Improving Transition Care: A Transition Toolkit Implementation Project

Julianne Cox  
*Brigham Young University*, julie.rigby.2@gmail.com

Bret Lyman  
*Brigham Young University*, bret-lyman@byu.edu

Matt Anderson  
*Brigham Young University*, matthew.anderson@byu.edu

Marie Prothero  
*Brigham Young University*, mprothero@comcast.net

Follow this and additional works at: [https://scholarsarchive.byu.edu/studentpub](https://scholarsarchive.byu.edu/studentpub)

**BYU ScholarsArchive Citation**
Cox, Julianne; Lyman, Bret; Anderson, Matt; and Prothero, Marie, "Improving Transition Care: A Transition Toolkit Implementation Project" (2022). *Student Works*. 340.  
[https://scholarsarchive.byu.edu/studentpub/340](https://scholarsarchive.byu.edu/studentpub/340)

This Master's Project is brought to you for free and open access by BYU ScholarsArchive. It has been accepted for inclusion in Student Works by an authorized administrator of BYU ScholarsArchive. For more information, please contact ellen_amatangelo@byu.edu.
Improving Transition Care: A Transition Toolkit Implementation Project

Julianne Cox

A project submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of
Master of Science

Bret Lyman, Chair
Matt Anderson
Marie Prothero

College of Nursing
Brigham Young University

Copyright © 2022 Julianne Cox
All Rights Reserved
ABSTRACT

Improving Transition Care: A Transition Toolkit Implementation Project

Julieanne Cox
College of Nursing, BYU
Master of Science

The purpose of this project was to develop an easy-to-use transition toolkit for clinics serving children and young adults with chronic illnesses who are transitioning from a pediatric model of care to an adult model of care. GotTransition’s six core elements served as a guiding framework for the toolkit. The toolkit was developed through an iterative process with substantial stakeholder input. Stakeholders included patient, parents, clinicians, and transition care experts. Project evaluation data were gathered from clinic stakeholders using a quantitative post-then survey based on GotTransition’s six core elements of transition care, as well as three open-ended questions. All six clinics that implemented the transition toolkit during the project timeframe participated in the evaluation. Paired sample T-tests and effect sizes were used to detect differences in the participating clinics’ implementation of GotTransition’s six core elements of care transition before and after adopting the toolkit. A large effect sizes (<0.8) were identified for all items evaluated. Qualitative responses revealed several themes pertaining to the benefits of and barriers to implementing the toolkit into a clinic’s transition care. Based on our findings, the transition toolkit was an effective approach to implementing transition care in the participating clinics.

Keywords: pediatric to adult transition care, chronic disease, toolkit, transfer of care, adolescents, youth and young adults
ACKNOWLEDGEMENTS

A special thank you to all the clinics and partners we worked with, your help was invaluable.
TABLE OF CONTENTS

Title Page ......................................................................................................................................... i

Abstract ........................................................................................................................................... ii

Acknowledgements ........................................................................................................................ iii

List of Tables .................................................................................................................................... vi

Improving Transition Care: A Transition Toolkit Implementation Project............................... 1

   Background ....................................................................................................................................... 2

      Primary Care Provider Role ........................................................................................................ 3

      Transition Care is Complex ......................................................................................................... 3

      Importance of Toolkits .............................................................................................................. 5

   Toolkits and Got Transition .......................................................................................................... 6

   Project Purpose ............................................................................................................................. 7

   Project Context and History ......................................................................................................... 7

Methods ............................................................................................................................................. 9

   Objectives .................................................................................................................................... 9

   Setting & Sample .......................................................................................................................... 10

   Research Background ............................................................................................................... 10

   Development ............................................................................................................................... 11

   Implementation ............................................................................................................................. 14

   Evaluation .................................................................................................................................... 15
LIST OF TABLES

Table 1 6 Core Elements Descriptions ................................................................. 35

Table 2 Organization Descriptions ..................................................................... 36

Table 3 Quantitative Results .............................................................................. 37
Improving Transition Care: A Transition Toolkit Implementation Project

People with chronic disease have better quality of life when they have the knowledge and skills to effectively manage their condition and navigate the healthcare system. For many, the preparation for thriving with chronic illness begins when they are young. While young, children receive care from a pediatric healthcare team, and their parents or other adults help them with daily and long-term management of their condition. As they grow up, children often become more independent and take more responsibility for their own care. Eventually they transition from receiving care in a pediatric care setting to an adult care setting. During this time, they receive a special kind of care called “transition care”, which is switching from a pediatric to adult care model with or without transferring to another doctor (White et al., 2018). The goal of transition care is to help young patients learn to become more independent and responsible for their own healthcare (Got Transition, 2020). Transition care helps prepare youth by choosing a good fit for a primary care physician, specialty providers, help sending medical records, and communication to adult providers about individual needs. In transition care, these children learn to develop self-advocacy, self-care, and decision making skills (Jensen et al., 2017).

Primary Care Providers (PCPs) play an integral role in ensuring appropriate transition to adult care and effective long-term management of their condition. Therefore, it is essential that PCPs have relevant, reliable information at hand to work with and further educate themselves and their patients on transition care. Toolkits are a resource filled with educational information that providers and other healthcare professionals can use to guide their practice. Although there are toolkits PCPs can use to support effective transition care, many are often too time consuming to use because of irrelevant information (Hempel et al., 2019). Therefore, for this project, a
generalized provider toolkit was created so PCPs can provide better transition care for children with chronic diseases.

**Background**

Due to advances in medical care and knowledge throughout the years, more children with chronic disease are living longer. For example, about 15% of children with CHD in the 1950s lived to adulthood while more than 90% of children with CHD now survive well into adulthood (Brida & Gatzoulis, 2019). The age of transfer into adulthood is often dependent on the provider. Got transition recommends anywhere from 18-23 years old (Got Transition, 2021). Overall, about 15-20% of the adolescent population ages 12-17 live with a chronic condition (Marani et al., 2020), including physical, developmental, behavioral, or emotional conditions (Lemke et al., 2018). Some of the most common childhood conditions include asthma, obesity, diabetes, congenital heart disease, attention-deficit disorder, and other behavioral disorders (CDC, 2021). Many of these children survive into adulthood, and 90% of them will require continuous healthcare management when transferring into adult care (Marani et al., 2020).

Due to high risk for complications during their adult life, transitional care is crucial for these children (Hosson et al., 2019). A successful transition is characterized by continuity of healthcare from one clinician to the next and patient education about managing their care. Effective transitional care for children is associated with, 1) better adherence to care (Bhawra et al., 2016; Lemke et al., 2018), 2) improved perceived health status, quality of life, and self-care skills (White et al., 2018), and 3) better health care quality, fewer medical complications, improved healthcare outcomes, increased satisfaction and independence, and lower healthcare costs (Lemke et al., 2018). Ineffective transition care is associated with 1) increased confusion about their disease and how to manage it, dissatisfaction with their care, foregone care,
preventable hospitalizations, and less adherence to care (Lemke et al., 2018), 2) more complications from chronic diseases, increase in noncompliant behaviors, higher costs in care for the patients and their families (White et al., 2018), and 3) greater number of patients who do not follow up/that are lost in follow up care (Coyne et al., 2017).

As has been demonstrated, there are substantial benefits of effective transitions and adverse costs from ineffective transitions. Despite this, of the 90% of children with chronic diseases that require continuous healthcare into adulthood (Marani et al., 2020), only 41% of them report receiving any transition care or guidance from their healthcare team (Lemke et al., 2018). Furthermore only 16.2% reported that they had received quality transition care (Marani et al., 2020).

**Primary Care Provider Role**

Primary Care Providers (PCP) see a wide array of patients, and can see patients throughout their whole lifetime. This includes those children with chronic diseases that require transition care. A PCP’s role for children with chronic diseases is to track, monitor, manage, coordinate with families and refer to appropriate specialties for treatment. For example, when caring for a child with diabetes, the primary care provider’s responsibilities are to monitor glucose and other lab work, assess, educate, and coordinate with the endocrinologist and dietician, educators, and social work. Additional expectations include transition from pediatric endocrinology care to adult endocrinology care.

**Transition Care is Complex**

Providing effective transition care for pediatric patients with chronic conditions can be particularly complex for several different reasons (Green Corkins et al., 2019). First, chronic conditions influence every aspect of the child’s life, and numerous people are often involved in
addressing the child’s medical, educational, social, and developmental needs. As a result, transition care requires broad oversight from the PCP, as well as communicating and collaborating with specialists involved (Hart et al., 2019). Second, children are also transitioning from adolescence to adulthood, so they are experiencing pressure to become more autonomous while simultaneously experiencing complex developmental changes that can include risk-taking, challenging rules, and defying authority (Green Corkins et al., 2019). Adolescents may not fully comprehend the importance of follow up care and the potential negative outcomes of not managing their chronic condition closely. Third, parents and/or caregivers are very involved in the child’s care, so the PCP must address their educational needs and help them navigate their changing role. Fourth, every child’s situation is different. Healthcare providers must take into consideration the education level, self-management skills, emotional support, and legal rights of the patient and parent, especially when the patient is not developmentally appropriate to make their own decisions in adult care (Green Corkins et al., 2018).

Although health care providers play a vital role in ensuring their clinics provide high-quality transition care, many voice concern about not having appropriate resources and knowing which transition care model to follow (Coney et al., 2019). Although education related to healthcare transitions has been shown effective (Hart, 2013), transition care is not widely taught in medical programs (Hart et al., 2019). In fact, one third of medical residency pediatric programs have not provided education about transition care (Castillo, 2017). The need for additional support and resources also manifests in clinical practice. In fact, Maddux & Ricks et al. (2015) found 60% of providers claim to prepare pediatric patients for adult care, yet much of that transition care is inadequate (e.g. simply offering a list of adult providers to choose from and transferring medical records to the new physician taking over). In summary, many clinicians can
benefit from additional support and resources to incorporate effective transition care into their clinical practice.

While there are many approaches to transition care and a variety of resources available to providers, it is hard for clinicians to decipher which one to choose for their clinic because there is not a set standard of care for transition (Marani et al., 2019), there is little evidence to guide clinicians in transition work (Bhawra, 2016), and there is not enough time for clinicians to research transition best practices (Hart et al., 2019). The process of selecting their clinic’s approach to transition care and finding appropriate resources can be even more difficult for specialists. As a result, providers tend to choose transition care resources that contain specialized information pertinent to their specific practice but fail to address general transition care needs. This may include health assessments that focus on the patient holistically compared to questions directed toward specific disease (Marani et al., 2019). As a result, providers need an organized resource that is complete yet concise to guide their transition care (White et al., 2018).

**Importance of Toolkits**

Toolkits are a key asset in transition care. Toolkits are a compiled list of resources to help providers and clinics organize their care for patients and families. They contain a collection of information, interventions, and materials to incorporate into practice, including links to community resources, lists of subspecialists in the area, and availability of pediatric consultation support for children with special health care needs (White et al., 2018). They help clinics plan care, organize care, manage care, and coordinate staff, patients, and families. Toolkits contain assessments and surveys that help identify deficits in education from both health care professionals and patients and aid in the plan of care. A good transition toolkit provides clinicians with the information, resources, and guidance they need to efficiently and effectively
transition children to adult care. Because PCPs and other specialists may see many different children with multiple chronic diseases each day, the most practical toolkit would contain a set of general, foundational resources essential for any child’s transition to adult care.

**Toolkits and Got Transition**

To address provider’s resource needs, Got Transition created a generalized toolkit to guide transition care. Got Transition is a federally funded program operated by The National Alliance to Advance Adolescent Health, a national nonprofit organization dedicated to advancing adolescent health care delivery (NationalAlliance.org, 2021). Got Transition’s goal is to provide educational materials for providers, patients, families, and other health care professionals so that children with chronic diseases transition to adult care safely and effectively (Got Transition, 2021). The Got Transition program is structured around The Six Core Elements of Health Care Transition. These core elements are a structured process that can be customized to any clinic/practice for transition care (White et al, 2018). The six core elements are: 1) Policy/guide, 2) Tracking and Monitoring, 3) Readiness, 4) Planning, 5) Transfer of Care, and 6) Transition Completion (Got Transition, 2021).

The Got Transition toolkit has been found effective for helping clinicians improve their transition care process and achieve better patient outcomes. For example, McManus et al. (2015) studied the incorporation of Got Transition into a Medicaid managed care plan. Using a transition process helped decrease use of emergency room visits and educate young adults with these chronic conditions of navigating their way and using health care services. Jones et al. (2019) similarly found implementing the Got Transition toolkit significantly improved patients’ readiness for care transition in each of 55 sites participating in the study.
Though effective, the Got Transition toolkit can be too time consuming for providers to use, suggesting the need to create a shorter, simpler, introductory guide for implementing Got Transition’s six core elements.

**Project Purpose**

In order to deliver quality transition care, clinics serving children and young adults with chronic illnesses need a shortened, simplified, introductory guide that includes the six core elements from Got Transition. These clinics play an important role in transition care, yet they do not always have the resources necessary to guide their work. Therefore, the purpose of this project was to provide such clinics an easy-to-use toolkit that addresses the 6 core elements recommended by Got Transition to help their patients transition from a pediatric model of care to an adult model of care.

**Project Context and History**

In 2016, Primary Children’s Hospital, the Utah Department of Health, and the Utah Parent Center formed a coalition to improve transition care for children with chronic illnesses. Each of these organizations has a different role, but all share a common interest in improving health for children in the state, and the population. As a result, they often pool their respective expertise, resources, and programs to serve the health needs of children in the state. So, when Primary Children’s Hospital identified an opportunity to improve and expand upon their long-standing transition care program for children with diabetes, the three organizations formed a small committee to collaboratively improve transition care and make it available for children with other chronic illnesses.

To help understand how each organization is involved in transition care, information about each is presented in Table 2.
The committee first identified the issues in transition care in their area. As the committee studied the issues, they saw these children were not appropriately prepared to transition into adult care and providers did not have the correct resources available for transition care. For example, some physicians and offices who were caring for children with chronic diseases did not have a set goal of an appropriate time to transition a child to adult care. Other physicians struggled having sources of referrals to adult clinicians capable of taking over the care of these children. They also struggled finding educational materials that could be used to teach children about transferring to an adult provider. Most clinics caring for children with chronic diseases lacked the use of a structured transition program with resources that applied to their community.

The committee decided a toolkit, based on Got Transition’s six core elements, would be useful and effective for local clinics in the need of transition care. The Teen to Adult Transition Clinical Project Leader had attended a conference session presented by co-director of Got Transition, reviewed at Got Transition’s website along with the transition care toolkit. However, the GT toolkit was extensive, not applicable to the State of Utah, and did not include references and resources that providers need in transition care. The Project Leader met with the executive clinical director of transition care at Intermountain Healthcare and presented the idea of modifying GT’s toolkit by condensing and personalizing it to meet the needs of the providers and patients in the state. The idea of the toolkit was then presented to the Utah Health Department and Utah Parent center, who were supportive of collaborating to create a transition toolkit, piloting the toolkit with a select group of clinics, and then expanding use of the toolkit to other primary care, general pediatric, and rural clinics throughout the state.

The committee then began to identify resources to include in their toolkit. During meetings, they discussed what specific information, educational material, and referrals to
resources for the toolkit that they thought providers could use in clinics that would benefit
transition care. Each organization brought their own ideas of what information and resources
they thought to be helpful for providers from what they have seen through their own experience
of what needs they have seen in transition care. They chose gottransition.org as a resource
because it is a major common resource to all of these corporations for transition care that they
are familiar with and have been working with for years. They have each used Got Transition’s
(GT) documents for their own corporation and found them helpful from their experience. We
decided to take the majority of our information for our toolkit and structure them around the six
core elements in Got Transition. Part of the reason we decided to make a more condensed
introductory toolkit for providers and care managers is so they do not feel overwhelmed and
deterred from programs like Got Transition and can get the basics of the six core elements of
transition care information before dismissing it.

I reached out to the transition committee in charge of creating the toolkit to see if I could
help them with any transition work. They wanted to implement a toolkit for transition care but
had not yet started on it. My job was to help research and find resources, create documents, meet
with clinics, and receive feedback from providers and others working with transition care to see
what would be the most helpful documents to include in the toolkit. I will also be evaluating the
toolkit to see if it was supportive to the clinic’s transition care program.

Methods

Objectives

The primary purpose of this project was to develop and implement a toolkit, based on the
six core elements, to help guide clinics in providing better transition care. Therefore, the
objectives for this project were to help clinic sites:
1. Have a transition policy in place
2. Establish a way to monitor children in transition care and their progress.
3. Have a place to document assessment needs for transition care
4. Have resources to help outline a plan for transition
5. Use a written plan of care for patient transfer to an adult provider
6. Develop a plan to follow up on children transferred to adult care

Setting & Sample

A total of six clinics implemented the toolkit during the timeframe of this project. Four of the clinics were pediatric specialty clinics, one was a general pediatric clinic, and one was a state run resource center. Some of these specialty clinics were associated with an academic medical center. Each clinic had one provider and staff to providers and staff involved in the transition care program. Youth involved in transition care in these clinics ranged from 12-26 years old. All of the participating clinics had a business relationship with the corporation leading the toolkit development process. The clinics were most interested in improving how they prepare children for the transition to adult care and facilitate a smooth transition so they volunteered to receive the toolkit.

Research Background

To further understand the barriers, interventions, outcomes, and principles of transition care, I searched scholarly sources for transition specific information. In consultation with the health science librarian, I initially searched CINAHL and PubMed, using the key phrases: evaluations of toolkits, information and research on transition care, transition care models, and other transition interventions for transition care. These databases were selected because they contain up to date peer reviewed journal articles reporting research in a healthcare setting.
Subsequently, the search was expanded to include the EMBASE database, which has broader coverage than CINAHL and PubMed. The results from my search showed that there has been research on transition care, some toolkits have been created, but little to no research specifically on the process of toolkit creation for transition care and assessment on its effectiveness on providers and their practice.

**Development**

After researching the background of transition care, meeting with the transition subcommittee, and receiving my own role in developing the transition care toolkit, I started searching for documents to include in the toolkit. I began by looking at GotTransition.org’s website and searching through what documents I thought would be helpful for providers and their clinics. Together with the Teen to Adult Transition Clinical Project Leader we decided on which documents we thought would be most helpful for providers in transition care. We then met with UDOH Program Manager to get feedback and what they thought would be helpful from a community and medical home point of view. Together with the Project Leader we then collaborated with the Program Manager at the Utah Health Department and Utah Parent Center to identify specific documents that incorporate the Six Core Elements of Got Transition to include in the toolkit. These documents were then compiled into a draft toolkit.

After developing a draft, we sought feedback from a diverse group to ensure the toolkit would meet their needs. The draft toolkit was sent to the transition subcommittee, which is made up of providers, care coordinators, members of the Health Department and Intermountain Healthcare, Utah Parent Center, families, patients, and others who are involved in transition care and interested in improving it. Feedback was given on the documents and specifics about what they liked and did not like about the documents and what they wished was included in the toolkit.
and what to eliminate from it. We also met with parents and patients with these chronic conditions who have been through the transition process and asked them for their input of what they wished they had during their experience, and what they would like to see providers teach about transition in their clinics. Additionally, we worked with the Co-Project Director of the national Got Transition organization and asked for their feedback about what they thought providers needed specifically in the toolkit, and what documents would help the clinics reach their goals of safely transitioning these children and their families. The feedback received from these parties were taken into consideration for changes in and formation of the toolkit.

To ensure the toolkit meets the individual of each clinic we went through multiple cycles of feedback and revision. First, clinics were contacted about our initiative to develop a transition toolkit, then meetings were set up to discuss the clinics’ transition needs. The toolkit was then presented to the clinic and their feedback was obtained. The Intermountain Healthcare Teen to Adult Transition Project leader reached out to these clinics, many of which already had a close, working relationship with Intermountain Healthcare as outpatient resources. She initially sent emails to identify whether their clinic was interested in resources to improve their transition care. Meetings were arranged with interested clinics. The first meeting was getting to know the clinic, why they were interested in transition care, what their needs were, and discussing “transition care champions” (designated people in the clinic who oversee implementing the toolkit) in their clinic. She then set up another meeting with the clinic transition champion to present the toolkit and receive feedback on what their suggestions were. The feedback was received from the transition care champions of the clinics. According to the feedback, follow up meetings were then set to further discuss revisions to the toolkits.
We then used cycles of feedback to help each clinic individualize the documents for their particular needs. We met with representatives from each clinic, presented the toolkit to them, and had a focused discussion about what would be helpful in their particular clinical setting. Although we set out to make a generalized toolkit for any child with any chronic condition transitioning to adult care, most clinics we met with were specialty clinics. Specialty clinics were most interested in transition care because their patients include children with chronic diseases who need education and help in transitioning to adult care. These clinics requested we adjust some documents and even create new documents to meet their specific needs. For example, in response to their requests, we created a simple document to educate patients about health insurance and sources of funding. Through additional cycles of feedback, we developed a transition care toolkit that addressed Got Transition’s six core elements of transition care, with some customized elements to serve the needs of the individual clinics.

The toolkit was then sent out for final editing and approval. The reviewers are dependent on the documents. Some documents were sent to the operation director for approval, others were sent to graphic design for a cohesive flow, and others that were made were sent to the legal department to make sure they were worded appropriately and credit to corporations are given. From there, it was then sent to graphic designers about the cohesive look of the documents and how to improve it. The graphic designers were involved in making new templates to improve the cohesive look of each document that was not taken from Got Transition’s website that was created. After responses from these departments for approval and editing for the toolkit were resolved, we finalized the toolkit (Intermountain Children’s Health, 2021).
Implementation

The finalized toolkit was then reintroduced to clinics (Intermountain Children’s Health, 2021). We started meeting with clinics again (who are the primary stakeholders) that were interested in the transition toolkit and discussed how it could be used. We met over “teams” with care coordinators and providers and obtained further feedback about documents in the toolkit to see if their needs were met. Because each clinic is set up differently and have different backgrounds in transition care, they either wanted specific documents and resources out of the toolkit, or wanted most all of the toolkit.

Implementing the toolkit required a series of steps. First each clinic’s baseline education of transition care needs were taken into account. Each clinic that wanted to be involved had varying levels of education about transition care. The prior meetings helped us identify transition educational needs of each clinic. Furthermore, a clinician needs assessment survey from Got Transition was also done for clinics that agreed to participate in it. If the needs assessment survey was not filled out by the clinic, then we conducted an informal interview asking about the transition needs of the clinic.

The second step was choosing transition champions. Got Transition (2021) and McManus et al. (2015) recommend designating specific staff roles related to transition care. While some practices might be reluctant to allocate dedicated time to transition care, doing so may speed implementation of transition care (Jones et al, 2019) and address the hesitancy providers’ often feel when asked to begin providing transition care (McManus et al., 2015). By offloading the need for providers to research, navigate, and learn the transition process individually, designating a transition care champion allows providers to remain focused on patient care. For this project, the Intermountain Healthcare Teen to Adult Transition Clinical Project Leader met with each
clinic interested in transition care and identified transition care champions. The clinics drew staff from a variety of different roles to serve as the transition care champions. For example, some of them were Registered Nurses (RNs), care coordinators, Medical Assistants (MAs), or providers.

Third, was educating each clinic on how to train staff to use the toolkit. To help guide us in the educational process of the toolkit, we created an education plan and a PowerPoint visual that walks through the toolkit and steps of transition care. As part of the toolkit we included a flowmap document that explains what document to use and the appropriate time to use that document. During implementation we educated the transition champions about each individual document in the toolkit and what ones apply to their practice. We also educated them about how each document lines up with each core element in transition care and how addressing these elements help create a care plan for the patient. After educating transition champions we met with other staff members who were more involved in transition care. Some clinics we met with them in staff meetings so we could help present the toolkit with the champions and further explain and answer any questions.

The fourth and final step was ensuring we addressed questions and obstacles arising during the implementation process. We communicated frequently with the clinics over e-mail and telephone to address their questions and their suggested modifications related to toolkit documents. For example, some clinics wanted an electronic version of the readiness assessment so that they could email the assessment to patients and families before appointments, instead of relying on a paper copy completed in the office. We continually addressed these issues as they arose to help the clinics better implement the toolkit and meet their patients’ transition needs.

Evaluation
To determine the degree to which the project objectives were met, an evaluation was conducted with all clinics implementing the toolkit by August 15th. A survey was developed (Appendix A) based on the six project objectives, which were informed by the six core elements of the Got Transition toolkit. The survey was sent out February 11th, 2022 and response deadline was February 28th, 2022. The survey was sent to each participating clinic’s designated liaison to the team that has been developing the transition toolkit. Participants answered eight questions that compare their transition process in their clinic immediately prior to and six months after implementing the toolkit. A post-then survey (Little et al., 2018) was used for this evaluation. In a post-then survey, participants are asked, after an intervention, to rate both their current and pre-intervention attitude, behavior, or skills. Post-then surveys help address response-shift bias by ensuring participants are using a common frame of reference when rating both their current and pre-intervention behavior. Specifically, prior to an intervention, participants often have a positively biased view of their behavior, which can inflate self-reported pre-test scores. By obtaining both current and pre-intervention ratings after the participant has developed a more realistic self-perception, they are able to provide a more accurate picture of how much their behavior has changed (Little et al., 2018).

The questions addressed each core element and the documents that correlate to each of them. The survey included three open-ended questions because it gave the participants the opportunity to voice their opinions about anything that was not addressed in previous questions. The questionnaire was sent out in February. While this might not have been enough time for the clinic to fully implement every aspect of the toolkit, we anticipated six months would be enough time for the clinics to become familiar with the toolkit, begin implementing it, and form opinions about what they found helpful with the toolkit. There will also be a long-term analysis of the
toolkit/transition program implementation that will be conducted by others involved in the retention of the transition program in these clinics.

**Analysis**

**Setting**

For this study, the setting was pediatrics specialty clinics and a state run resource providing transition care for pediatric patients.

**Sample**

The sample for this study was clinics that have started implementing the toolkit by August 15th. All of the clinics that implemented the toolkit during the timeframe of this project also participated in the evaluation process.

**Data Analysis**

Data were analyzed using a paired sample t-test and a calculation of effect size. The paired sample T-test was used to detect differences in the participating clinics’ implementation of GotTransition’s six core elements of care transition before and after adopting the toolkit. T-tests are often used to statistically compare the means of two independent groups, generally to test whether outcomes differ between a control group and an intervention group. In this case, there is only an intervention group (i.e. all of the clinics adopting the toolkit) and no control group. However, each group will receive two scores (i.e. both before and after adopting the toolkit), thus the before and after scores are dependent on each other. As opposed to the independent, two-sample t-test, the paired-sample t-test specifically accounts for this dependence and is thus more appropriate for this analysis. While the paired sample t-test offers insight into whether the pre- and post-toolkit implementation scores are statistically different, it is only a step (albeit an important one) toward determining the clinical significance of that difference.
A standard approach to determining the clinical significance of an intervention is to calculate its effect size. The effect size is a normalized measure of how many standard deviations of difference exist in the outcomes of a control versus an intervention group (or a pre- versus post-treatment group). Effect sizes are calculated as a secondary analysis of an inferential statistic like the paired t-test. Because the effect size is normalized, it offers a more meaningful and more broadly applicable interpretation of an intervention’s impact. For this study, Hedges’ G was used as the statistic for effect size. Compared to Cohen’s D, Hedges’ G is a more accurate method for estimating effect size when sample sizes are small (Brydges, 2019). Based on a meta-analysis of 2941 studies, Brydges (2019) suggests effect sizes of 0.15, 0.40, and 0.75 should be interpreted as small, medium and large effects, respectively.

This is why it was helpful to use this type of assessment for my project, because I was able to see the clinics’ related scores from each other before they had started the toolkit implementation process and after they had implemented the toolkit and was able to relate their scores from not only their independent clinics, but compared them to other clinics that also received the same toolkit.

**Results**

After evaluating the toolkit in the 6 participating clinics, 5 out of 6 of them reported that their clinics improved their transition process in some way, 1 of them reported that there was not much change, and 0 of them said there were any negative effects/lost progress. Each clinic evaluated was unique to its own transition care journey. We evaluated the toolkit implementation process based off of the six core elements of transition care that the toolkit was structured around.

**Quantitative Results**
As shown in Table 3, post-implementation mean scores for each of the 8 items were higher than the pre-implementation mean scores. Due to the relatively small sample size, we did not expect the paired samples t-test to detect any statistically significant differences between the pre-implementation and post-implementation scores. However, the one-sided t-statistic for one related to planning (resources) was significant at $p<0.05$. For this analysis, the more meaningful statistic is the Hedges’ $G$, which indicated a large effect size for all 8 of the items.

**Qualitative Feedback**

These results show positive feedback and outcomes from clinics who did use a more structured transition process in their clinics.

For those experienced in transition care, there were few changes. For others who were newer to transition care, the process of implementing a toolkit got them talking about transition care and saw more change and improvement in their transition care process.

**What was Beneficial?**

Almost every clinic found the toolkit beneficial in some way (5 out of 6 clinics). Depending on their populations and experience in transition care each clinic had their own unique feedback about various documents. This showed that by providing a variety of documents while addressing each element of the transition care process, parts of the toolkit were beneficial and effective to every specialty. When given various documents and resources, clinics might not benefit from each and every one of them, but will benefit from provided resources that they might be missing from their transition care process.

Themes identified, included improved transition processes, improved communication about transition care, and the ability to provide families with more resources. In terms of improvement in the transition process, clinics reported more organized, more efficient, better
follow-up. Communication was improved by providing a more structured and formal way to discuss important ideas. Clinic resources and documents were enhanced by being able to provide families and patients with additional sources to get reliable information for their transition process. Each clinic benefitted in some way and most found the toolkit beneficial in similar concepts.

**What were the Barriers?**

When implementing the transition toolkit, barriers were similar to the benefits in that each clinic had their own unique barriers dependent on their experience in transition care and patient population. 5 out of 6 clinics found barriers (one clinic reported no change in their transition care process, so they did not include barriers in their feedback). Barriers were related to documentation of the transition process, documents non-specific or not applicable to the clinics’ patient populations, not having enough time to create/tailor documents to their population, trying not to overwhelm families with the number of documents included in transition care, and documents not specific enough with not enough information.

Specific barriers that clinics found when implementing the toolkit include: documentation of transition care in EMR systems, the need for more specific forms and resources related to their specialty clinics' populations, and the amount of time implementing the transition process. Clinics found that it was difficult to put transition care information into their EMR systems, as there was often not a specific place in their system to document or input forms of transition care. Many clinics found that they would have liked additional resources and documents tailored to their population and their specific issues they would like to address. In relation to this, they also found some of the questions on transition questionnaires not specific enough or too vague for the information they needed for their specialty. Others found it difficult to create even more time to...
try to specify the documents to implement them into their transition care process. Receiving this feedback and identifying similarities in clinic barriers to transition will be beneficial to help improvement of the toolkit.

**Discussion**

Our findings suggest our intervention was an effective approach to implementing transition care in the participating clinics. Similarly, others have found implementing a transition toolkit can improve transition care in clinics. Building upon others’ evaluations of transition care interventions, we found it valuable to assess how clinics perceived the toolkit intervention and its impact within their clinics. In addition, our findings indicate the best transition care toolkit may be a generic toolkit that can be adapted to clinics’ specialized needs.

The quantitative results indicate the toolkit implementation process was effective at improving the six core elements in the group of clinics implementing the toolkit. Because few other studies have tried to implement a toolkit intervention across multiple clinics, direct comparisons with other projects and studies are difficult. For example, our project involved developing a toolkit for use with a variety of patient populations, while most other interventions have to do with implementing transition tools designed for use with very specific populations (e.g. patients with diabetes, rheumatological diseases, sickle cell disease) (Edmunds et al., 2012), (Hanks et al., 2012), (Overbury et al., 2021). Our results suggest a more generalized toolkit that can later be tailored to specific clinics’ needs can also be effective.

Similar to ours, others have implemented toolkits across multiple sites, but their evaluations focused on measuring patient outcomes and experiences (Coyne et al., 2016), (Marani et al., 2020), (McManus et al., 2015), (Varty et al., 2020). While patient outcomes are
important, our project demonstrates an effective, efficient approach to gathering the perspective of the clinic staff who are implementing the change.

Our findings align with other studies on transition care, which indicate interventions to improve transition care tend to be effective (Hart et al., 2018; Yassaee et al., 2018). More specifically, other studies of toolkit interventions based on the six core elements also found they were relatively simple, scalable, and efficient (Ilango et al., 2021; Jones et al., 2019; White et al., 2018). However, a direct comparison across studies is difficult. Even though others have also used transition care models based on the six core elements, they often utilized the entire GotTransition toolkit (McManus et al., 2015) or only used a select few GotTransition documents (Ilango et al., 2020; Overbury et al., 2021; White et al., 2020). Our study suggests that the best solution may be a balance between a very specialized and comprehensive toolkit.

The qualitative results show there were specific benefits related to communication, organization, and efficiency. Specific benefits include improved transition processes within the clinic; improved communication about transition care (i.e. it provided a more structured, formal way to discuss important topics), and the ability to provide families with more sources to get reliable information. Comparable to our findings, others have found implementing structured transition processes clarifies staff roles related to transition care and improves transition care plans (Jones et al., 2019), (McManus et al., 2015), provides useful resources for staff (White et al., 2020), and provides staff better understanding of what the transition process entails (Edmunds et al., 2012). As such, this project further validates what others have found regarding benefits clinics may expect from adopting a structured approach to transition care.

The barriers identified by clinics participating in the present project were also similar to others who have implemented transition programs. Our barriers included; documentation of
transition care in EMR systems, needing more specific forms and resources related to the specialty clinics’ populations, and amount of time implementing the transition process. For example, Jones et al. (2019) and White et al., (2020) also found incorporating toolkits into the EMR to be difficult. White et al. also found it challenging to make time to implement transition care into a clinic’s already busy schedule, include all team members in the process, and systematize the transition process (White et al., 2020). Similar to McManus et al. (2015) we found some participating clinics struggled to include all six Core Elements of Got Transition into their transition process. Overall, the barriers identified in the present project aligned with those identified elsewhere in the literature.

Overall, findings from this project align with other studies that have implemented interventions to improve transition care (Jones et al., 2019; McManus et al., 2015; White et al., 2020). Similar to their findings, our results suggest our intervention improved transition care in the clinics where it was implemented. As such, this project also adds to the body of literature supporting Got Transition as an effective framework for transition programs. Similar to other studies informed by Got Transition (Cleverley et al, 2020; Jones et al., 2019; Lemke et al., 2018; Lemly et al., 2013; McManus et al., 2015; Overbury et al., 2021; Volertas & Rossi-Foulkes, 2017; White et al., 2020), the clinics participating in this project found the Six Core elements of Got Transition were relevant to their transition practice. The clinics found the Got Transition resources were valuable, especially when it was possible to customize them to the clinics' specific needs.

Implications
This project has relevance for others creating transition toolkits and/or implementing them in one or more clinics caring for pediatric patients and young adults. It may also be instructive for other projects requiring a structured implementation process.

**Developing a Toolkit**

Throughout implementation of the transition toolkit, we learned a number of lessons that may be instructive for others. These include: 1) keeping information organized, 2) understanding clinics’ needs, 3) creating templates and uniformity, 4) feedback cycles, 5) allowing for customization, 6) implementing toolkits in individual practices, and 7) implementing toolkits in multiple practices.

**Keeping Information Organized**

Implementing transition toolkits requires a structured approach to organizing information pertinent to the process. Effectively managing the implementation process requires tracking a significant amount of detailed, complex information. The present project was particularly challenging because it involved helping multiple clinics implement transition toolkits. Initially, we did not have an effective system for organizing important information, which made it difficult to have a clear understanding of each clinic’s needs and progression through the implementation process. Later, a project manager helped us create and maintain a spreadsheet with information such as: meeting times and dates, contact information for each clinic’s care coordinators, other key staff involved in the process, which transition documents the clinic already had and still needed, and the clinics’ requests for document revisions. Helpful strategies for keeping information organized throughout the implementation process are: (1) creating a spreadsheet for tracking crucial project information, (2) designating a person responsible for
updating the spreadsheet, and (3) establishing goals, timelines, reminders, and accountability for keeping the spreadsheet updated.

**Understanding the Clinics’ Needs**

Understanding the clinics’ needs is a helpful strategy when determining which resources to include in the toolkit. By planning and scheduling multiple meetings with each individual clinic, we were able to determine their baseline knowledge about the transition process, resources, available support, and their progress in their transition journey. With this information, we were able to set individual clinic goals and determine how often to meet with them. During the meetings, it was also important to note each clinic’s specific resources and barriers related to implementing transition care. For example, some clinics had a designated staff member with resources dedicated for transition work, while staff in other clinics just had to incorporate transition work into their existing schedule. We also found it important to anticipate and respond with flexibility when key staff took time off. We used this information about each clinic’s unique situation when planning the next steps for their transition process.

**Feedback Cycles**

Using multiple feedback cycles when finalizing a toolkit improves its quality and applicability. Throughout the process of finalizing our toolkit, we went through multiple feedback cycles that were both formal (e.g. surveys) and informal (e.g. email messages and impromptu meetings). After implementing the toolkit, we went through similar formal and informal feedback cycles, adapted to each clinic’s unique needs. A couple months after implementation we asked stakeholders in each clinic to complete a survey about their progress related to transition care and for feedback about the toolkit. This information would help us make
changes to the toolkit that would better meet clinic’s transition needs as well. It is worthwhile to go through multiple feedback cycles when preparing to distribute the toolkit.

**Allowing for Customization**

Creating a toolkit with digital, customizable documents allows the clinics to revise and use the documents according to their unique needs. While developing our toolkit, our partner clinics recommended we provide each document in a digital format that the clinic could customize for their clinic, and with fillable fields to further customize certain documents for each patient. Additionally, the clinics wanted the toolkit documents incorporated into their electronic medical record systems to streamline the process of documenting and accessing transition-related information. While creating digital, customizable documents requires additional effort and technical expertise than creating paper documents, investing the resources necessary to create a more functional toolkit may be worthwhile.

**Implementing Toolkits in Individual Practices**

When creating a toolkit for a single clinic, carefully consider the clinic’s available resources and start the process with small changes. For example, in rural clinics and others without substantial resources, implement a single transitional resource the clinic is in need of. Many transition documents are easily accessible online through Got Transition, or through a local health department. Doing this will enhance the clinic staff’s familiarity with transition care and stimulate discussions between parents, children and providers about youth transitioning to adult care. After working through the process of implementing one transition document, the clinic can continue taking manageable steps toward building robust transition care services.

**Implementing Toolkits in Multiple Practices**
When assisting multiple clinics with toolkit implementation, it can be helpful to group those clinics according to clinic specialty and experience in providing transition care. While implementing the toolkit with multiple practices, we found clinics’ needs were largely dictated by their specialty type and their previous experience with transition care. Grouping clinics according to these differences may streamline the process of developing a toolkit that meets their needs. Clinics with a shared specialty care for patients with similar transition needs and will likely need similar documents in their transition toolkits. Clinics extensively experienced in transition care may need a toolkit that addresses more complex aspects of transition care, whereas those with less experience may benefit most from a toolkit with basic introductory transition documents. Grouping clinics according to clinical specialty and experience with transition care will make it easier to develop toolkits that meet their needs.

**Pulling it All Together (Templates and Uniformity)**

Creating a general toolkit template that addresses foundational aspects of transition care makes it more functional for a variety of clinics. For example, a template with a consistent design and color scheme that does not include organization-specific logos can be shared across clinics. In this project, we were fortunate to have access to a graphic design team. After creating finished drafts of the toolkit documents, we collaborated with our graphic design team to give the toolkit a uniform appearance. Using a more generic template resulted in a toolkit that was useful to many participating clinics.

**Limitations & Future Work**

There were two primary limitations to this evaluation that could be addressed in future work. First, this evaluation had a small sample size and primarily included specialty clinics, making it difficult to generalize the findings to a larger, more diverse sample. We only used
clinics, and 6 transition care champions filled out the feedback survey for the clinics. Compared to a rural general clinic, most of the clinics were specialty clinics and in an urban setting. These clinics also had previous ties to the companies involved in this project. Future evaluations could address this by using a larger, more diverse sample.

**Conclusion**

A growing number of youth and young adults with chronic disease are transitioning into adulthood. When transitioning to adult care, providers are in need of resources to help improve these children’s transition processes. However, many providers and others involved in transition care are often not equipped with the resources needed. A generalized toolkit was created and implemented in multiple clinics. Through the experience of creating, implementing, and assessing the implementation of this toolkit, we gained new insights that will be helpful for others who are designing and/or implementing transition toolkits in one or more clinics. When providers are given the proper documents, an organized process, and written direction, the transition process in their clinics can be enhanced.
References


http://dx.doi.org/10.3928/19382359-20170426-01


https://doi.org/10.1016/j.jadohealth.2018.11.023
Table 1

6 Core Elements Descriptions

<table>
<thead>
<tr>
<th>6 Core Elements</th>
<th>Definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Policy/Guide</td>
<td>Explains the goals of transition care. Educates the staff about the patient’s approach to transition and the different roles of youth, parents, and the care team in the transition process.</td>
</tr>
<tr>
<td>Tracking and Monitoring</td>
<td>Tracking and monitoring of youth progress of transition so they know where they are at in the process and what needs to be done.</td>
</tr>
<tr>
<td>Readiness</td>
<td>A baseline assessment of where parents and youth are in the transition process and how it is understood/perceived.</td>
</tr>
<tr>
<td>Planning</td>
<td>Planning of transition care for youth is based on their readiness assessment and their specific health care goals needed to transition to adult care.</td>
</tr>
<tr>
<td>Transfer of Care</td>
<td>Transfer of adult centered care to an adult practice. Information on who and when to contact adult providers.</td>
</tr>
<tr>
<td>Transition Completion</td>
<td>Follow up with youth who have transitioned into adult care and assess if their transition care needs were met.</td>
</tr>
</tbody>
</table>
Table 2

Organization Descriptions

<table>
<thead>
<tr>
<th>Organization in Transition Care</th>
<th>What they do</th>
</tr>
</thead>
<tbody>
<tr>
<td>Utah Health Department (UDOH)</td>
<td>The state’s maternal child health agency for Utah and help address the needs for children and youth with special health care needs and their families. The UDOH oversees many programs for children with healthcare needs. The Utah Children with Special Health Care Needs (CSHCN) is part of the UDOH. Their main role in transition care is making sure children with special health care needs will receive coordinated ongoing comprehensive care in the medical home.</td>
</tr>
<tr>
<td>Utah Parent Center</td>
<td>The Utah Parent Center helps parents help their children and youth with disabilities become as independent as possible and live among their community. They help provide resources for parental/family support, education, and advocate parents for children with disabilities.</td>
</tr>
<tr>
<td>Intermountain Healthcare</td>
<td>Large nonprofit healthcare organization based out of Utah. They have helped create a transition teen to adult program for children and youth with chronic diseases and their families.</td>
</tr>
</tbody>
</table>
Table 3

Quantitative Results

<table>
<thead>
<tr>
<th>Core Element / Question</th>
<th>Pre-Implementation Mean (SD)</th>
<th>Post Implementation Mean (SD)</th>
<th>One-sided t-statistic (p value)</th>
<th>Effect Size (Hedges’ G)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Policy/Guide</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q. 1</td>
<td>4.0 (1.55)</td>
<td>4.67 (0.52)</td>
<td>1.58 (0.087)</td>
<td>1.12</td>
</tr>
<tr>
<td>Tracking and Monitoring</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q. 2</td>
<td>4.0 (1.55)</td>
<td>4.67 (0.52)</td>
<td>1.58 (0.087)</td>
<td>1.12</td>
</tr>
<tr>
<td>Readiness</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q. 3</td>
<td>3.67 (1.75)</td>
<td>4.5 (0.55)</td>
<td>1.54 (0.093)</td>
<td>1.44</td>
</tr>
<tr>
<td>Q. 4</td>
<td>3.67 (1.75)</td>
<td>4.5 (0.55)</td>
<td>1.54 (0.093)</td>
<td>1.44</td>
</tr>
<tr>
<td>Planning</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q. 5</td>
<td>3.0 (1.55)</td>
<td>4.17 (1.17)</td>
<td>2.44 (0.029)</td>
<td>1.27</td>
</tr>
<tr>
<td>Q. 6</td>
<td>3.83 (1.47)</td>
<td>4.5 (0.55)</td>
<td>1.58 (0.087)</td>
<td>1.12</td>
</tr>
<tr>
<td>Transfer of Care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q. 7</td>
<td>3.67 (1.75)</td>
<td>4.5 (0.55)</td>
<td>1.54 (0.093)</td>
<td>1.44</td>
</tr>
<tr>
<td>Transfer Completion</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q. 8</td>
<td>3.33 (1.21)</td>
<td>3.83 (0.75)</td>
<td>1.46 (0.102)</td>
<td>0.91</td>
</tr>
</tbody>
</table>
Appendix A:

Toolkit Evaluation Survey

**Instructions:** We are interested in learning how implementing the toolkit has influenced the transition care provided in your clinic. Please consider transition care in your clinic prior to implementing the toolkit and what transition care is like today. Read the following statements and indicate the degree to which you agree with them.

<table>
<thead>
<tr>
<th>Questions</th>
<th>Prior to Implementation</th>
<th>Post Implementation</th>
</tr>
</thead>
<tbody>
<tr>
<td>We have a policy or protocol in place outlining our healthcare transition practice.</td>
<td>Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree</td>
<td>Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree</td>
</tr>
<tr>
<td>We use an established process to monitor youth and young adults progress through their healthcare transition.</td>
<td>Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree</td>
<td>Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree</td>
</tr>
<tr>
<td>We use a readiness assessment to start the conversation about the youth and parent working together on self-management skills at home.</td>
<td>Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree</td>
<td>Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree</td>
</tr>
<tr>
<td>We use the readiness assessment to evaluate the youth’s progress in learning self-management skills.</td>
<td>Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree</td>
<td>Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree</td>
</tr>
<tr>
<td>We have the resources/documents we need to support and educate youth in healthcare transition skills.</td>
<td>Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree</td>
<td>Strongly Agree Agree Neither Agree nor Disagree Disagree Strongly Disagree</td>
</tr>
</tbody>
</table>
## Open-Ended Questions

1. How has the transition process in your clinic changed as a result of this toolkit?

2. Now that you have used the toolkit in your clinic, what pieces were beneficial, which were not beneficial, and what additions would you like to see?

3. If you haven’t utilized your toolkit yet, what have been your barriers?