



The Education Healthcare Transition (EdHCT): Working Together to Assist Youth with
Chronic Illness Transition to Adulthood

White Paper: The Interdisciplinary Collaborative on Healthcare and
Education Transition (ICHET)

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Abstract

Education Healthcare Transition (EdHCT) refers to a collaborative process in which the fields of healthcare and education work *together* to help prepare youth for all aspects of adult living. EdHCT is based on the premise that a young person with a health condition does not (cannot) segment life into “health” and “education/career.” For people with chronic illnesses health and health management are integral to all aspects of life. Thus health must be integrated into all components of preparation for adult living and adult lifestyle must be adapted to health needs.

This White Paper emerged from the work of The Interdisciplinary Collaborative on Healthcare and Education Transition (ICHET) <https://education.ufl.edu/education-healthcare-transition/ichet/> – a collaboration between the University of Florida’s Colleges of Medicine and Education. The mission of ICHET is to:

Enhance service, provide training and conduct research supporting the successful, comprehensive transition of youth and young adults with special healthcare needs from pediatric to adult oriented healthcare; from school to higher education and employment and from adolescence to adulthood and the ongoing pursuit of dreams and ambitions.

Members of ICHET, who represent the family, education and healthcare communities, meet to plan and implement collaborative activities and to explore the communication challenges inherent in bringing education and healthcare together. To date we have conducted research, developed an online graduate certificate program, published articles, and presented at conferences.

Throughout the work of ICHET it has become clear to members that the education and healthcare systems approach transition very differently. Even though ICHET members have been working together for over seven years they often misunderstand each other's word use and intent of actions. These miscommunications seem to occur as a result of the different professional cultures, training and perspectives of the group members. ICHET members are committed to working through these misunderstandings. We hope to use the knowledge gained from our misconceptions and misperceptions to find ways to facilitate collaboration among EdHCT stakeholders. In this White Paper information is presented on the necessity for and implementation of Education Healthcare Transition (EdHCT). Recommendations are given to foster the collaboration between the education and healthcare transition processes necessary to implement EdHCT.

Basic Education Healthcare Transition (EdHCT) Concepts

Need for EdHCT

Youth with chronic illness are living into adulthood in larger numbers than even a decade ago. A comparison of U.S. Census Bureau (2011) data collected in 1999 and 2007 shows decreased death rates for chronic illnesses including diabetes (10%), lower respiratory (10%), cerebrovascular (32%), cancer (11%) and pulmonary (28%). Between 15-18% of all children may appear healthy but actually have a chronic illness such as diabetes, asthma, cystic fibrosis, cancer, AIDS or heart problems (University of Michigan Health Systems, 2011). The following discussion of cystic fibrosis illustrates that youth with chronic illness need coordinated transition services that address their unique concerns as they move into adulthood (see Figure 1).

Figure 1: Cystic Fibrosis

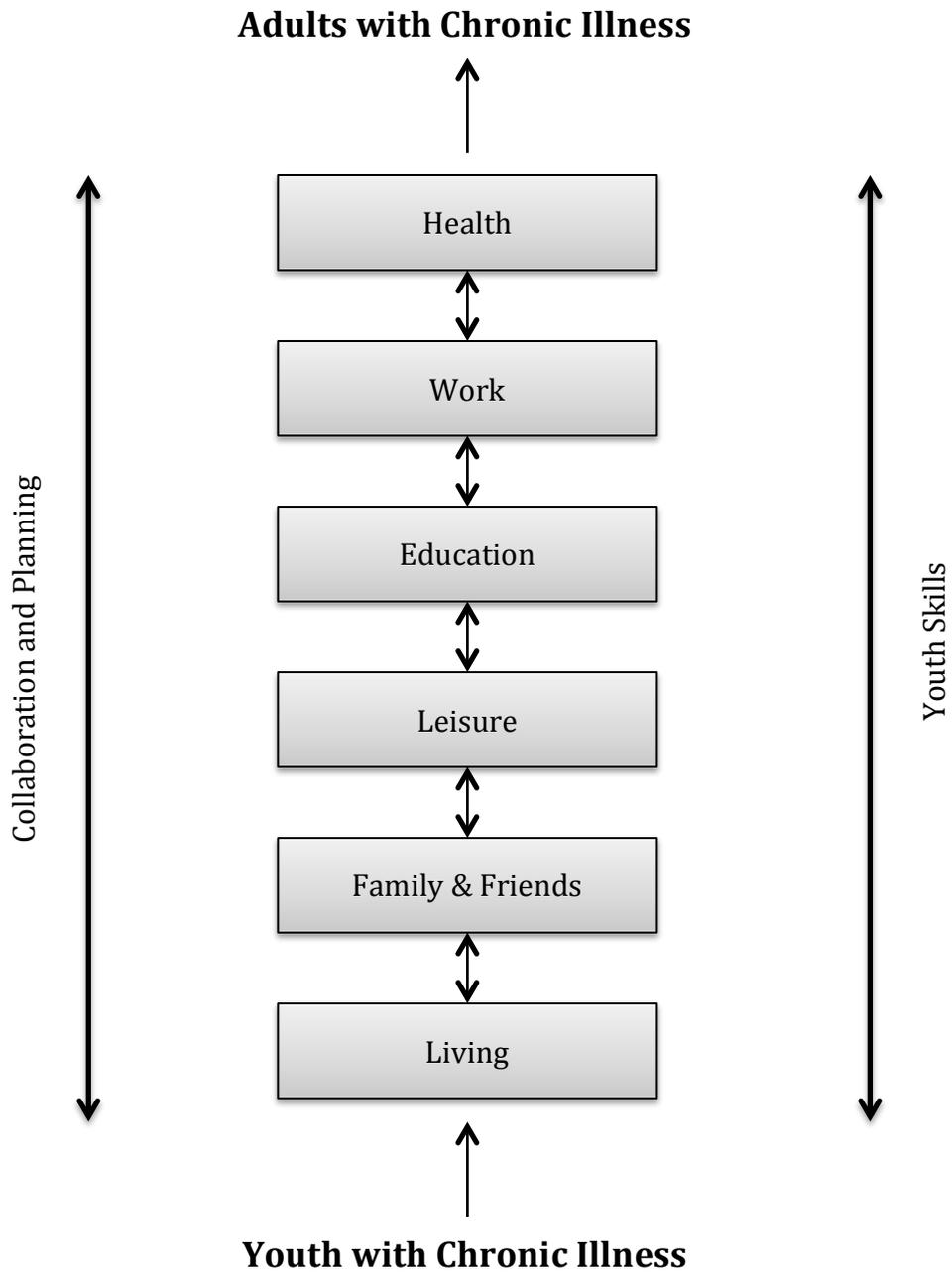
Cystic fibrosis (CF) is a genetically based, life-shortening illness affecting primarily the lungs and the digestive system. The treatment regimen for CF is burdensome and includes nebulized and oral medications and airway clearance. The full regimen takes between 1-3 hours per day. Consequently, CF centers emphasize self-management skills and healthcare transition. Education transition is also imperative for youth with cystic fibrosis. Cystic fibrosis does not affect cognition but people with CF need accommodations in order to learn effectively (e.g., permission to take enzymes, use restrooms, take nutritional supplements or help making up school missed due to pulmonary exacerbations). Requesting accommodations from school districts is

supported by the CF Foundation therefore many youth with CF have Individualized Education Plans (IEPs) in school (CF Education Committee, 2015). Due to new developments in medications, most children with cystic fibrosis (CF) live into adulthood and nearly half of people with CF are over the age of 18 (Cystic Fibrosis Foundation, 2014). Teens with CF and their families must now plan for adulthood and adult healthcare (American College of Physicians, Transitions Clinical Report Authoring Group American Academy of Pediatrics, 2011; Freyer, 2010; Treadwell, Telfair, Gibson, Johnson & Osunkwo, 2010). Therefore, postsecondary education and employment must take into account the ability of the person with CF to balance work with self-care. Career and life choices must be reasonable for someone with CF, considering their respiratory limitations.

Key Features of EdHCT

Youth with chronic illness and their families are, for the most part, left on their own to navigate the two separate worlds of education transition and healthcare transition. Although both disciplines advocate for transition, the skills and tasks in each are viewed differently. This leaves youth and their families to decide how these two concepts of transition can be addressed in a cohesive manner to guide their movement into adulthood. An expanded view is needed to support the collaboration between education and healthcare transition to assist youth with chronic illness in developing one cohesive transition plan. The Education Healthcare Transition (EdHCT) Model addresses such an expanded view of transition. The model integrates the maintenance of health with usual life activities throughout adult life span (see figure 1).

Figure 2: Education Healthcare Transition (EdHCT) Model



The importance of healthcare and education collaboration in transition is highlighted in the Federal Partners in Transition Workgroup report entitled *The 2020 Federal Youth Transition Plan: A Federal Interagency Strategy (2015)* as well as implied in education transition (IEP) mandates to include “related services” along with transition planning for post-school employment, education, and community life (IDEA, 2014). Healthcare providers have acknowledged that both educational and vocational goals are important (Ferguson, 2010; Wong et al, 2010), although the medical literature rarely includes career and educational goals when discussing healthcare transition (Ferguson, 2010, Wong et al, 2010; Healthy and Ready to Work, 2014; American Academy of Pediatrics Committee on Children with Disabilities, 2002). The converse is also true for education professionals who are largely unaware of healthcare transition (Repetto, Gibson, Lubbers, Gritz, Reiss, 2008a) and rarely consider health-related factors in transition planning for students with disabilities (Repetto, Jarress, Lindsay, Bea, 2016). The EdHCT Model (see figure 2) illustrates the collaboration between healthcare transition and education transition to improved adult outcomes.

Central to the EdHCT Model are the core areas of life in which adults are expected to take an active role (e.g., work, education, leisure, family). Unique to the Model is the inclusion of health as a specific area of life. Special attention is needed in this area due to the heightened need for youth with chronic illness to acquire the skills to maintain their health throughout their lives. Supporting these core areas is the collaboration between youth, family, educators and health professionals to develop transition plans centered on the individual needs of the youth with chronic illness. Crucial

to the development of these core areas are the skills developed by youth with chronic illness such as self-determination and self-advocacy along with more specific transition skills related to the core areas. The EdHCT Model expands upon current education and healthcare evidence-based practices to include the needed focus and collaborations to support the transition of youth with chronic illness into adulthood.

Adult with Chronic Illness Outcomes

In order for adults with chronic illness to maintain their health, so that they can survive and enjoy life, they need to remain attentive. This attentiveness must be applied across all areas of life to ensure consistency (see figure 3). For example, when considering employment an adult with a chronic illness needs to choose a job that will not be detrimental to their health and also to make sure any needed accommodations are in place so that the work environment supports good health. Adults with chronic illness need to be consistently alert to their health needs and aware of the consequences if they are not. This is true for everyone to some extent, but the difference is that for an adult with chronic illness the consequences can be long-term and can threaten quality of life and even life itself. Therefore, it is imperative to foster collaboration between education, healthcare and the youth/family to expand transition to address the needs for youth with chronic illness.

Figure 3: Adult with Chronic Illness Outcomes

Health	<ul style="list-style-type: none">•Keep appointments•Take medication•Have Health insurance•Balance health needs with other life activities
Work	<ul style="list-style-type: none">•Obtain and keep a job•Have a safe work environment•Earn a salary with benefits•Have needed supports•Gain skills for success and advancement
Education	<ul style="list-style-type: none">•Attend postsecondary education•Obtain needed supports
Leisure	<ul style="list-style-type: none">•Participate in activities to maintain health•Participate in free time activities
Family & Friends	<ul style="list-style-type: none">•Interact socially•Interact with family•Family support, guidance, advocacy, coordination of care
Living	<ul style="list-style-type: none">•Live in a safe living environment•Be financially sound•Be responsible for all aspects of independent living

Foundation for EdHCT Model

Youth moving into adulthood can benefit from preparation assisting them in learning skills and information needed in adult roles. Beyond needing basic guidance as they emerge into adulthood, youth with chronic illness have unique needs that need to be addressed (Federal Partners in Transition Workgroup, 2015; Repetto et al. 2008b; Wong et al., 2010). Their needs are addressed in secondary education through mandated provisions providing transition planning (IDEA, 2004) and in the healthcare field by policies calling for planning for the move from pediatric to adult health care (American Academy of Pediatrics Committee on Children with Disabilities, 2002; US Department of Health and Human Services, 2011). The Education Health Care Transition (EdHCT) Model illustrates an education and health care collaboration necessary to support the transition of youth with chronic illness. The importance of such a healthcare – education collaboration in transition is highlighted in the 2015 Federal Partners in Transition Workgroup report entitled *The 2020 Federal Youth Transition Plan: A Federal Interagency Strategy (2015)*.

Foundational to the understanding of the Education Healthcare Transition (EdHCT) Model are three components (a) youth with chronic illness, (b) laws and policies governing the model and (c) guiding principles for implementation of the model. Each of the components will be discussed.

Youth with Chronic Illness

Medical advances supporting individuals with chronic illness have led to increased lifespans. As a result of these medical advances children with a chronic illness who a decade ago were not expected to live past twenty are now surviving into their

thirties and forties (University of Michigan Health System, 2011; U.S. Census Bureau, 2011). In addition to medical advances, legal mandates and policies address the needs of youth with invisible chronic illness (see Table 1) thus improving their live expectancy (Healthy and Ready to Work, 2015; IDEA, 2004). These youth not only can expect to live longer but to have an improved quality of life (American Academy of Pediatrics Committee on Children with Disabilities, 2002).

Table 1: List of Common Chronic Illnesses

AIDS
Allergies
Arthritis
Asthma
Cancer
Celiac Disease
Cerebral Palsy
Chronic Fatigue Syndrome
Congenital Heart Problems
Cystic Fibrosis
Diabetes
Epilepsy
Lupus
Obesity
Scoliosis
Sickle Cell Anemia
Spina Bifida

Adolescents with chronic illness have a long-lasting health condition that differs from an acute health condition, which lasts a shorter period of time (e.g., cold, flu, broken

bone). A chronic illness can be but is not always critical (life-threatening) although it can have long-lasting physical, social, emotional and financial affects. *Chronic illness* is an umbrella term covering illnesses with different characteristics and treatments but that last over a long period of time. In the United States 15% of youth are diagnosed with a chronic illness (American Academy of Pediatrics Committee on Children with Disabilities, 2002). These youth may have frequent doctor appointments or hospitalizations, chronic pain, and daily time-consuming treatments causing them to feel different from peers.

Youth with chronic illness develop in a manner similar to that of all adolescents, meeting the same challenges and milestones. The main difference is the impact of their illness on their ability to grow and develop at each stage (see Table 2). These youth have unique physical, social and psychological challenges that can impact their development (McNeely & Blanchard, 2009). An awareness of these challenges can assist in thinking about the best way to support the transition to adulthood for individual youth with chronic illness.

Table 2: Impact of Chronic Illness on Adolescent Development

Developmental Task	Impact of Chronic Illness
<u>Physical Development</u> <ul style="list-style-type: none"> • Growth spurts occur • Puberty • Acclimate to changes in body • Conscious about physical appearance 	<u>Physical Development</u> <ul style="list-style-type: none"> • Possible delays or modifications of development due to medication or illness • Self-conscious because of these modifications development
<u>Cognitive Development</u> <ul style="list-style-type: none"> • Ability to think abstractly expands • Can take others perspective into account • Problem solving expands • Expand ability to take risks 	<u>Cognitive Development</u> <ul style="list-style-type: none"> • Medication may impact cognitive functioning • Problem solving can be more complex • Risk taking is impacted by illness
<u>Emotional and Social Development</u> <ul style="list-style-type: none"> • Friendship based loyalty expands • Ability to choose which adults to trust • Start to pull away from family • Develop sense of personal identity • Become more independent • Develop work identity • Develop ethics 	<u>Emotional and Social Development</u> <ul style="list-style-type: none"> • Possible isolation due to illness • Increased dependence on family to help manage illness • Impact of illness on sense of identity • Possible impact of illness on work life

In addition, youth with chronic illness and their families form the lynchpin of the EdHCT process. In the worst of cases, youth and their families are left to navigate the independent processes of education transition and healthcare transition on their own,

cobbling them together as best as possible. In the best of circumstances, the education system, the healthcare system and the youth/family work as a triad to help the young person with chronic illness emerge, well equipped to embrace adulthood with an adaptive healthcare/education/lifestyle balance.

Legal and Policy Underpinnings

The transition of youth with chronic illness is supported by education and civil rights laws as well as by healthcare transition policies. Discussed in the following are brief overviews of selected laws and policies that impact the transition of youth with chronic illness.

The Individuals with Disabilities Education Act of 2004 and Amendments

(IDEA <http://idea.ed.gov/>). Under IDEA a Transition Individualized Education Program (IEP) needs to be in effect by a student's 16 birthday. The transition IEP team develops appropriate measurable goals based on student's individual strengths, needs, interests and preferences and focused on improving the academic and functional achievement of the student. Transition planning should be a result-orientated process covering needed student instruction, related services, community experience, daily living skills, and functional vocational assessment. All services and supports should be planned to prepare the student to transition in to postsecondary employment, school and living. As a student prepares to exit secondary school a Summary of Performance (SOP) is developed to provide useful information to postsecondary agencies about the student pursuing transition goals in employment, training or postsecondary education.

Section 504 of the Rehabilitation Act of 1973 and Subsequent Amendments

(<http://www2.ed.gov/about/offices/list/ocr/504faq.html>). This law prohibits discrimination against persons with disabilities in any program or activity receiving federal funds. The law provides for the development and implementation of coordinated **Healthy People 2020** transition planning covering independent living, vocational assistance, and inclusion in community. Students having a physical or mental impairment that substantially limits one or more major life roles are covered under this law. Under this law individualized 504 Plans are used to guide student programming and supports.

The Americans with Disabilities Act of 1990 and 2008 Amendments (ADA) (<http://www.ada.gov/>). This is a civil rights act that prohibits discrimination against anyone with a physical or mental disability performing major life roles. Under ADA major life activities include caring for oneself, performing manual tasks, employment, public services, transportation, public accommodations, and telecommunications.

Healthy People 2020 (<http://www.healthypeople.gov/>). Healthy People 2020 (HP 2020) is the national strategic plan for public health. In HP 2020 goals for the healthcare community to meet by 2020 are outlined. Several of the goals relate to the transitioning of youth with chronic illness from pediatric to adult health care. Also included are goals related to youth success in school (e.g., higher high school graduation rates, increased in youth considering school work meaningful) and increased employment for people with disabilities.

Physicians' Consensus Statements. A number of consensus statements have called for health care providers to understand the importance of health care transition, have the skills to facilitate the process, and know the appropriate time to transition youth

to adult health care (American College of Physicians, Transitions Clinical Report

Authoring Group American Academy of Pediatrics, 2011)

Federal Agency Policy Statements. A number of federal government agencies, individually or in collaboration with others, have completed policy statements regarding the importance of collaboration between health and education in the transition process (Healthy and Ready to Work, 2015; Federal Partners in Transition Workgroup, 2015)

Confidentiality Legislation. Confidentiality laws and regulations impact the collaboration and sharing of information related to the chronic illnesses of youth. Additionally, an understanding of these laws is important in the day-to-day interactions with youth with chronic illness (Repetto, Gibson, Lubbers, Gritz, & Reiss, 2008b). Most school districts and health care facilities have guidelines in place to ensure compliance with these mandates. A brief overview is given below of two confidentiality laws necessary to understand before crucial information can be shared among all stakeholders in the transition of youth with chronic illness. The overviews below are provided for informational purpose only and not meant as implementation guidelines. Readers should become familiar with the guidelines used by their institutions.

The Family Education Rights and Privacy Act of 1974 (FERPA <http://www2.ed.gov/policy/gen/guid/fpco/ferpa/index.html>). The Federal law protects the families and students pertaining to educational records and the information contained within those records. Families and students can choose to share this information with other parties but teachers may not without prior written parental permission. However, teachers may share this information without parent written consent with (a) other school officials, (b) another district the student plans to attend, (c) certain judicial and law

enforcement agencies and (d) authorized government officers (Murdick, Gartin & Fowler, 2013; Schwab et al., 2005)

Health Insurance Portability and Accountability Act of 1996 (HIPAA <http://www.hhs.gov/hipaa/index.html>). This federal law protects the security and privacy of health information transmitted electronically. Medical records transmitted by health facilities as well as schools are covered under HIPAA (Center for Health and Health Care in Schools, 2013; Schwab et al., 2005).

Interdisciplinary collaboration among families, educators and medical professionals is crucial to building the level of understanding and trust needed to provide the correct transitions supports and services to youth with chronic illness. Not understanding the laws and policies of all disciplines can hinder and even block the ability for interdisciplinary collaboration resulting in uncoordinated supports and services leaving youth with chronic illness less prepared for their transition into adulthood.

Guiding Principles

The EdHCT Model builds on standards and policies in both the education and health care fields. Two recent studies support collaboration between these two fields by assessing the knowledge that education and healthcare professionals had of the healthcare transition process and their interest in learning more (Horky, Repetto, Rowe, Miney and Saidi, submitted; Repetto, Gibson, Lubbers, Gritz, & Reiss, 2008a) show minimal current knowledge (42-57%) but a high level of interest in learning about the topic (92-94%). Results from the studies further demonstrated that funding, lack of time and lack of a perceived mandate are barriers to inter-system collaboration. The following guiding

principles are practical next steps for collaboration between healthcare transition and education transition.

Well-being and Empowerment. Collaborative efforts must center on building self-determination, empowering youth and promoting their quality of life (Pais, Guedes & Menezes, 2012).

Advocacy, Rights and Communication. Education and Healthcare professionals need to understand, consider, protect rights and teach advocacy skills (Yates et al., 2010).

Clear communication and interdisciplinary in-service. Clear and consistent communication between school and healthcare professionals is fundamental to collaboration between healthcare transition and education transition. This will be enhanced by training in each setting about the roles, functions and practices of the other.

Understanding guidelines and terminology. Collaboration between these two settings presents challenges. Each has confidentiality laws (Repetto, Gibson, Lubbers, Gritz, & Reiss, 2008b) restricting the communication. Professionals in both fields are overworked, with little time to spare. Differing cultures, norms and terminology may inhibit understanding. Finally, there is an asymmetry between the two transition processes: Education transition is legally mandated and has standardized processes and procedures. Healthcare transition is only recommended and takes many forms. Professionals from both fields will benefit from increased understanding of the other field's mandates and constraints (Saidi, et al., 2011).

Joint planning meetings. The ultimate goal of communication is to bring the planning processes from the education and healthcare settings together, to identify joint goals, and to work together to meet these goals. Ideally, educators and healthcare providers would hold joint education/healthcare transition planning meetings to develop integrated (healthcare and education) goals. These meetings would allow better understanding of the teenager's overall needs, limitations and status and lead to jointly developed transition activities.

Jointly developed goals and collaborative transition activities. Jointly developed goals will allow each field to reinforce skills learned in the other. These will also avoid redundancy and enhance outcomes.

Time saving options. As time has been identified as a significant barrier, identifying timesaving options is important (e.g., web portal, telecommunication, shared forms)

Family and Youth centered approaches. Patients and their families are at the center of transition planning and services should be designed for their benefit. Families' needs and views should be central. Families can help coordinate healthcare transition and education transition. However, a collaborative system should be in place to support the family.

EdHCT Model Components: Student Focus

Since transition is an outcome-oriented process it is important to take a look at how successfully young adults function in adult roles once they leave school. A comparison of the functioning of youth with chronic illness and that of healthy youth helps to provide a better understanding of the need to provide education and health care transition supports and services to these youth to improve their outcomes. A recent meta-analysis (Pinquant, 2014) compared the achievement of developmental milestones (e.g., postsecondary education, employment, moving out of parent's home and becoming parents) for youth with and without chronic illness between the ages of 18 and 30. Differences between groups on meeting specific milestones ranged between 22- 38% with youth with chronic illness in the lower ranges. In addition, youth with chronic illness earned lower salaries than their healthy peers. Pinquant (2014) recommends implementing interventions aimed at increasing rates of obtaining milestones for youth with chronic illness.

Within the education system these interventions can be planned for during transition Individual Education Programs (IEPs) meetings (IDEA, 2004) or 504 Plans (Section 504 of the Rehabilitation Act of 1973). Youth with chronic illness are often covered under the category of Other Health Impaired (OHI) if their health concerns adversely impact their education performance (National dissemination Center for Children with Disabilities, 2009; Shaw & McCabe 2007). A student may also qualify for services under a 504 Plan even if they do not receive services under IDEA. The 504 Plan ensure that students have the necessary supports and accommodations to have full access to education programs. Education goals and needed supports are planned for during IEP

meetings; once a student turns 16 these plans also require measurable postsecondary goals, along with needed transition services, for training, education, employment, and independent living taking into account the individual strengths and needs of students (IDEA, 2004). For students with chronic illness it is crucial to consider the impact their illness may have on their transition planning (Repetto et al., 2012; Repetto, Jaress, Lindsey & Bea, 2016).

Within the health care system transition planning focuses on assisting the youth with chronic illness with the move from child-centered pediatric care to adult-oriented care (American College of Physicians, Transitions Clinical Report Authoring Group, 2011). Such management includes the development of skills ranging from independently taking medications or doing treatments, calling the doctor when symptoms increase, ordering medications, scheduling appointments and negotiating with health insurance companies. The attainment of these skills is often necessary but not sufficient for full autonomous adult functioning. Ideally, skills are enhanced by an internal sense of motivation and responsibility (analogous to what is termed “self determination” in the education world) that underlies the provision of one’s own healthcare. As healthcare transition is not legally mandated it is not a standardized process. Healthcare transition planning is approached in different ways in different settings. In some healthcare settings, transition skills are verbally incorporated into each outpatient visit, with provider interaction increasingly focused on the youth, rather than the parent. In many settings, parents are only present in the examination room for part of the visit, allowing the youth to have an independent conversation with the healthcare provider for some of the visit. Many settings also use forms to document healthcare transition readiness along a number

of dimensions. Typically, healthcare transition forms focus solely on an individual's health-related self-management skills and do not include such topics life goals, work or post secondary goals, hobbies, or family planning considerations.

Since each youth with a chronic illness has unique strengths and needs he or she will require individual planning. A given youth may have a Transition IEP or 504 Plan and a Healthcare Transition Plan. Ideally, these plans should be coordinated. Such coordination between the healthcare goals and education goals is central to the Education Health Care Transition (EdHCT) Model. Basically, the premise for EdHCT is that all transition planning for youth with chronic illness should be coordinated so that all systems can work as one to support the youth. This coordination will limit fragmentation and overlap, fostering a holistic effort for preparing youth with chronic illness for adulthood.

Table 3 provides examples of student skills possible in both Education and Healthcare that can benefit youth with chronic illness. The focus of Table 3 is student skills while Tables 4 & 5 (in the next section focus on system change). In the EdHCT Model youth with chronic illness are assumed to take an active role, engaged as informed planners and learners in the transition process.

Table 3: EdHCT Student Skills

	EdHCT Positive Adult Outcomes	Sample Health Care Transition Skills	Sample Education Transition Skills	Student Role
HEALTH	<ul style="list-style-type: none"> Independently follow Treatment Plan (e.g., keep appointments, take medication) • Maintain Health insurance 	<ul style="list-style-type: none"> • Teach and practice communicating effectively with MD (in visits and calling clinic if symptoms increase). 	<ul style="list-style-type: none"> • Teach strong math, written and verbal skills • Teach assertiveness skills • Foster confidence • Teach self- 	<ul style="list-style-type: none"> • Active learner

		<ul style="list-style-type: none"> • Teach and practice taking medication. 	advocacy skills	
WORK	<ul style="list-style-type: none"> • Locate appropriate job • Attain Safe work environment • Achieve maximum salary with benefits • Obtain needed supports • Develop skills for success and advancement 	<ul style="list-style-type: none"> • Provide information on insurance reimbursement • Discuss how illness impacts work • Provide information on needed work accommodations 	<ul style="list-style-type: none"> • Foster self-determination • Foster self-advocacy • Discuss needed accommodations • Take illness into account when discussing job choice 	<ul style="list-style-type: none"> • Active learner
EDUCATION	<ul style="list-style-type: none"> • Achieve appropriate education level • Locate needed supports 	<ul style="list-style-type: none"> • Discuss needed education accommodations 	<ul style="list-style-type: none"> • Discuss education accommodations • Discuss self-advocacy 	<ul style="list-style-type: none"> • Informed engaged planner
LEISURE	<ul style="list-style-type: none"> • Participate activities to maintain health • Ensure fun free time 	<ul style="list-style-type: none"> • Provide information on how to maintain health 	<ul style="list-style-type: none"> • Provide information on health leisure activities 	<ul style="list-style-type: none"> • Informed engaged planner
FAMILY & FRIENDS	<ul style="list-style-type: none"> • Manage appropriate social interactions • Ensure appropriate family interactions 	<ul style="list-style-type: none"> • Practice how to talk with friends about illness • Provide parents ways to decrease involvement while youth take larger role in their health 	<ul style="list-style-type: none"> • Involve family in transition planning • Practice how to talk with friends about illness 	<ul style="list-style-type: none"> • Informed engaged planner
LIVING	<ul style="list-style-type: none"> • Maintain safe living environment • Remain financially sound 	<ul style="list-style-type: none"> • Provide information on health insurance 	<ul style="list-style-type: none"> • Teach skills needed to understand health insurance • Teach how to balance a budget 	<ul style="list-style-type: none"> • Active learner

EdHCT Model Implementation: System Focus

Youth with chronic illness and their families interact with many systems (e.g., healthcare, insurance, schools, disability services) on a daily basis therefore it is important for all these systems to work together as active partners to construct coordinated services for youth (Pais, Guedes & Menezes, 2012; Yates et al, 2010). This interconnection between various systems supporting the development of one person is manifested in the ecological model (Bronfenbrenner, 1979) which purposes that multiple factors work together to provide an individual's life experience. In addition, education transition legislation supports a coordinated set of activities to support a student's transition through district level interagency transition counsels and student level multidisciplinary transition IEP meetings (IDEA, 2004). Healthcare transition planning, also, calls for collaboration among disciplines (American Academy of Pediatrics Committee on Children with Disabilities, 2002; Federal Partners in Transition Workgroup, 2015). For youth with chronic illness the main groups that need to work together are family, education professionals and health care professionals. The first step, in collaboration is understating how each of these systems function (see Table 4). As is evident in Table 4 each system operates under different rules and ways of work. Therefore, it may not be advantageous to advocate for a complete merger of the systems but rather to strive for a collaborative way of working. For example, is there a way for doctors and educators to share information about the impact of a chronic illness on the future employment of a youth that can be gathered within a 15 minute doctor's

appointment and not violate privacy laws? The following is a list of additional questions that might be considered when developing collaborative work plans.

- How can professionals make sure they are following privacy laws when sharing information with each other or with colleagues or other students?
- How can the healthcare and education systems support youth and families as they actively engage in transition planning?
- How can youth with chronic illness not feel isolated?
- How can existing education transition evidenced and research based practices (<http://transitionta.org>) be expanded to meet the need of youth with chronic illness (Repetto et al, 2012)?
- How can the Six-Core Elements of Health Care Transition (<http://www.gottransition.org/>) be expanded to provide better linkage with school systems?
- What professional development is needed to make sure all partners have an understanding of the transition needs of youth with chronic illness (<https://education.ufl.edu/education-healthcare-transition/what-is-edhct/>)?
- What professional development is needed to better understand all the systems involved in transition planning for youth with chronic illness (<https://education.ufl.edu/education-healthcare-transition/what-is-edhct/>; <http://www.floridahats.org/>; <http://www.gottransition.org/>)?
- How can a collaborative work plan be developed to support each youth with ongoing evaluation and system adjustment?

One framework for such a collaborative effort that begins to address these questions is the Education Health Care Transition (EdHCT) Model, which stresses the importance of the family, education system and health care system to work together to support youth with chronic illness. Table 5 provides examples of collaborative steps that can be taken to support positive adult outcomes for youth with chronic illness.

Table 4: Components of EdHCT Systems

Component	Health Care	Education	Family
Funding	<ul style="list-style-type: none"> • Grants • Insurance Reimbursement • Professional salary may or may not be based on billable hours 	<ul style="list-style-type: none"> • Grants • Federal, state and local funds • Professionals salary is not based on billable hours 	<ul style="list-style-type: none"> • Health Insurance
Time	<ul style="list-style-type: none"> • Office/clinic appointment (usually 15 minutes) 	<ul style="list-style-type: none"> • Set class and school hours 	<ul style="list-style-type: none"> • Fit into work and family schedules
Law/Policy	<ul style="list-style-type: none"> • HIPPA • Transition Policy • ADA • ACA 	<ul style="list-style-type: none"> • FERPA • IDEA • ADA • Vocational Rehabilitation Act 	<ul style="list-style-type: none"> • ACA • HCT Policy Papers
System organization	<ul style="list-style-type: none"> • Disease specific 	<ul style="list-style-type: none"> • Curriculum and outcome based across disability and disease 	<ul style="list-style-type: none"> • Individual child
Professional Training	<ul style="list-style-type: none"> • Course work • Conferences • State certification • In-service Training • CEUs 	<ul style="list-style-type: none"> • Course work • Conferences • State certification • In-service Training • CEUs 	<ul style="list-style-type: none"> • Informational materials • Conferences

Table 5: EdHCT Collaboration and Planning

	EdHCT Positive Adult Outcomes	Sample Health Care Transition Responsibility	Sample Education Transition Responsibility	Sample Family Responsibility
HEALTH	<p>Independently follow Treatment Plan (e.g., keep appointments, take medication)</p> <ul style="list-style-type: none"> • Maintain Health insurance 	<ul style="list-style-type: none"> • Develop and implement a process for transition from pediatric to adult care • Work with educators to develop and implement a system to share needed patient information • Provide professional development to better understand education transition, education laws and culture • Invite education professional to join health care transition planning councils 	<ul style="list-style-type: none"> • Expand current education transition practice to include health care. • Work with educators to develop and implement a system to share needed patient information • Provide professional development to better understand health care transition, education laws and culture. • Invite health care professional to join district and or state interagency transition councils 	<ul style="list-style-type: none"> • Practice making and keeping appointments • Teach how to order and take medication • Involve in completing health insurance forms
WORK	<ul style="list-style-type: none"> • Locate Appropriate job • Attain Safe work environment • Achieve maximum salary with benefits • Obtain needed 	<ul style="list-style-type: none"> • Provide information educators health care insurance information that will impact youth. • Provide information to educators on how illness impacts work • Provide information to educators on needed work 	<ul style="list-style-type: none"> • Invite health care professional to IEP meetings to discuss the health needs of the youth • Translate health reports into needed work accommodations • Take illness into account when 	<ul style="list-style-type: none"> • Discuss future dreams • Support choices • Attend and be involved in IEP meetings.

	supports <ul style="list-style-type: none"> • Develop skills for success and advancement 	accommodations	discussing job choice	
EDUCATION	<ul style="list-style-type: none"> • Achieve appropriate education level • Locate needed supports 	<ul style="list-style-type: none"> • Provide information to educators on how illness impacts work • Provide information to educators on needed work accommodations 	<ul style="list-style-type: none"> • Invite health care professional to IEP meetings to discuss the health needs of the youth • Translate health reports into needed education accommodations • Take illness into account when discussing education decisions. 	<ul style="list-style-type: none"> • Discuss future dreams • Support choices • Attend and be involved in IEP meetings.
LEISURE	<ul style="list-style-type: none"> • Participate activities to maintain health • Ensure fun free time 	<ul style="list-style-type: none"> • Provide information to educators on how illness impacts leisure • Provide information to educators on needed leisure accommodations 	<ul style="list-style-type: none"> • Invite health care professional to IEP meetings to discuss the health needs of the youth • Translate health reports into needed leisure accommodations • Take illness into account when discussing leisure activities 	<ul style="list-style-type: none"> • Involve in leisure activities • Attend and be involved in IEP meetings.
FAMILY & FRIENDS	<ul style="list-style-type: none"> • Manage appropriate social interactions • Ensure appropriate family interactions 	<ul style="list-style-type: none"> • Work with families to advocate for youth with the education system • Providers educators with reports on the social implications of illness 	<ul style="list-style-type: none"> • Work with families to advocate for youth in the health care system • Translate reports from health care providers on the social implications of illness 	<ul style="list-style-type: none"> • Model healthy family involvement
LIVING	<ul style="list-style-type: none"> • Maintain safe living 	<ul style="list-style-type: none"> • Provide information educators health care 	<ul style="list-style-type: none"> • Invite health care professional to IEP 	<ul style="list-style-type: none"> • Model a safe living

	environment <ul style="list-style-type: none"> • Remain financially sound 	insurance information that will impact youth. <ul style="list-style-type: none"> • Provide information to educators on how illness impacts living arrangements • Provide information to educators on needed living accommodations 	meetings to discuss the health needs of the youth <ul style="list-style-type: none"> • Translate health reports into needed living accommodations • Take illness into account when discussing living choices 	environment <ul style="list-style-type: none"> • Attend and be involved in IEP meetings.
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Recommendations

Healthcare transition and education transition operate separately. Professionals on both sides should become more aware of the transition processes and resources available in both fields and work to develop collaborative goals and activities. There are a number of ways that education and healthcare professionals can work collaboratively to plan for appropriate employment opportunities and to assist youth in developing the skills necessary to live independently, balancing work and self-care. We discuss below practical next steps for collaboration between healthcare transition and education transition. Given the absence of prior research in this area, these recommendations are based on consensus and expert opinion.

Practical Next Steps

Provision of cross-discipline professional development. Professional development is a key first step in the collaboration between education and healthcare in the transition process. Cross discipline professional development can foster greater understanding of the culture, norms, terminology and constraints of the other.

Professional development is also needed to teach practical ways that school professionals

and healthcare providers can best work together. Training on collaborative approaches and strategies for including education and health transition activities in both settings can be provided. It is crucial to have family input during trainings. In order to achieve this type of cross-fertilization, the University of Florida has developed an online, graduate level Certificate Program in Education and Healthcare Transition.

Joint planning meetings. Cross-setting communication and planning may most effectively be achieved by bringing the education and healthcare settings together. In-person meetings between family, healthcare professionals and education professionals facilitate the identification of joint goals and ideally the development of integrated (healthcare and education) transition plans. These meetings allow better understanding of the teenager's overall needs, limitations and status and lead to jointly developed transition activities. The unique expertise and perspective of each group is essential: Educators can recommend vocational or educational resources and help healthcare providers understand how to access these supports. Healthcare providers can help explain the impact of a teen's health condition on their education and career choice. Joint planning meetings could be piloted by hospital-based teachers or in school-based health centers, as these settings already provide collaboration between education and healthcare.

Use of Distance Technology. As time has been identified as a significant barrier, identifying timesaving options is important. Secure telehealth tools such as Vidyo, Adobe Connect or other HIPAA-compliant conferencing platforms save travel time between clinics and schools, shortening the time needed to develop curricula and conduct patient care meetings. In addition, family access to the youth's online medical

record and educational records would allow family members to facilitate the coordination between family, education and healthcare in the transition process.

Use of an identified point-person. Full team participation in jointly developed planning and curriculum development may not be feasible. Alternatively, each team could identify one point-person to be the representative for each student. Rapley and Davidson (2010) suggest introducing a designated transition coordinator in order to improve outcomes in healthcare transition and a parallel role could be developed in education. The healthcare transition coordinator could attend the Transition IEP meeting, and the education coordinator (e.g., school nurse, guidance counselor) could periodically visit clinic. In the absence of a well-developed EdHCT process, the parent becomes the point person. In the EdHCT approach we wish to relieve parents and families of undue burden that is not their responsibility, while also providing them with access, input and power. Ideally, the healthcare and/or education point person would work directly with the parent/family member and facilitate the coordination of family, education system and healthcare system.

Use of shared forms. The most time effective approach would involve the development of collaboratively used transition forms. Healthcare providers could provide healthcare information and goals for incorporation into the transition IEP. IEP goals could be sent to the healthcare team for implementation in the healthcare transition plan. A web portal or wiki might be developed to allow education professionals, healthcare providers, and the family to participate in the development a shared document.

Collaboratively developed transition activities. Jointly developed transition activities will allow each field to reinforce skills learned in the other, with the potential for improving outcomes. Collaborative transition activities would take into account the interrelationships of life skills, post-secondary and career goals and health. Schools could teach skills necessary for managing health within their curricula, perhaps using the Center for Disease Control's *National Health Education Standards* (2015) as a guide. Additionally, existing curricula could be revised to include health related activities (National Technical Assistance Center on Transition, 2016). For example, as part of life-skills instruction, students could reinforce organizational and self-management skills by planning how to balance treatments with other activities. Math activities could include calculating the number of days until a student next needs to order medication. Science and literacy could include learning about the physiology of specific health conditions and the ways that treatments work. Health, Speech and English classes could be used to develop verbal communication, self-advocacy and self-determination skills.

Healthcare providers could then reinforce and build on these skills by practically applying them to an individual teen's health condition. Healthcare providers could focus more broadly than they currently do on a youth's career and independent living goals, tying self-management to achieving these goals and assisting with resources to facilitate attainment of overarching personal objectives.

Family centered approaches. Patients and their families are at the center of transition planning. It is essential that services be designed with their input and for their

benefit. Families can help coordinate healthcare transition and education transition.

However, a collaborative system should be in place to support the family.

Model development and research. It will be important to develop and study various collaboration models. Models might focus on shared forms, electronic communication, real-time meetings, professional development and family involvement. Research should assess the viability of these models and their impact on youth outcomes. Federal and State Departments of Education and Health, as well as illness-specific foundations, should fund relevant research and set policy supporting the integration of the two forms of transition. It is important to develop a flexible model that can adapt to the needs of individual youth and family.

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