implement an adult model of care; plan for the transfer of specialty care to adult medical subspecialists; and support broader transition planning that includes issues such as educational attainment, career choices, and independent living needs. Internists find it challenging to care for a child or youth with special health care needs when the youth lacks preparation to be his or her own health advocate and the referring physician sends only minimal information about the youth and/or his or her condition.[17] Despite the recent spread of the family-centered medical home model for the redesign of primary care, payment reforms for non–encounter-based services (such as transition planning and care coordination) still have not materialized to a significant degree. Finally, with relatively few model practices exemplifying high-quality transition supports, training providers in the principles of health care transition remains challenging.

When there are obstacles, there are also opportunities. The need is stronger than ever for the seamless transfer of care and personal health information from pediatric care settings to more adult settings and for all youth to function as independently as possible in promoting their own health as adults. The 2007 AAP Annual Leadership Forum designated the resolution "transitioning youth with special health care needs to adult health care" as a top-10 priority. *Bright Futures* provides a framework for anticipatory guidance throughout childhood and adolescence that encourages parental support of self-management and independent decision-making about health.[18] Explicitly planned care as the product of a partnership among health care professionals, youth, and families has become an essential characteristic of the primary care medical home for which recognition standards have become more firmly established, such as the Physician Practice Connection for the Patient-Centered Medical Home of the National Committee on Quality Assurance and the Medical Home Index of the Center for Medical Home Improvement.[19,20] Providing high-quality transition care and support may become one of the standards that both pediatric and adult primary care practices would need to meet to be recognized as a medical home and become eligible for new payment scenarios.

These new opportunities have set the stage for a reaffirmation of the principles in the original consensus statement by the AAP, American Academy of Family Physicians, and American College of Physicians. All 3 professional groups also recognize the need to translate those principles into practical operational guidance for the care of all children and youth as they transition to adulthood. Although youth with special health care needs require a broader range of considerations during their transitions, all youth need education, guidance, and planning to prepare to assume appropriate responsibility for their own health and well-being in adulthood.[21] Most youth with chronic illnesses will survive into adulthood and, depending on the severity and specifics of their disability, should transition to an adult model of care. After the age of majority,† all youth deserve to be treated as adults and to experience an adult model of care, although some people may require decision-making support from a third-party proxy, such as through guardianship or power of attorney. Recent evidence has shown that higher executive function affecting impulsivity and decision-making continues to mature through the mid-20s. Older adolescents and young adults may require guided decision-making assistance from clinicians and family members as they enter adult systems of care.[22] Nevertheless, most youth will benefit from advance planning and preparation for that experience regardless of whether they remain with their pediatric provider or medical subspecialist after the age of 18.

This report assumes that it is the youth, not the clinician, who is transitioning in his or her movement from one stage of life and development to another. The actions of the youth's medical home involve not the transition of care but, rather, the transfer of some or all elements of care to an adult medical home setting or, in the case of a family medicine medical home, to an adult medical home model. The medical home visit is a different process when the patient has reached the age of majority; adult patients have specific considerations and necessitate providers' attention to new requirements such as adopting consent for treatment processes and Health Insurance Portability and Accountability Act (HIPAA)–compliant forms. Health care transfer is an element of transition and has a defined end point that may vary from patient to patient. Because both transition and transfer are influenced by environmental, socioeconomic, medical, and other factors, it is the responsibility of the medical home—in partnership with patients and their families—to coordinate efforts that ensure optimal outcomes for every patient.

The patient- and family-centered medical home model of primary care includes 3 distinct but interrelated care processes: preventive care; acute illness management; and chronic condition management (CCM). CCM constitutes an explicit and defined approach that involves planned and proactive care rooted in evidence- and consensus-based guidelines, written care plans, and active care coordination. The medical home uses a registry to track the status of its patients with special health care needs and may stratify the registry in terms of the severity or complexity of the patient's condition. Those with more complex conditions may be identified for written care plans, care coordination, and a more intense, amplified transition plan. CCM also includes an explicit approach to comanagement with medical subspecialists in which the roles of primary and specialty care are clearly articulated. (Comanagement involves an explicit and transparent process in which providers involved in a patient's care determine—in collaboration with the patient or family—which provider will be responsible for which aspects of the patient's care. Comanagement can occur between primary care providers and 1 or more medical subspecialists. It might also occur during the transfer of care from a pediatric to an adult setting.) Transition activities for youth with special health care needs should include a comanagement-transition plan that articulates the process and timing for the transfer of care from pediatric to adult medical subspecialists. (These components of CCM are described in greater detail later in this report.)

This clinical report aims to advance the practice-based implementation of planning, decision-making, and documentation processes for youth who are approaching transition, including those who have special health care needs and those who do not. It intends to provide a structure for training, continuing education, and research to further the understanding of best practices for transition of adolescents to adult care. It does not detail the activities conducted by receiving providers who accept patients into an adult model of medical home care. Because there is currently only limited outcome literature about transition, this clinical report is based on expert opinion and consensus recommendations rather than on specific evidence. The report provides a decision-making algorithm (Fig 1) for all youth, beginning at 12 years of age. The algorithm includes a branch with expanded, generic guidelines for transitioning youth with special health care needs who require CCM.[23] These chronic condition guidelines can, in turn, provide a template for later, more detailed, and specialized applications of the algorithm to specific conditions and specialty care

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†The "age of majority" is a legal definition of the age at which a person is considered to be an adult. In most states, this age is 18 years; exceptions are Alabama and Nebraska (19 years) and Washington, DC, and Mississippi (21 years).

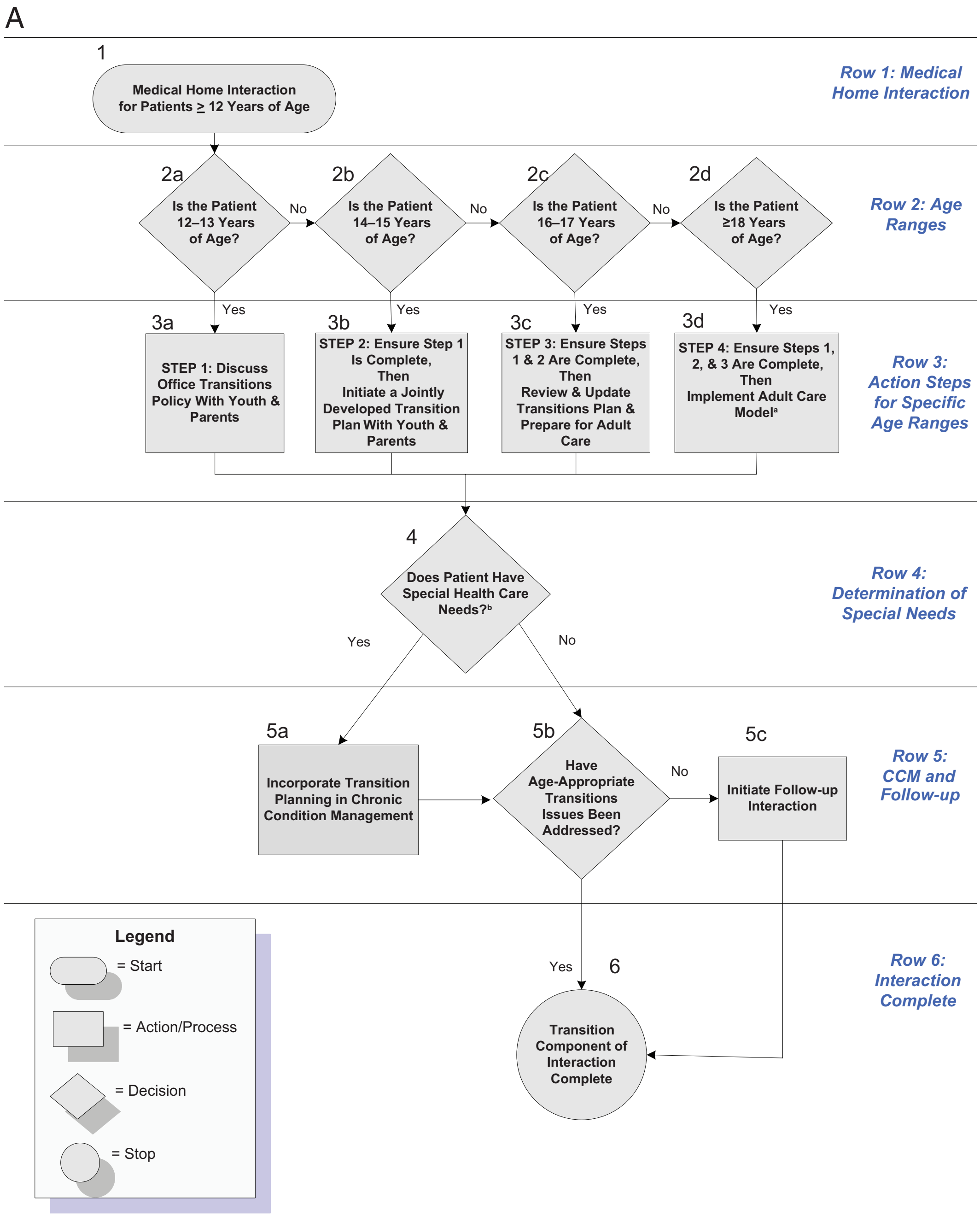


FIGURE 1

A, Health care transition-planning algorithm for all youth and young adults within a medical home interaction. [a] For pediatric practices, transfer to adult provider; [b] the MCHB defines children with special health care needs as "[t]hose 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." B, Reverse side of the algorithm.[21]

situations. These guidelines, recommendations, and resources will also be useful to the medical subspecialist engaging in the transition process; primary care providers and medical subspecialists are encouraged to make this process specific for their own needs.

Methodology

The AAP and the National Center for Medical Home Implementation (a cooperative agreement between the AAP and the MCHB) have prioritized the issue of transitioning youth from a pediatric to an adult medical home with the goal of facilitating the effective transition of all youth from pediatric to ap-

B

ALGORITHM COMPONENT	DESCRIPTIVE TEXT
Medical Home Interaction for Patients ≥12 Years of Age	*1.* Initiate first step in the health care transition planning process at age 12.
Is the Patient 12–13 Years of Age? Is the Patient 14–15 Years of Age? Is the Patient 16–17 Years of Age? Is the Patient ≥18 Years of Age?	***2a, 2b, 2c, 2d. Age Ranges.*** By age 12, conduct surveillance to assess any special health care needs. Start actual transition planning by age 14. By ages 16–17, transition planning should be well established. At age 18, initiate an adult model of care for most youth, even if there is no transfer of care. If transition planning does not occur on the schedule described by the algorithm, a concentrated effort is required (eg, special visits) to complete the process successfully.
STEP 1: Discuss Office Transitions Policy with Youth & Parents	***3a.*** Every practice should have a written transition policy that is prominently displayed and discussed with youth and families. The policy should explicitly state the practice's expectations and care process for the health care transition of their adolescent patients to an adult model of care.
STEP 2: Ensure Step 1 is Complete, then Initiate a Jointly Developed Transition Plan with Youth & Parents	***3b.*** The practice should use a standard transition plan that can be adapted for each patient's needs. This tool should include components to obtain an accurate assessment of the patient's ability to transition successfully. Providers should interview youth and family members to identify needs and assess the intentions and motivations for youth independence.
STEP 3: Ensure Steps 1 & 2 are Complete, then Review & Update Transitions Plan & Prepare for Adult Care	***3c.*** Transition plans must be reviewed regularly and updated as necessary. The provider must also perform surveillance for changes in the youth's medical status and address youth and family concerns that may warrant changes in transition goals. Failure to achieve transition-readiness goals warrants reevaluation of the existing plan and increased frequency of medical home interventions/visits. A "pretransfer" visit to the adult medical home could be conducted during the year before the transfer.
STEP 4: Ensure Steps 1, 2, & 3 are Complete, then Implement Adult Care Model* **for pediatric practices transfer to adult provider*	***3d.*** Transition to an adult model of care occurs appropriate for youth's developmental level, which is followed as appropriate by transfer to an adult medical home. Complete medical records should be delivered to the adult provider, along with a portable summary, which is also provided to the patient or guardian. For children and youth with special health care needs, direct communication between pediatric and adult providers is essential, because adult medical personnel may be unfamiliar with certain pediatric conditions.
Does Patient Have Special Health Care Needs?**	***4.*** Transition planning for children and youth with special health care needs should include specific CCM activities such as use of registries; care plans; care coordination; CCM office visits; and comanagement with medical subspecialists. Transition goals must be individualized to account for variations in the complexity of a youth's condition and in the youth's intellectual ability and guardianship status.
Incorporate Transition Planning in Chronic Condition Management	***5a.*** Youth with special health care needs require an expanded transition-planning process. Transition planning in CCM includes addressing the exchange of complex health information; competencies for self-care; transfers of specialty care; and issues related to insurance, entitlements, guardianship, and eligibility for adult services. In a medical home, such youth may have a written care plan as part of the medical record. At age 14, this plan should include a section titled "transition plan," which should be expanded and developed as the youth approaches age 18 and beyond.
Have Age-Appropriate Transitions Issues Been Addressed?	***5b.*** Use of transition-planning tools and readiness checklists facilitate the provider's ability to ensure that all age-appropriate transition issues have been addressed. Each action step must be completed in order, even if it means the provider has to schedule specific visits to initiate and complete steps missed earlier in the process to catch up before the next visit.
Initiate Follow-up Interaction	***5c.*** Focused tasks involving little detail or complexity can be addressed by the medical home care coordinator, medical provider, or other appropriate staff through telephone or electronic media. More complex issues may necessitate face-to-face office visits.
Transition Component of Interaction Complete	***6.*** The provider is finished with the transition tasks for that specific interaction or visit; transition planning is an ongoing activity that occurs at every interaction.

FIGURE 1
Continued.

propriate adult care. The Executive Committee and staff of the AAP Council on Children With Disabilities (COCWD) are leading the transitions initiative, which has received funding support from the National Center for Medical Home Implementation and the COCWD. The ultimate goal of this initiative is to help medical home providers, patients, and their families ensure a successful transition to appropriate adult care.

In 2008, the AAP convened a meeting to review and provide advice on proposed transition initiatives. Current literature and activities were highlighted, and areas in which assistance is needed for pediatric providers to properly address transitioning youth to adult care within their practice were identified. The first activity of the transitions initiative was to develop a clinical report to provide pediatric providers with the information they need to facilitate youth receiving high-quality, developmentally appropriate health care services as they transition to adulthood. A Transitions Clinical Report Authoring Group was subsequently assembled and cochaired by Drs Carl Cooley and Paul Sagerman. Other disciplines and/or groups represented on the authoring group include pediatric primary care and subspecialty physicians, adult health care providers, family members, and a young adult who recently completed his own health care transition.

These stakeholders partnered to develop this clinical report on the importance of youth receiving high-quality, developmentally appropriate health care services as they transition to adulthood. It provides practitioners with a clear time line and algorithmic protocol for succeeding in this process. A draft version of this clinical report underwent extensive peer review by committees, councils, sections, and additional groups within the AAP as well as by external people or groups who were either identified as experts in the field or had requested the reviewing opportunity. The resulting comments were incorporated into the report, as appropriate. It is expected that all subsequent AAP transition initiatives will use the publication of this clinical report, and the guidance therein, as a foundation for education, training, and quality measurement.

2. GETTING READY FOR TRANSITION

Transition planning should be a standard part of providing care for all youth and young adults, and every patient should have a transition plan regardless of his or her specific health care needs. Successful transition involves the engagement and participation of the medical home team (physicians, nurse practitioners, physicians assistants, nurses, care coordinators), the family and other caregivers, and the individual youth collaborating in a positive and mutually respectful relationship (ie, one that honors diversity and is consistent with each family's cultural and religious beliefs). The medical home team does not engage in transition planning alone; rather, it jointly creates and implements the plan with the youth and his or her family/caregivers. The medical home team facilitates a process that is planned, smooth, and patient- and family-centered. The parents' role is to actively engage in the process and move in and out of the decision-making position as appropriate. The youth's role is to maximize his or her independence and primacy in the decision-making process to foster lifelong functioning and self-determination. The receiving adult providers also need to be identified and engaged and, as needed, to provide developmentally appropriate support for the family and young adult during the transition process. This process is described in both the algorithm and "Adult Medical Home (Receiving Provider): Roles and Responsibilities."

a. Provider Readiness

A key component of supporting the transition process is the primary care medical home having an explicit office policy that describes the practice's approach to health care transition, including the age and process at which youth shift to an adult model of care. This office policy applies to all youth (both with and without special health care needs), guides the process, and helps the youth and family members (or other caregivers) understand both their and the medical home team's roles and responsibilities. The office transition policy should be visible and readily available to patients and their families, including depicting them in brochures, posters, and/or Web-based information about the practice. This office policy should clearly describe the goal of transition as part of lifelong preparation for a successful adult life and articulate how transition planning facilitates the patient's movement from a pediatric to an adult care mode.[17] Additional components of the office policy are described later in the algorithm.

To achieve the goal of transition planning as a standard of care, the medical home team must receive training and technical assistance to implement transitions effectively and adopt transition-related practices (eg, discussing the office transition policy, assessing family and youth transition readiness, developing referral relationships in the adult care system). Adult medical homes and medical subspecialists may need to build their capacities to provide services to young adult patients, particularly those with cognitive impairments and other special health care needs. Education and clinical experience for medical home team members will provide essential skills for the successful transition of youth both with and without special needs. Issues of provider readiness are described further in "Adult Medical Home (Receiving Provider): Roles and Responsibilities."

b. Family Readiness

The medical home team members must understand and address patients' and parents' perspectives and needs during transition and recognize that this process is complex and potentially emotional for parents and other caregivers/guardians. Although families make multiple transitions during their children's lives, for many parents, the pediatrician has been a constant, and they may find transition from the known to the unknown to be stressful. This is particularly likely to be true for parents of children with special health care needs. To make the process smoother for all involved, transition planning must anticipate and address challenges that parents may face as the youth enters adulthood.

It is important for physicians and other health care professionals to engage parents and youth with education and information about their role in the transition process. This education should include information about how the health care environment changes when the youth legally becomes an adult at 18 years of age as well as differences between pediatric and adult medicine models. The provider's goals are to normalize the transition process, address the families' anxieties or questions, and foster a team approach to help facilitate the acquisition of skills and tools that the youth can use both in transition and beyond. The family members or other caregivers should be engaged and open to the process (eg, learning about any upcoming changes in health coverage), encourage autonomous decision-making and self-care on the part of the youth, and share their questions and/or concerns with the provider as they adjust to their role shifting from primary decision-maker and caregiver to a more supportive role.

c. Youth Readiness

For transition planning to succeed, providers, and parents/caregivers must view the youth as the driver in the process and encourage the youth to assume increasing responsibility for his or her own health care to the fullest extent possible. Empowering youth through transitions fosters the development of self-management skills and tools needed for them to gain more control in, and over, their lives.[24] Although this is the case for youth both with and without special health care needs, it is particularly critical for the former, who may require a broader range of considerations during the transition process.[25]

Although this report presents optimal ages for initiating and conducting transition planning, it is never too early to begin conversations among the provider, family/caregivers, and patient about planning for the future. This is especially true for children with special health care needs. For this population, it is likely that similar conversations are occurring in the educational system regarding Individualized Education Plans (IEPs); these various conversations can reinforce and buttress one another.[25] Prioritizing and reinforcing the value of independence and decision-making as part of the transition-planning process not only reinforces such messages on the part of providers, family members/other caregivers, and the broader community but also facilitates the patient's successful transition to adult medical care and active participation in maintaining his or her own health.

3. FRAMING THE ALGORITHM

An algorithm is a finite list of steps connected by various decision-making points that can be taken to move from a known beginning to a predictable end state. As a decision-making tool, an algorithm presents clear-cut questions that, when answered, delineate standardized pathways that lead to the process's next step(s) and a desired outcome. Clinical algorithms have long been popular and effective tools for helping clinicians understand and implement a diagnostic, therapeutic, or management process. Algorithms also provide a logic model for the incorporation of processes of care into electronic health records (EHRs). Algorithms have been included recently in AAP policy documents as strategies to support health care professionals to develop a pattern and practice to address developmental concerns in children from birth through 3 years of age and to engage in early identification of children with autism spectrum disorders.[23,26]

The algorithm contained in this clinical report (Fig 1) specifies the protocol for managing the transition process; assists physicians and other health care professionals to implement the transition process; and provides a transition structure for youth and their families. It is intended for use by clinicians within a medical home setting as a "jumping-off point" for the identification of youth who have reached a point in their lives at which health care transition should be integrated as a routinely recognized part of the office visit. Individual steps along the transition process will vary from one youth to the next depending on individual patient, family/caregiver, health care professional, and community-resource factors. The transition process is best initiated by the time a child is 12 years of age and ideally should occur during a health maintenance or CCM visit. Transfer itself should occur within the 18- to 21-year age range, although it can occur earlier because some internists accept new patients at 15 years of age, particularly if they see other family members as well. Some youth may experience a variety of health care settings as they move from pediatric to adult models of care (eg, while in college or military service), but these settings are not likely to provide a comprehensive medical home. Youth should either remain in their pediatric medical home or be well established in their adult medical home while receiving episodic care in these settings.

a. Explanation of the Algorithm Components

Row 1: Medical Home Interaction

Medical Home Interaction
for Patients ≥12 Years of Age

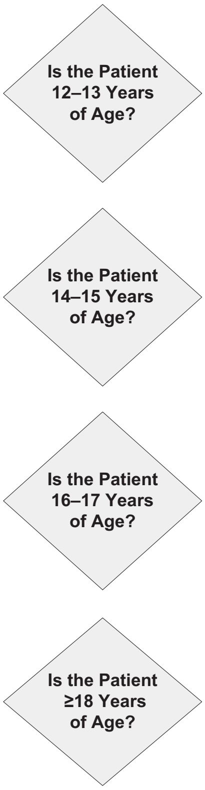
All youth, regardless of whether they have identified special health care needs, should be assessed for transition readiness. Preparation for adult life should be a routinely addressed topic for any health maintenance visit that occurs within the medical home during the adolescent years. The *Bright Futures* initiatives provide content materials on this subject matter.[20] Medical homes can provide appropriate transition services, support, and planning. Transition planning with patients and families must be initiated during an office visit to allow face-to-face communication, because the parties involved may not have previously considered this subject matter. Subsequent medical home transition-planning "interactions" may include, but not be limited to, office visits for health maintenance or acute illness, CCM visits, nursing visits, telephone or e-mail consultations, provision of office policies, and/or record reviews and updates. It is of paramount importance that the primary care medical home recognize which youth in the practice have reached the age for transition planning and prompt these families to come in for a visit to initiate the process. Each action step does not require a separate medical home visit, and multiple action steps can be addressed during a visit, although doing so requires a greater investment of time and resources.

Although opinions differ on the age for initiating the transition process, the most appropriate time is early adolescence, when youth become developmentally capable of engaging in activities regarding their personal futures. Therefore, this clinical report recommends initiating the first step in the health care transition-planning process at the age of 12, which allows sufficient time to adequately prepare patients, families, and medical providers before the youth legally becomes an adult at the age of 18. Several clinical studies have found this age to be an appropriate time to initiate the process to most successfully affect the transition's outcome.[27–29]

Children and youth with special health care needs and their families may benefit from discussions regarding adult transitioning that begin earlier than 12 years of age, depending on specific patient circumstances. Expectations for vocation, independent living, guardianship, reproduction, life expectancy, and other topics should be discussed at the earliest possible opportunity with parents and/or other appropriate caregivers if it is determined that the child's transition process will be different from that of children without special health care needs. In addition, some children with chronic medical conditions (eg, asthma or diabetes) may be introduced to developmentally appropriate self-care at ages younger than 12. The timing of these discussions must be individualized.

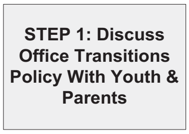
Row 2: Age Ranges

The second row of the algorithm assists health care providers in developing a practice of recognizing the need for transition for all patients 12 years or older. The use of emerging health information technology is likely to aid in this process (eg, through registries and age-related prompts). The age ranges presented in the algorithm are designed to aid the provider in assessing the most appropriate ages for implementing specific stages of transition planning. For most patients, this appropriateness is determined by age, whereas for others, it may be modified on the basis of developmental considerations. The provider's flexibility and judgment are important in this process. Actual transition planning should be initiated at the age of 14. The goal is to identify patients who are either entering or within the 14- to 15-year age range to initiate the development of a patient-specific transition plan at the child's next visit.



Row 3: Action Steps for Specific Age Ranges

Transition is a dynamic and fluid process that includes 4 major action steps. Each of the first 3 action steps (discussion of medical home transition policy, initiation of transition plan, and review/update of the transition plan) lays the foundation for the next. The fourth action step (implementation of an adult care model) prepares the youth and/or caregiver for the transfer to an adult care model. Regardless of the age at which the patient's transition process is initiated, the 4 action steps for transition planning must be accomplished in a linear fashion. For example, if transition is being initiated for a 16-year-old who presents for a health maintenance visit, steps 1 and 2 of the algorithm must be completed before moving to step 3 (the age-appropriate stage for a 16-year-old). As noted, a separate medical home visit is not required for each action step, and multiple action steps can be addressed in a single visit.



In (3a) step 1, the provider shares and discusses the office transition policy with the youth and his or her family or other caregivers. As described previously, every pediatric practice should have a well-defined policy that clearly states the expectations for the health care transition of their adolescent patients to an adult model of care. This policy should be displayed in a location where youth and their caregivers can easily read it (eg, posted in front offices and waiting rooms and described in brochures and on the practice's Web site). The policy should reflect the appropriate level of health literacy, reading and language proficiency, and cultural norms for the population the practice serves. Components of the office transition policy include, but are not limited to:

- the expected age of patient transfer to an adult model of health care;
- the patient's responsibilities in preparing for transition;
- the parent, family, and/or caregiver responsibilities in preparing for transition; and
- the medical provider's responsibilities in preparing for transition.

In addition to posting the transitions policy, providers should provide a written copy of the office policy to all patients who are aged 12 or older and their families. Optimally, this policy is provided before a face-to-face encounter between the family/caregivers and the medical provider to allow the patient and family/caregivers sufficient time to become familiar with the policy and prepare any questions they may have before the office visit. Office policies can be given to the transitioning youth and family/caregivers while in the waiting room or be sent to their home before the visit. The delivery and discussion of the office transition policy should be documented in the patient's medical records. Medical home providers should be familiar with each of the transition policy's components to facilitate discussion and respond to questions posed during the office visit. Having a transitions policy that is presented early to the patient and family and other caregivers removes any doubt about the timing of transfer and raises awareness that the medical home will be a valuable support for those who need additional assistance.

For youth without special health care needs, no further transition-specific activities are required until the 14- to 15-year visits. For adolescents with special health care needs, however, the period from 12 to 14 years of age is likely to be spent beginning preparations for transition readiness. For this reason, during the 12- to 13-year visits, the medical home provider must identify those patients who are at risk of having a more complicated transition because of special medical, developmental, social, and/or environmental needs. Some children with particularly complex health care needs may benefit from the early implementation of a formal transition plan before the age of 14.

STEP 2: Ensure Step 1 Is Complete, Then Initiate a Jointly Developed Transition Plan With Youth & Parents

In (3b) step 2, the medical home provider initiates a transition plan that is jointly developed with the youth and his or her parents. Starting at age 14 (or before, for some children with special health care needs, as described previously), a formal transition plan should be initiated for all youth and placed in the medical record for review during future office visits. The written plan should document the youth's current readiness to assume a greater role in self-management of his or her health care, the steps to be conducted to achieve a successful transition, and the transmittal of information to the youth and family/caregivers. It forms the basis for records to be provided to the receiving provider and youth on the transfer of care between the ages of 18 and 21. Implementation and review of the transition plan can be an important measurable quality-improvement effort on the part of the medical home.

The starting point for this step is the recognition of patient capabilities and delineation of responsibilities between patient, family and other caregivers, and medical providers for overall patient care. Practices should select a readiness-assessment tool to use that can be modified for specific patient situations. Readiness tools reveal areas of both strength and weakness on which patient education can be focused to accomplish future goals in self-management. Regardless of the tool chosen, it should contain specific minimum components that provide an accurate, point-in-time assessment of the individual patient's ability to transition successfully. (These components are described below. Many readiness-assessment tools and skills checklists exist for conducting this assessment; some are listed in "Resources.")

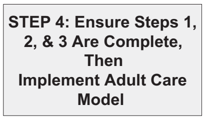
No matter what tool is used to assess and document readiness, providers should interview family members or other caregivers and the youth independently of one another to identify needs and assess intentions and motivations for the patient's independence. The identification of special health care needs (medical or otherwise) requires the medical home to be proactive in facilitating relationships between the youth and appropriate community and/or state resources.

STEP 3: Ensure Steps 1 & 2 Are Complete, Then Review & Update Transitions Plan & Prepare for Adult Care

In (3c) step 3, the medical home provider reviews and updates the transition plan and works with the patient to engage in the transition process. The transition plan documentation should be reviewed on a regular basis to promote recognition by the patient, the family/caregivers, and the provider of successes and/or deficits in readiness preparation. Medical providers and caregivers can reprioritize the readiness goals with respect to changes in the youth's medical status and/or concerns on the part of the caregivers. Although the number of times this review occurs depends on the frequency of the patient's visits to the medical home, it should be conducted at least annually. Focused efforts and intensified communication (among the patient, family members and other caregivers, and providers) may uncover systemic roadblocks or deficiencies in the patient's abilities to achieve previous expectations.

If there has been a failure to achieve transition-readiness goals, a reevaluation of the existing plan is warranted; it may be necessary to increase the frequency of medical home interventions or visits. Because 16- to 17-year-olds are significantly closer to the age of expected transfer of care to an adult model, accomplishing transition goals may not be feasible within the annual health maintenance schedule. Readiness plans will require revision on the basis of the outcome of such communication.

Successful transition requires the identification of an adult care medical home, and completion of this task is one of the most important for pediatric providers. The patient and/or family (and other caregivers) may need assistance identifying available and qualified adult care providers; when they select an adult provider, it is the pediatric medical home's responsibility to ensure appropriate communication of any and all medical needs to the receiving provider. In the final year before transfer from the pediatric medical home, the youth and family/caregivers might benefit from a visit with the potential adult provider(s) to explore the potential of a long-term relationship. Pediatric care occurring within a family medicine practice obviates the need for such a visit but not the need for preparation for an adult model of care.



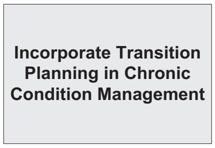
In (3d) step 4, the medical home provider implements an adult care model or affects the transfer to an adult medical home provider. After documented completion of the readiness goals in the individual youth's transition plan, the pediatric provider's role is to facilitate transfer of care to an adult medical home. For young adults with complex health care issues, direct communication between pediatric and adult providers is essential, because adult medical personnel may be unfamiliar with certain pediatric conditions.[17] For youth with complex needs, families are almost always a significant part of this conversation, because they are likely to be highly involved in not only caring for the youth but also arranging for, and supervising, others who provide care. The provider, youth, and family must jointly prepare a portable medical summary and, for children with special health care needs, a care plan, which should be delivered to the patient (or his or her legal guardian) and to the receiving provider. EHRs should also be provided to the adult provider. Medication reconciliation should be performed by the pediatric medical home before the record is transferred and by the receiving adult medical home when the record is received. (The components of this summary are described in "Implementing the Algorithm.")

Health care transition does not necessarily end with transfer. Some patients and/or caregivers may need additional support from the adult medical home to complete specific transition tasks. Providing this support through care coordination and consultation within the adult medical home optimizes the patient's self-management skills. In addition, the pediatric provider should make himself or herself available to the adult provider as a resource for any needed information or assistance during the immediate posttransfer period.

Row 4: Determination of Special Needs

The transition process may be simpler for youth without disabilities or chronic health conditions compared with those with special health care needs. If the youth has no special health care needs, the provider's primary task is to ensure that all age-appropriate transition issues are addressed and that a smooth transfer to an adult model of care occurs. For the youth with special health care needs, the transition process should be initiated at the age of 12 and may necessitate specific CCM activities (these components are described below). The MCHB definition encompasses a wide variety of conditions and range of severities, including children with developmental disabilities and chronic illnesses as well as those with mental health and behavioral disorders.[21] The development of patient registries to aid in the identification of these children is a core component of CCM within the medical home model. An important feature of such planning is the recognition that many tasks that lead to patient self-management are beyond the capability of young adults whose medical conditions include cognitive challenges. Transition goals must be individualized to account for such variations.

Row 5: CCM and Follow-up

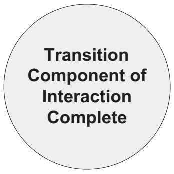


To the extent possible, basic transition planning and preparation for an adult health care model should be the same for children and youth with and without special health care needs. For many children and youth with chronic medical, developmental, and/or behavioral conditions, however, an expanded process of transition planning is necessary to address the exchange of more complex health information, competencies for self-care, and the transfer of specialty care from pediatric to adult medical subspecialists. In addition, broader transitional issues related to health insurance, entitlements, guardianship, and eligibility for adult community-based services must be addressed also. In a medical home, some youth with special health care needs will have a written care plan as part of the medical record that can serve as a script for care coordination and care planning. At the age of 14, this written care plan should begin to include a section titled “transition plan”; this transition section should be developed steadily as the youth approaches the age of 18 and beyond. (Transition planning in CCM is more described fully below.)

Regardless of whether the child has special health care needs, providers should ensure that age-appropriate transition issues have been addressed at every medical home visit and that the process is on track. Use of appropriate transition-planning tools and readiness checklists will facilitate the provider’s ability to answer this question. The act of “addressing” transition issues is not synonymous with the successful completion of the process, however. Identification of items in need of attention, and the formulation of plans to accomplish them, may be sufficient to complete this action step. If patients have fallen behind the transition-planning schedule, providers are likely to need to schedule a special visit to complete all of the tasks related to transition planning.

Follow-up interactions may take one of several forms. Focused tasks that involve little detail or complexity can be addressed by staff such as the medical home care coordinator or medical provider via telephone communication or electronic media (eg, secure e-mail). Larger or more complex issues may necessitate 1 or more face-to-face office visits, which should not be relegated to the next periodic health maintenance visit.

Row 6: Interaction Complete



This point does not mean that the office visit is complete or that the provider does not continue to provide care, merely that the part of the process of providing care that centers around transition planning has been completed for this specific office visit or interaction.

4. IMPLEMENTING THE ALGORITHM

Every youth who reaches the age of transition from a pediatric medical home or becomes a legal adult within his or her current medical home needs to have a basic transition plan developed through collaboration among the youth, family, and provider. Those with special health care needs require additional components specifically to address their chronic care management (see “Integrating Transition Planning Into CCM for Children and Youth With Special Health Care Needs”).

a. Transition Plan Components for Every Child and Youth

There are 4 recommended components for a transition plan, each of which can be augmented by the use of specific tools to facilitate the work of the provider, youth, and family.

1. *Assess* for transition readiness. The provider, family, and youth begin by articulating realistic goals for transition and identifying new skills that will be needed by the patient to meet those goals successfully. Although it is not the main focus of the medical home, the assessment should be “person-centered” and include identification of other areas of readiness for transition into the adult world in general, including education/vocation, independent living, and patient awareness of medical needs and age-appropriate preventive care, as outlined by resources such as *Bright Futures*.[18] Numerous tools are available in the form of “readiness checklists” that allow providers to obtain a baseline idea of the current capacity of the youth, family and other caregivers, and providers to successfully achieve the outlined goals. Transition progress should be measured through periodic reassessment using the same checklists at each visit (see “Resources” for selected transition-readiness materials).
2. *Plan* a dynamic and longitudinal process for accomplishing realistic goals. The first step of transition planning is the establishment of goals that allow the youth to achieve as seamless a transition as possible. A formal, written transition plan that outlines specific actions that are necessary to meet the stated goals should be part of the patients’ medical record by the

age of 14. The written transition plan should account for cultural, developmental, organizational, and contingency-related concerns. In general, categories recommended to be incorporated into the transition plan include the plan's main goal(s), identification of who within the medical home will be responsible for overseeing and/or coordinating the plan, the time line for accomplishing stated goals, the skills required by the youth to achieve maximum self-management, the families' or other caregivers' role, and an articulation of proposed financing of the youth's adult health care (see "Resources" for selected transition-planning tools).

3. *Implement* the plan through education of all involved parties and empowerment of the youth in areas of self-care. After the transition plan has been outlined and goals have been established, specific activities to ensure that the youth acquires needed skills should begin. Examples of these goals include the ability to schedule one's own medical appointments, obtain medications, have a one-on-one dialogue with a medical provider, and be familiar with one's medical history and any needed medications. Ongoing discussion of the transition plan at all health care visits is a key step in accomplishing transition goals. This should be a dynamic process that begins gradually and is continually assessed at regular intervals. The timing of these reassessments depends on the capacity of the youth and his or her family and other caregivers as well as the amount of time remaining until the anticipated transfer of care to the adult medical home. The transition-readiness checklists used during the initial assessment to establish goals (outlined previously) are the tools of choice for documenting successful accomplishment of specific goals and tasks. It is highly recommended that a medical home use the same checklists throughout the entire transition process for an individual patient to provide continuity over time and assist youth, families, and providers to stay "on track" regarding specific goals that have yet to be accomplished.

   Throughout this process, the provider should continually strengthen the partnership with the patient and family members and other caregivers by engaging in active dialogue and information-sharing to empower the youth to take on new roles, as appropriate. It is important to recognize that, at the age of maturity, the youth becomes a legal adult (except when guardianship by another person has been obtained). As a result of confidentiality laws, the youth should be seen alone unless other arrangements have been legally made. One to 2 years before the anticipated transfer of medical care, the pediatric provider should assist the youth and/or family/caregivers to identify potential adult practices, prepare the appropriate documentation for transition, and suggest that the youth interview the adult practice before making a final transfer.

4. *Document* progress to enable ongoing reassessment and movement of medical information to the receiving (adult care) provider. Many excellent tools for documenting the transition process exist, including some that can be used within an EHR system and others that are paper-based. For example, providers might place a transition front sheet on the patient's chart or use a "dashboard" tool in the patient's EHR at the age of 12. Both of these methods work well in flagging important actions that have occurred and/or need to be scheduled as part of the transition process. Regardless of the specific tool used, it should provide a flexible method for assessing the youth's readiness for transition and progress made toward that goal. Gathering relevant information to document the patient's transition progress is of paramount importance as the anticipated transfer date approaches. It is well documented that a common barrier to adult medical providers' acceptance of transitioning youth is a lack of accompanying medical documentation.[16] It is critical that medical documentation be portable and include 3 components: (1) the transition plan (see above); (2) longitudinal readiness checklists (see above), which demonstrate both successes and deficits in self-management skills; and (3) a portable medical summary. The portable medical summary contains basic medical and social data to give adult medical providers the information necessary to begin assuming care for the patient. All youth receive this portable medical summary, because the data it contains are essential topics and elements that are critical to the transition summary. Although the categories of the medical summary are appropriate for all chronic health conditions, specific information should be tailored to the patient's conditions.

b. Integrating Transition Planning Into CCM for Children and Youth With Special Health Care Needs

Transition planning applies to all children and youth and should follow the steps defined in the algorithm. The presence of chronic health conditions and/or developmental disabilities (ie, children or youth with special health care needs) imposes specific primary care requirements on the family-centered medical home characterized as CCM. Effective CCM, in turn, demands additional considerations related to transition planning. CCM involves an explicit, planned process of coordinated, proactive care aimed at achieving the best possible clinical and functional outcomes for the individual patient and for the population of patients with chronic conditions. While following the general sequence and timing of the transition algorithm, transition planning for children or youth with special health care needs will usually be incorporated into the broader CCM process. Early in the transition-planning process, it will be important to determine whether the youth is likely to be a completely independent decision-maker as an adult or require decision-making support from a third-party proxy such as through guardianship or power of attorney. Even with these considerations in mind, it is important to plan with the youth and family/caregivers to achieve the maximum possible participation of the youth in the transition-planning process.

1. Registry. The family-centered medical home CCM process may include a registry of the practice's patients with special health care needs. The registry should be searchable on the basis of patient age so that youth who are ready for each stage of the transition process (see algorithm) can be identified. The registry might also include fields indicating which steps in the transition process are due for completion, have been completed, or are past due for completion. Additional fields unique to the transition of children or youth with special health care needs might include "discussed guardianship," "identified adult subspecialists," etc.
2. Care Plan. Some children or youth with special health care needs will have an action-oriented care plan for tracking current problems and health-related needs including what action is needed, who will be responsible, and by when the action should have occurred. When a child or youth with special health care needs enters the age group covered in the transition algorithm, the action-oriented care plan should begin to contain a transition section that will become the youth's transition plan. The incorporation of the transition plan into the general action-oriented care plan will ensure integration of transition planning with other health-related actions.
3. Care Coordination. Care coordination is one of the foundations of the family-centered medical home and assumes special importance for children or youth with special health care needs who utilize the health care system frequently and who may have multiple health care and other service providers. Those who coordinate health care for the child or youth with special health care needs will need to take into consideration the youth's transition plan and the current stage of the transition-planning process. Care coordination may be instrumental in supporting the transfer of care from various pediatric medical subspecialists to their adult specialty counterparts.
4. CCM Visits. The family-centered medical home provides periodic CCM visits that may occur in addition to health maintenance and acute illness management visits to monitor the status of patients with chronic conditions and implement/update their care plans. These CCM visits would provide the occasions for transition education and planning.
5. Comanagement. Explicit comanagement between primary care physicians and medical subspecialists ensures communication and prevents both omissions and redundancies of care. It explicitly identifies the respective roles of the primary care medical home and the medical subspecialists in a manner that is clear to each provider and the youth and family and other caregivers. The locus of management may shift from time to time between primary care and specialty care depending on the youth's age and the complexity and acuity of specific health problems. Comanagement with medical subspecialists assumes particular importance for transition planning, because it provides the framework in which to plan for and implement the transfer of care from pediatric subspecialists to adult medical subspecialists and surgical specialists. Comanagement may also be the context for a dialogue of explicit communications between the youth's medical home and the future adult medical home provider. Comanagement planning with respect to transition planning should include the timing and process for specific transfers of care in each relevant specialty area. In some cases, the plan may be to retain a pediatric subspecialist into adulthood because of the absence of appropriately qualified adult medical subspecialists.

It should be noted that some diagnosis-specific programs, including clinics for hemophilia and cystic fibrosis, have established strong programs to guide subspecialty transfer. The National Hemophilia Foundation established a nationwide network of hemophilia diagnostic and treatment centers and, in 2003, adopted transition guidelines that provide age-related recommendations. These models and transition guidelines acknowledge that there are continuing areas for improvement such as addressing preventive health needs or promoting the adult model of decision-making by young adult patients.[30,31]

i. Components of the Transition Plan for Youth With Special Health Care Needs: Necessary Information for the Receiving Provider, Patient, and Family Members/Caregivers

In addition to the items in the transition plan for all youth (described previously), additional components should be included in transition plans and records for youth with disabilities and/or special health care needs. All transition plans should be tailored to the individual patient and his or her needs.

Additional data elements that are likely to be included in the transfer documentation for youth with special health care needs include baseline functional and neurologic status; the patient's cognitive status, including formal test results and date of administration, when possible; condition-specific emergency treatment plans and contacts; and the patient's health education history and assessment of his or her understanding regarding health conditions, treatments, and prognosis with particular attention to entry into adult life, including procreation potential and genetic information.

Information about advance directives should include an identification of the decision-maker proxy or guardian and any history of advance-directive planning. For patients with communication impairments, the transition documentation should include the patient's communication preferences and anticipated needs for accommodations in both communication and clinical care (ie, use of sign language interpreter, augmentative communication device, etc).

ii. Components of the Transition Plan for Youth With Special Health Care Needs: Assessment and Documentation of Readiness

As part of the transition-planning process, a member of the medical home team should regularly assess the patient and his or her family and other caregivers on progress toward achieving transition readiness and preparation for adult life. Interventions to address individual difficulties and/or provide extra resources should be conducted during visits. Education and empowerment techniques should be used to ensure that development of needed skills is embraced by the patient and families and continues to occur. Providers must ensure that they document both the patient's and family's progress toward successfully completing the plan's components as well as any plan revisions. A formal method should be used to document the stepwise completion of developmentally appropriate tasks required to prepare the transitioning patient for adult life. Flow sheets, registry reminders, and planned visit templates for specific ages are all possible means to do so. In addition, documentation is particularly important in certain specific areas.

Insurance Coverage

The 2010 Patient Protection and Affordable Care Act (PPACA) health care reform legislation will affect coverage, access to care, and care coordination in the short-term and/or long-term. Specific provisions of the PPACA expand children's and youth's access to coverage and ongoing care, including changes that permit children to remain on their parent's insurance until the age of 26; eliminate insurers' ability to exclude coverage on the basis of preexisting conditions; improve coverage portability; create a high-risk pool insurance for people who cannot access coverage through other sources; enhance Medicaid payment to primary care physicians; and mandate that nearly all people (including young adults) have coverage. Although these changes are likely to prove beneficial, it is likely that parents, caregivers, and transitioning youth alike will need assistance to understand this complex legislation and its impact on their lives and the transition process. In addition, PPACA provisions are to be implemented over time, and youth must be encouraged to proactively plan to avoid suffering substantial coverage gaps and/or delays in coverage because of "preexisting conditions" until 2014, when this practice is prohibited under PPACA. In addition, age eligibility and coverage requirements may vary for programs such as Title V, Medicaid, Supplemental Security Income (SSI), and Social Security Disability Income (SSDI). Youth with chronic conditions should be encouraged to evaluate future employment options that are most likely to offer insurance coverage for high-risk people (ie, employers who participate in large group plans and, thereby, spread out risk). Parental employment-based coverage limitations also vary widely; although a few plans cover adults with disabilities who are dependents of their parents, they are the exception. Because of the critical nature of insurance coverage for people with special health care needs, it is essential that providers discuss insurance issues with these patients and document plans to ensure continued coverage.

Self-Advocacy

Critical topic areas for the empowerment of youth with special health care needs include self-advocacy and making plans about decision-making status, educational and/or employment opportunities, living arrangements, and community-inclusive opportunities. It is critical to encourage families to initiate training and decision-making opportunities for children with special health care needs at a young age. Families should receive assistance from experts in self-advocacy when considering the range of potential support, which may include personal informal advocates, power of attorney, and limited-to-full guardianship. Important resources include organizations, such as Family Voices; local chapters of The Arc; and lawyers who are experienced in disability issues. Because of the importance of self-advocacy for youth with special health care needs, it is essential that providers initiate conversations about decision-making and begin to plan advocacy support for these youth far in advance of the age of majority.

Legal Issues

The assessment of the patient's potential capacity to consent occurs as part of the ongoing CCM process. Providers should suggest goals and action steps that help youth achieve their fullest potential and participate as much as possible in assent and consent processes during their clinical care. It is critical that youth and family members and other caregivers alike understand the significant health system changes associated with the age of majority, including support-service or program-eligibility changes, selective service registration requirements, consent and confidentiality provisions, and guardianship issues. Youth and family members/caregivers need to think about how health care decisions will be made once the youth turns 18. Because of the particular importance of legal issues for youth with special health care needs, it is essential that providers ensure that both the patients and family members understand and are prepared for legal changes associated with adulthood. In addition, problems can arise when a youth is incapacitated and unable to direct his or her own care. Preparing a health care proxy or power of attorney for the young adult will avert such a situation.

Health Education

People with chronic conditions should receive periodic, updated health education about their condition. Necessary information includes an understanding of the patient's specific condition; typical disease process and prognosis; current treatment and treatment options; medication knowledge; self-assessment; and self-care issues, especially in defining emergent situations and responses. Particular attention should be paid to issues of puberty that may not have presented earlier, such as sexual expression, reproductive issues, and genetic transmission. Because of the importance of the patient's understanding his or her own condition, it is essential for providers to document that this information has been provided to, and understood by, the patient.

Caregiver's Issues

Assessment of family/caregiver adaptation is another component of the transition-readiness assessment for families of children and youth with chronic conditions. Attention should be paid to coping on the part of the youth, his or her parents and siblings, and any other appropriate family members and other caregivers. Parents and caregivers must adapt to the transition of authority from parent to youth that occurs when the youth has the capacity to accept the transfer and may experience grief if the child lacks the capacity to assume independent decision-making. For this reason, providers must be ready to help parents and caregivers cope with the life changes associated with chronic conditions as well as with transfer planning. Because these situations can be stressful for the youth and family members/caregivers alike, it is essential that providers assess patients' coping mechanisms and provide referrals for additional care, as appropriate.

5. ADULT MEDICAL HOME (RECEIVING PROVIDER): ROLES AND RESPONSIBILITIES

The transition of a young adult will make it necessary to identify an adult practice that is prepared to accept the patient and provide the full range of care and care coordination in an appropriate, patient-centered care model. Most young adults are healthy and require only the continuation of health maintenance and promotion and the availability of an adult medical home when acute illnesses arise. Yet, even the population of young adults without special health care needs includes those with adolescent-type risky behaviors, mental health issues, and reproductive health needs that require enhanced attention. Young adults with disabilities and chronic medical conditions are more vulnerable to failures in the transition of health care services and require more attention from providers and the health care system. Fundamentally, clinical hurdles and process hurdles present major challenges for a successful move to adult-oriented care for young adults with special health care needs.

The transition of a young adult necessitates the identification of an adult practice that is prepared to accept the patient and provide the full range of care and care coordination in an appropriate patient-centered care model. Shortages in the adult medical home workforce may limit future capacity to do so. Thus, clinical hurdles largely encompass deficits in education and/or experience of some adult providers to effectively care for this diverse patient population, as well as financial disincentives that limit access to adult-oriented care. The authors of several recent articles have explored the perspective of adult providers participating in the medical transition of young adults with special health care needs. Okumura et al[15] found that, when adult medical care providers were exposed to the process of transitioning young adults in the context of their residency training experiences, they were much more likely to incorporate it into their practices after residency. Anecdotally, however, these residency training experiences are not common, and many practicing physicians have learned "on the job" to manage patients with complex needs. A recent survey of internists' needs when accepting a transitioning youth revealed that education in congenital and childhood-onset conditions was critical.[17] In addition, the respondents cited the need for identified medical subspecialists to help with management decisions. Although adult medical providers have the role of assuming the care and management of these youth, they should not be expected to do so without supports that are more readily available to pediatric providers.

Caring for young adults with special health care needs may represent a challenge that some adult primary care practices are currently not prepared to meet. Further work is needed to characterize, demonstrate, and teach an adult model of care that is responsive to the particular needs of all young adults and sensitive to the specific challenges associated with providing high-quality care to young adults with specific chronic conditions (eg, autism, cerebral palsy, intellectual disability, sickle cell disease). Ideally, the health care payment system would encourage early and ongoing professional relationships with pediatric providers in anticipation of transitions and also support comanagement with pediatric primary care and medical subspecialty providers while the patient is becoming established with the adult practice. At some point, the responsibility for the transitioning young adult will become that of the adult provider, at which time, the adult provider and his or her clinical team should assume a key role in supporting the young adult and his or her family and other caregivers in finding a new balance in the adult medical setting. The transitioning youth's developmental and functional abilities may influence the transition's success. The continued involvement of the family/caregivers should be expected and encouraged during this transition period. In addition, working with the family and other caregivers and other supports to ensure adequate health care insurance and financing for these youth is a major goal of transition.

Second, process hurdles include challenges in the communication of appropriate medical records; community resources; preparation of the young adult and his or her family/caregivers to integrate into an adult-focused medical system; and issues related to payment. Adult providers should not expect a "handoff" from pediatric practices but, rather, a "handshake." Establishing collegial relationships between pediatric and adult medical providers is important for facilitating ongoing access to medical care for patients in transition. Although every transition is different, the best transitions include several core elements. Receivers (providers to whom the youth transitions for care) may reasonably expect that, as the adult medical home team, they will be provided with concise and accurate medical information about the youth and his or her condition, as described previously. In addition, receivers should ensure that:

- the responsible party for medical decision-making has been clearly identified;
- unambiguous adult consent and confidentiality policies have been explained to the patient and his or her family and other caregivers;
- communication has occurred about how the practice operates for issues such as paperwork and medication refills; and
- access to the practice for routine and after-hours care has been discussed with the patient and his or her family and other caregivers.

Although many young adult patients will transition to adult practices from pediatric-based practices, the unique relationship that many family physicians have with their patients allows for ongoing care throughout the life span. Although transfer of care many not occur in these situations, it is likely that young adults with special health care needs have pediatric subspecialists who may wish to facilitate transfer to their adult counterparts. The family physician has the special responsibility to be aware of these needs and, in some situations, to potentially play the role of both the "sender" and "receiver."

Certainly, successful transition is a test of the degree to which a practice operates within the ideals encompassed in the medical home model of care. A team approach to the challenges of transition is necessary for facilitating the level of care for which adult providers strive. Inclusion of local public health and community-based resources should be considered whenever possible to ensure that the medical home approach is followed, particularly for vulnerable patient populations with special health care needs.

Payment for Health Care Transition Work

The steps involved in the health care transition algorithm are intended to be part of existing office visits using well-established billing codes. For youth without special health care needs, transition preparation and planning would be incorporated into regularly scheduled health maintenance visits and billed as such (Current Procedural Terminology [CPT] codes 99394 and 99395). For youth with special health care needs who have sufficient complexity to justify periodic CCM visits in addition to health maintenance visits, health care transition preparation and planning are intended to occur during a CCM visit billed as a prolonged encounter with an established patient (CPT codes 99214 or 99215). Such visits can be documented as involving counseling for more than 50% of the visit. Youth with highly complex needs may require a CCM visit in which the counseling provided is devoted entirely to transition, but these visits are still reimbursable when using the prolonged-encounter codes and the counseling rule. Activity outside of office encounters involved in the management of a youth's transition plan (whether it stands alone or is incorporated into a more general care plan for a chronic condition) constitutes "care plan oversight." Such work may involve phone calls to prospective adult primary care physicians or medical subspecialists, conversations with the youth and family regarding transition plans, or communication with community agencies integral to the transition process. These activities can be billed by using care plan oversight CPT codes 99374 (15–29 minutes) and 99375 (≥30 minutes) through which the physician can bill monthly for the cumulative time spent on care (or transition) plan oversight. Similar coding and billing options may be exercised after the transfer of care from a pediatric medical home to an adult medical home.

6. CLINICAL GUIDANCE AND FUTURE SUGGESTIONS

This report attempts to address the need for guidance to aid practitioners' implementation of youth transition planning into practice. Yet, transitions cannot occur in a vacuum. Systemic barriers that have been reported as factors that hamper clinicians from implementing needed changes include lack of training and payment for transition activities, receivers to accept these patients, research to identify best practices, and advocacy to advance the research results. Increased training on the critical skill of transitioning can be integrated into an adolescent medicine rotation in internal medicine and into the adolescent medicine and continuity clinic rotations for pediatric residents. Med-peds, pediatrics, and family medicine residencies may provide significant training opportunities in this area. Dually boarded med-ped physicians would seem ideally equipped to care for transitioning adolescents and young adults and to assist in the training of other primary care generalist physicians regarding care over this age range. Unfortunately, the med-peds workforce remains too small and is not likely to grow sufficiently to affect the health care transition of most youth and young adults.

Graduate medical education programs may also provide a forum for pediatric and adult providers to build and maintain relationships that are needed to enhance collaboration and improve communication, ultimately facilitating comanagement of complex conditions. Payment is a crucial element in the promotion of transition planning. Incorporating transition planning into CCM is a process that costs time and money and should be included in conversations about care coordination and payment. Further research is required to define best practices, clinical pathways, and cost-effectiveness for transition planning. Quality-improvement science may provide additional methodologies to inform the understanding of potential strategies. Once best practices are identified, advocacy and education efforts will need to be directed toward several areas including:

- enhanced payment for transition services;
- case-finding of those in need of transition services who are not receiving them;
- insurance coverage for patients in need of transition planning;
- standards of care and credentialing of providers;
- training for primary care physicians and medical subspecialists to promote transitions within the medical home; and
- promotion of training and clinical learning experience on transition and transfer of youth and young adults (both with and without special needs) for trainees in all medical fields.

7. CONCLUSION

A well-timed, well-planned, and well-executed transition from child- to adult-oriented health care, ideally occurring between the ages of 18 and 21, enables youth to optimize their ability to assume adult roles and activities. For this reason, transition planning should be a standard part of providing care for all youth and young adults, and every patient should have an individualized transition plan regardless of his or her specific health care needs. The AAP, American Academy of Family Physicians, and American College of Physicians recognize that providers need assistance to accomplish this goal. Education of practicing and resident physicians in training is essential for the integration of the concepts of the patient- and family-centered medical home, the principles of transition of care, and the processes for successful transfer of care. Therefore, this clinical report provides a consensus on activities to support the practice-based implementation of transition planning for youth with and without special health care needs. It describes a series of activities designed to ensure that uninterrupted, high-quality, and developmentally appropriate health care services are available to patients moving from adolescence to adulthood. The clinical report provides a clear time line, beginning at 12 years of age, to assist providers in implementing the 4 specific activities in transition: discussing the medical home transition policy; initiating a transition plan; reviewing/updating the transition plan; and implementing an adult care model. It also includes an algorithm that specifies the protocol for managing the transition process, helps providers implement the transition process, and provides a transition structure for patients and their families. The algorithm includes a branch with expanded, generic guidelines for transitioning youth with special health care needs who require CCM. Primary care providers and medical subspecialists are encouraged to make this process specific for their own and their patients' needs.

8. RESOURCES

a. General Resources

- National Health Care Transition Center (www.gottransition.org).
- Family Voices, Inc (www.familyvoices.org).
- Family-to-Family Health Information & Education Center (www.bridges4kids.org/f2f).
- Kids as Self Advocates (KASA) (www.fvkasa.org).
- National Alliance to Advance Adolescent Health (www.thenationalalliance.org).

b. Transition Care Plans

- AAP/National Center for Medical Home Implementation (www.medicalhomeinfo.org/how/care_delivery/transitions.aspx).
- British Columbia Ministry of Children and Family Development, "Transition Planning for Youth With Special Needs" (www.mcf.gov.bc.ca/spec_needs/pdf/support_guide.pdf).
- University of Washington, Adolescent Health Transition Project (http://depts.washington.edu/healthtr).

c. Transition Assessment and Evaluation Tools

- AAP/National Center for Medical Home Implementation (www.medicalhomeinfo.org/health/trans.html).
- JaxHATS, evaluation tools for youth and caregivers and training materials for medical providers (www.jaxhats.ufl.edu/docs).
- Texas Children's Hospital transition template (http://leah.mchtraining.net/bcm/resources/tracs).
- Carolina Health and Transition Project (CHAT) (www.mahec.net/quality/chat.aspx?a=10).
- University of Washington, Adolescent Health Transition Project (http://depts.washington.edu/healthtr).
- Wisconsin Community of Practice on Transition (www.waisman.wisc.edu/wrc/pdf/pubs/THCL.pdf).

d. Portable Medical Summaries

- AAP/National Center for Medical Home Implementation (www.medicalhomeinfo.org/how/care_delivery/transitions.aspx).
- National Diabetes Education Program (www.YourDiabetesInfo.org or www.ndep.nih.gov).
- Sick Kids (www.sickkids.ca/good2go).
- University of Washington, Adolescent Health Transition Project, medical summary (http://depts.washington.edu/healthtr/medsum/portable_medsum.pdf).

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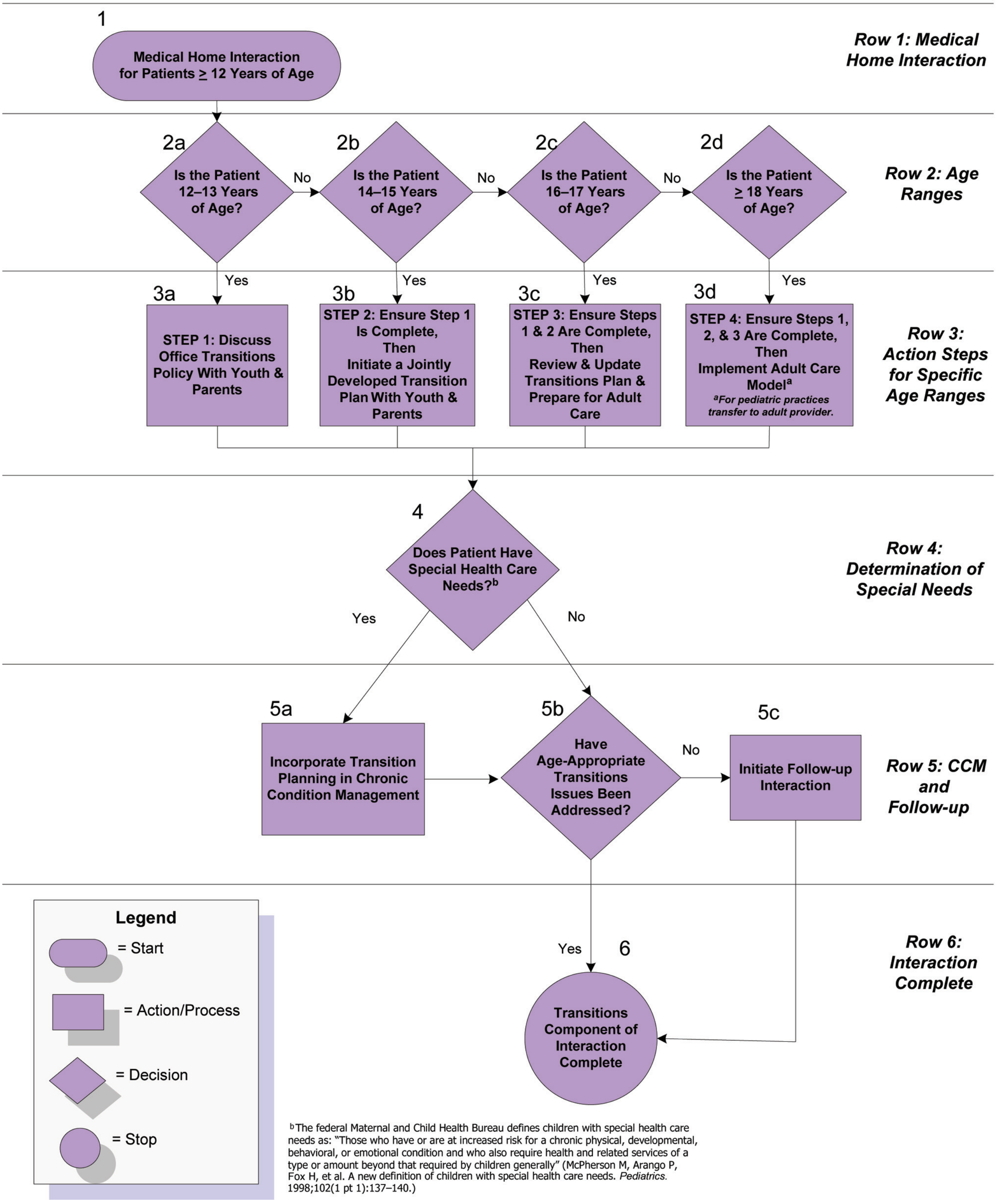
Health Care Transition Planning Algorithm for All Youth and Young Adults Within a Medical Home Interaction



[b]The federal Maternal and Child Health Bureau defines children with special health care needs 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" (McPherson M, Arango P, Fox H, et al. A new definition of children with special health care needs. *Pediatrics.* 1998;102(1 pt 1):137–140.)

APPENDIX 1

Medical Home Interaction for Patients ≥ 12 Years of Age

1. Initiate first step in the health care transition planning process at age 12.

Is the Patient 12–13 Years of Age?

Is the Patient 14–15 Years of Age?

Is the Patient 16–17 Years of Age?

Is the Patient ≥ 18 Years of Age?

2a, 2b, 2c, 2d. Age Ranges. By age 12, conduct surveillance to assess any special health care needs. Start actual transition planning by age 14. By ages 16-17, transition planning should be well established. At age 18, initiate an adult model of care for most youth, even if there is no transfer of care. If transition planning does not occur on the schedule described by the algorithm, a concentrated effort is required (eg, special visits) to successfully complete the process.

3a. Every practice should have a written transition policy that is prominently displayed and discussed with youth and families. The policy should explicitly state the practice's expectations and care process for the health care transition of their adolescent patients to an adult model of care.

STEP 1: Discuss Office Transitions Policy with Youth & Parents

STEP 2: Ensure Step 1 Is Complete Then Initiate a Jointly Developed Transition Plan With Youth & Parents

3b. The practice should utilize a standard transition plan that can be adapted for each patient's needs. This tool should include components to obtain an accurate assessment of the patient's ability to successfully transition. Providers should interview youth and family members to identify needs and to assess the intentions and motivations for youth independence.

3c. Transitions plans must be reviewed regularly and updated as necessary. The provider must also perform surveillance for changes in the youth's medical status and address youth and family concerns that may warrant changes in transition goals. Failure to achieve transition readiness goals warrants reevaluation of the existing plan, and increased frequency of medical home interventions/visits. A "pretransfer" visit to the adult medical home could be conducted during the year before the transfer.

STEP 3: Ensure Steps 1 & 2 Are Complete, Then Review & Update Transitions Plan & Prepare for Adult Care

STEP 4: Ensure Steps 1, 2, & 3 Are Complete, Then Implement Adult Care Model[a]

[a] *For pediatric practices transfer to adult provider*

3d. Transition to an adult model of care occurs appropriate for youth's developmental level. This is followed as appropriate by transfer to an adult medical home. Complete medical records should be delivered to the adult provider, along with a portable summary, which is also provided to the patient or guardian. For children and youth with special health care needs, direct communication between pediatric and adult providers is essential, as adult medical personnel may be unfamiliar with certain pediatric conditions.

4. Transition planning for children and youth with special health care needs should include specific chronic condition management (CCM) activities such as: use of registries; care plans; care coordination; CCM office visits; and comanagement with medical subspecialists. Transition goals must be individualized to account for variations in the complexity of a youth's condition and in the youth's intellectual ability and guardianship status.

Does Patient Have Special Health Care Needs?[b]

Incorporate Transition Planning in Chronic Condition Management

5a. Youth with special health care needs require an expanded transition planning process. Transition planning in CCM includes addressing the exchange of complex health information; competencies for self-care; transfers of specialty care; and issues related to insurance, entitlements, guardianship, and eligibility for adult services. In a medical home, such youth may have a written care plan as part of the medical record. At age 14, this plan should include a section titled "transition plan," which should be expanded and developed as the youth approaches age 18 and beyond.

5b. Use of transition planning tools and readiness checklists facilitate the provider's ability to ensure that all age-appropriate transition issues have been addressed. Each action step must be completed in order, even if this means the provider has to schedule specific visits to initiate and complete steps missed earlier in the process in order to catch up before the next visit.

Have Age-Appropriate Transitions Issues Been Addressed?

Initiate Follow-up Interaction

5c. Focused tasks involving little detail or complexity can be addressed by the medical home care coordinator, medical provider, or other appropriate staff through telephone or electronic media. More complex issues may necessitate face-to-face office visits.

6. The provider is finished with the transition tasks for that specific interaction or visit; transition planning is an ongoing activity that occurs at every interaction.

Transitions Component of Interaction Complete

APPENDIX 1 CONTINUED

Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home

American Academy of Pediatrics, American Academy of Family Physicians, and
American College of Physicians, Transitions Clinical Report Authoring Group

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ORIGINAL ARTICLES

Outcome Evidence for Structured Pediatric to Adult Health Care Transition Interventions: A Systematic Review

Phabinly Gabriel, BA[1,2], Margaret McManus, MHS[1], Katherine Rogers, MPH, PhD[3], and Patience White, MD, MA[1]

Objective To identify statistically significant positive outcomes in pediatric-to-adult transition studies using the triple aim framework of population health, consumer experience, and utilization and costs of care.

Study design Studies published between January 1995 and April 2016 were identified using the CINAHL, Ovid MEDLINE, PubMed, Scopus, and Web of Science databases. Included studies evaluated pre-evaluation and postevaluation data, intervention and comparison groups, and randomized clinic trials. The methodological strength of each study was assessed using the Effective Public Health Practice Project Quality Assessment Tool.

Results Out of a total of 3844 articles, 43 met our inclusion criteria. Statistically significant positive outcomes were found in 28 studies, most often related to population health (20 studies), followed by consumer experience (8 studies), and service utilization (9 studies). Among studies with moderate to strong quality assessment ratings, the most common positive outcomes were adherence to care and utilization of ambulatory care in adult settings.

Conclusions Structured transition interventions often resulted in positive outcomes. Future evaluations should consider aligning with professional transition guidance; incorporating detailed intervention descriptions about transition planning, transfer, and integration into adult care; and measuring the triple aims of population health, experience, and costs of care. *(J Pediatr 2017;188:263-9).*

Transitioning from pediatric to adult care encompasses preparation for managing one's health and needed health care, transferring to adult-centered care with current medical information, and engaging in adult health care. Establishing a continuum of transition support that is coordinated between pediatric and adult care settings can be challenging, however.

Published literature consistently shows that most youths and young adults, including those with special health care needs and their parents, receive limited or no transition preparation, transfer assistance, and facilitated integration into adult care.[1-3] As a result, many are at risk for lower-than-expected health literacy,[4] discontinuity of care,[5,6] delays in securing an adult medical home and specialty care,[7] problems with treatment adherence,[8,9] dissatisfaction with care,[10-12] excess morbidity,[12] and even mortality.[13] To ameliorate these adverse outcomes, the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American College of Physicians (ACP) developed a joint clinical report on health care transition in 2011.[14] This professional consensus calls for specific transition activities beginning at age 12 years and continuing through young adulthood.

Various interventions have been used to improve the transition process, most of which have been of limited scope and generalizability. In 2014, the Agency for Healthcare Research and Quality (AHRQ) reported difficulties in determining which transition interventions are most effective because of limited evidence.[15] The Institute of Medicine, also in 2014, identified transition as a persistent problem with "minimal systematic implementation and evaluation of institutional change."[16]

Recent systematic reviews have focused on effectiveness of health care transition interventions[17,18] and measurable outcomes.[19] Crowley et al[20] studied health outcomes of transition programs and found that 6 of 10 included studies showed statistically significant improvements in outcomes. These positive improvements were found only in studies of patients with diabetes; the interventions associated with significant outcomes were patient education and transition clinics.

This review, which builds on Crowley's 2012 study, examines significant outcomes of health care transition using the triple aim framework, including a quality assessment of included evaluation studies. This review also addresses evidence gaps and implications for future studies, building on previous work related to transition measures using the triple aim domains of population health, patient experience, and costs of care.[21]

AAFP	American Academy of Family Physicians
AAP	American Academy of Pediatrics
ACP	American College of Physicians
AHRQ	Agency for Healthcare Research and Quality
EPHPP	Effective Public Health Practice Project Quality Assessment Tool for Quantitative Studies
HbA1c	Hemoglobin A1c

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Methods

Following the PRISMA checklist,[22] we conducted a search strategy of articles published between January 1995 and April 2016 using the CINAHL, Ovid MEDLINE, PubMed, Scopus, and Web of Science databases. Only English-language articles were included, and a combination of medical subject headings and keywords were used, as described in the **Figure** (available at www.jpeds.com).

Included studies described a transition intervention for youths transferring from pediatric to adult outpatient health care. Studies that addressed only self-care skills without reference to transition planning or transfer were excluded. The primary outcome was health care transition (not vocational or educational transition). Studies included preintervention and postintervention data, intervention and nonintervention comparisons, and randomized controlled trials. Prospective and retrospective studies were included. Excluded studies relied only on qualitative data or failed to specify the sample size, impeding quality rating.

One reviewer screened the initial identified titles and abstracts. Articles meeting the inclusion criteria were read in their entirety by 2 reviewers. When there were differences in opinion, 2 additional reviewers examined the full article in question.

The Effective Public Health Practice Project Quality Assessment Tool for Quantitative Studies (EPHPP) was used to assess methodological strength of each study.[23] This tool and its accompanying dictionary are available at http://www.ephpp.ca. The study components analyzed were selection bias, study design, confounders, blinding, data collection methods, withdrawals, and dropouts. Intervention integrity and analyses also were evaluated, but were not included in the global rating. Component ratings of strong, moderate, or weak were assigned along with an overall study rating based on the summation of ratings; a strong rating indicates no weak rating, a moderate rating indicates 1 weak rating, and a weak rating indicates 2 or more weak ratings (**Table I**; available at www.jpeds.com). Two assessors independently scored each included study for quality; differences were resolved by discussing the rationale for the rating and sharing information used to justify the rating. The 2 reviewers resolved all discordant ratings using this approach.

The following data were extracted from each study (**Table II**; available at www.jpeds.com): study design and population, medical condition(s) of the study population, US or international-based study, type of transition intervention, outcome measures and results, and overall quality assessment ratings. Study results are summarized in **Table II** in terms of statistically significant outcomes as an increase, a decrease, or no change, except for 1 study in which results were reported in terms of positive or negative effect sizes.[44] Special designations were assigned to outcome results with incomplete data. Statistically significant outcomes were confirmed by 2 reviewers.

Statistical Analyses

Outcomes from the included studies were categorized according to population health, experience of care, and utilization/cost domains. This triple aim framework was used in previous work,[21] but the categorization of results could differ in this study to align with statistically positive outcome criteria. This study also follows the framework of the Institute for Healthcare Improvement's *Guide to Measuring the Triple Aim*[65] and the AHRQ's *Early Evidence on the Patient-Centered Medical Home*.[66] In **Table II**, population health outcomes are organized according to adherence to care (including disease-specific outcomes), patient-reported health and quality of life, and self-care skills. Experience of care outcomes are organized according to satisfaction with care and barriers to care. Utilization/cost measures are classified into service utilization (including clinic, hospital, surgery, and procedures), process of care (including communications among providers and documentation of transition clinical processes), and costs of care. Only those studies with significant positive transition outcomes are reported in **Table III**.

Transition interventions were analyzed in terms of activities aligned with the AAP/AAFP/ACP Clinical Report: transition preparation, transfer of care, and integration into adult care. Article descriptions, albeit limited, were used. With respect to transition preparation, the following activities were counted when mentioned: transition process/policy, transition readiness assessment, self-care/disease education, plan of care, transition clinic in pediatric setting, and community resource linkages. With respect to transfer, the following activities were counted when mentioned: appointment scheduling assistance, preparation of a transfer package/medical summary, communication between pediatric and adult provider, and joint pediatric/adult clinic. With respect to integration into adult care, the following activities were counted when mentioned: welcome/orientation process, appointment scheduling and follow-up assistance, self-care assessment, self-care/disease education, plan of care, and young adult clinic. The presence of a designated coordinator to assist with the transition process was noted as well.

Results

This systematic review examined the evidence from 43 articles out of 3844 articles initially identified (**Figure**). **Table II** provides a summary of each study's characteristics. All but 5 studies[26,27,35,41,52] evaluated transition interventions for youths with a single condition, most often type 1 diabetes, followed by kidney or liver transplants and juvenile idiopathic arthritis. Among the handful of multiple-condition studies, only 1 study[31] included youths with neurodevelopmental conditions. No included study examined transition outcomes for youths with mental/behavioral health conditions or common chronic conditions, such as asthma. In addition, no study focused on youths without chronic conditions.

US studies accounted for one-third of the studies in this systematic review, with almost as many from the United Kingdom. Two of the UK studies[11,12] were conducted with the same study population using the same intervention, but evaluating different outcomes. Study population sizes of 100 or more were found in approximately one-quarter of the 43 studies.

Table III. Summary of positively significant transition outcomes in population health, experience of care, and utilization and cost of care

Population health outcomes	Experience of care outcomes	Utilization and cost outcomes
Adherence to care Decrease in HbA1c level[31,39,45,50,58,62] Decrease in HbA1c level for males[54] Decrease in HbA1c level for Hispanics[58] Increase in foot examinations[31] Increase in microalbuminuria screenings[31] Increase in eye assessments[31] Increase in hypertension screenings[39] Increase in nephropathy screenings[39] Decrease in prevalence of nephropathy[39] Increase in carbohydrate counting[62] Increase in weight[62] Decrease in number of hypoglycemic episodes[62] Decrease in incidence of severe hypoglycemia[58] Increase in insulin modification, specifically in proportion of rapid-acting insulin/day[62] Decrease in tacrolimus SD levels[24] Increase in medication adherence[34] Decrease in self-reported nonadherence to medications[51] Lower median change in serum creatinine at 1 year post-transfer[51] Lower change in eGFR at 1 year post-transfer[51] Decrease in changes in nonsteroidal immunosuppressive therapies[55] Lower mean decline in eGFR at 3 years after transfer[63] Decrease in frequency of INR testing[26] Patient-reported health and quality of life Increase in participation score (London Handicap Scale)[27] Increase in activity limitation score (Barthel Index)[27] Increase in dependency subscale score (Personal Adjustment and Role Skills Scale III)[4] Increase in mean score for performance (Canadian Occupational Performance Measure) with life-course goals and healthcare-related goals[41] Increase in 1-month global well-being[58] Decrease in frequency of symptoms/poorer functions in quality of life score (Juvenile Arthritis Quality of Life Questionnaire)[12] Decrease in anxiety score (State/Trait Anxiety Inventory for Adults)[64] Increase in perceived health status[33] Self-care Increases in arthritis-related knowledge among parents and adolescents[12] Increase in diabetes-related knowledge scores (Diabetes Knowledge Questionnaire)[62] Increase in proportion performing self-adjustment of insulin doses, specifically basal adjustments[62] Increase in transition readiness score[64] Increase in percentage of young people carrying self-monitoring cards[57] Mortality Decrease in deaths or graft loss[24]	Satisfaction Increase in satisfaction with structured transition[31] Increase in overall satisfaction with transfer in District C and District D[48] Increase in satisfaction with transitional care scores among patients and parents (Mind The Gap Scale)[11,12] Increase in opportunities for adolescents to be seen in clinic alone and decide who should be present in consultations/examinations (Mind The Gap Scale)[52] Increase in satisfaction with transition process and care[55] Increase in mean score for satisfaction (Canadian Occupational Performance Measure) with life-course goals and healthcare-related goals[41] Decrease in transfer meaning a large change in patients' life[55] Increase in ratings for "Youth Kit" in helpfulness in developing supportive and respectful relationships with health care workers[41] Increase in ratings for "Online Mentor" in helpfulness in sharing information and communicating about your health care and in setting and working toward your goals[41] Barriers to care Decrease in specific bottlenecks in transition experienced by health professionals: no joint mission between pediatric and adult care, parents having trouble ceding control to adolescents, lack of coordination between pediatric and adult care, adolescents taking too little responsibility for self-care, lack of resources for joint care services, psychosocial problems of adolescents, noncompliance of adolescents with therapy, and social participation of adolescents[52] Decreases in need for home physicians and social workers in home community, and in inadequate knowledge about disease status, names of prescribed medications, and dosages[64]	Utilization Decrease in time between last pediatric visit and first adult visit[31] Increase in adult clinic attendance rates[31,34,42] Increase in percent attending first clinic visit[38] Increase in successful transitions (≥1 routine adult visit among transitioned patients[58] Increase in number seeing adult rheumatologists at least once[46] Decrease in hospital admission rates[34] Decrease in DKA hospital admission rates[45] Decrease in length of stay of DKA readmissions[45] Decrease in surgery rates[34] Decrease in mean cumulated radiation exposure[34] Process of care Increase in discussions with families about transition[53] Increase in sending copy of transition letters to young people[57] Increase in documentation: transitional care components, parental transition needs, aspects of adolescent readiness Increase in discussion of transitional issues[57] Costs of care None

Research designs were almost always quasi-experimental using pre-post population cohorts or retrospective cohorts. Only 2 studies used a randomized controlled study design,[28,60] and 8 studies used a prospective cohort.[24,26,35,37,41,43,46,58]

Structured transition interventions for youths with chronic conditions have resulted in statistically significant beneficial outcomes, as shown in **Tables II** and **III**; 28 of the 43 included studies (65%) found statistically significant positive outcomes, most often measured in terms of population health and, to a lesser extent, in terms of experience of care and service utilization. Only 1 study[31] found positive outcomes in all 3 domains; 5 other studies[12,37,41,55,64] reported positive outcomes in population health and experience of care, and 4 other studies[34,45,57,58] found positive outcomes in population health and utilization of care. Statistically significant negative results were found in 2 studies, one[40] in which adult clinic attendance declined at 3 years after transfer and another[53] in which hemoglobin A1c (HbA1c) and International Federation of Clinical Chemistry and Laboratory Medicine mmol/mol increased 1 year after follow-up to an adult clinic.

Population health outcomes were measured in 37 of the 43 studies, as shown in **Table II**; 20 of these 37 studies (54%) found statistically positive population health outcomes. Most often these pertained to improvements in adherence to care. Positive changes also were reported in terms of patient-reported health and quality of life, self-care skills, and in 1 study, mortality reduction.

Owing to the large number of transition studies on type 1 diabetes, adherence to care was most often reported in terms of declines in HbA1c levels. Other positive diabetes outcomes pertained to increases in foot and eye examinations; screening for microalbuminuria, hypertension, and nephropathy; and carbohydrate counting and body weight. Decreases in the prevalence of nephropathy and hypoglycemic episodes were found as well. Among the transition studies related to liver or kidney failure/transplants, positive outcomes were reported as adherence to care, defined as lower tacrolimus SD levels, lower change/decline in estimated glomerular filtration rate, and lower change in serum creatinine; medication adherence was improved as well.

As a result of structured transition interventions, improvement in patient-reported quality of life and perceived health status was reported in several studies, often using validated instruments. These quality of life improvements were reported in terms of perceived health and mental health status, global well-being, functional status, stress, distress, depression, anxiety, life satisfaction, health goals, and social integration. Statistically significant positive outcomes were also found pertaining to self-care skills and measured in terms of improvements in disease-specific knowledge, self-adjustment of insulin doses, transition readiness scores, global well-being, and carrying important medical information. One liver transplant study[24] found a significant reduction in mortality and graft loss.

Experience of care outcomes were measured in 15 of the 43 studies. Statistically significant positive outcomes were found in 8 of these 15 studies (60%).[11,12,31,41,48,52,55,64] Although the studies varied in terms of what consumers were asked to report on, positive outcomes were shown related to satisfaction with transition, transfer, and life-course and health-related goals; helpfulness of a specific tool or online resource; and autonomy and increased time alone with a health care provider. Reductions in specific transition barriers were found in 2 studies.[52,64]

Utilization and costs of care outcomes were examined in 24 of 43 studies. In 9 of these 24 studies (39%), outcomes were statistically significant and most often measured in terms of service use.[31,34,38,42,45,46,53,57,58] Although 3 studies examined costs, none found significant cost savings; however, several studies found that having a structured transition process resulted in increased visits to the new adult provider and a reduced time lag between the last pediatric visit and the first adult visit. Studies also reported reductions in hospital admissions and length of stay for readmissions, surgery rates, and radiation exposure. Finally, improvements in the transition process of care were cited in 2 studies.[53,57]

Analysis of transition intervention descriptions found that 35 studies described transition preparation activities. The same number mentioned transfer activities, and fewer (ie, 25) specified integration to adult care activities. Just 15 of the 43 studies referenced having all 3 transition activities. Across all transition activities, the most common was self-care/disease education (in 28 studies), typically part of transition preparation. The next most common intervention was having a transition clinic, either a separate pediatric or young adult clinic and/or a joint clinic (in 26 studies), followed by explicit communication between adult and pediatric departments (in 24 studies) and preparation of transfer/medical summary information (in 20 studies) and plans of care (in 20 studies). Mentioned somewhat less often was readiness/self-care assessment (in 16 studies, almost always as part of preparation), a welcome/orientation process for adult practice (in 15 studies), scheduling assistance (in 13 studies), and linkages to community resources (in 10 studies). Having a designated transition coordinator to assist with the transition process was noted in 18 studies.

The overall quality assessment ratings for the included studies demonstrate their variability in risk of bias, with only 7 studies rated as strong, 18 rated as moderate, and 18 rated as weak (**Table I**). With respect to selection bias, 35 studies were rated as moderate and 8 were rated as weak, mainly because of a small study population. The study design was almost always rated as moderate (n = 41) because cohort or cohort analytic studies were used; randomized clinical trials were used in only 2 studies. Confounders were not well described or controlled, with 28 studies rated as weak because of issues related to identification, stratification, matching, or analysis. Blinding scores were always moderate, either because the blinding process was not explained or because the participants or researchers were unaware of the research question. Data collection was ranked as moderate in 25 studies and weak in 16, with weaker ratings associated with the use of measures or instruments of unknown reliability or validity, sometimes designed for the study itself without previous use. With respect to withdrawal and dropouts, one-half of the studies did not report these because of a retrospective study design or the use of one-time surveys or other data collection. The remaining studies received weak (n = 7) or moderate (n = 5) rankings, because follow-up rates were sufficiently low to pose a risk of introducing bias. Although not included in the summary results, no studies reported the percentage of participants who received the complete intervention, the consistency of the intervention measured, or whether subjects received any unintended intervention. Statistical analysis in all studies were appropriate. No studies reported intention-to-treat analysis.

Discussion

This systematic review found that almost two-thirds of transition evaluation studies (28 of 43) had statistically significant positive outcomes. Twenty studies found improvements in population health, 8 studies reported benefits in terms of consumer experience or reduction in transition barriers, and 9 studies cited positive service utilization impacts. Only 3 studies examined costs, but none found significant savings.

In an analysis of studies that received moderate to strong quality ratings and also had statistically significant positive outcomes, the most common beneficial outcome found was adherence to care, reported in 11 of the 15 studies with moderate to strong ratings. Only 1 of the 15 studies reported positive outcomes in all 3 triple aim domains.[31]

Even though almost two-thirds of the 43 transition studies included in this systematic review reported positive outcome results, the state of transition intervention research is still in its infancy. This is not surprising, given that the primary care professional organizations released their clinical algorithm in 2011,[14] which called for a structured transition process for all youths starting early in adolescence and continuing into young adulthood. Incorporated into the AAP/AAFP/ACP algorithm are recommended steps for transition planning, transfer to an adult model of care, and integration into adult care. These clinical recommendations were subsequently translated into the Six Core Elements of Health Care Transition, with sample tools for pediatric, family medicine, med-peds, and internal medicine practices and measurement resources.[67] Future studies evaluating transition will benefit from providing more detailed descriptions of their interventions, preferably using the framework of the AAP/AAFP/ACP Clinical Report and the Six Core Elements to enable comparisons among studies and associations between transition processes and outcomes.

Although this systematic review uncovered a few common outcomes within the triple aim domains, the measures used to evaluate health care transition interventions were widely variable and seldom addressed all 3 domains. Population health, consumer experience, and utilization/costs provide an explicit conceptual model that can be used to guide the selection of future transition outcome evaluations.[21]

With respect to population health outcomes, several issues need to be considered in terms of measures related to adherence to care, perceived health and quality of life, and self-care skills. Few chronic conditions have disease-specific adherence to care measures, such as HbA1c for those with diabetes or tacrolimus levels for those who have received a transplant. Probably one of the most reasonable population health measures to consider is evaluating medication adherence before and after transfer.[68] Although population outcomes measured in terms of perceived health and quality of life have the advantage of available validated health and quality of life instruments, clinicians and researchers need to consider the extent to which specific transition interventions rather than other aspects of care are likely to influence these impacts. Although quality of life measures are laudable outcomes, they may be beyond the scope of what transition interventions can reasonably expect to achieve. Self-care measures–generic or disease-specific–are another important population outcome. An issue for future transition researchers will be the selection of appropriate tools to measure self-care skills. Importantly, consideration should be given to incorporating generic self-care skills regarding health and health care, not only disease-specific skills.

With respect to experience of care, this systematic review documents positive outcomes but reveals the need for more specificity in eliciting consumer feedback on particular aspects of transition planning, transfer of care, and integration into adult care. Too often, transition evaluation studies ask broad questions about satisfaction with “transitional care” or with the “transition process,” or they focus on just a few issues, for example, “time alone with doctor,” which refers to speaking with the doctor privately without a parent in the room. More specific questions addressing particular elements of transition should be considered, such as those found in the Transition Feedback Survey in the Six Core Elements, which includes many tested questions from national surveys and Boston Children’s Hospital’s ADAPT questionnaire.[69] Obtaining anonymous youth and parent feedback will be critical for continuously refining pediatric-to-adult transition interventions.

With respect to service utilization and cost outcomes, this systematic review documented improvements in ambulatory care use among young adults with various chronic conditions and also reductions in hospitalization among those with inflammatory bowel disease and diabetes. Recognizing the vulnerability of young adults in terms of their low service utilization patterns and the finding of declining utilization at 3 years after transfer,[40] future studies may want to include attendance not only at the initial adult visit, but also at subsequent ambulatory care visits. In addition, the time between the last pediatric visit and the initial adult visit represents an important utilization marker of continuity of care. Short-term utilization results associated with a successful transfer indeed may show increased ambulatory care use, which represents a transfer success. The extent to which this added cost would offset reductions in emergency room and hospital use, particularly for young adults with chronic conditions, is an important issue worthy of investigation. The absence of evaluation studies on cost effectiveness of transition interventions represents a significant roadblock to the adoption of much-needed transition interventions among payers and large pediatric and adult systems of care.

This systematic review has several limitations. Studies often lacked detailed descriptions of their transition process. This makes categorizing similar transition interventions difficult and linking outcomes to a specific transition process impossible. It also impedes future replication efforts. Transition to adult care is a complex intervention with many steps that alone or together have the potential to influence outcomes. The small size of most studies resulted in lack of statistical power, limiting the measurement of pre-post or between-group differences and the generalizability of study findings. Similarly, several studies used data collection methods of unknown or untested validity and reliability. Characterization of studies using the EPHPP tool attempts to assist readers in understanding methodological limitations given the inclusion of all studies in presenting statistically significant positive outcomes.

Future evaluation studies are needed to examine triple aim impacts on a broader population of youths with and without chronic conditions, with special attention directed to the cost effectiveness of transition interventions aligned with the AAP/AAFP/ACP Clinical Report. ■

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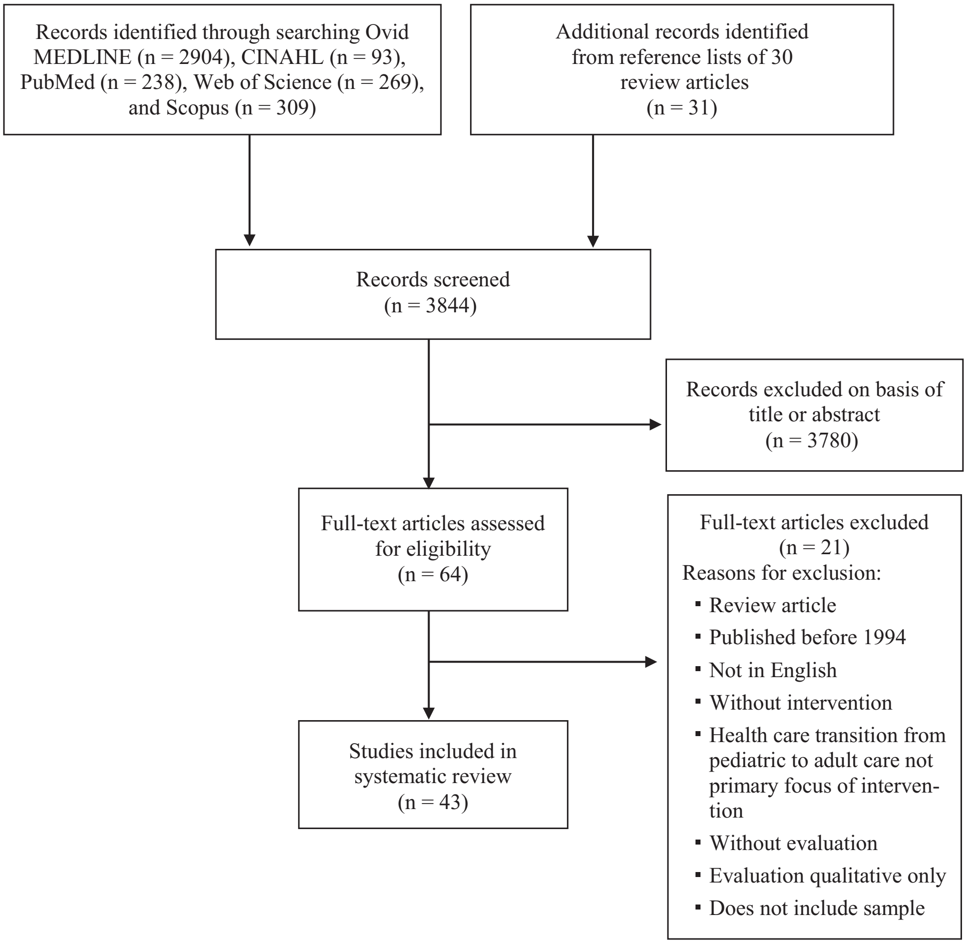

Figure. Summary of evidence search and selection. *(Continues)*

Databases Searched	Search Terms Used	Number of Results
Scopus	(**TITLE** (((_adolescent*_ OR _"young adult"_ OR _teen*_ OR _pediatric*_ OR _paediatric*_ OR _"young adults"_) AND (_transition*_ OR _transfer*_) AND (_adult_ OR _adults_))) AND **TITLE-ABS-KEY** ((_evaluation_ OR _evaluations_ OR _outcome_ OR _outcomes_ OR _comparison_ OR _assessment_)))	309
Web of Science	**TITLE:** (((adolescent* OR young adult OR teen* OR pediatric* OR paediatric* OR young adults) AND (transition* OR transfer*) AND (adult OR adults))) _AND_ **TOPIC:**((evaluation OR evaluations OR outcome OR outcomes OR comparison OR assessment)) **Indexes:** SCI-EXPANDED, SSCI, A&HCI, CPCI-S, CPCI-SSH, BKCI-S, BKCI-SSH, ESCI, CCR-EXPANDED, IC.	269
PubMed	transition to adult care or transferring to adult care or transfer to adult care or pediatric transition to adult care AND satisfaction or barriers or needs AND cost or health care costs	238
CINAHL	transition from pediatric to adult care OR transferring to adult care OR transfer to adult care OR pediatric transition to adult care	93
Ovid Medline	#1 exp Adolescent/ (1719867) #2 exp Adolescent Health Services/ (4797) #3 exp Young Adult/ (490866) #4 1 or 2 or 3 (1942883) #5 "adolescen*".ab,ti. (198853) #6 “teen*".ab,ti. (23933) #7 (pediatric* or paediatric*).ab,ti. (206624) #8 "young adult*”.ab,ti. (67004) #9 5 or 6 or 7 or 8 (456977) #10 exp Transition to Adult Care/ (515) #11 exp "Continuity of Patient Care”/ (41963) #12 (transition* or transfer*).ab,ti. (763286) #13 “adult*".ab,ti. (920926) #14 9 and 11 and 12 and 13 (704) #15 10 or 14 (908) #16 9 and 12 and 13 (5229) #17 15 or 16 (5433) #18 exp Evaluation Studies/ (215219) #19 exp Clinical Trial/ (732784) #20 exp Cohort Studies/ (1520288) #21 exp Retrospective Studies/ (573018) #22 Comparative Study/ (1735618) #23 exp Follow-Up Studies/ (540603) #24 exp "Outcome and Process Assessment (Health Care)"/ or exp "Outcome Assessment (Health Care)”/ (823378) #25 18 or 19 or 20 or 21 or 22 or 23 or 24 (3906781) #26 “evaluat*".ab,ti. (2534493) #27 “outcome*".ab,ti. (1110204) #28 “compar*".ab,ti. (4039677) #29 “assess*".ab,ti. (2065653) #30 26 or 27 or 28 or 29 (7141318) #31 25 or 30 (8674412) #32 4 or 9 (2152383) #33 17 and 31 and 32 (3276) #34 limit 33 to (abstracts and english language and yr="1995 -Current”) (2904)	2904

Figure. Continued.

Table I. Quality assessment of transition studies based on criteria from the Effective Public Health Practice Project

Study	Year	Overall rating	Selection bias	Study design	Confounders	Blinding	Data collection	Withdrawals and dropouts
Annunziato et al[24]	2013	Moderate	Moderate	Moderate	Weak	Moderate	Moderate	Moderate
Annunziato et al[25]	2015	Moderate	Moderate	Moderate	Weak	Moderate	Moderate	NA
Bauman et al[26]	2016	Moderate	Moderate	Moderate	Weak	Moderate	Moderate	Strong
Bent et al[27]	2002	Strong	Moderate	Moderate	Strong	Moderate	Strong	NA
Betz et al[28]	2010	Weak	Weak	Strong	Strong	Moderate	Weak	Strong
Blaauwbroek et al[29]	2008	Moderate	Moderate	Moderate	Weak	Moderate	Moderate	Strong
Broztman et al[30]	2001	Moderate	Moderate	Moderate	Weak	Moderate	Moderate	NA
Cadario et al[31]	2009	Moderate	Moderate	Moderate	Strong	Moderate	Weak	NA
Chaturvedi et al[32]	2009	Weak	Moderate	Moderate	Weak	Moderate	Weak	NA
Chaudhry et al[33]	2013	Moderate	Moderate	Moderate	Strong	Moderate	Weak	NA
Cole et al[34]	2015	Moderate	Moderate	Moderate	Weak	Moderate	Moderate	NA
Cramm et al[35]	2013	Moderate	Weak	Moderate	Strong	Moderate	Moderate	Strong
Dabadie et al[36]	2008	Weak	Moderate	Moderate	Weak	Moderate	Weak	NA
Egan et al[37]	2015	Weak	Moderate	Moderate	Weak	Moderate	Strong	Weak
Fredericks et al[38]	2015	Moderate	Moderate	Moderate	Weak	Moderate	Moderate	NA
Gholap et al[39]	2006	Moderate	Moderate	Moderate	Weak	Moderate	Moderate	NA
Glesson et al[40]	2013	Moderate	Moderate	Moderate	Weak	Moderate	Moderate	NA
Gorter et al[41]	2015	Weak	Weak	Moderate	Moderate	Moderate	Weak	Moderate
Hankins et al[42]	2012	Weak	Weak	Moderate	Weak	Moderate	Moderate	NA
Harden et al[43]	2012	Moderate	Moderate	Moderate	Weak	Moderate	Moderate	NA
Hilderson et al[44]	2016	Strong	Moderate	Moderate	Strong	Moderate	Moderate	Strong
Holmes-Walker et al[45]	2007	Strong	Moderate	Moderate	Moderate	Moderate	Moderate	Strong
Jensen et al[46]	2015	Weak	Weak	Moderate	Weak	Moderate	Weak	Weak
Johnston et al[47]	2006	Moderate	Moderate	Moderate	Weak	Moderate	Moderate	NA
Kipps et al[48]	2002	Moderate	Moderate	Moderate	Weak	Moderate	Moderate	Moderate
Lane et al[49]	2007	Moderate	Moderate	Moderate	Weak	Moderate	Moderate	NA
Logan et al[50]	2008	Moderate	Moderate	Moderate	Weak	Moderate	Moderate	NA
McDonagh et al[12]	2007	Weak	Moderate	Moderate	Moderate	Moderate	Weak	Weak
McQuillan et al[51]	2015	Strong	Moderate	Moderate	Strong	Moderate	Moderate	NA
Nieboer et al[52]	2014	Weak	Weak	Moderate	Weak	Moderate	Moderate	Weak
Okumura et al[53]	2014	Weak	Moderate	Moderate	Weak	Moderate	Weak	Weak
Orr et al[54]	1996	Moderate	Moderate	Moderate	Weak	Moderate	Moderate	Strong
Pape et al[55]	2013	Weak	Weak	Moderate	Weak	Moderate	Moderate	NA
Prestidge et al[56]	2012	Strong	Moderate	Moderate	Moderate	Moderate	Moderate	Moderate
Robertson et al[57]	2006	Weak	Moderate	Moderate	Weak	Moderate	Weak	NA
Sequeira et al[58]	2015	Strong	Moderate	Moderate	Strong	Moderate	Moderate	Moderate
Shaw et al[11]	2007	Weak	Moderate	Moderate	Moderate	Moderate	Weak	Weak
Smith et al[59]	2011	Weak	Moderate	Moderate	Weak	Moderate	Weak	Weak
Steinbeck et al[60]	2015	Weak	Weak	Strong	Strong	Moderate	Weak	Strong
Van Walleghem et al[61]	2008	Weak	Moderate	Moderate	Weak	Moderate	Weak	NA
Vidal et al[62]	2004	Weak	Moderate	Moderate	Weak	Moderate	Weak	Strong
Weitz et al[63]	2015	Strong	Moderate	Moderate	Strong	Moderate	Moderate	NA
Wiener et al[64]	2007	Weak	Moderate	Moderate	Weak	Moderate	Weak	Strong

NA, not applicable.

Table II. Summary of studies evaluating outcomes of health care transition interventions

Study	Year	Location	Study design	Study population	Condition(s)	Transition intervention(s)	Outcome measures and results	Overall quality assessment[†]
Annunziato et al[24]	2013	US	Prospective cohort with historical comparison/pre-post	20 intervention group; 14 comparison group	Liver transplant	Care coordinator/ preparation for transition, transfer assistance, integration into adult care	Population health: Tacrolimus SD level ↓* Deaths or graft loss ↓* Short Form 36 physical health ↑ Health care management skills ↑ Short Form 36 mental health ↓	Moderate
Annunziato et al[25]	2015	US	Retrospective cohort	12 intervention group; 10 comparison group	Kidney transplant	Preparation for transition, transfer assistance	Population health: GFR ↑ Tacrolimus SD level ↓ Episodes of rejection ↓ Mean arterial pressure ↑	Moderate
Bauman et al[26]	2016	Canada	Prospective, longitudinal cohort	19	Chronic conditions requiring warfarin therapy	Preparation for transition, transfer assistance	Population health: Frequency of INR testing ↓* Warfarin knowledge scores ↑ No median INR values <1.6 and ≥5 No adverse events (bleeding and thrombotic) Patient time in therapeutic range ↓ Utilization/cost: Number of calls to anticoagulation team for support ↓ Clinic attendance ↔	Moderate
Bent et al[27]	2002	England	Retrospective cohort	119 intervention group; 135 comparison group	Physical disabilities (cerebral palsy, spina bifida, traumatic brain injury, and degenerative muscular disease with mild or no learning disability)	Preparation for transition	Population health: Barthel Index ↑* London Handicap Scale ↑* Euroqol Visual Analog Scale ↑ General Self-Efficacy Scale ↑ Perceived Stress Scale ↓ Rosenberg Self-Esteem Scale ↓ Nottingham Health Profile Subscales • Pain ↓ • Sleep ↓ • Energy ↔ Proactive Attitude Scale ↔ Utilization/cost: Total and average cost[a]	Strong
Betz et al[28]	2010	US	Randomized controlled trial	31 intervention group; 34 comparison group	Spina bifida	Preparation for transition	Population health: Personal Adjustment and Role Skills Scale III ↑ • Dependency subscale ↑* Community Life Skills Scale ↓ • Regularity-organization-routines subscale ↓* Denyes Self-Care Practice Instrument ↑	Weak

(*continued*)

Table II. Continued

Study	Year	Location	Study design	Study population	Condition(s)	Transition intervention(s)	Outcome measures and results	Overall quality assessment[†]
Blaauwbroek et al[29]	2008	Netherlands	Pre-post	121	Cancer	Transfer assistance, integration into adult care	Population health: RAND 36-Item Health Survey • Social functioning[b] • Physical functioning[b] • Role limitation due to physical problems[b] • Role limitation due to emotional problems[b] • Mental health[b] • Vitality[b] • Bodily pain[b] • General health perceptions[b] Experience: Patient satisfaction with shared care follow-up[a]	Moderate
Brotzman et al[30]	2001	US	Pre-post and retrospective cohort	226 intervention group; 200 comparison group	Sickle cell	Preparation for transition, integration into adult care	Utilization/cost: Percentage of patients appropriately prescribed hydroxyurea ↑ Percentage of inpatients not given demerol ↑ Percentage of patients seen in ED and not given demerol ↑ Number of hospital days ↓ Number of ED visits ↓ Treatment cost per patient (excluding surgical/operation items) ↓	Moderate
Cadario et al[31]	2009	Italy	Retrospective cohort	30 intervention group; 32 comparison group	Type 1 diabetes	Care coordinator/ preparation for transition, transfer assistance, integration into adult care	Population health: HbA1c ↓* Foot examinations ↑* Eye assessments ↑* Microalbuminuria screenings ↑* Experience: Satisfaction with structured transition ↑* Utilization/cost: Time between last pediatric visit and first adult visit ↓* Adult clinic attendance ↑*	Moderate
Chaturvedi et al[32]	2009	Australia	Pre-post and retrospective cohort	11	Kidney transplant	Preparation for transition, transfer assistance	Population health: Serum creatinine[a] Utilization/cost: Adult clinic attendance[a] Inpatient hospital days[a]	Weak
Chaudhry et al[33]	2013	US	Retrospective cohort	44 intervention group; 47 comparison group	Cystic fibrosis	Care coordinator/ preparation for transition, transfer assistance, integration into adult care	Population health: Perceived health status ↑* Independence ↑ Anxiety ↑ Experience: Satisfaction with adult care ↑	Moderate

(*continued*)

Table II. Continued

Study	Year	Location	Study design	Study population	Condition(s)	Transition intervention(s)	Outcome measures and results	Overall quality assessment[†]
Cole et al[34]	2015	UK	Retrospective cohort	44 intervention group; 28 comparison group	Inflammatory bowel disease	Preparation for transition, transfer assistance, integration into adult care	Population health: Medication adherence ↑* Radiation exposure ↓* Proportion achieving optimum level of growth and development ↑ Utilization/cost: Adult clinic attendance ↑* Hospital admission rates ↓* Surgery rates ↓*	Moderate
Cramm et al[35]	2013	Netherlands	Prospective cohort	138 respondents (T0); 188 respondents (T1); 123 respondents (T0 and T1)	Type 1 diabetes, juvenile idiopathic arthritis, neuromuscular disorder	Care coordinator/ preparation for transition, transfer assistance	Population health: DISABKID instrument: • Social quality of life ↑ • Physical quality of life ↑ • Emotional quality of life ↓ Experience: Mind the Gap instrument • Satisfaction with transitional care ↑	Moderate
Dabadie et al[36]	2008	France	Retrospective cohort	20 intervention group; 14 comparison group	Inflammatory bowel disease	Preparation for transition, transfer assistance, integration into adult care	Population health: Attendance at joint medical visit ↑	Weak
Egan et al[37]	2015	US	Prospective cohort	29	Type 1 diabetes	Care coordinator/ transfer assistance, integration into adult care	Population health: Parents Diabetes Distress Scale[c] HbA1c ↓ Diabetes Quality of Life[b] Experience: Health Care Climate Questionnaire[c] Utilization/cost: Adherence to follow-up visits ↔	Weak
Fredericks et al[38]	2015	US	Retrospective cohort	19 comparison group; 26 intervention group	Liver transplant	Preparation for transition	Population health: Percent adherent with immunosuppressant therapy posttransfer ↑ Number of posttransfer biopsy-proven rejections ↓ Number of undetectable immunosuppressant therapy values posttransfer ↓ Number of deaths posttransfer ↔ Number of participants with posttransfer graft loss ↔ Utilization/cost: Percentage attended first clinic visit ↑* Percentage of clinic adherence (≥85%) posttransfer ↓ Clinic attendance rate posttransfer ↓	Moderate

(*continued*)

Table II. Continued

Study	Year	Location	Study design	Study population	Condition(s)	Transition intervention(s)	Outcome measures and results	Overall quality assessment[†]
Gholap et al[39]	2006	England	Retrospective cohort	68 intervention group; 397 comparison group; 46 intervention (patients with diabetes ≥7 y); 266 comparison group	Type 1 diabetes	Preparation for transition, transfer assistance (Alphabet Strategy)	Population health: Screening rates for hypertension ↑* Screening rates for nephropathy ↑* Prevalence of nephropathy ↓* HbA1c ↓* Prevalence of retinopathy ↓ Prevalence of hypertension ↑ Utilization/cost: Attendance at young adult diabetes clinic[a]	Moderate
Gleeson et al[40]	2013	England	Retrospective cohort	24 intervention group; 37 comparison group	Congenital adrenal hyperplasia	Preparation for transition, transfer assistance, integration into adult care	Utilization/cost: Adult clinic attendance 3 y after transfer ↓* Loss to follow-up[a]	Moderate
Gorter et al[41]	2015	Canada	Prospective cohort	50	Various chronic conditions and neurodevelopmental conditions	Preparation for transition (Youth KIT; Online Transition Mentor [TRACE])	Population health: Canadian Occupational Performance Measure: • Mean score for performance with life-course goals ↑* • Mean score for performance with healthcare-related goals ↑* Experience: Canadian Occupational Performance Measure: • Mean score for satisfaction with life-course goals ↑* • Mean score for satisfaction with healthcare-related goals ↑* Interventions' helpfulness in self-management areas: Youth KIT: • Developing supportive and respectful relationships with health care workers ↑* • Sharing information and communication about your health care[b] • Setting and working toward your goal[b] • Taking charge of your own health care[b] Online Mentor (TRACE): • Taking charge of your own health care ↑* • Sharing information and communication about your health care ↑* • Developing supportive and respectful relationships with health care workers[b] • Setting and working towards your goal[b] Ratings of utility of the Youth KIT[a] Utilization/cost: Frequency of use of Youth KIT[a]	Weak
Hankins et al[42]	2012	US	Pre-post and retrospective cohort	34 intervention group; 49 comparison group; 75 historical comparison group	Sickle cell	Care coordinator/transfer assistance, integration into adult care	Experience: Helpfulness of transition program[a] Utilization/cost: Adult clinic attendance ↑*	Weak
Harden et al[43]	2012	England	Prospective cohort with historical control	12 intervention group; 9 comparison group	Kidney failure	Transfer assistance, integration into adult care	Population health: Acute rejections[a] Graft loss[a] Number of deaths[a]	Moderate

(*continued*)

Table II. Continued

Study	Year	Location	Study design	Study population	Condition(s)	Transition intervention(s)	Outcome measures and results	Overall quality assessment[†]
Hilderson et al[44]	2016	Belgium	Quasi-experimental study using a 1-group pretest-posttest with a nonequivalent posttest-only comparison group	27 adolescents (longitudinal analysis); 12 adolescents; 16 parents; 23 intervention group; 23 comparison group	Juvenile idiopathic arthritis	Care coordinator/ preparation for transition, integration into adult care	Population health: (Note: Refer to table key for effect size symbols) Longitudinal analysis: *Adolescents:* *Primary outcomes:* • Improved psychosocial health ++ • Improved treatment ++ • Improved communication + • Improved pain and hurt + • Improved daily activities + • Improved physical health + • Improved worry = *Secondary outcomes:* • Improved quality of life +++ • Improved illness-related knowledge + • Increased motivation = • Reduction in mental fatigue = • Increased activity = • Reduction physical fatigue = • Reduction in general fatigue – • Medication adherence = *Parents:* *Secondary outcomes:* • Increased autonomy support + • Increased promotion of independence + • Reduced behavioral control + • Improved communication = • Improved daily activities = • Improved psychosocial health = • Improved worry – • Improved pain and hurt – • Reduced psychological control – • Improved treatment – • Improved physical health – Comparative analysis: *Adolescents:* *Primary outcomes:* • Improved psychosocial health ++ • Improved treatment + • Improved communication + • Improved pain and hurt = • Improved daily activities + • Improved physical health + • Improved worry = *Secondary outcomes:* • Improved quality of life + • Improved illness-related knowledge = • Increased motivation + • Reduced mental fatigue + • Increased activity + • Reduced physical fatigue + • Reduced general fatigue + • Medication adherence – –	Strong

(*continued*)

Table II. Continued

Study	Year	Location	Study design	Study population	Condition(s)	Transition intervention(s)	Outcome measures and results	Overall quality assessment[†]
							Parents: *Secondary outcomes:* • Increased autonomy support – • Increased promotion of independence – – • Reduced behavioral control ++ • Improved communication – – – • Improved daily activities + • Improved psychosocial health – • Improved worry ++ • Improved pain and hurt = • Reduced psychological control – – • Improved treatment + • Improved physical health –	
Holmes-Walker et al[45]	2007	Australia	Pre-post	191	Type 1 diabetes	Care coordinator/integration into adult care	Population health: HbA1c ↓* Utilization/cost: DKA hospital admission rates ↓* Length of stay of DKA readmissions ↓* DKA hospital readmission rates[b]	Strong
Jensen et al[46]	2015	US	Prospective cohort	210 intervention group; 26 comparison group	Juvenile idiopathic arthritis	Care coordinator/preparation for transition, transfer assistance	Experience: Satisfaction with transitional process[a] Utilization/cost: Saw adult rheumatologist at least once ↑*	Weak
Johnston et al[47]	2006	Northern Ireland	Retrospective cohort	18 intervention group; 15 comparison group	Type 1 diabetes	Transfer assistance, integration into adult care	Population health: HbA1c[a] Utilization/cost: Number of missed appointments[a]	Moderate
Kipps et al[48]	2002	England	Retrospective cohort	106 intervention group; 123 comparison group	Type 1 diabetes	Transfer assistance, integration into adult care. Transfer from a pediatric clinic to an adult clinic (District A); transfer from a pediatric clinic to a young adult clinic held in a diabetes center at a different hospital (District B); transfer from a pediatric clinic to a young adult clinic held in the same hospital, with patients introduced to the adult physician in the pediatric clinic before transfer (District C); initial move from a pediatric clinic to an adolescent clinic held in the same diabetes center (run jointly by the pediatrician and adult physician) before transfer to the adult clinic (District D)	Population health: Within-district HbA1c: • District A ↓ • District B ↓ • District C ↑ • District D ↔ Experience: Overall satisfaction with transfer in Districts C and D ↑* Utilization/cost: Clinic attendance[a]	Moderate

(*continued*)

Table II. Continued

Study	Year	Location	Study design	Study population	Condition(s)	Transition intervention(s)	Outcome measures and results	Overall quality assessment[†]
Lane et al[49]	2007	US	Retrospective cohort	96 intervention group; 153 comparison group	Type 1 diabetes	Integration into adult care	Population health: HbA1c ↑	Moderate
Logan et al[50]	2008	England	Pre-post	93	Type 1 diabetes	Preparation for transition, transfer assistance, integration into adult care	Population health: HbA1c ↓* Retinal screening[a] Microalbuminuria screening[a] Foot screening[a] Change in insulin regimen[a] Utilization/cost: Clinic attendance[a]	Moderate
McDonagh et al[12]	2007	UK	Pre-post	308 adolescents; 303 parents	Juvenile idiopathic arthritis	Care coordinator/ preparation for transition, transfer assistance	Population health: Juvenile Arthritis Quality of Life Questionnaire score ↓* Parent arthritis-related knowledge ↑* Adolescent arthritis-related knowledge ↑* Independent health behaviors: • Self-medication ↑ • Independent visits ↑ Experience: Mind the Gap Scale: • Patient satisfaction with transitional care ↑* • Parent satisfaction with transitional care ↑*	Weak
McQuillan et al[51]	2015	Canada	Retrospective cohort	16 intervention group; 16 comparison group	Kidney transplant	Preparation for transition, transfer assistance, integration into adult care	Population health: Self-reported nonadherence with medications ↓* Lower change in eGFR at 1 y posttransfer ↓* Lower change in eGFR at 2 y posttransfer ↓ Lower median change in serum creatinine in the first year ↓* Lower median change in serum creatinine in the second year ↓ Undetectable calcinurin inhibitor levels ↓ eGFR (first year posttransfer) ↓ eGFR (second year posttransfer) ↓ Acute rejections during first year ↔ Utilization/cost: Nonattendance for blood tests ↓ Nonattendance at clinic ↓	Strong

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Table II. Continued

Study	Year	Location	Study design	Study population	Condition(s)	Transition intervention(s)	Outcome measures and results	Overall quality assessment[†]
Nieboer et al[52]	2014	UK	Pre-post	128 professionals; 389 adolescents	Type 1 diabetes, juvenile idiopathic arthritis, cystic fibrosis, kidney failure/transplant, congenital urological conditions, neuromuscular disorders	Care coordinator/ preparation for transition, transfer assistance (On Your Own Feet Ahead)	Experience: Mind the Gap Scale • Gives me opportunities to be seen in the clinic alone (if I want to) ↑* • Allows me to decide who should be in the consultation/examination room ↑* • Has staff who I can talk to about sensitive or difficult issues ↑ • Has a specific staff member who is coordinating my transitional care ↑ • Helps me to plan for my future ↑ • Helps me to prepare for my move to adult services ↑ • Treats me as an individual and understands my specific needs ↓ • Has staff who understand the realities of being a teenager ↓ • Providers work well together ↓ • Is interested in me as a person, not just the illness ↓ • Allows me to make my own decisions about health care options in my own time ↓ • Provides information to other professionals involved in my health care ↓ • Providers from pediatric and adult care arrange joint appointments/consulting hours for adolescents ↓ • Does not waste my time at the clinic ↓ • Has staff who know how to talk and listen to teenagers ↔ • Helps me to improve independence by using an action plan ↔ Bottlenecks in transitional care perceived by health professionals • No joint mission between pediatric and adult care ↓* • Parents having trouble ceding control to adolescents ↓* • Lack of coordination between pediatric and adult care ↓* • Adolescents taking too little responsibility for self-care ↓* • Lack of resources for joint care services ↓* • Psychosocial problems of adolescents ↓* • Noncompliance of adolescents with therapy ↓* • Social participation of adolescents ↓*	Weak

(*continued*)

Table II. Continued

Study	Year	Location	Study design	Study population	Condition(s)	Transition intervention(s)	Outcome measures and results	Overall quality assessment[†]
Okumura et al[53]	2014	US	Pre-post and retrospective cohort	18 pediatric; 10 adult; 9 intervention group; 20 comparison group	Cystic fibrosis	Care coordinator/ preparation for transition, transfer assistance, integration into adult care	Population health: Transition Readiness Questionnaire (TRAQ): • Self-management scores for paired-pediatric patients ↑ • Self-advocacy scores for pediatric patients compared with baseline adult center program ↑ • Self-advocacy score for unpaired-pediatric patients ↑ • Self-advocacy scores for paired-pediatric patients ↑ • Self-management scores for unpaired-pediatric patients ↓ BMI[a] Utilization: Discussions of transition with families ↑* Hospitalizations ↓	Weak
Orr et al[54]	1996	US	Pre-post	82	Type 1 diabetes	Preparation for transition, transfer assistance, integration into adult care	Population health: HbA1c ↑ • HbA1c for males ↓*	Moderate
Pape et al[55]	2013	Germany	Retrospective cohort	66	Kidney transplant	Preparation for transition, transfer assistance, integration into adult care Three adult care settings: specialized transition clinic, general transplantation clinic, and nephrologist	Population health: Changes in nonsteroidal immunosuppressive therapies ↓* Change in GFR: • Change in eGFR in setting 1 vs setting 3 ↑ • Change in eGFR in setting 1 vs setting 2 ↓ Arterial hypertension: • Blood pressure in setting 1 vs setting 3 ↓ • Blood pressure in setting 1 vs setting 2 ↑ Patient survival[a] Graft survival[a] Acute rejection episodes[a] Serum creatinine[a] Trough levels of nonsteroidal immunosuppressant drugs[a] Dose levels of nonsteroidal immunosuppressant drugs[a] Experience: Satisfaction with transition process and care ↑* Transfer means a large change in patients' life ↓* Utilization/cost: Number of antihypertensive medications ↓ Mean steroid dose ↑ Clinic attendance[a]	Weak
Prestidge et al[56]	2012	Canada	Retrospective cohort	12 intervention group; 33 comparison group	Kidney transplant	Care coordinator/ preparation for transition, transfer assistance	Population health: Death or allograft loss ↓ Serum creatinine[a] Utilization/cost: Average annual cost per patient[a]	Strong

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Table II. Continued

Study	Year	Location	Study design	Study population	Condition(s)	Transition intervention(s)	Outcome measures and results	Overall quality assessment[†]
Robertson et al[57]	2006	UK	Retrospective cohort	38 intervention group; 55 control group	Juvenile idiopathic arthritis	Care coordinator/ preparation for transition, transfer assistance, integration into adult care	Utilization/cost: Sending copy of transition letters to the young person ↑* Discussion of transitional issues[c] Aspects of adolescent readiness[c] Parental transition needs[c] Preparatory visits to adult clinics[b] Addressing disease-specific educational needs[b] Patient phoning with own queries[b] Preparation for intra-articular injections done while awake[b] Items sent to adult services[b] • Medical summaries[c] • Core outcome variables[c] Self-advocacy development: • Age when independent visit concept introduced[b] • Age when independent visits began[b] • Age when self-medication discussed[b] • Age when self-medicating[b] • Age when making own appointments[b] • Multidisciplinary involvement[a]	Weak
Sequeira et al[58]	2015	US	Prospective cohort/pre-post	51 intervention group; 30 control group	Type 1 diabetes	Care coordinator/ preparation for transition, transfer assistance, integration into adult care	Population health: 12-mo HbA1c ↓* Change in HbA1c from baseline to 12 mo ↓* Overall monthly rate of HbA1c change for Hispanic group ↓* 12-mo incidence of severe hypoglycemia ↓* 6-mo A1c ↑ 1-mo global well-being ↑* 24-h global well-being ↑ Diabetes knowledge ↑ Diabetes empowerment ↑ Life satisfaction ↑ Perceived stress ↓ Depression ↑ Utilization/cost: Successful transition (≥1 routine adult visit in study period) among those who transitioned ↑*	Strong
Shaw et al[11]	2007	UK	Pre-post	303 parents; 308 adolescents	Juvenile idiopathic arthritis	Care coordinator/ preparation for transition, transfer assistance	Experience: Mind the Gap Scale: • Adolescents' satisfaction with transitional care scores ↑* • Parents' satisfaction with transitional care scores ↑*	Weak
Smith et al[59]	2011	US	Pre-post	33	Sickle cell	Preparation for transition, integration into adult care	Population health: Sickle Cell Disease Quiz score ↑ Sickle Cell Transfer Questionnaire score[a]	Weak

(*continued*)

Table II. Continued

Study	Year	Location	Study design	Study population	Condition(s)	Transition intervention(s)	Outcome measures and results	Overall quality assessment[†]
Steinbeck et al[60]	2015	Australia	Randomized clinical trial	14 intervention group; 12 comparison group	Type 1 diabetes	Care coordinator/ preparation for transition, transfer assistance, integration into adult care	Population health: HbA1c at 1-y follow-up ↑* IFCC mmol/mol at 1-y follow-up ↑* Global self-worth score ↑ Development of new microvascular complications[a] Utilization/cost: ≥1 diabetes-related hospitalization in past 12 mo ↓ Transfer from pediatric to adult diabetes service occurred ↓ Retention in original adult service referred to ↓ Time taken to transfer from pediatric to adult care ↑ Estimated adult diabetes service visits per year ↑	Weak
Van Walleghem et al[61]	2008	Canada	Pre-post and retrospective cohort	64 intervention group (younger group); 101 comparison group (older group)	Type 1 diabetes	Care coordinator/ preparation for transition, integration into adult care (Maestro Project)	Population health: Long-term DM complications[a] Utilization/cost: DKA hospital admissions ↑ Hypoglycemia hospital admissions ↑ Dropout rate for adult medical care[a] Number of medical visits[a] Number of education visits[a] Experience: Difficulties and frustration with establishing regular follow-up with adult team[a]	Weak
Vidal et al[62]	2004	Spain	Pre-post	72	Type 1 diabetes	Preparation for transition, transfer assistance, integration into adult care	Population health: Number of hypoglycemic episodes ↓* HbA1c ↓* Diabetes Knowledge Questionnaire 2 score ↑* Weight ↑* Carbohydrate counting ↑* Self-adjustment of insulin doses: • Basal adjustment (%) ↑* • Preprandial adjustments (%) ↑ Insulin modification: • Rapid-acting/day (IU) ↑ • NPH/day (IU) ↓ Diabetes meal plan: • Carbohydrates ↑ • Proteins ↓ • Fats ↓ Diabetes quality of life: • Social preoccupation ↑ • Satisfaction ↓ • Impact ↔ • Diabetes preoccupation ↔ Total daily insulin dose[b]	Weak

(*continued*)

Table II. Continued

Study	Year	Location	Study design	Study population	Condition(s)	Transition intervention(s)	Outcome measures and results	Overall quality assessment†
Weitz et al[63]	2015	Switzerland	Retrospective cohort	33 intervention group; 26 comparison group	Kidney transplant	Care coordinator/ preparation for transition, transfer assistance, integration into adult care	Population health: Change in GFR • Mean decline in eGFR at 3 y after transfer ↓* • Mean decline in eGFR at 1 y after transfer ↓ Number of acute rejections ↓ Mean systolic blood pressure: • Blood pressure at 1 y after transfer ↓ • Blood pressure at 3 y after transfer ↓ Proteinuria, g/mmol: • Level at 1 y after transfer ↓ • Level at 3 y after transfer ↓	Strong
Wiener et al[64]	2007	US	Pre-post	51	Human immunodeficiency virus	Preparation for transition, transfer assistance	Population health: Transition readiness score ↑* State/Trait Anxiety Inventory for Adults score ↓* Experience: Transition barriers: • Needs a physician in home community ↓* • Lacks knowledge of disease status, name of prescribed medication and dosages ↓* • Needs social worker in home community ↓* • Lacks confidence in home physician ↓ • Needs health insurance ↓ • Lacks funds to cover out-of-pocket expenses ↓ • Need for pharmacy in home community ↓	Weak

BMI, body mass index; *CHAQ*, Childhood Health Assessment Questionnaire; *DKA*, diabetic ketoacidosis; *DM*, diabetes mellitus; *ED*, emergency department; *eGFR*, estimated glomerular filtration rate; *INR*, international normalized ratio; *NPH*, neutral protamine Hagedorn; *TRAQ*, Transition Readiness Assessment Questionnaire.

Significance was reported as defined in each article (typically $P < .05$ or $< .01$).

†Quality assessment of included studies was generated from the EPHPP tool with overall ratings denoted in Table I.

Reporting statistical significance:

↑*Increase and statistically significant result.

↑Increase and not significant result.

↔No change.

↓Decrease and not significant result.

↓*Decrease and statistically significant result.

[a] No inferential statistics reported for a given outcome.

[b] Results were not significant, however, incomplete data provided.

[c] Results were statistically significant, however, incomplete data provided.

Reporting effect size for Hilderson et al 2016:

+Small positive effect size.

++Medium positive effect size.

+++Large positive effect size.

–Small negative effect size.

– –Medium negative effect size.

– – –Large negative effect size.

=No effect size.