

SUCCESS THROUGH TRANSITION: A TRANSITION PLANNING CHECKLIST  
FOR DIABETES CARE TRANSITION

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**Title**

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CHECKLIST FOR DIABETES CARE TRANSITION

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**DOCTOR OF NURSING PRACTICE**

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## **ABSTRACT**

Adolescence is one the most challenging stages for a person with Type 1 diabetes. Despite the significant importance of tailoring healthcare services to adolescents' unique needs including their rapid psychosocial growth and development, high quality adolescent healthcare services are not universal in the United States. The current system of health services is ill suited for providing the proper mix of clinical and preventative services to youth. According to the Consensus Statement on Health Care Transition for Young Adults with Special Health Care Needs, "each year more than half a million children with disabilities and chronic illness transition from adolescence into adulthood".

In response to the need for transition care the National Diabetes Education Program transition-planning checklist was adapted and implemented for use with youth ages 16-22 years in a primary care clinical practice to provide a more structured process in healthcare transition planning for providers and patients.

The project took place at Sanford Health children's diabetes department in Fargo, North Dakota from July 2015 through December 2015. The checklist was used by healthcare providers to introduce the concept of transition and topics important to successful transition in the future. After implementation, use of the tool with qualified patients and evaluation of provider feedback about the checklist was used to improve utility of the evidence-based checklist in practice application for future use.

Across six months of implementation, 25% of all eligible youth with Type 1 diabetes seen were presented the transition-planning checklist. The providers agreed the transition-planning checklist incorporated good structure and content. All providers desired to continue to use the checklist in the future to provide transition-planning care to youth with Type 1 diabetes.

Providing holistic care for youth with Type 1 diabetes is important for successful transition to adult care services. Implementing a transition –planning checklist in the children’s diabetes department was found to be helpful and well received despite limited use (25% of eligible patients). Future efforts should be made to extend the project to be more inclusive of all areas needed for successful transition.

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## **CHAPTER ONE. INTRODUCTION**

The incidence of diabetes in the United States has risen at an alarming rate over the last ten years. Between 2001 and 2011, the rate of diagnosed diabetes increased 33% (from 1.2% to 1.6%) for people aged 0–44 years. The Diabetes in Youth study conducted by the Centers for Disease Control (CDC) and the National Institutes of Health (NIH) concluded 15,600 youth were newly diagnosed with Type 1 diabetes annually between 2002 and 2005 (Center for Disease Control and Prevention [CDC], 2012). In 2010, it was estimated 215,000 people under the age of 20 had Type I diabetes (CDC, 2012). The increased incidence of Type 1 diabetes in the United States has also led to an increased utilization of diabetes care services.

Individuals with diabetes can have an active, long life by maintaining control over blood glucose values. Controlling diabetes through self-management of the disease is a life-long process, and incorporates principles of health promotion as part of the recommendations for optimal care (Patino, Sanchez, Edison, & Delamater, 2005). Due to the improvement of the care of diabetes in the past 30 years, trends have shown a decrease in mortality of youth under 10 years old by 78% and 52% in youth ages 10 to 19 years (CDC, 2012). Failing to maintain tight control of blood glucose, however, can cause complications that shorten life and decrease quality of life, such as eye, nerve, and kidney damage (United States Department of Health and Human Services, Healthy People 2020 [Healthy People], 2011).

Multi-disciplinary health teams can contribute to an individual's empowerment for diabetes management. Diabetes is a chronic disease requiring good self-management to maintain near normal blood glucose control thus reducing the risk of long-term complications. A hemoglobin A1c (HbA1c) level is the main tool for monitoring glucose control (Down, 2013). HbA1c measures a three-month average of the glucose that adheres to hemoglobin cells creating

a percentage. Goals for HbA1c levels vary by age and additional risk factors in order to prevent hypoglycemia (blood glucose less than 70mg/dL). Recommendations from the American Diabetes Association (2012) for an individual with Type I diabetes include an HbA1c goal as near to normal (< 6%) as possible. The Diabetes Control and Complications Trial recommends a HbA1c of <7.3% (Eeg-Olofsson, Cederholm, Nilsson, Gudbjornsdottir, & Eliasson, 2007). Healthy People 2020 (2011) suggest a guideline of <7.0% as the baseline target for Objective D-5.2: Increase the proportion of the diabetic population with an HbA1c less than 7 % (See Table 1). In order to maintain the suggested goal HbA1c percentages, blood glucose levels must be maintained between 126 mg/dL and 154 mg/dL on average (ADA, 2012).

Blood glucose control is achieved through daily diabetes self-management, with 95% of diabetes management conducted by the person with diabetes (Guo, Whittmore, & He, 2011). Management consists of frequent daily blood glucose monitoring, measuring carbohydrate intake, and replacement of insulin through subcutaneous (under the skin) injections multiple times a day to sustain life. Blood glucose levels vary based on nutritional intake and medications, which are part of the self-management plan. Other factors affecting blood glucose levels include activity, illness, and stress due to the different hormone fluctuations related to these events (Down, 2013). Understanding how all of these factors change blood glucose patterns will enhance the person's ability to successfully control his/her diabetes and promote better long-term outcomes. Consistent guidelines for management of blood glucose assist a person with diabetes in setting attainable goals throughout the life cycle of diabetes care.

Adolescence is one the most challenging stages for a person with diabetes. Despite the significant importance of tailoring healthcare services to adolescents' unique needs including

their rapid psychosocial growth and development, high quality adolescent healthcare services are not universal in the United States (National Research Council [NRC], 2009).

### **Problem Statement**

Adolescence is a time of transition as youth develop patterns of behavior and relationships that are carried into adulthood thus affecting long-term outcomes, such as acute and chronic disease rates and life expectancy (NRC, 2009). Understanding the needs of youth is critical to providing proper care during adolescence. Addressing high-risk behaviors such as alcohol, drug, and tobacco use with youth can decrease or prevent poor outcomes in the future.

Although most youth are healthy, adolescence is an exceptionally turbulent time of development for youth with chronic health conditions. Youth are vulnerable as they move towards young adulthood; physical, social, and emotional changes all play a role in the ability of youth to deal with the chronicity of the disease (Rapley & Davidson, 2010). Balancing daily diabetes management responsibilities with school, work, and peer relationships can be difficult for youth. Youth need support from family, peers, and the healthcare community to promote successful outcomes. Providing appropriate care to youth with diabetes during and after transition to adult care is an increasing challenge for adult care services due to the unique changes during adolescence.

The current system of health services is ill suited for providing the proper mix of clinical and preventative services to youth (NRC, 2009). There is a lack of education for providers about adolescent needs during this time as well as few adolescent health family practice or specialty providers (NRC, 2009). In 2009, the National Research Council (NRC) and Institutes of Medicine (IOM) released a report identifying multiple gaps in care for adolescents in the United States. One barrier acknowledged in the NRC/IOM (2009) report recognized that current health

services “consist of separate programs and series that are often highly fragmented, poorly coordinated, and delivered in multiple public and private settings” (p. 7). Healthcare providers are poorly equipped to foster disease prevention and health promotion for youth without coordinated access to the proper services.

A disconnect between pediatric and adult care services also contributes to a difficult transition from pediatric to adult health care for youth and their families. Pediatric services have a predilection to care for the whole family or support system of each patient, whereas adult services are more patient-centered, putting the patient in charge of healthcare decisions (Rapley & Davidson, 2010). In order to support adolescents with diabetes through the care transition, research suggests the need for a softening of the adult services approach (Allen, Channon, Lowes, Atwell, & Lane, 2011). Adult health care services have been described by young adults as “threatening and depersonalized” in contrast to the “protective, warm” environment of pediatric care (Kirk, 2008, p. 570). Many patients describe feeling a loss when transferring to adult care since the patient has typically been with pediatric care services since diagnosis (Allen, et al., 2011). The loss was seen as a barrier to forming trust in the new adult care office. Youth moving through adolescence and into young adulthood may struggle not only with the responsibilities of adulthood and chronic medical management needs but also with the shift in the structure of health care services.

Poor transition preparation and follow through by pediatric and adult care services can lead to decreased quality of life and deterioration of diabetes control for youth. Although many current models of health services for youth exist, the evidence does not support one model over another (NRC, 2009). There are few transition programs for youth with chronic disease in the United States. Providing a structure for transition preparation will allow youth to understand the

necessary responsibilities for health promotion, disease prevention, and disease management moving into young adulthood. Discussion over time about transition care and needs of youth will allow youth and their families to ask questions and prepare mentally and emotionally for the transition in care.

### **Purpose of the Project**

The purpose of the project was to develop and implement a transition-planning checklist for use at Sanford Health children's diabetes department. The checklist was used by healthcare providers, including physicians and nurses, to introduce the concept of transition and topics important to successful transition in the future. The checklist was presented to youth, ages 16-22 years old, with Type 1 diabetes preparing to transition from pediatric to adult care services in the future, typically between ages 18 to 24. After implementation, evaluation of provider feedback about the checklist was used to improve utility of the evidence-based checklist in practice application for future use. This document uses the word "youth" to represent those ages 16-22 years of age.

### **Project Objectives**

The transition checklist project was driven by the following objectives:

Objective 1: To generate provider buy in to support transition care services for youth with diabetes at Sanford Health.

Objective 2: Design a transition-planning checklist to improve the preparation for transition from pediatric to adult health services among youth with Type 1 diabetes at Sanford Health diabetes center.

Objective 3: Implement the transition-planning checklist into practice at Sanford Health children's diabetes department and evaluate provider feedback regarding the efficacy and utility of the transition-planning checklist.



## **CHAPTER TWO. LITERATURE REVIEW**

### **Diabetes Pathophysiology**

Type 1 diabetes mellitus is a chronic disorder characterized by hyperglycemia (blood glucose greater than 150mg/dL) due to insulin deficiency caused by autoimmune destruction of pancreatic Beta-cells, which are responsible for all endogenous (from the body) insulin production (Inzucchi & Sherwin, 2012). Insulin is a hormone necessary for passage of glucose to the muscle and adipose connective tissue as an energy source (Copstead & Banasik, 2010). The lack of endogenous insulin for the regulation of glucose transport requires lifelong management. A healthy lifestyle including physical activity and dietary control, along with the above mentioned treatment modalities of checking blood glucose levels, calculating carbohydrate consumption, and administering insulin, is crucial in preventing long-term complications, such as eye, nerve, and kidney disease (Inzucchi & Sherwin, 2012). The diagnosis of Type 1 diabetes typically occurs between infancy and puberty although recent data from Inzucchi & Sherwin (2012) suggest 30% of those diagnosed with Type 1 diabetes were over the age of 20 years. Living healthy with Type 1 diabetes from childhood to adulthood and into the geriatric years is attainable with proper care and health promotion to avoid complications.

### **Diabetes Morbidity and Mortality**

According to Healthy People 2020 (HP 2020), diabetes mellitus is a condition responsible for significant morbidity and mortality in the United States (Healthy People, 2011). Complications of diabetes contribute to increased mortality; death rates from stroke and heart disease are two to four times higher in individuals who experience diabetes compared to non-diabetics (Norris et al., 2002). Additional morbidity complications include blindness, end stage

renal (kidney) disease, and nerve damage leading to amputation. Estimates of the annual cost of all diabetes related care to the United States healthcare system were \$306 billion in 2012 according to the American Diabetes Association (American Diabetes Association [ADA], 2013).

Effective diabetes self-management is essential in reaching the recommended goals of the HP 2020 initiative. HP 2020 suggests providers, patients, and communities should focus on the following diabetes related goals (Table 1), aiming for a 10 percent improvement over a 10-year period when the Healthy People 2020 goals are re-evaluated.

**Table 1. Healthy People 2020 diabetes related goals (2011).**

Goal	Description of goal
D-2	Reduce the death rate among persons with diabetes
D-3	Reduce the diabetes death rate
D-5	Improve glycemic control among persons with diabetes
D-5.2	Increase the proportion of the diabetic population with an A1c less than 7 %
D-7	Increase the proportion of persons with diagnosed diabetes whose blood pressure is under control
D-10	Increase the proportion of individuals with diabetes who have an annual dilated eye examination

Youth managing diabetes during the adolescent period are at increased risk of poor diabetes control, psychiatric problems, and diabetes complications (Weissberg-Benchell, Wolpert, & Anderson, 2007). Weissberg-Benchell et al. (2007) reported acute complications, namely hypoglycemia and diabetic ketoacidosis, were responsible for 68% of diabetes-related deaths in those 20-29 years old. Diabetic ketoacidosis is a serious complication of diabetes, occurring when there is a lack of insulin and the body produces high levels of blood acids called ketones, which can result in coma if left untreated. Identifying and addressing concerns for youth with diabetes may prevent such complications and death down the road. Providers are

frontline educators to assist with the meeting of these health goals and reducing the negative long-term effects of poorly controlled diabetes.

## **Adolescence**

For most youth, adolescence is a time of growth and development, not illness. When threats to health arise, they are often related to physical and social exploration and experimentation, developmental pressures, and increased risk-taking behavior, all of which are a normal part of adolescent development (Goldenring & Rosen, 2004). The changes during adolescence are marked with pubertal growth spurts and other hormonal inconsistencies (Allen, Channon, Lowes, Atwell, & Lane, 2011), leading to emotional fluctuations and physiologic body changes. Healthcare providers have a responsibility to provide age appropriate health promotion with youth during this time of rapid change in adolescence (NRC, 2009).

The American Academy of Pediatrics separates adolescent development into three stages: early, middle, and late adolescence (American Academy of Pediatrics [AAP], 2013). During each stage, physiological, cognitive, and social-emotional changes occur that help build the youth's identity and prepare he/she for becoming an adult. The first stage, early adolescence occurs from ages 11 to 13 years of age, and is full of many physical changes such as body hair and sexual organ growth as well as height and weight gain (AAP, 2013). Cognitively, early adolescents are beginning to use abstract thinking but rarely set their sights beyond the present, which explains their inability to consider the long-term consequences of their actions. Socially and emotionally, early adolescents struggle with their body and desire to be "normal" when compared to their peers. This stage is also burdened by moodiness and limit-testing (AAP, 2013).

Middle adolescence, youth ages 14-18 years, includes fewer physical changes occurring among girls although boys continue physical growth (AAP, 2013). During middle adolescence, puberty is complete and goal setting and moral reasoning begin to develop. Socially, middle adolescents continue to worry about being normal and become self-involved as they distance themselves from their parents and replace their support with peers.

Finally, as the late stage of adolescence approaches, between ages 19-21 years, growth for young women is complete while young men continue to gain height, weight, muscle mass, and body hair (AAP, 2013). Late adolescents begin to look to the future and think ideas through, with an ability to delay gratification as needed. This population is also more confident in themselves as well as more emotionally stable and capable of thinking of others, moving past the middle adolescent stage characterized by self-involvement (AAP, 2013).

Not all youth enter and exit the stages of adolescence at the same age or display these same behaviors. Throughout much of adolescence, a young person can be farther along in some areas of development than in others. Girls may appear older than their chronological age, which can complicate their ability to deal with changes in growth and development emotionally and socially (AAP, 2013). Furthermore, experimentation with substance use, sexual curiosities, and operation of motor vehicles puts youth at increased risk for accidental injury or hospitalization. A greater understanding of adolescent development within the healthcare system is suggested to improve the delivery of care to the adolescent population especially to those with chronic health conditions (Visentin, Koch, & Kralik, 2006).

### **Challenges for Youth with Diabetes**

Youth with Type 1 diabetes face even more challenges during adolescent development than their healthy counterparts. Psychological and physical changes occurring during puberty,

including the stress of school, work, and peer pressures, is compounded by daily diabetes management responsibilities. Hormonal changes contribute to glycemic (glucose) fluctuations making glucose control inconsistent and frustrating. Peer pressure and emotional immaturity may contribute to difficulty in obtaining optimal glycemic control during adolescence due to struggles to manage diabetes and finding their own identity as well as meeting peer expectations (Wilson, 2010). Insulin misuse for weight management may also contribute to disordered eating among youth with Type 1 diabetes, which adds to the complexities of managing diabetes in youth (Weissberg-Benchell et al., 2007).

Youth with Type 1 diabetes may not be capable of managing the complex and high maintenance requirements of a chronic disease along with the daily life demands of developing into a young adult. Coupled with the increased incidence of anxiety and depressive disorders in young people with diabetes, adolescence can be a period of increased dysfunction for the youth and family (Peters & Laffel, 2011). Diabetes itself does not automatically result in high risk of mental health concerns but feelings of distress at this stage are inevitable (Rapley & Davidson, 2010). Thus, adherence to self-care behaviors, glycemic control, screening for complications, and medical follow-up care are often not a priority for youth with Type 1 diabetes (Garvey, Markowitz, & Laffel, 2012). A decline in quality of life concerning participation in social events also plays a role in the struggle to manage diabetes in youth (Wilson, 2010). The additional monitoring and medication administration to manage Type 1 diabetes deters some youth from participating in sports, school events, and peer situations. The physical, emotional, and mental changes during adolescence need to be understood and addressed by the healthcare community to enhance youths' ability to manage a chronic disease during adolescence.

## **Delivery of Care**

Utilizing developed assessment tools, such as the HEEADSSS tool, to assess youths' psychosocial status can lead to the development of more adolescent friendly care (McDonagh & Gleeson, 2011). The tool is implemented exclusively between the youth and provider to learn about **H**ome environment, **E**ducation and employment, **E**ating, peer-related **A**ctivities, **D**rugs, **S**exuality, **S**uicide/depression, and **S**afety from injury and violence (HEEADSSS) (Goldenring & Rosen, 2004). Use of the HEEADSSS tool proceeds naturally from expected and less threatening questions to more personal and intrusive questions (Goldenring & Rosen, 2004). This gives the provider a chance to establish trust and rapport with the youth before asking the more difficult questions in the psychosocial interview. Taking the time to learn about the perspective of the youth and adequately addressing their comprehensive healthcare needs may require changes to healthcare provider education and the services offered to this unique population. The "principles of adolescent medicine are core to their health care" including transition preparation and care (McDonagh & Gleeson, 2011, p. 24). The use of assessment tools, such as the HEEADSSS tool, can assist healthcare providers in meeting the needs of all youth.

## **Transition Challenges**

According to the Consensus Statement on Health Care Transition for Young Adults with Special Health Care Needs (2002), "each year more than half a million children with disabilities and chronic illness transition from adolescence into adulthood" (Blum, Hirsch, Kastner, Quint, & Sandler, 2002, p. 1304). Based on the number of youth moving to adult care services each year, the need for successful transition programs in the United States is evident. Transition is defined as "purposeful, planned movement of adolescents and young adults with chronic physical and

medical conditions from child-centered to adult-oriented health care systems”(Blum, 2002, p. 1301). Yet transition from pediatric to adult health care providers often occurs very abruptly as the older teen enters the next developmental stage, referred to as emerging adulthood, which is a critical period for young people who have diabetes (Peters & Laffel, 2011; Weissberg-Benchell et al., 2007). During this period of major life transitions, emerging adults begin to move out of their parents’ home and must become more responsible for their diabetes care including the many aspects of self-management, making medical appointments, and at times financing health care. In 2012, the American Diabetes Association released a position statement regarding the standards of medical care for diabetes. The statement addresses multiple subgroups including children and adolescents, encouraging special attention to such issues as family dynamics, developmental stages, and physiological differences related to sexual maturity, when developing and implementing an optimal diabetes regimen (American Diabetes Association [ADA], 2012). This statement supports the specialized attention necessary to ensure youth with diabetes are able to transition to adult care services successfully, including adequate preparation.

Current literature also delineates the continued need for interdependent management of diabetes between the youth and parents/caregiver through adolescence into adulthood (Peters & Laffel, 2011; Allen et al., 2011). Research by Owen & Beskine (2008) reinforced that moving to complete self-care too soon was detrimental to the overall care of the patient. Gillibrand et al. (2006) also studied young adults (ages 16-25 years) with Type 1 diabetes and found a high level of family support was the strongest indicator of adherence to the diabetes management plan.

A study by Kime (2013) outlined other barriers to delivery of care for adolescents and young adults. Poor communication between youth, parents, and healthcare providers contributed to barriers to successful transition of care. Kime (2013) also found the healthcare providers

assumed the youth possessed adequate knowledge about care needs, i.e. diabetes knowledge, rather than addressing such topics directly. Additionally, awareness of the need for transition of care to adult services was assumed by the healthcare providers but not actually discussed with the youth and parent (Kime, 2013). Similarly, two large surveys (n=5,500 and n=4,000 respectively) by Lotstein et al. (2005) and Scal & Ireland (2005) reported only half of parents ever discussed the need to transition with the primary care or pediatric provider; of those only 30-42% actually discussed transfer of care to adult care services. This may be in light of the need to “hold on” to the pediatric patient. Kime (2013) identified the pediatric teams nurtured the pediatric patients and were reluctant to let them move on to the adult care services, thus, prohibiting the preparation for the transfer of care.

### **Need for Transition Services**

As discussed above, there are multiple barriers and challenges to transition care for youth in the current health system. An integral component to developing and providing adolescent friendly healthcare services involves the incorporation of guidelines tailored to the adolescent populations’ unique psychosocial needs (Goldenring & Rosen, 2004). Over the last decade, the complex needs of youth have provoked the healthcare community to identify how to bridge the gap for providing more comprehensive healthcare to this population. The American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Physicians suggest a need for the development of “best practices” for the management of adults with diseases of childhood, such as diabetes, cystic fibrosis, and congenital heart disease, due to these unique needs (Weissberg-Benchell et al., 2007).

The existence of models for transition are hard to find and non-functional in the current health systems. The Chronic Care Model has been studied for use in this process, which



encompasses a systematic approach to restructuring medical care to create partnerships between health systems and communities (Rapely & Davidson, 2010). The Chronic Care Model was the basis for the Chronic Conditions Model from the World Health Organization, which implements a holistic-approach to transition care, including collaboration between the healthcare organizations, the community, and the patient. Regrettably, the Chronic Care Model is based more on diagnosis and age rather than actual readiness and need for the transition (Rapely & Davidson, 2010).The unfortunate nature of most current models is they are not being made into policy and executed in practice.

A lack of implementation may be related to the general understanding of formal transition. Formal transition, or the transfer of care to adult care services, is merely the event when the young adult begins care with the adult care providers. McDonagh and Gleeson (2011) identify the actual transfer of care as a misconception when providers think of transition. Providers need to identify transition and transfer as separate concepts. Transition is a process and transfer is the event that occurs once the transition preparation is complete. The literature supports the involvement of both pediatric and adult providers in the first few visits after formal transition, finding combined care is best achieved through multidisciplinary clinics if available (Bowen, Henske, & Potter, 2010; Garvey, Markowitz, & Laffel, 2012; Haskins et al., 2012; Kime, 2013).

Another recommendation proved to be effective in diabetes transition care is case management (Task Force on Community Preventative Services [Task Force], 2001). Case management is the set of activities whereby the needs of a population of patients at risk for excessive resource utilization, poor outcomes of poor coordination of services are identified and addressed through improved planning, coordination, and provision of care (Task Force, 2001).

Within the services of case management includes the intervention of diabetes self-management education. Aligning the patient with a diabetes educator who is able to assess and instruct the patient on the necessary diabetes skills and topics will enhance the patient's ability to succeed during and after the transfer of care. In order to achieve adequate preparation for transition, tools such as checklists and transition information booklets should be included within case management resources. Utilizing tools from the National Diabetes Education Program (NDEP), which is a partnership of the National Institutes of Health, the Centers for Disease Control and Prevention, and more than 200 public and private organizations, ensures the most current information is available to health care providers and the youth. The NDEP offers transition-planning checklists (see Figure 1.), education slide sets, and online resources for youth and health care providers when working toward transition (<http://ndep.nih.gov/transitions/>). Direct effects of self-care behaviors that result from case management and diabetes education is improvement in short and long term goals (Norris, et al., 2002).



## National Diabetes Education Program

A program of the National Institutes of Health and the Centers for Disease Control and Prevention

# Pediatric to Adult Diabetes Care Transition Planning Checklist

This checklist helps the health care provider, young adult, and family discuss and plan the change from pediatric to adult health care. While a variety of events may affect the actual timing when this change occurs, below is a suggested timeline and topics for review. The young adult, family, and health care provider can obtain a copy of this checklist and access many online transition resources at the NDEP website ([www.YourDiabetesInfo.org/transitions](http://www.YourDiabetesInfo.org/transitions)).

- 1 to 2 years before anticipated transition to new adult care providers** [Date completed \_\_\_\_\_]
  - Introduce the idea that transition will occur in about 1 year
  - Encourage shared responsibility between the young adult and family for:
    - Making appointments
    - Refilling prescriptions
    - Calling health care providers with questions or problems
    - Making insurance claims
    - Carrying insurance card
    - Reviewing blood sugar results with provider between visits
  - Discuss with teen alone\*:
    - Sexual activity and safety
    - How smoking, drugs, and alcohol affect diabetes
    - How depression and anxiety affect diabetes and diabetes care
  
- 6 to 12 months before anticipated transition** [Date completed \_\_\_\_\_]
  - Discuss health insurance coverage and encourage family to review options
    - Assess current health insurance plan and new options, e.g. family plan, college plan, employer plan, and [healthcare.gov](http://healthcare.gov)
    - Consider making an appointment with a case manager or social worker
    - Discussion of career choices in relationship to insurance issues
  - Encourage family to gather health information to provide to the adult care team  
(See *Clinical Summary for New Health Care Team* at [www.YourDiabetesInfo.org/transitions](http://www.YourDiabetesInfo.org/transitions))
  - Review health status: diabetes control, retina (eye), kidney and nerve function, oral health, blood pressure, and lipids (cholesterol)
  - Discuss with teen alone\*:
    - Sexual activity and safety
    - Smoking status, alcohol, and other drug use
    - Issues of independence, emotional ups and downs, depression, and how to seek help

\* For more information on addressing psychosocial issues in adolescents, see the [HEEADSSS assessment](#).

(over)

Figure 1. National Diabetes Education Program checklist.

**NATIONAL DIABETES EDUCATION PROGRAM (NDEP)**  
**Pediatric to Adult Diabetes Care Transition Planning Checklist**  
*Continued*

- 3 to 6 months before anticipated transition** [Date completed \_\_\_\_\_]
  - Review the above topics
  - Suggest that the family find out the cost of current medication(s)
  - Provide information about differences between pediatric and adult health systems and what the young adult can expect at first visit
    - Patient's responsibilities
    - Other possible health care team members such as a registered dietitian or diabetes educator
    - Confidentiality/parental involvement (e.g., HIPAA Privacy Act and parents need permission from young adult to be in exam room, see test results, discuss findings with health care providers), health care proxy
  - Help identify next health care providers if possible or outline process
  - Discuss upcoming changes in living arrangements (e.g., dorms, roommates, and/or living alone)
  
- Last few visits** [Date completed \_\_\_\_\_]
  - Review and remind of above health insurance changes, responsibility for self-care, and link to online resources at [www.YourDiabetesInfo.org/transitions](http://www.YourDiabetesInfo.org/transitions)
  - Obtain signature(s) for release for transfer of personal medical information and for pediatric care providers to talk with the new adult health care providers
  - Identify new adult care physician
    - If known – request consult (if possible) and transfer records/acquire hard copy of most recent records
    - If unknown – ask teen to inform your office when known to transfer records and request consult
  - Review self-care issues and how to live a healthy lifestyle with diabetes
    - Medication schedules
    - Self-monitoring of blood glucose schedule
    - Importance of managing diabetes ABCs (A1C, blood pressure, cholesterol)
    - Meal planning, carb counting, etc.
    - Physical activity routine and its effects on blood glucose
    - Crisis prevention-management of hypoglycemia (low blood glucose), hyperglycemia (high blood glucose), and sick days
  - Need for wearing/carrying diabetes identification
  - Care of the feet
  - Oral/dental care
  - Need for vision and eye exams
  - Immunizations
  - Staying current with the latest diabetes care practice and technology
  - Preconception care (preparing for a safe pregnancy and healthy baby)
  - Discuss with teen alone\*:
    - Sexual activity and safety
    - Screening and prevention of cervical cancer and sexually transmitted infection
    - Risk taking behaviors, e.g. tobacco/alcohol/drug use
  - Consider ongoing visits with current diabetes educator as part of transition
  - Suggest options for a diabetes “refresher” course

**To learn more about living well with diabetes contact NDEP:**  
 1-888-693-NDEP (6337), TTY: 1-866-569-1162 or [www.YourDiabetesInfo.org](http://www.YourDiabetesInfo.org)



February 2014

**Figure 1. National Diabetes Education Program checklist (continued).**

The evaluation of the transition process after the transfer of care is complete is a phase many healthcare programs overlook. Research reveals evaluation of the efficacy of the transition is essential to reducing gaps in care and risks of complications by improving the process for transition (De Beaufort, et al., 2010). Evaluating transition programs post-transition can also provide feedback on current health status of program participants, as empiric evidence on post-transition outcomes is limited, particularly in the United States (Garvey et al., 2012).

A current review of the literature identifies gaps in care for youth during adolescence as well as youth with chronic disease. There is a need for change to the current health system when providing care for youth to improve outcomes and enhance behavior change in this population. Education for health care providers on adolescent development and ways to address health promotion may lead to improved care for this population.

### **Effective Transition of Care Models**

Although transition programs are not abundant in the United States, there are successful care models for transition discussed in the literature. Australia and Canada have had success with transition coordinators or patient navigation systems to improve transition care (Holmes-Walker, Llewellyn, & Farrell, 2007; Van Walleggem, MacDonald, & Dean, 2011). Transition coordinators are healthcare providers, mainly diabetes educators, who assist the patient in following the transition plan. The coordinators serve as a contact person for the youth as they make their way through the timeline on the plan. Even after the youth start the formal transfer to adult care, the coordinator is still there to assist in booking and re-booking missed appointments and serve as a resource until the patient is comfortable with the transition (Holmes-Walker, et al., 2007). The transition coordinator program was able to help maintain clinic appointment rates and reduce hospital admission rates and length of stay if admitted after entering the program.

The savings in reduced hospital admissions covered the cost of the program (Holmes-Walker, et al., 2007).

Another program, The Maestro Project, utilized a patient navigator system in Canada to improve rates of medical and education follow-up visits, consequently, reducing complications from diabetes (Van Wallegghem, et al., 2011). The navigator is not a healthcare provider, although the navigator helps the patient access services and resources, identify barriers, and provide emotional support. Patient navigator programs have been successful in the United States for cancer care since the late 1980's (Van Wallegghem, et al., 2011). The literature did not contain any existing information on patient navigator programs for diabetes in the United States.

There is little data from the United States in regards to transition programs. The Joslin Center in Boston published a study in August 2012 on transition characteristics and glycemic control. The results revealed less than 50% of respondents received an adult provider recommendation and less than 15% reported having a transition appointment or written instruction for transition. It was also found the pre-transition HbA1c, age, and education level was related to the post-transition HbA1c result (Beste, et al., 2012). There was no association between the level of transition preparation and post-transition HbA1c. The Joslin study (Beste, et al., 2012) is the first and largest cross-sectional study describing transition characteristics in Type 1 diabetes in the United States.

### **Theoretical Framework: Modeling and Role-Modeling**

Identifying and addressing healthcare issues in the adolescent population is of utmost importance, as the decisions made during this period have the potential to not only affect the population's immediate health status but also the population's long-term health status throughout adulthood (NRC, 2009). Applying the Modeling and Role-Modeling (MRM) theory can assist

providers/nurses in achieving the proper understanding of the youths' perspective in order to deliver appropriate care. The MRM theory is applicable to every age group and for the purposes of this section of the paper the word "client" will represent youth in adolescence.

Helen Erickson began formulating what is now known as the MRM theory in the mid-1970s after reflecting on her personal experiences, clinical practice, and influence from her father-in-law, well-known psychotherapist, Milton Erickson (Schultz, 2009). MRM is a client-centered nursing theory that places the client's perceptions at the center of the provider-client interaction. Although the practice improvement project was directed toward process development for providers, the use of the MRM theory emphasizes the importance of understanding the client's perception before making a plan of care with the client for better transition.

The concepts defined in the MRM theory are important in understanding the use of the theory in practice. The concepts can be categorized into those relating to the nurse and those relating to the client. Erickson defines nursing as "an interactive process that nurtures client strengths to enable development" (Schultz, 2009, p. 237). The goal in nursing is to achieve a state of perceived optimal health and contentment. Through facilitation, the nurse assists the client to identify, develop, and mobilize personal strengths (Schultz, 2009). Nurturance by the nurse occurs when the nurse "seeks to understand and support the client's model of the world and appreciate the value of the client's self-care knowledge" (Schultz, 2009, p. 237). The role of nurturance in the practice improvement project is of utmost importance as the clients move from childhood through adolescence and into adulthood. It is imperative to gain perspective and understanding of the psychologically complex phase of exploration the client is experiencing to better match the provider's approach toward each unique client (Weissberg-Benchell et al.,

2007). The provider/nurse must nurture the client to maintain rapport, understand how the client sees himself or herself in the world, and support the client through change.

The final concepts regarding the nurse in the MRM theory are modeling and role modeling. Modeling is the foundation of the theory and is defined as “the process the nurse uses to develop an image and understanding of the client’s world” (Schultz, 2009, p. 238). The nurse must suspend his or her own judgments during the modeling phase to avoid casting his/her own views on to the situation. After the nurse understands the client’s view of the world, role modeling can be facilitated. Role modeling is accomplished through assisting the client in “attaining, maintaining, or promoting health through purposeful interventions” (Schultz, 2009, p. 238).

There is a multitude of concepts within the MRM theory relating to the client. The key concepts relating to the transition-planning project are discussed here. Erickson outlined important generalized concepts about the client. People are unique but alike as they are holistic, experience growth, and have a need for affiliated-individuation (Schultz, 2009). The concept of people experiencing growth and development throughout life is a key concept in the transition-planning project. The physiologic changes youth experience have previously been discussed, now the psychological changes are discussed here. Erik Erickson defined eight critical stages of life based on psychosocial crisis. Erickson defines two major stages in relation to the biological maturation and social demands, which occur during the adolescent years (Erickson, 1997). Between the ages 6 and 12, youth are struggling with industry versus inferiority. Industry represents the desire to learn basic skills such as reading, writing, and math and becoming competent in such skills and striving for approval in the work completed. During industry versus inferiority, adolescents often compare themselves with their peers (Erickson, 1997). Success or



failure during this specific stage can significantly influence a variety of decisions made by early adolescents. If adolescents experience industry, they are more likely to develop reassuring academic and social skills, which can be helpful throughout adolescent development and adulthood (Erickson, 1997). However, if the adolescent is not able to develop the skills necessary to achieve industry, feelings of inferiority may result (Erickson, 1997).

The next life cycle described by Erickson is identity versus identity confusion (Erickson, 1997). During this life cycle, the client learns more about himself/herself and how and where he or she fit in the world. Identity confusion may lead to defiance between the client and parents or other support systems as the client struggles to be accepted as he/she is. Understanding the role of life development in the application of the MRM theory will help the provider maintain or adjust interventions chosen by the client for better health.

Affiliated-individuation is the concept identified in the MRM theory in where people need to be able to be dependent on support systems while maintaining independence from the support systems (Schultz, 2009). Encouraging and facilitating affiliation with health support systems throughout the lifespan provides a sense of security in making health related decisions. Individuation allows the client a sense of self apart from the support systems and the ability to make individualized decisions in regards to health.

The basis of the modeling and role-modeling theory is understanding the client's perception of his or her self and the world around him/her. Combining the concepts of the MRM theory as well as an understanding of Erickson's life cycle of psychosocial development provides a solid foundation in considering the needs during the development of a transition-planning checklist.

## **Conclusion**

Living with a chronic medical condition, such as Type 1 diabetes, is demanding and complicated at times. Managing chronic disease through the adolescent years is specifically challenging. Healthcare providers need to be conscientious of the needs of youth during adolescence to provide the best care possible. Understanding the needs of youth and the stages of physical and psychosocial development youth progress through helps healthcare providers meet the needs of youth, especially those youth with chronic conditions.

The review of literature regarding Type 1 diabetes and complications related to Type 1 diabetes, as well as adolescence and the transition-planning process moving to adult health services suggests the use of a structured transition process to improve outcomes for the patient with chronic disease (Peters & Laffel, 2011; Cadario et al., 2009). There are numerous successful methods used for transition care that are discussed in the literature including case management, patient navigator systems, and transition coordinators. Each of the methods involves a structured process that was implemented with healthcare providers and the youth. Utilizing concepts from the Modeling and Role-Modeling theory to learn more about perceptions of transition care and preparation of youth with diabetes as well the knowledge gained from the current literature supports the necessity for a transition-planning checklist development and implementation process at Sanford Health children's diabetes department.

## CHAPTER THREE. PROJECT DESIGN

### Project Implementation

The overall goal of the project was to develop and implement a transition-planning checklist to be utilized by healthcare providers with youth with Type 1 diabetes. The project was guided by current research, including statements from the American Diabetes Association, the American Academy of Pediatrics, and the Endocrine Society, stating a structured process for transition preparation is important to successful outcomes during and after the transfer of care to adult care services has occurred (Peters, & Laffel, 2011).

The first step in reaching the goal of this project was to generate provider buy in for transition care of youth with diabetes at Sanford Health. To identify possible key stakeholders for the project the investigator contacted Linda Bartholomay by electronic mail on November 29<sup>th</sup>, 2013, to solicit possible individuals interested in the topic of transition care as well as identify opportunities for meetings with the group. Mrs. Bartholomay was a contact point for the adult diabetes department staff, including nurses, dietitians, physicians, and advanced practice providers. Additionally, staff from the children's diabetes department were contacted by phone to solicit involvement in the project using established contacts of the project investigator. After initial contact with possible key stakeholders, a meeting for any interested stakeholders was held on March 25, 2014, at Sanford Health diabetes center in Fargo, ND. The attendees of the meeting included the investigator, Alan Kenien, MD, Niyutchai Chaithongdi, MD, Bill Newman, MD, Luis Casas, MD, Brenda Thurlow, MD, Jennifer Richtsmeier, RN, and Sarah Maack, RN. The attendees represented four adult and/or pediatric endocrinology providers, one pediatrician who also manages Type 1 diabetes patients, and two registered nurses with pediatric diabetes educator experience.

The investigator led the meeting and copies of the original NDEP checklist (see Figure 1) were distributed to the attendees. Time was allowed to review the document. After review, the project investigator gave a brief oral review of the current literature on transition preparation and care for youth, especially youth with Type 1 diabetes. A discussion about the literature findings led to a more in depth discussion in regards to the current process in place at Sanford Health for transition preparation. A set of pre-determined questions (Appendix A) were asked of the attendees to learn more about provider perspective on challenges and current barriers to transition care, feedback on the original NDEP checklist, and to elicit comments on preferences for the transition preparation process, for example, age to begin and best ways to communicate between pediatrics and adult diabetes services. The meeting concluded and a verbal agreement to provide additional information as needed to the investigator was given by all attendees. The information gained through the face-to-face meeting was compiled by the project investigator in writing to identify common themes later in order to move to the next step in the project.

The next step in the project was to design a transition-planning checklist to improve the preparation for transition from pediatric to adult health services among youth with Type 1 diabetes at Sanford Health diabetes center. The original NDEP transition-planning checklist was transferred into a modifiable word document (see appendix B). Permission for use of the NDEP checklist is found on the National Diabetes Education Program website (<http://ndep.nih.gov/transitions/>) and is copyright free. Permission to reproduce and distribute the original checklist to the youth during this project is also provided on the NDEP website. By introducing the providers to the NDEP checklist for transition planning and preparation and providing brief instruction on the use of the checklist in practice, each provider was familiarized

with current practice guidelines to benefit their patients for transfer of care to adult health services.

After reviewing the stakeholder comments and preferences in regards to the current transition-planning checklist, requested adaptations were made to the word document. The adaptations made included removing the pre-set timeline on the original checklist to allow for more flexibility in using the checklist for the pilot project as well as condensing the topics listed in order to simplify the checklist for provider use. On May 5, 2014, the lead investigator met with Brenda Thurlow, MD to review the changes for approval. The document was also sent to Sarah Maack, RN and Jennifer Richtsmeier, RN via electronic mail for review on May 5, 2014. Brenda Thurlow, Sarah Maack, and Jennifer Richtsmeier all gave approval for the changes made. In addition to the adapted transition-planning checklist the providers felt an informational booklet and one page introduction sheet on transition would be useful. The department chose to hand out a booklet titled “Moving Up and Moving Out”, created and distributed by Lilly Diabetes Care in collaboration with the American Diabetes Association (see appendix C). As requested a one page fact sheet (see appendix D) on transition was created with guidance from the NDEP transition website to be distributed by the health care provider to youth with Type 1 diabetes.

During the identification of stakeholders and collection of perspective on transition needs of youth with diabetes at Sanford Health, the lead investigator was directed to meet with Patrick Schultz, Clinical Nurse Specialist in quality management at Sanford Health. A meeting was held May 13, 2014 to discuss the practice improvement project. After reviewing the purpose and objectives of this practice improvement project P. Schultz suggested that quantitative data be collected by Sanford Health to identify how many patients were given the information during the

specified implementation period (July 2004 through December, 2014). He provided a contact, Mary Kara, in the quality improvement department who would ascertain if a report was possible. After meeting with Patrick, an inquiry on including the quantitative data was sent via electronic mail to Molly Secor-Turner, NDSU nursing department and project chair on May 16, 2014. The inclusion of the data was deemed helpful to the project and an addendum to the original IRB approval through NDSU was requested and approved on May 22, 2014 (see appendix E). The project investigator continued to work with Mary Kara to outline what was included on the report. On May 26, 2014, the final changes were made to the report request and a decision was made for the first report to run August 1, 2014 to include data from July 2 to July 31, 2014. Reports were subsequently generated each month to collect data reflecting the number of patients age 16-22 years with Type 1 diabetes seen each month by all healthcare providers at the children's diabetes department and of those seen, the number of patients with the problem corresponding with transition counseling between July and December, 2014.

The final step was to implement the transition-planning checklist into practice at Sanford Health children's diabetes department and evaluate provider feedback regarding the potential efficacy and utility of the transition-planning checklist. Following approval of the checklist, implementation commenced at Sanford Health. The stakeholders agreed to give the transition-planning checklist and related information (Appendix C and D) to youth, age 16 years and older with Type 1 diabetes during project timeframe. Identification of the appropriate patients was completed by the physicians and nurses in the Sanford Health children's diabetes department. If time allowed, the nurses would look ahead two to three days to see which patients had appointments and if they qualified to receive the transition information. If a patient was seen and

given the transition-planning checklist (Appendix B), Lilly booklet (Appendix C), and one-page transition information sheet (Appendix D) then documentation of this was completed.

The stakeholders requested that the checklist be documented in the electronic medical record (EMR) at Sanford Health. The project investigator used Sanford Health student access to review options for placing the word document into the EMR. The first step was to identify a way to signify the patient had been given transition information in the EMR. In order to accomplish this, a “problem” or diagnosis needed to be added to the patient’s problem list. There was an existing problem entitled “counseling for transition from peds to adult care provider” (442395) in the EMR at Sanford Health. The key stakeholders, Brenda Thurlow, MD, Sarah Maack, RN, and Jennifer Richtsmeier, RN, approved this problem selection for documentation in relation to the transition-planning checklist process. With the assistance of Jennifer Richtsmeier, RN, the project investigator was able to develop a dot phrase (.pedstransition) action. A dot phrase is a short cut in the EMR that directly places specific information into the EMR, in this case the pre-populated transition-planning checklist word document (Appendix B). The document could then be modified to note when the checklist was implemented, which provider gave the information, and any other pertinent information. Access to the dot phrase was shared with all staff involved in the implementation project. Continued adjustments to the implementation process were made with the final adjustments completed after feedback from the following stakeholders on June 4, 2014; Luis Casas, MD, Brenda Thurlow, MD, Jennifer Richtsmeier, RN, and Sarah Maack, RN. Due to difficulties meeting with all providers to provide education on the checklist and implementation process, the initial roll out of the project commenced on July 2, 2014, with the essential information provided face to face on an individual basis with each of the providers. The process for implementing the checklist and

accompanied documentation was entered into a word document (Appendix F) and shared in print and through electronic mail for reference upon initiation of the checklist implementation on July 2, 2014.

Lastly, the process of evaluating provider reaction regarding the potential efficacy and utility of the transition-planning checklist is discussed. Prior to completion of the transition-planning implementation project, six evaluation questions (Appendix A) were developed in collaboration with Molly Secor-Turner, chair of clinical dissertation committee at North Dakota State University, to be executed during project evaluation meetings. The questions were designed to identify the usefulness of the transition-planning checklist and the implementation process, challenges or barriers in the project, and recommendations for improvement of the project. On completion of the project implementation period, (December 31, 2014) dates were set to meet with the five providers involved, Alan Kenien, MD, Luis Casas, MD, Brenda Thurlow, MD, Jennifer Richtsmeier, RN, and Sarah Maack, RN, to evaluate the project including the transition-planning checklist. All meetings were conducted the week of January 5, 2015; four occurred at Sanford Health, Fargo, ND and the final meeting was held at a local restaurant. The investigator met with each provider individually for approximately 15-20 minutes to ask the six evaluation questions. The responses were recorded in writing on paper by the investigator and labeled only by date, time, and provider A, B, C, etc. Additional comments on the project were also noted on each printed copy of the evaluation questions. The responses to the evaluation questions were stored in a locked cabinet at the investigators home. All responses were compiled on a word document arranged by question asked and then grouped by theme. The findings of the practice improvement are discussed in chapter five.



## **Institutional Review Board Approval**

This project was declared exempt by the North Dakota State University institutional review board (IRB) as protocol PH14221 on March 18, 2014 (Appendix G). The diabetes transition planning checklist development project did not involve any patient contact or collection of personal identifying information by the project investigator at Sanford Health. There was little to no risk to the patients or providers during the development, implementation, or evaluation of this project. There was no involvement of patient interaction in the development of the transition-planning checklist with no concern of inclusion of women, children, or minorities. An informed consent document for the health care providers outlining the purpose, risks and benefits, as well as the voluntary nature of the project, was developed (Appendix H) and accompanied the IRB request. An addendum was submitted to the North Dakota State University IRB on May 16<sup>th</sup>, 2014 for additional inclusion of raw quantitative data, without personal identifying information, which was approved on May 22<sup>nd</sup>, 2014 (See appendix E).

## CHAPTER FOUR. EVALUATION

### Evaluation

The main goals of the project were to generate provider buy in and perspective on transition care for youth with Type 1 diabetes and implement a transition-planning checklist into practice at Sanford Health children’s diabetes department. To evaluate if the goals were met quantitative and qualitative data were collected. The investigator utilized a logic model to guide the evaluation of the project (see Table 2).

**Table 2. Transition-planning checklist logic model.**

Situation	Inputs	Activities	Outputs	Outcomes
Lack of structured process for preparing youth with Type 1 diabetes for transition to adult health care services at Sanford Health	Health care system  Key stakeholders  Youth with Type 1 diabetes  Physicians and Nurses  Evidence-based model (NDEP checklist)  Current research supporting better transition care for youth	Assess current needs at Sanford Health	41 patients given transition information	Knowledge
		Review current research on transition care		Gained perspective on transition needs at Sanford Health
		Identify key stakeholders	5 provider interviews completed	Actions
		Develop transition checklist		Increased use of evidence-based practice
		Develop process for implementation of checklist		Improved patient care
		Implement checklist		Condition
		Evaluate provider feedback of project		Improved coordination of services Improved diabetes outcomes for patients

Upon collection of the data, the investigator analyzed the qualitative responses by organizing the data into themes to reflect provider feedback and perspective. The quantitative data were combined across the months and to generate descriptive statistics.

## CHAPTER FIVE. RESULTS

### Presentation of Findings

The transition-planning checklist implementation project was implemented at Sanford Health children's diabetes department in Fargo, ND between July and December, 2014. The department serves approximately 250 patients with diabetes, including Type 1 and Type 2. The project was directed towards health care providers of patients between the ages of 16 and 22 years with Type 1 diabetes. The overall goal of the project was to develop and implement a transition-planning checklist in order to provide a more structured approach to evidence-based patient care.

### Use of Transition Checklist

Approximately 12-36% of all youth with Type 1 diabetes seen were presented the transition-planning checklist on any given month (mean = 25%). As noted in table 3, the initial rate of implementation was higher compared to lower rates later in the project.

**Table 3. Transition checklist utilization.**

Month	Number of patient visits	Number given checklist	Percent given checklist
July	22	8	36.40%
August	31	9	29.00%
September	34	11	32.40%
October	32	4	12.50%
November	19	4	21.10%
December	27	5	18.50%
<b>Total</b>	<b>165</b>	<b>41</b>	<b>24.90%</b>

### Provider Perspective Regarding Checklist Utilization

The purpose of the provider evaluation questions was to generate provider perspective about the potential efficacy and utility of the transition-planning checklist and implementation process (see Table 4).

**Table 4. Provider feedback regarding implementation of checklist.**

Question	Provider Responses
In what ways was the checklist helpful?	<ul style="list-style-type: none"> <li>-Good information</li> <li>-A good guide for a process that is large</li> <li>-Helps organize and narrow down what needs to be talked about with the patient</li> <li>-Checklist is actually very good, layout was good</li> <li>-Helped to guide you with visit with the patient and the timeline was helpful too</li> <li>-Reminds us of what we need to cover with the patient</li> <li>-It acts as a safeguard to make sure the patient is ready to move to adult care before we move them</li> <li>-Yes, it was good to make sure we weren't dropping the ball, gave us direction</li> </ul>
What barriers or challenges did you encounter in using the checklist?	<ul style="list-style-type: none"> <li>-Do not have a lot of patients with diabetes in the age range</li> <li>-“I am used to keeping my peds patients until they are older so I don't always talk about all these things.”</li> <li>-Every patient is at a different place (readiness level) for the information</li> <li>-Currently no way to follow up and know who needs to be seen again or what needs to be discussed at next appointment</li> <li>-Getting the MD to be more involved in getting the information out there and follow through with additional information at future visits</li> <li>-Need more communication between MD's and nursing to be successful</li> <li>-No major challenges really, maybe knowing where the patient is in the process</li> <li>-Time constraints-teenagers are complicated and sometimes you run out of time in the visit to talk about things like the transition checklist/topics</li> </ul>
How has the checklist changed your practice?	<ul style="list-style-type: none"> <li>-Really has not at this point-would use more when have more patients</li> <li>-Yes, the checklist gives us a way to start the discussion for the transition information, which we did not have before</li> <li>-It has made me more aware of the need to talk with the patient and parents about getting ready to transition</li> <li>-I already discuss the topics with the patient so putting the checklist into my practice was hard to remember at times. I would talk to them but forget to note that in the EMR.</li> <li>-Helped me start the conversation sooner than I used to in my practice, which was needed</li> </ul>
Do you have any recommendations for improving or changing the checklist?	<ul style="list-style-type: none"> <li>-Checklist includes most of what is necessary</li> <li>-Good to give the checklist and booklet to the patient</li> <li>-The checklist was good, all the information is included that needs to be covered</li> </ul>

**Table 4. Provider feedback regarding implementation of checklist (continued).**

<p>Do you have any recommendations for improving or changing how it is used in practice?</p>	<ul style="list-style-type: none"> <li>-A readiness evaluation would be helpful to know when to starting talking about the topics to prepare for transition</li> <li>-Build information into progress note, may help us remember to implement the information</li> <li>-Need a better way to identify who needs the information</li> <li>-Entering the code and information into EMR was good</li> <li>-Need to revise implementation process</li> <li>-Would be good to have a trigger in the EMR to help us remember to continue to work on the checklist topics with the patient, part of a smart set/best practices or something</li> <li>-Need to further the process with coordinating the actual move to the adult service and work with adult educator to do this</li> <li>-Make sure last few educator visits are happening (more structured expectations) to make sure the final steps are covered before the patient moves to adult services</li> <li>-It would be good to sit down as a department and go through the patients that are in the transition ages to see if they have started the preparation, if so what they need to continue to work on and if they are getting close to making the move to adult care services. Talking even every 6 months would be good.</li> </ul>
<p>How well received was the transition information when presented to the patients?</p>	<ul style="list-style-type: none"> <li>-Depends on what topic is being discussed</li> <li>-“Sometimes they (patients) are interested and sometimes they are clueless.”</li> <li>-Good- “I saw a lot of lightbulbs go off”</li> <li>-Patients seemed to like the idea of being able to do things more on own</li> <li>-Good-brought up things that patient and parents had not thought about yet</li> <li>-Patients and parents appreciated the information</li> <li>-Well received by patient and family, sometime parents are even more relieved that some of these topics are brought up by an MD or RN</li> <li>-Most patients were open to the discussion, some were disinterested</li> <li>-Parents were happy to have the information presented, seemed to open the door for them to talk with the patients at home</li> </ul>
<p>Do you plan to continue to use the checklist?</p>	<ul style="list-style-type: none"> <li>-Would like to continue to use this (checklist) more in the future</li> <li>-I think we should, as well as put the information into the charting system to make it more user friendly</li> <li>-I hope we do “I think it (checklist) is good for the patients.”</li> <li>-The whole concept of preparing to transition is a great idea. We need to keep working on this in the department</li> <li>-Yes, I would like to but we need to actively work towards putting this into our department expectations to make it last</li> </ul>

Overall, the providers agreed the transition-planning checklist incorporated good structure and content. There were no suggestions for additions or changes to the checklist upon

evaluation. All providers desired to continue to use the checklist in the future to provide transition-planning care to youth with Type 1 diabetes.

The providers perceived the process for implementation as ‘good’. The feedback on the implementation process for the project identified the need for a better way to identify which patients should be receiving the transition information along with the possibility of utilizing a readiness evaluation prior to providing the information. All providers acknowledged the process could be extended beyond what was delineated in the project.

Obstacles to implementing the checklist included time constraints during patient care thus preventing education on the transition checklist topics. Providers also found differences in patient readiness, finding not every patient at age 16 is ready or willing to consider transition planning. However, most providers identified the information was well received when shared with youth and families.

## **CHAPTER SIX. DISCUSSION AND RECOMMENDATIONS**

### **Interpretation of Results**

The use of the transition-planning checklist in practice varied between all providers involved. Physicians as well as RN diabetes educators in the children's diabetes department provided the information to the youth. Based on the quantitative data results, barriers to implementing the checklist process were a factor in the project. All providers supported the concept of the transition-planning checklist; they also agreed the process for implementation needed improvements and expansion to better serve the youth in providing evidence-based care, including a better system to identify patients needing the information as well as implementing collaboration with adult care services to ensure transition was successful. The practice improvement project demonstrated implementation of a new intervention for transition planning is not only helpful to providers but for the youth as well.

Current literature suggests there are many possible methods of providing transition-planning care but implementation is the most difficult part of a successful program (Peters & Laffel, 2011; Visentin, Koch, & Kralik, 2006). This practice improvement project experienced similar challenges. The tools and process for transition planning were provided and successfully administered to approximately 25% of eligible patients demonstrating room for improvement for this project. Although the provider buy in for a transition care planning project was supportive, the modest implementation rates suggest transition care may not be a top priority for providers at Sanford Health children's diabetes department. Of the three physicians participating in the project, one cared for pediatric and adult patients, which may have altered the perspective of the need for transition care planning since most patients will only move to a different office versus a different provider. Additionally, another physician had a long-standing history of retaining his



patients well past the pediatric age (24 years) so changing practice for this provider may have been especially difficult. Overall efforts towards improving implementation rates of the checklist are of utmost importance to enhance evidence-based care for youth with Type 1 diabetes at Sanford Health.

### **Limitations**

The project involved multiple limitations involving location, provider preferences, and general time constraints. The project was conducted at a single site in one health care system with only five providers over six months. The quantitative data has no identifying information and ideally youth with Type 1 diabetes are seen every three months so there is a possibility the final number of patients seen and number given the information may include duplicate entries from various months in the 6-month trial period. Due to the small sample size the information gained through this project is not generalizable and further efforts in multiple departments with additional providers would offer a wider knowledge base for generalization.

There are differences in provider preference and perspective on transition care at Sanford Health, which may have altered the implementation rate and evaluation of the transition-planning checklist. Possible reasons the information was not given include, time restraints with patients, provider preference, and lack of time to recognize which patients were able to receive the information. One significant part of this project is the role of the RN diabetes educators. The educators facilitated the implementation of the project and in many instances assisted the physicians in relaying the transition-planning checklist to the patients after the physician visits were complete. The project may have been more successful if the nurses and physicians made equal efforts to implement the project.

## **Recommendations**

It is recommended that the transition-planning checklist and implementation process continue to be utilized at Sanford Health children's diabetes department to provide evidence-based care to youth with Type 1 diabetes. The project should be refined to include the following steps. First, create a better process for the identification of the youth who should be receiving the information. Utilize the EMR to create a reminder which occurs at age 16 to introduce the transition planning information. The entire checklist can be presented at this time along with accompanying documents (appendix B and C). The information should be presented at the annual education visit at or after age 16. The physician should reinforce and encourage the transition information before and after presentation. Changing the process for patient identification will be more standardized and less laborious for staff in the children's diabetes department, thus, potentially improving the implementation rate of the transition information.

Along with standardizing the identification method, an additional recommendation to separate the checklist topics into sections is suggested. Breaking the information into sections will allow for better tracking of what information has been presented to each patient. The section presented can be documented in the EMR so all providers are aware of the information that has been given and what additional information needs to be covered as the patient progresses towards transition. A brief summary of what information will be in each section is shown in Table 5. The provider should refer to the complete NDEP checklist (Figure 1) for more in depth description of each topic area.

**Table 5. Transition content by section.**

Section	Content
Section 1 (age 16 years)	<ul style="list-style-type: none"> <li>-Introduce the idea that transition will occur in about 1 year</li> <li>-Encourage shared responsibility between the young adult and family</li> <li>-Discuss alcohol, tobacco, sexual activity, anxiety/depression with teen alone</li> </ul>
Section 2 (by age 18)	<ul style="list-style-type: none"> <li>-Discuss health insurance coverage and encourage family to review options</li> <li>-Encourage family to gather health information to provide to the adult care team</li> <li>-Review health status: diabetes control, retina (eye), kidney and nerve function, oral health, blood pressure, and lipids (cholesterol)</li> <li>-Review alcohol, tobacco, sexual activity, anxiety/depression with teen alone</li> </ul>
Section 3- (3-6 months before transition)	<ul style="list-style-type: none"> <li>-Review the previous topics</li> <li>-Suggest that the patient/family find out the cost of current medication(s)</li> <li>-Provide information about differences between pediatric and adult health systems and what the young adult can expect at first visit</li> <li>-Help identify next health care providers if possible or outline process</li> <li>-Discuss upcoming changes in living arrangements</li> </ul>
Section 4 (last few visits before transition)	<ul style="list-style-type: none"> <li>-Review and remind of above health insurance changes, responsibility for self-care, and link to online resources</li> <li>-Obtain signature(s) for release for transfer of personal medical information and for pediatric care providers to talk with the new adult health care providers</li> <li>-Identify new adult care physician, educator, and dietitian</li> <li>-Review self-care issues and how to live a healthy lifestyle with diabetes</li> <li>-Consider ongoing visits with current diabetes educator as part of transition</li> <li>-Suggest options for a diabetes “refresher” course</li> </ul>

Additionally, the providers may choose to assign a “homework” task for the patient and family to complete before the next visit in order to achieve a comfort level with that task. An example of a task may be calling to make the next appointment or calling to refill his/her prescriptions. The patient will achieve skill building through completion of the tasks as well as ownership in managing diabetes.

The next recommendation is continuing to receive the monthly reports to monitor for use of the transition-checklist. The reports should be altered to break numbers down by provider so

the department can see who may need additional support to deliver the information. Lastly, create set times of communication within the children's diabetes department to discuss the transition for all patients in the process of preparing to transition. Department meetings every three to six months to discuss transition matters would allow for adjustments to the process and ongoing care of those patients who are already in the process of transition planning. The recommendation is to not only continue the project but also expand the goals of the project to enhance the utility of the process and promote collaboration within the children's diabetes department. It is recommended that all staff in the children's diabetes department be involved in continuing the project and future expansion efforts but the nursing staff spearheads the coordination of the project.

This practice improvement project is in congruence with the vision of Sanford Health, of "Improving the human condition through exceptional care, innovation, and discovery." Using innovation to continue a structured transition process utilizing the transition-planning checklist provides exceptional, streamlined care for adolescents moving to adult care services.

The transition-planning checklist would be applicable to other health care systems as well. The information provided on the checklist is appropriate for all providers who care for those with Type 1 diabetes to discuss at or around age 16 years. Although some providers may not be as comfortable with managing Type 1 diabetes, they can still provide holistic care by reinforcing the topics on the checklist. Over time, that information will help the youth and families prepare for adult health care services. The process used in the project would need to be adapted to meet the needs of the health care facility and department depending on the resources available.

## **Implications for Practice**

The overall significance of the transition-planning checklist and implementation process contributed to further knowledge of the challenges in meeting the needs of youth during transition preparation. The outcomes of the project improved the provider's awareness of youth and transition and can be translated for use in additional health care settings. Another important finding is the challenges met when attempting to implement a new process into practice. Obtaining feedback from the providers about the project implementation provided guidance for future projects and processes in transition care. By making adaptations to the checklist and implementation process, there will be improved workflow and aid in increased use of the checklist thereby promoting implementation of evidence based-practice. The information gained through the project will enhance the health care provider's knowledge, which can be shared and utilized throughout the health care system.

Dissemination of the project findings will influence the current knowledge of adolescent care, especially in regards to transition care needs. The findings will be presented through power point presentation to the staff at Sanford Health children's diabetes department, with possible dissemination at the Sanford Health adult diabetes center and spring meeting of the Red River Diabetes Educator Group, which is comprised of nurses, dietitians, and advanced practice providers from North Dakota and west central Minnesota who manage diabetes in practice. Additionally, the project findings will be displayed at a poster presentation at North Dakota State University in spring of 2015 and possibly the fall 2015 North Dakota Nurse Practitioner Association conference.

## **Implications for Future Research**

The information gained through the practice improvement project should be piloted in other health care systems and settings. Although the information in the transition-planning checklist is specific to diabetes, the checklist could be tailored to meet the needs of the general adolescent population and adolescents with other chronic disease states, such as cystic fibrosis, asthma, and congenital heart conditions. Refining of the implementation process with expansion of the services offered after the initial introduction of the transition-planning checklist would be advisable. The literature supports a structured program to include not only initiation of information but follow-up visits and evaluation upon completion of the transition to adult care services. The scale of the transition process was large with multiple avenues to cover. Additional work towards a more complete process would be useful in practice.

## **Application to DNP Role**

The transition-planning practice improvement project provides advanced knowledge of the successes and challenges of implementing a new process into practice. The nurse practitioner (NP) with the Doctor of Nursing Practice (DNP) level education serves as a leader in assisting with the implementation of new evidence-based practice processes. Nurse practitioners work in many different health care areas, from primary care to specialty services, encountering adolescents in many of these areas. The DNP prepared NP is capable of assessing the current knowledge level of the youth and family and if appropriate, implementing the transition-planning checklist. The NP provides a great opportunity for collaboration between services as an advocate for the youth and their families. DNP prepared NPs have a history of providing holistic care to all patients, and the application of the transition-planning project facilitated and led by NP's is an ideal use of the skills, knowledge, and attitudes of the DNP prepared NP.

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## **APPENDIX A. PROVIDER EVALUATION QUESTIONS**

1. In what ways was the checklist helpful?
2. What barriers or challenges did you encounter in using the checklist?
3. How has the checklist changed your practice?
4. Do you have any recommendations for improving/changing the checklist or how it is used in practice?
5. How well received was the transition information when presented to the patients?
6. Do you plan to continue to use the checklist?

## APPENDIX B. TRANSITION TOPIC CHECKLIST

Target transfer of care date \_\_\_\_\_

Introduce the idea that transition will occur in about 1 year (give handout) \_\_\_\_\_

Encourage shared responsibility between the young adult and family \_\_\_\_\_

Review how smoking, drugs, and alcohol affect diabetes (handouts Krames) \_\_\_\_\_

Discuss health insurance issues and encourage family to review options \_\_\_\_\_

Review health status: \_\_\_\_\_ (give handouts)

-Diabetes control, retina (eye), kidney and nerve function, teeth and mouth, lipids (cholesterol), blood pressure, smoking status (handouts in Krames)

Discuss issues of independence, emotional ups and downs, depression, and how to seek help \_\_\_\_\_

Review the above topics if necessary \_\_\_\_\_

Suggest that the family find out the cost of current medication(s) \_\_\_\_\_

Provide information about differences between pediatric and adult health systems and what the young adult can expect at first visit \_\_\_\_\_

- Patient's responsibilities, Confidentiality/parental involvement (e.g., HIPAA Privacy Act)

**Last few visits** (See educator every 6 months prior to transfer of care)

Help identify next health care providers if possible or outline process \_\_\_\_\_

Discuss upcoming changes in living arrangements (e.g., dorms, roommates) \_\_\_\_\_

Encourage family to gather health information to provide to the adult care team \_\_\_\_\_

Review and remind of above health insurance changes, responsibility for self-care, and link to NDEP's list of resources \_\_\_\_\_

Obtain signature(s) for release for transfer of personal medical information and for pediatric care providers to talk with the new adult health care providers \_\_\_\_\_

Identify new adult care physician \_\_\_\_\_ (local or not)

Review self-care issues and how to live a healthy lifestyle with diabetes \_\_\_\_\_

**Final pediatric diabetes educator and provider visit \_\_\_\_\_**

-set up dietitian visit \_\_\_\_\_ -set up adult CDE visit \_\_\_\_\_ -set up Adult provider visit \_\_\_\_\_

1 month after adult appointments-set reminder to call patient to check in \_\_\_\_\_

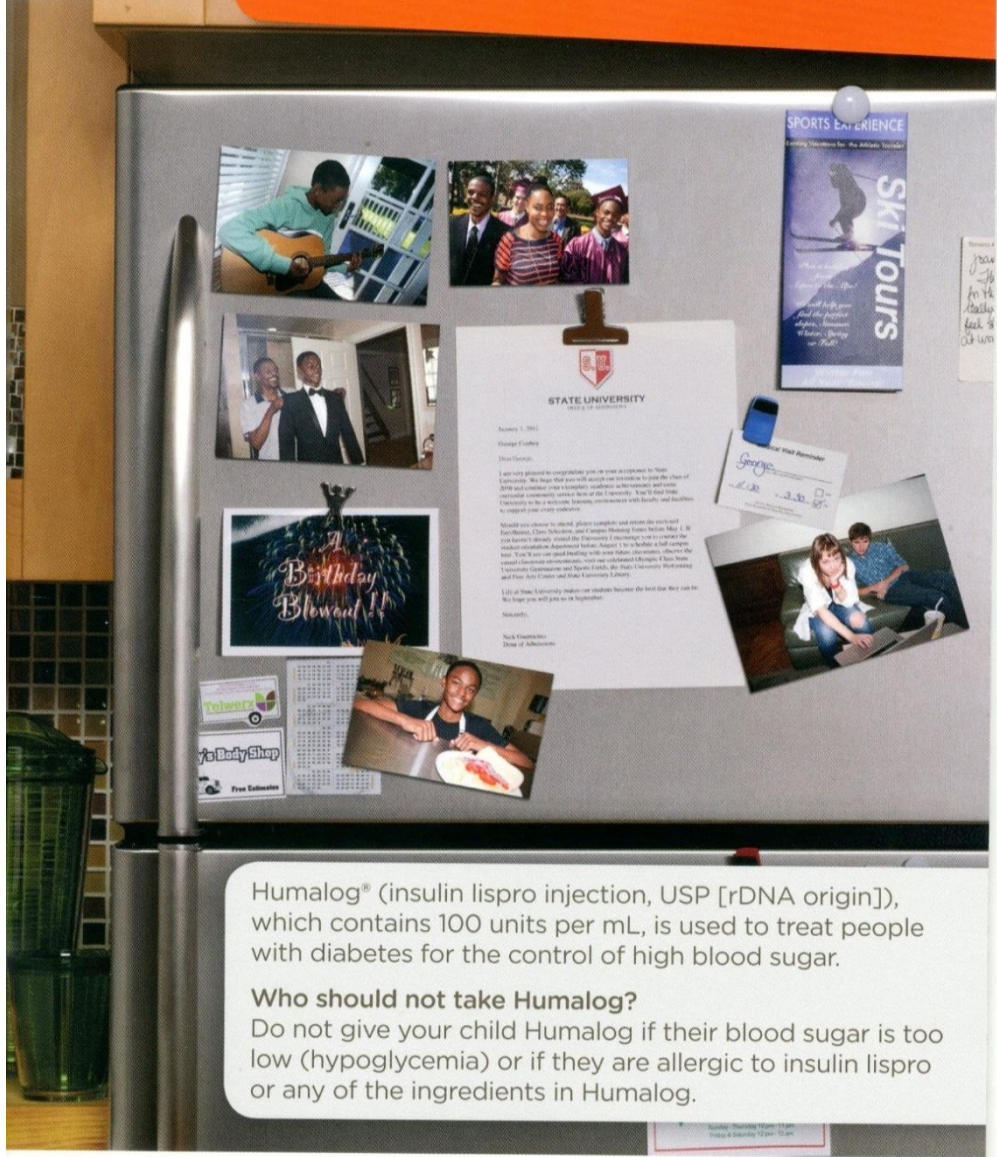
# APPENDIX C. PATIENT EDUCATIONAL BOOKLET

EVERYDAY LIFE  
2

humalogtype1.com/teen

## Moving Up and Moving Out

Real Responsibility: Driving, Traveling Independently, and Living Away from Home with Type 1 Diabetes



Humalog® (insulin lispro injection, USP [rDNA origin]), which contains 100 units per mL, is used to treat people with diabetes for the control of high blood sugar.

**Who should not take Humalog?**  
Do not give your child Humalog if their blood sugar is too low (hypoglycemia) or if they are allergic to insulin lispro or any of the ingredients in Humalog.

Please see Important Safety Information on pages 34-35 and accompanying Full Prescribing Information, including Patient Information.





## **APPENDIX D. TRANSITION INFORMATION SHEET**

### **What is transition? Something you need to care about.**

Transition of care is a period of time when you move from pediatric-based care into the adult based healthcare system. During this time, you are preparing to not only move to a new diabetes healthcare team but also to take over more responsibility for your healthcare.

### **How do you prepare for transition? Plan ahead to make the move.**

Things you and your caregivers can do to prepare for the transition of care include:

- Talk about your current healthcare responsibilities and how comfortable you are with taking care of yourself
- Share your concerns about moving to a new healthcare team with caregivers and your current provider
- Start making appointments, calling your pharmacy for refills, and learning about insurance coverage
- Work on preparing for transition over time

### **When should you transition? Everyone is unique.**

- There is not right or wrong time to move to your new team
- Some prefer to move before they leave high school and others wait until they are in their early twenties

It is best to set a target date for transition with your healthcare team.

# APPENDIX E. INSTITUTIONAL REVIEW BOARD ADDENDUM



## INSTITUTIONAL REVIEW BOARD

office: Research 1, 1735 NDSU Research Park Drive, Fargo, ND 58102  
mail: NDSU Dept. #4000, PO Box 6050, Fargo, ND 58108-6050  
p: 701.231.8995 f: 701.231.8098 e: [ndsuirb@ndsu.edu](mailto:ndsuirb@ndsu.edu) w: [www.ndsu.edu/irb](http://www.ndsu.edu/irb)

RECEIVED  
MAY 22 2014

IRB Protocol #:  
PH 14221

### Protocol Amendment Request Form

Changes to approved research may not be initiated without prior IRB review and approval, except where necessary to eliminate apparent immediate hazards to participants. Reference: [SOP 7.5 Protocol Amendments](#).

Examples of changes requiring IRB review include, but are not limited to changes in: investigators or research team members, purpose/scope of research, recruitment procedures, compensation strategy, participant population, research setting, interventions involving participants, data collection procedures, or surveys, measures or other data forms.

#### Protocol Information:


Protocol #: PH14221 Title: "Success through transition: A transition planning checklist for diabetes care transition"

Review category:  Exempt  Expedited  Full board

Principal investigator: Molly Secor-Turner Email address: [molly.secor-turner@ndsu.edu](mailto:molly.secor-turner@ndsu.edu)  
Dept: Nursing

Co-investigator: Vanessa Skolness Email address: [vanessa.skolness@my.ndsu.edu](mailto:vanessa.skolness@my.ndsu.edu)  
Dept: Nursing

Principal investigator signature, Date: Molly Secor-Turner (email) 5/20/14

 In lieu of a written signature, submission via the Principal Investigator's NDSU email constitutes an acceptable electronic signature.

#### Description of proposed changes:

1. Date of proposed implementation of change(s)\*: **6-15-2014**  
\* Cannot be implemented prior to IRB approval unless the IRB Chair has determined that the change is necessary to eliminate apparent immediate hazards to participants.
2. Describe proposed change(s), including justification:  
We would like to collect deidentified data about the number of patients between the ages 15-22 years seen at the project site for diabetes during the project implementation period (June through December 2014) and how many of those patients were given the transition planning checklist. This information will not include any personal identifying information and is already routinely collected as the patients are registered in the electronic medical record. The data requested will be extracted

from the Sanford electronic medical record by Sanford personnel and given to the researchers in terms of total number of patients seen and total number of patients that received the transition checklist. Again, no identifying information will be collected or received. The use of this data would allow us to evaluate how often the checklist was given out in relation to the number of patients seen and may give us insight on the successes and obstacles in this project.

3. Will the change involve a change in principal or co- investigator?

No - skip to Question 4

Yes:

- *Include an Investigator's Assurance (last page of protocol form), signed by the new PI or co-investigator*
- *Conflict of Interest disclosure. Does any investigator responsible for the design, conduct or reporting of the project (including their immediate family members) have a financial, personal or political interest that may conflict with their responsibility for protecting human participants in NDSU research? (SOP 6.2 Conflict of Interest in Human Research, Investigator and Research Team)*

No - As PI, I attest that I have conferred with my co-investigators and key personnel and confirmed that no financial, personal or political interests currently exist related to this research.

Yes - Describe the related financial, personal or political interests, and **attach documentation of COI disclosure and review (as applicable).**

Financial, personal or political interests related to the research (the sponsor, product or service being tested, or a competing product or service) may include:

- compensation (e.g., salary, payment for services, consulting fees)
- intellectual property rights or equity interests
- board memberships or executive positions
- enrollment or recruitment bonus payments

(Refer to NDSU Policy 151.1, *External Activities and Conflicts of Interest*, and NDSU Policy 823, *Financial Disclosure - Sponsored Projects* for specific disclosure requirements.)

*Note: If the change is limited to addition/change in research team members, skip the rest of this form.*

4. Will the change(s) increase any risks, or present new risks (*physical, economic, psychological, or sociological*) to participants?

No

Yes: *In the appropriate section of the protocol form, describe new or altered risks and how they will be minimized.*

5. Does the proposed change involve the addition of a vulnerable group of participants?

Children:  no  yes - include the *Children in Research* attachment form

Prisoners:  no  yes - include the *Prisoners in Research* attachment form

Cognitively impaired individuals:  no  yes\*

Economically or educationally disadvantaged individuals:  no  yes\*

*\*Provide additional information where applicable in the revised protocol form.*

6. Does the proposed change involve a request to waive some or all the elements of informed consent or

documentation of consent?

no

yes -  Attach the *Informed Consent Waiver or Alteration Request*.

7. Does the proposed change involve a new research site?

no

yes




**If information in your previously approved protocol has changed, or additional information is being added, incorporate the changes into relevant section(s) of the protocol. Highlight (e.g. print and highlight the hard copy, or indicate changes using all caps, asterisks, etc) the changed section(s) and attach a copy of the revised protocol to this form. (If the changes are limited to addition/change in research team members, a revised protocol form is not needed.)**

**Impact for Participants (future, current, or prior):**

1. Will the change(s) alter information on previously approved versions of the recruitment materials, informed consent, or other documents, or require new documents?

No

Yes -  attach revised/new document(s)

2. Could the change(s) affect the willingness of *currently* enrolled participants to continue in the research?

No

Yes - describe procedures that will be used to inform current participants, and re-consent, if necessary:

3. Will the change(s) have any impact to *previously* enrolled participants?

No

Yes - describe impact, and any procedures that will be taken to protect the rights and welfare of participants:

-----FOR IRB OFFICE USE ONLY-----

Request is:  Approved  Not Approved

Review:  Exempt, category #: \_\_\_\_\_  Expedited method, category # \_\_\_\_\_  Convened meeting, date: \_\_\_\_\_  
 Expedited review of minor change

IRB Signature: *Kirsty Shuley*

Date: *5/22/14*

**Comments:**

NDSU is not engaged in human subjects research since Sanford will de-identify records prior to our involvement.

## **APPENDIX F. PROCESS FOR CHECKLIST IMPLEMENTATION**

For patients 16 years and older: provide transition handout and briefly discuss transition care

1. Add problem 442395 (counseling for transition from peds to adult care provider) to problem list
2. In text box of problem 442395 enter dot phrase (.pedstransition )
3. Within the pre-populated text, date and initial any topics that were covered in visit
4. Notify endocrine staff of patient's entry into the transition process for tracking
5. Monthly reports with number of patients seen and number of visits with transition care documentation will be sent to Vanessa Skolness

# APPENDIX G. INSTITUTIONAL REVIEW BOARD APPROVAL



March 18, 2014

FederalWide Assurance FWA00002439

Dr. Molly Secor-Turner  
Nursing  
Sudro Hall

**Re: IRB Certification of Exempt Human Subjects Research:  
Protocol #PH14221 , "Success through transition: A transition planning checklist for diabetes care transition"**

Co-investigator(s) and research team: **Vanessa Skolness**

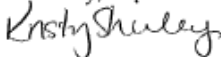
Certification Date: 3/18/14                      Expiration Date: 3/17/17  
Study site(s): **Sanford Health Broadway Clinic, Fargo, ND**  
Funding: **n/a**

The above referenced human subjects research project has been certified as exempt (category # 2) in accordance with federal regulations (Code of Federal Regulations, Title 45, Part 46, *Protection of Human Subjects*). This determination is based on protocol materials (received 3/17/14).

Please also note the following:

- If you wish to continue the research after the expiration, submit a request for recertification several weeks prior to the expiration.
- Conduct the study as described in the approved protocol. If you wish to make changes, obtain approval from the IRB prior to initiating, unless the changes are necessary to eliminate an immediate hazard to subjects.
- Notify the IRB promptly of any adverse events, complaints, or unanticipated problems involving risks to subjects or others related to this project.
- Report any significant new findings that may affect the risks and benefits to the participants and the IRB.
- Research records may be subject to a random or directed audit at any time to verify compliance with IRB standard operating procedures.

Thank you for your cooperation with NDSU IRB procedures. Best wishes for a successful study.

Sincerely,  


Kristy Shirley, CIP, Research Compliance Administrator

**INSTITUTIONAL REVIEW BOARD**  
NDSU Dept 4000 | PO Box 6050 | Fargo ND 58108-6050 | 701.231.8995 | Fax 701.231.8098 | ndsu.edu/irb  
Shipping address: Research 1, 1735 NDSU Research Park Drive, Fargo, ND 58102

NDSU is an EO/AA university.

## APPENDIX H. PROJECT CONSENT

**NDSU**      **North Dakota State University**

Department of Nursing

Campus Address

NDSU Dept. 2670

PO Box 6050

Fargo, ND 58108-6050

701.231.5692

### **Title of Practice Improvement Project: Success through transition: A transition planning checklist for diabetes care transition**

To Whom It May Concern:

My name is Vanessa Skolness. I am a graduate student in Nursing at North Dakota State University, and I am conducting a practice improvement project to adapt and implement a transition-planning checklist for youth transitioning to adult health care services. It is our hope, that with this project, we will learn more about utilizing a structured planning checklist for care transitions.

Because you are a provider of diabetes care, you are invited to take part in this project. Your participation is entirely your choice, and you may change your mind or quit participating at any time, with no penalty to you.

It is not possible to identify all potential risks in research procedures, but we have taken reasonable safeguards to minimize any known risks. These known risks include: loss of confidentiality, and emotional or psychological distress.

By taking part in this project, you may benefit by learning more about youth transition planning barrier and facilitators. However, you may not get any benefit from being in this study. Benefits to others are likely to include advancement of knowledge, and /or possible benefits to persons in the prospective subject's position.

The checklist implementation will take place over a six-month timeframe with face-to-face interviews necessary for evaluation of the checklist after the implementation period is complete. You will not receive any compensation for taking part in this project.

We will keep private all project records that identify you. Your information will be combined with information from other people taking part in the project, we will write about the combined information that we have gathered. You will not be identified in these written materials. We may



publish the results of the project; however, we will keep your name and other identifying information private.

If you have any questions about this project, please contact me at 701-866-6485 or [vanessa.skolness@my.ndsu.edu](mailto:vanessa.skolness@my.ndsu.edu), or contact my advisor Molly Secor-Turner at [molly.secor-turner@ndsu.edu](mailto:molly.secor-turner@ndsu.edu).

You have rights as a project participant. If you have questions about your rights or complaints about this project, you may talk to the researcher or contact the NDSU Human Research Protection Program at 701.231.8908, toll-free at 1-855-800-6717, by email at [ndsu.irb@ndsu.edu](mailto:ndsu.irb@ndsu.edu), or by mail at: NDSU HRPP Office, NDSU Dept. 4000, P.O. Box 6050, Fargo, ND 58108-6050.

Thank you for your taking part in this project. This document serves as informed consent and no signature will be required to take part in this project.

## **APPENDIX I. EXECUTIVE SUMMARY**

### **Background**

The individual with diabetes can have an active, long life by maintaining control over blood glucose values. Controlling diabetes through self-management of the disease is a life-long process and incorporates principles of health promotion as part of the recommendations for optimal care (Patino, Sanchez, Edison, & Delamater, 2005). Failing to maintain tight control of blood glucose, however, can cause complications that shorten life and decrease quality of life, such as eye, nerve, and kidney damage (United States Department of Health and Human Services, Healthy People 2020 [Healthy People], 2011). Adolescence is one the most challenging stages for a person with diabetes. Despite the significant importance of tailoring healthcare services to adolescents' unique needs, including their rapid psychosocial growth and development, high quality adolescent healthcare services are not universal in the United States (National Research Council [NRC], 2009). The current system of health services is ill suited for providing the proper mix of clinical and preventative services to youth (NRC, 2009). According to the Consensus Statement on Health Care Transition for Young Adults with Special Health Care Needs (2002), "each year more than half a million children with disabilities and chronic illness transition from adolescence into adulthood" (Blum, Hirsch, Kastner, Quint, & Sandler, 2002, p. 1304). Based on the number of youth moving to adult care services each year, the need for successful transition programs in the United States is obvious.

### **Project Summary**

In response to the current literature on adolescent care and transition-planning needs, the project to develop and implement a transition-planning checklist for use in a pediatric diabetes clinic was designed . The checklist was used by healthcare providers, including physicians and

nurses, to introduce the concept of transition and topics important to transition in order to provide enhanced, individualized care and optimize patient outcomes. The checklist was presented to youth, ages 16-22 years old, with Type 1 diabetes in preparation to transition from pediatric to adult care services in the future. After implementation, evaluation of provider feedback, through face-to-face interviews, about the checklist was used to improve utility of the evidence-based checklist in practice application for future use.

## **Results**

The main goals of the project were to generate provider buy in and perspective on transition care for youth with Type 1 diabetes and implement a transition-planning checklist into practice at Sanford Health children's diabetes department. To evaluate if the goals were met quantitative and qualitative data were collected. The quantitative data generated by the Sanford Health quality improvement department reflects that approximately 12-36% of all youth with Type 1 diabetes seen were presented the transition-planning checklist on any given month.

Overall, from interviews the providers agreed the transition-planning checklist incorporated good structure and content. There were no suggestions for additions or changes to the checklist upon evaluation. All providers desired to continue to use the checklist in the future to provide transition-planning care to youth with Type 1 diabetes. The providers felt the process for implementation was 'good'. The feedback on the implementation process for the project identified the need for a better way to identify which patients should be receiving the transition information along with the possibility of utilizing a readiness evaluation prior to providing the information.

Obstacles to implementing the checklist included time limitations during patient care thus preventing adequate education on the transition checklist topics. Providers also found

differences in patient readiness, finding not every patient at age 16 are ready or willing to consider transition planning. Although, most providers identified that the information was well received when shared with youth and families.

## **Recommendations**

It is recommended that the transition-planning checklist and implementation process continue to be utilized at Sanford Health children's diabetes department to provide evidence-based care to youth with Type 1 diabetes. The project should be refined to include the following steps. First, create a better process for the identification of the youth who should be receiving the information by utilizing the EMR to create a reminder which occurs at age 16 to introduce the transition planning information. The information should be presented at the annual education visit at or after age 16. In addition to standardizing the identification method, an additional recommendation to separate the checklist topics into sections is suggested. Breaking the information into sections will allow for better tracking of what information has been presented to each patient.

Secondly, the providers should continue to receive monthly reports to monitor the frequency of use of the transition-checklist. Lastly, create set times of communication within the children's diabetes department to discuss the transition for all patients in the process of preparing to transition. The recommendation is to not only continue the project but also expand the goals of the project to enhance the utility of the process and promote collaboration within the children's diabetes department. It is recommended that all staff in the children's diabetes department be involved in continuing the project and future expansion efforts with nursing staff to spearhead the coordination of adaptations to the project.

## **Conclusion**

Providing holistic care to youth is imperative in order to meet the changing physical and psychosocial needs during adolescence. Youth with chronic medical conditions have even more complex issues including the need for transition planning to move to adult care services towards the end of adolescence. Implementing a transition–planning checklist in the children’s diabetes department was found to be helpful and well received, although only applied approximately 25% of the time. Further efforts to continue and improve the use and implementation of a transition-planning process are recommended.