

# Health Care Transition for Emerging Adults with Chronic Health Conditions and Disabilities

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Work on the issue of health care transition began in the late 1980s when US Surgeon General C. Everett Koop, MD, and other child health leaders recognized that pediatric providers and facilities alone could not address the ongoing medical and related needs of a rapidly growing population of emerging adults with chronic health conditions and disabilities.

Since then, efforts to improve the health care transition (HCT) process have included the development of position papers,<sup>1</sup> consensus statements,<sup>2</sup> and guidelines;<sup>3</sup> federal funding of demonstration projects;<sup>4,5</sup> and the implementation of condition-specific transition programs.<sup>6</sup> However, the pediatric community has been slow to implement recommended HCT practices.<sup>7</sup> Most pediatric practices do not routinely of-

fer transition support services, only one third of pediatricians report making referrals to adult physicians for even some of their patients, and less than 15% provide transition educational materials to adolescents and their parents.<sup>8</sup>

As documented in the growing HCT literature, multiple provider, patient/family, and system-level issues contribute to this slow progress. These issues range from the limited time available to prepare adolescents and their families,



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to resistance by youth and families to leave pediatric care, and the reluctance of providers to discharge patients and families with whom they have a long-term connection and who do not have the requisite knowledge and skills to successfully negotiate the adult system.<sup>9</sup>

Limited adoption may also be the result of physicians seeing HCT as a new, distinct task that is being added to the many clinical activities that must be carried out during time-limited medical visits with adolescents. This perception that HCT is a new and separate service may be, in part, an unintended consequence of efforts to draw attention to the issue and change physician behaviors through promulgation of HCT guidelines, consensus statements, and clinical reports.<sup>10</sup>

However, whereas some HCT-related tasks are distinct, such as developing a written transition plan or identifying adult providers, most clinical activities that promote readiness for the eventual move out of pediatrics are integral to providing developmentally appropriate care. These include promoting a patient's self-management knowledge and skills,<sup>11</sup> and meeting with adolescent patients individually for part of the medical visit.<sup>10,12,13</sup>

Transition-Oriented Health Supervision (TOHS, pronounced "toes"), based upon the American Academy of Pediatrics' (AAP) Bright Futures<sup>14</sup> developmental approach to health supervision, focuses on the social and emotional functioning of the child and family, and emphasizes promoting health and well-being.

TOHS presents ways to use typical clinical activities to facilitate the active, developmentally appropriate involvement of children and adolescents in their own care, based on key findings from the HCT literature,<sup>15</sup> and research on brain development<sup>16</sup> and the facilitation of change.<sup>17</sup>

## TRANSITION-ORIENTED HEALTH SUPERVISION

TOHS is comprised of eight developmentally-linked activities or steps:

1. Build and Maintain a Working Alliance with the Family.
2. Envision a Future.
3. Promote Parent Effectiveness in Medical Management.
4. Promote the Child's Developmental Potential (including self-care).
5. Promote Autonomy (Early adolescence).
6. Promote Self-Efficacy (Middle adolescence).
7. Promote Individuation, Independence, and Exploration (Late Adolescence and Emerging Adulthood).
8. Transfer Emerging Adult to Adult-Focused Providers and Facilities.

### Step 1: Alliance with the Family

The first step is to build a working alliance with the patient's parents/caregivers, and the patient (as appropriate, given the patient's age and developmental status). "Working alliance" is used in the psychotherapy literature to describe a set of therapist-client relationship attributes that are associated with positive psychotherapy outcomes. These include explicit client-provider agreement on treatment goals, tasks, and activities; and an emotional bond between client and provider that is characterized by respect and trust. In the medical literature, "working alliance" (ie, development of common goals amidst a strong personal bond) has been identified as a key dimension of patient-centered medical care.<sup>18</sup>

A working alliance is similar to the Bright Futures concept of "forming an effective partnership with families;" but involves a greater level of discussion and negotiation about treatment goals/tasks, and the changing roles that family members play in the management of the patient's chronic health condition and the promotion of well-being.

Strategies for developing a working alliance include the "partnership" activities recommended in Bright Futures, such as adopting a family-centered approach to care; modeling open communication; and acknowledging family values and priorities. However, working alliances also require the physician to initiate and facilitate negotiations among family members about treatment priorities, tasks, and activities; and to promote change, over time, in the individual's care taking roles and responsibilities. Practitioners will find that Motivational Interviewing,<sup>18</sup> which is based in part on the working alliance literature, is a well-defined and effective approach for leading negotiations and for supporting the planned transfer of condition management from parent to child.

### Step 2: Future Vision

"Envisioning a future" with a child's family has been found to be a critical component of the HCT process<sup>10,19</sup> and should be initiated when a disability or chronic health condition is first identified or diagnosed.

This step involves asking parents (and the patient, as appropriate) questions, such as:

- How did you envision your child's long-term future before the diagnosis was made?
- When s/he is an adult, where will your child live? Who will your child live with?
- When s/he is an adult, will your child have their own family?
- What kind of job will your child have? Will your child be financially independent?
- How will health care needs and supports change and be met when s/he is an adult?

It also involves reminding parents that, even though their child has been diagnosed with a significant chronic condition or disability, s/he will reach adulthood.

TABLE.

**Roles of Professionals, Family/Caregivers, and the Pediatric Patient in the 8 Steps of the “Transition-Oriented Health Supervision” (TOHS) Approach to Health Supervision**

Step	Professional	Parent	Child/Adolescent/ Emerging Adult
1	<ul style="list-style-type: none"> <li>• Build and maintain working alliance</li> </ul>	<ul style="list-style-type: none"> <li>• Participate in working alliance</li> </ul>	<ul style="list-style-type: none"> <li>• Participate in working alliance</li> </ul>
2	<ul style="list-style-type: none"> <li>• Envision the future</li> </ul>	<ul style="list-style-type: none"> <li>• Envision the future</li> </ul>	<ul style="list-style-type: none"> <li>• Envision the future (when developmentally possible)</li> </ul>
3	<ul style="list-style-type: none"> <li>• Promote parent effectiveness</li> </ul>	<ul style="list-style-type: none"> <li>• Provide care</li> <li>• Gain knowledge, skills, experience, and confidence</li> </ul>	<ul style="list-style-type: none"> <li>• Receive care</li> </ul>
4	<ul style="list-style-type: none"> <li>• Promote child’s developmental potential</li> <li>• Engage child in care</li> <li>• Facilitate change</li> <li>• Renegotiate alliance</li> </ul>	<ul style="list-style-type: none"> <li>• Promote developmental potential</li> <li>• Provide care</li> <li>• Teach shared knowledge, promote healthy habits</li> </ul>	<ul style="list-style-type: none"> <li>• Participate in own care</li> <li>• Gain knowledge, develop skills, acquire healthy habits</li> <li>• Assume some responsibilities</li> </ul>
5	<ul style="list-style-type: none"> <li>• Promote autonomy</li> <li>• Model individuation</li> <li>• Facilitate change</li> <li>• Renegotiate alliance</li> </ul>	<ul style="list-style-type: none"> <li>• Promote autonomy</li> <li>• Share care, decision making, and advocacy</li> </ul>	<ul style="list-style-type: none"> <li>• Participate in and initiate care</li> <li>• Gain knowledge, skills, and experience in decision making and advocacy</li> <li>• Assume more responsibilities</li> </ul>
6	<ul style="list-style-type: none"> <li>• Promote self-efficacy</li> <li>• Teach parents how to be a coach and supervisor</li> <li>• Facilitate change</li> <li>• Renegotiate alliance</li> </ul>	<ul style="list-style-type: none"> <li>• Promote self-efficacy</li> <li>• Coach and supervise adolescent’s self-care and self-advocacy</li> <li>• Share decision making</li> </ul>	<ul style="list-style-type: none"> <li>• Primary “do-er”</li> <li>• Apply knowledge, skills with supervision</li> <li>• Gain knowledge, skills, experience, and confidence</li> <li>• Share in decision making</li> </ul>
7	<ul style="list-style-type: none"> <li>• Mentor</li> <li>• Provide structure and support</li> <li>• Promote individuation, independence, and exploration</li> </ul>	<ul style="list-style-type: none"> <li>• Support</li> <li>• Provide transition assistance and structure</li> <li>• Assist in decision making and advocacy</li> </ul>	<ul style="list-style-type: none"> <li>• Emerging CEO</li> <li>• Lead decision maker and “do-er” within structure and with support</li> </ul>
8	<ul style="list-style-type: none"> <li>• Transfer emerging adult to adult system</li> <li>• Make expertise available</li> </ul>	<ul style="list-style-type: none"> <li>• Consultant</li> <li>• Assist in decision making, advocacy as asked</li> </ul>	<ul style="list-style-type: none"> <li>• CEO</li> <li>• Fully in charge and responsible</li> <li>• Decision maker, “do-er,” and makes good use of all available resources</li> </ul>

Source: Adapted from Kieckhefer and Trahms<sup>22</sup>

This process of envisioning and asking questions about the future helps families and professionals focus on the importance of continuously enhancing the child's capacity to realize their potential, satisfy their needs, play an active role in their own health care, and interact successfully with their peers and society as a whole.

Providers should also offer anticipatory guidance about how parental roles in managing the medical condition should change over time, and why the move from pediatrics to the adult system is a necessary and positive step for all patients. The Table (see page 431) identifies and describes the roles of professionals, family/caregivers, and the pediatric patient in each of the eight TOHS steps.<sup>20</sup> This Table should be used periodically to help set new goals and define new roles so that the patient/family makes continuous progress toward TOHS steps 7 and 8.

### Step 3: Parental Medical Management

The third step in TOHS is enabling parents to effectively address the roles in their child's day-to-day health care needs. Over time, parents gain expertise in managing their child's chronic condition(s). This storehouse of knowledge and practical skills is part of what needs to be transferred to the child during Step 6, when parents transition to the role of coach, and their adolescent takes an increasing level of responsibility for his or her own care.

### Step 4: Developmental Support for the Patient

The fourth step in TOHS is promoting the child's cognitive, physical, and psychosocial developmental potential (including their potential to manage their own health care needs) during middle childhood (age 4 years to age 10 years). For typical children, developmental tasks and achievements of

middle childhood include, but are not limited to:

- Developing one or more close friendships.
- Expressing feelings to parents, other adults, and peers.
- Believing in their own capacity for success.
- Reading, writing, and communicating increasingly complex and creative thoughts.
- Assuming responsibility for belongings, chores, homework, and good health habits.
- Playing with and relating well to siblings and peers.

These are also critical developmental tasks for children with a chronic illness or disability. Optimal psychosocial development is supported by stressing to parents the importance of holding high expectations for their growing child and not treating the child with a chronic condition as "special" or different from the other children.

Parents need to know that children with special health needs who develop and maintain friendships with peers are more likely to become independent and happy adults, and that good social skills can make up for limitations in cognitive and motor development. Parents also need to know that the period from age 4 to 10 years is the best time to teach children to take responsibility for themselves and that they also have responsibilities to others. Although their condition might limit the type and number of household chores children can do, they should still be expected to do their "fair share." Research shows that being given house chores as a child increases the likelihood that an emerging adult with a disability will be self-sufficient and gainfully employed.<sup>21,22</sup>

Physicians must also model behaviors that promote the child's active participation in his or her own health care. This can be done, for example, by directing some questions to the

child, coaching parents to let their child answer fully before adding information, and suggesting the child say his/her own name when checking in for appointments. A focus on the future can be maintained by taking time to ask children with chronic conditions the questions asked of typical children such as, "What do you want to do when you grow up?"; "What is your favorite thing to do?"; and "What things do you enjoy at school?"

Some children, such as those with diminished intellectual or motor capacity, may not be able to participate in their own care as soon, or in the same ways, as other children. Inform parents that "participation in care" is a critical developmental task, and describe ways that the child can participate, in keeping with the child's developmental strengths and limitations.

### Step 5: Patient Autonomy

The fifth step in TOHS is to promote autonomy during early adolescence (age 11 years to age 14 years). Early adolescence is a very difficult time for youth with physical disabilities and chronic health conditions. With the move to middle school, grammar school friendships often end, and establishing new friends and a new social group can be a challenge for teens that are different from the "typical" in some way.

During this period the brain develops to the point where adolescents have increased potential for abstract, complex thinking, but their cognition is focused primarily on the "here and now".<sup>23</sup> The emerging autonomy of adolescent patients can be supported by helping them be proactive about their safety and well-being (eg, carry a health passport with emergency contact information,<sup>24</sup> write out what to do in case of a medical emergency, put "in case of emergency" numbers into their cell phone).

Overprotectiveness can be minimized by helping parents set clear, concrete, age appropriate, and safe limits. Help parents understand the importance of supporting, rather than fighting, their child's efforts to be more independent and self-reliant. These are necessary steps on the road to adulthood.

During early adolescence, patients should have some private time (ie, time without a parent) with their primary care provider and subspecialists. By meeting with the patient individually, a physician affirms that the teen is becoming more autonomous and helps the patient feel more comfortable asking questions, sharing concerns, identifying personal goals, and honestly discussing adherence issues. A written transition plan can help parents teach their adolescent how to carry out an increasing number of health care-related tasks and activities. The plan can incorporate information about the upper age limit of your medical practice and affiliated hospital, and also make them aware of what they need to do to be prepared for the eventual move to adult health care.

### Step 6: Self-Efficacy Support

During middle adolescence (age 15 years to 17 years), teens with normal cognitive development become more capable of solving complex problems by considering multiple elements simultaneously, systematically, and exhaustively. However, this is an emerging skill, requiring structured opportunities to apply new knowledge, practice decision making skills, and learn from mistakes.

With self-efficacy, the patient becomes the primary “do-er” of daily self-care tasks and related activities, while parents provide structure and oversight and serve as a coach and cheerleader. Teens should spend more time alone with health care providers

to build an independent trusting relationship, ask questions, share concerns in confidence, develop a health care transition plan, and get help integrating their health condition or disability into a positive self-concept.

Pediatric subspecialists should assure that all patients have a primary care physician (PCP) who is actively

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involved in their care. Subspecialists often address primary care needs for younger patients because some general pediatricians are reluctant to care for children and youth with complex health conditions. However, because the primary care of adolescents encompasses a broader range of health care issues (eg, sexuality and reproductive health, use/abuse of alcohol and other substances, peer relations, personal safety) most subspecialists do not have the time or expertise required to meet these patient needs.<sup>25</sup>

Involving a new PCP at this time has the added advantage of giving the adolescent an opportunity to learn how to develop a working relationship with a new provider (which they will have to do when they move to the adult care system), and to work with a provider who does not have a pre-existing relationship (alliance) with their parents.

Patients with diminished intellectual capacity may not be able to make important decisions on their own or fulfill Step 6 roles and responsibilities. In that case, it is helpful to work with the family to address issues of

guardianship and other legal supports so that these matters are settled before the patient turns 18 and assumes the legal rights and responsibilities of an adult.

### Step 7: Individuation, Independence, and Exploration

The key developmental tasks of emerging adulthood, ages 18 to 25 years, include:

- Continuing the process of separating from parents – both financially and physically.
- Exploring a broad range of situations, roles, and opportunities.
- Continuing to develop a healthy positive self-image.
- Forming and exploring a range of interpersonal relationships.
- Setting and achieving educational and vocational goals.
- Establishing a world view and system of personal value.

During the patient's emerging adulthood, families should shift toward the Step 7 roles and responsibilities. Parents no longer provide continuous oversight of their child's self-care activities, but are available to provide advice, support, and structure.

Although individuals have legal adult status at age 18 years, their brains continue to change and develop until about age 25 years. Therefore they may not have fully matured emotionally, intellectually, or socially, so can continue to benefit from mentoring and external structures and supports.

In keeping with this change in legal status and ongoing brain development, renegotiate the “working alliance.” The physician's primary relationship should be with the patient and involves providing needed structure and serving as a sounding board or “medical mentor” as the patient makes decision about medical treatment, and when to transfer to adult providers and facilities.

In keeping with the written HCT plan, Step 8, the final stage of transfer to adult care, should be initiated some time during emerging adulthood.

### Step 8: Adult-Focused Providers and Facilities

The eighth and last step in TOHS is transferring the patient to adult-focused providers and facilities. Key tasks for physicians include:

- Assessing patient readiness for transfer.
- Identifying adult-focused health care and service providers (eg, physician, occupational therapist, physical therapist, durable medical equipment, and home care).
- Preparing a medical summary.
- Identifying potential health insurance and financing problems.
- Helping the patient understand the culture of adult-focused medicine.

Determining when the patient is ready to transfer should be a collaborative process among the patient, the family (as appropriate), and primary and specialty care providers. Data from the Transition Readiness Assessment Questionnaire (TRAQ)<sup>26</sup> can also be used to help assess readiness. Recommended strategies and mechanisms for addressing these key transfer tasks are addressed, in detail, in a recent clinical report endorsed by the AAP, American Academy of Family Physicians, American College of Physicians.<sup>2</sup>

Some patients in their 20s may decide to transfer to an adult-focused internist or family physician but continue with pediatric subspecialists. This “mixed” approach has potential benefits since an adult PCP is more likely to talk about sexuality, fertility, and reproductive health; and to screen and treat more adult health problems (eg, hypertension). Because adult primary care providers work in the adult system, they can also assist in identifying appropriate adult-focused subspecialists

and facilities.

Scheduling a “good-bye” visit so that everyone has an opportunity to talk about ways to cope with significant change also can be beneficial. Physicians can also use this visit to:

- Review and validate the long-term gains and accomplishments the patient and their family have made.
- Affirm the current level of knowledge and skills of the patient.
- Reframe the upcoming discharge from pediatrics as a “commencement” or the beginning of a new phase of life and development, during which the emerging adult will continue to make progress in realizing their hopes and their dreams.
- Talk about ways they would like to be involved with the patients in the future (be copied on reports from adult providers; hear about significant future events, like college graduation, employment, marriage, and starting a family).

### CONCLUSION

Transition-Oriented Health Supervision (TOHS) is a new long-term stepwise approach to HCT that advises how every clinical encounter can be used to prepare pediatric patients with chronic health conditions and disabilities, and their families, for the eventual and necessary move from pediatric to adult care.

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