

## Novel Interventions in Children’s Health Care (NICH): Innovative Treatment for Youth With Complex Medical Conditions

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There is a well-known subgroup of children and adolescents with complex medical conditions who have many psychosocial challenges that put them at risk for repeated and, at times, avoidable hospitalizations. Intensive behavioral health interventions that address the multitude of problems associated with complex medical conditions have proven effective in improving adherence to treatment, improving overall psychosocial functioning, and reducing avoidable hospitalizations. Based largely on this research, we adapted and augmented a family-based problem-solving intervention for youth with complex medical conditions who have been repeatedly hospitalized. The intervention involves intensive family based problem solving augmented with care coordination and case management. The intervention is implemented in the family’s home, in the hospital, in the clinic, over e-mail, via video teleconferencing, and by text. To our knowledge, this effort is a first in the application of intensive behavioral health care for youth with complex medical conditions who are repeatedly hospitalized. We describe the theoretical and empirical underpinnings of the intervention, provide a description of the intervention using a case example, and present “lessons learned” from our efforts toward reducing hospitalizations and utilization of services in a population of youth with complex medical conditions who have repeatedly experienced avoidable hospitalizations.

*Keywords:* chronic illness, repeat hospitalizations, treatment

Complex medical conditions present problems for pediatric patients, their families, care providers, and society. For instance, complex and chronic medical conditions are associated with a greater risk of negative outcomes (e.g., mental health problems) for pediatric patients and their families (e.g., Cohen, 1999). In addition, pediatric patients with such conditions are

often difficult to treat, resulting in increased time and stress for health care providers with these challenges increasing exponentially (Burns, Casey, Lyle, Bird, Fussell, & Robbins, 2010; Simon et al., 2010). Furthermore, because of the chronic and difficult-to-treat nature of complex medical conditions, substantial costs are associated with the management of such illnesses in pediatric populations. Taken together, these problems argue for the development and application of effective, and cost reducing, treatments for complex illnesses among pediatric populations.

Effective interventions are needed to reduce costs and better meet the challenges of individuals with chronic and complex medical conditions. When it comes to overall health care spending, a very small percentage of the population is responsible for a disproportionate amount of health care spending. For example, Neff and colleagues (2006) identified that chil-

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This article was published Online First May 6, 2013.

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dren with lifelong, progressive medical conditions constituted 0.4% of the population but were responsible for 11% of health care charges and 24% of all pediatric hospital charges (Neff, Sharp, Popalisky, & Fitzgibbon, 2006). In many cases, individuals with chronic and complex medical conditions are repeatedly hospitalized, and many of those hospitalizations are avoidable. For example, the cost for patients with Type 1 diabetes mellitus (T1DM) hospitalized for diabetic ketoacidosis (DKA) is estimated to be around \$2.4 billion annually (Kitabchi, Umpierrez, Miles, & Fisher, 2009), with the primary reason for these repeated hospitalizations being poor adherence to prescribed treatment regimens (Randall et al., 2011). Thus, advocates suggest that a primary focus of interventions should be the integration of care. That is, care should be coordinated among providers coupled with access to and integration of behavioral health care that addresses issues of poor adherence to complex treatment regimens, that provides treatment for co-occurring psychological problems that negatively affect adherence, and that implements strategies that improve general health behaviors such as exercise and nutrition (American Hospital Association, 2012; Friedman & Basu, 2004; Liptak, Burns, Davidson, & McAnarney, 1998). Indeed, past work has found that behavioral health care can offset medical costs upward of 20% among some patient populations (Chiles, Lambert, & Hatch, 1999).

Besides being a failing of our health care system and causing significant problems for both health care providers and for patients and their families, a lack of integrated care for youth with complex medical conditions is a huge financial burden on both the health care system and the insurers (American Hospital Association, 2012; Friedman & Basu, 2004; Liptak et al., 1998). With adherence rates for most complex medical conditions hovering around 50%, but as low as 10% for certain health behaviors (DiMatteo, Giordani, Lepper, & Croghan, 2002), nonadherence costs the United States alone as much as 100 billion dollars annually (Osterberg & Blaschke, 2005). It is also estimated that upward of 50% of hospitalizations for children with complex medical conditions are attributable to poor adherence to treatment or are avoidable (Flores, Abreu, Chaisson & Sun, 2003). Whereas the mean cost for the

hospitalization of a child is approximately \$5,200 (Yu, Wier, & Elizhauser, 2011), the cost for the hospitalization of a child with a complex medical condition is considerably more. For example, the mean cost for one hospitalization for DKA in someone with T1DM is approximately \$15,000 (Kitabchi et al., 2009). Given that many hospitalizations for individuals with complex medical conditions are avoidable and likely linked to poor adherence (Friedman & Basu, 2004; Jiang, Russo, & Barrett, 2009; Liptak et al., 1998; Stranges, Merrill, & Steiner, 2008), the cost savings in preventing these hospitalizations can be impressive when one compares the cost of intensive behavioral health care against repeated hospitalizations linked to poor adherence (e.g., American Hospital Association, 2012; Ellis et al., 2008; Harris & Mertlich, 2003; Liptak et al., 1998).

Intensive behavioral health interventions that address complex medical conditions have proven effective in improving adherence to treatment, improving overall psychosocial functioning, and reducing avoidable hospitalizations (e.g., Ellis et al., 2008; Harris & Mertlich, 2003; Wysocki et al., 2007). However, many youth do not have access to integrated care with behavioral health professionals who specialize in the care and treatment of youth with complex medical conditions. Either because families live too far from tertiary medical centers that provide specialized care to youth with complex medical conditions or because youth are underinsured, getting the necessary specialized care is often difficult, placing these youth at high risk for deterioration in their health and repeated hospitalizations resulting from suboptimal adherence.

The purpose of this article is to describe a demonstration project, Novel Interventions in Children's Health care (NICH), which involves the implementation of an intensive behavioral health intervention for youth with complex medical conditions who are at risk for repeated hospitalizations and who are covered by Medicaid. In this article we will outline the intervention used in this demonstration project and its empirical base. We will also describe critical components of our intervention, as well as anecdotal findings and our progress to date. Finally, we will discuss some "lessons learned" in the implementation of this demonstration project in addition to our future plans. Throughout the article, examples of how this intervention

can be applied to a typical NICH case will be provided.

### Participants of NICH

Thus far, NICH is being provided to youth identified by medical staff in a tertiary care setting as having experienced potentially avoidable hospitalizations and not responding to typical medical interventions. Inclusion criteria for participation in NICH include children and adolescents between birth and 21 years of age who (1) have a complex medical condition such as cystic fibrosis, T1DM, end-stage renal disease, inflammatory bowel disease, chronic pain, cancer, and others; and (2) have experienced multiple hospitalizations that were deemed by care providers to be associated with poor adherence, poor parental supervision of health behaviors, lack of effective coping, or other related behaviors. Exclusion criteria include a youth or primary caregiver with (1) an intellectual disability; or (2) an untreated severe mental illness such as schizophrenia, psychosis, or bipolar disorder. Of those youth who were referred by medical staff, one refused to participate (adolescent with intractable headaches), one changed from Medicaid to commercial insurance (adolescent with back pain), and one moved out of the state (adolescent with T1DM).

Before enrollment in NICH, baseline assessment information was gathered to inform treatment via self-report measures completed by parents and youths, when able, and medical chart reviews conducted by NICH staff. At the time of this report, 35 patients, between 2 and 20 years of age, were enrolled in NICH and receiving intensive behavioral health services (see Tables 1 and 2). As displayed in Table 2, these families experience risk factors at a higher rate than is evidenced in typical pediatric patient populations. Patients and their families have completed or will complete evaluation measures after treatment close. Future data collection will involve chart reviews that examine the number of hospitalizations and emergency department (ED) visits during treatment, the number of days spent in the hospital during treatment, the reasons for hospitalizations and ED visits, as well as relevant lab findings (e.g., HbA1c values).

Table 1  
*Demographic Factors of Youth Enrolled in NICH*

Mean age	13.7 yrs
Female	48%
Caucasian	74%
Medical diagnosis	
Cancer	5%
Cystic fibrosis	11%
Diabetes mellitus	45%
Pain disorder	20%
Renal disease	8%
Other	11%

Note.  $n = 35$ .

### NICH: Example Case Referral

The following case example highlights characteristics of patients seen in NICH thus far and is provided to describe how NICH approaches pediatric patients with complex medical conditions. Jake is a 17-year-old male referred for poorly controlled T1DM. Jake lived with his mother and his mother's boyfriend in rural Oregon. Jake was diagnosed with T1DM when he was 14 years old and has been hospitalized three times for DKA for a total of 11 days during the five months before NICH involvement. Jake was referred by medical staff who believed that his repeated hospitalizations were preventable and that typical interventions were unsuccessful (i.e., diabetes education in the hospital, referral to county mental health provider, and increased number of outpatient clinic appointments for closer monitoring of diabetes care). Jake was minimally adherent to his treatment regimen, as he rarely checked his blood glucose levels and seldom counted carbohydrates. He took approximately half of his morning insulin injections but infrequently adhered to his afternoon and evening doses. Since his diagnosis, Jake had evidenced HbA1c values in the 12% and higher range, indicating extremely poor metabolic control. His mother had "given up on him" and believed that "he is old enough to make his own health choices." Jake was not in school at the time he was referred to NICH and was living alone at his mother's home. His mother had moved in with her boyfriend in another part of the state. We will refer to this case throughout the article to provide examples of the application of NICH to difficult-to-treat pediatric patients.

Table 2  
*Psychosocial Risk Factors of Youth and Families  
 Enrolled in NICH*

Family	
Single-parent status	51%
Parent unemployed or under-employed	63%
Living 20+ miles from medical center	42%
Medicaid insurance	100%
Unstable housing	40%
DHS involvement	23%
Youth	
Living separate from parent(s)	17%
Truant	40%
Psychological or mental health diagnosis	31%
Previous mental health care	60%
Psychotropic medication	40%
Alcohol and/or drug use	43%
Sexually active	40%
Parent	
Psychological or mental health diagnosis	33%
Previous mental health care	43%
Psychotropic medication	20%
History of alcohol drug problems	46%
History of domestic violence	29%

Note.  $n = 35$ .

### NICH: The Intervention

Youth enrolled in NICH receive intensive behavioral health in the form of family-based problem solving, care coordination, and case management. An intensive form of Behavioral Family Systems Therapy (BFST) is delivered to each family with a focus on problem solving, communication skills training, cognitive restructuring, and family systems interventions (Robin & Foster, 1989; Wysocki, Harris, Greco, Mertlich, & Buckloh, 2001). BFST is a family-based skills-based intervention that identifies and remediates dysfunctional family interactions that directly and indirectly have an impact on the youth's management of his or her health (Wysocki et al., 2001; Wysocki et al., 2006). The care coordination component of NICH involves working closely with all the medical providers and the youth/family to facilitate the appropriate delivery of health care services. The NICH interventionists work as liaisons between the medical team and the youth/family to ensure that everyone has the necessary information to maximize adherence to the prescribed treatment regimen and adjustments to the regimen to accommodate the unique challenges of the youth/family. It is not uncommon for the NICH inter-

ventionist to attend clinic appointments with the patients and families. Finally, the case management component of care involves working with extrafamilial systems that are involved with the youth and family. The NICH interventionists work with schools, child protective services, and other agencies that are directly involved with the youth and family. Many of the youth served by NICH have not been in school for some time and need assistance with reentering school or identifying alternative school arrangements that are more accommodating for the youth's specific health challenges. In addition, the NICH interventionists work with community agencies and other organizations that may have resources to help the youth/family.

Currently, two masters-level interventionists carry a caseload of 12 to 15 patients, considered to be a full caseload by other intensive behavioral health programs. The intervention occurs in the hospital, in the clinic, at the youth's home, over the phone, and over the computer via e-mail and video chat. To effectively manage financial resources and provide as much access as possible, technology was used whenever possible. The use of technology in behavioral health services for youth with complex medical conditions is well-studied and has been demonstrated to be quite effective in improving health behaviors, increasing adherence to treatment, and reducing avoidable hospitalizations (e.g., Harris, Freeman, Duke, Hirschfield, & Boston, 2012).

### Theoretical Underpinnings of NICH

Although the success of innovative programs like NICH is largely a function of the people who are involved, there are some distinct attributes of NICH that are reproducible and necessary in addition to having a strong team. Most importantly, the intervention must be grounded both theoretically and empirically. The theoretical base of NICH guides the interventionist in implementation of the proven methods with purpose and direction, and the two together best address the needs of the families by bridging what is proven to be effective with real-world challenges and the multitude of demands of life. NICH is grounded in Urie Bronfenbrenner's (1979) social ecological theory of human development. Attending to the "normal developmental demands" of youth with complex medical

conditions is critical along with analyzing and understanding the impact of the various systems or contexts in which these youth live.

Bronfenbrenner's (1979) theory attends to a child's development within the context of the systems that impact him/her both directly and indirectly. Bronfenbrenner (1979) describes five distinct systems including microsystems, mesosystems, exosystems, macrosystems, and chronosystems. Microsystems encompass a child's immediate surroundings and environment (e.g., family, school, peers, health care system). Mesosystems are those linkages between a child's microsystems (e.g., interactions between parents and health care providers). Exosystems are those systems that a child is not directly involved in, but have the potential to impact him/her such as a parent's work schedule, local and county organizations, and health insurance. Macrosystems represent cultural values, customs, and laws. Finally, chronosystems refer to the timing of development and life events such that a child may react differently to different events based on his or her age and development (e.g., being diagnosed with T1DM as a child vs. an adolescent). Without a fundamental theoretical paradigm, a program like NICH is merely a set of evidence-based interventions that cannot be successfully implemented outside of controlled conditions and in the unpredictable world of real-life challenges. As a result, NICH cases are conceptualized based on development within the context of systems that have both direct and indirect impact on the child.

### Empirical Base for NICH

Although grounded in Bronfenbrenner's (1979) social ecological theory of human development, the specific interventions used in NICH are drawn largely from BFST (Robin & Foster, 1989). BFST has received notable attention and is one of the most researched behavioral health interventions for youth with chronic health conditions. BFST is a structured, manualized intervention that includes four primary components: problem solving training, communication skills training, cognitive restructuring, and family systems interventions. Problem solving training entails teaching family members specific skills for recognizing issues that are causing interpersonal or other conflicts and a process for suc-

cessfully generating and testing solutions for those issues in a collaborative manner. Communication skills training emphasizes language and phrasing that can be used during family exchanges that promote healthy discussions among family members and avoid blaming or overreactions. Cognitive restructuring involves teaching individuals how to recognize faulty or maladaptive beliefs that may influence actions (e.g., "My son is just lazy. He would take care of his health if he really cared"), as well as strategies for altering those beliefs. Finally, family systems interventions include approaches that help ensure appropriate relationship boundaries and relational structure exist within the family (e.g., ensuring parents work together, engendering appropriate negotiation of roles and responsibilities). In combination, the various components of BFST directly target many of the family functioning and personal variables shown to have an impact on the health status of adolescents with diabetes.

Extant literature on BFST is highly supportive of both its efficacy and effectiveness. For example, an initial test of BFST with 119 adolescents with T1DM and their families showed that BFST improved family communication and problem solving compared with standard medical care or an educational support group (Wysocki et al., 2000; Wysocki et al., 1999), benefits that persisted for 12 months (Wysocki, Greco, Harris, Bubb, & White, 2001). In addition, a modified version of this treatment (BFST for Diabetes, BFST-D) demonstrated significant improvements in youth glycemic control, youth treatment adherence, and diabetes-related family conflict immediately posttreatment (Wysocki et al., 2006) and over a 12-month follow-up (Wysocki et al., 2007). Moreover, a home based version of BFST-D produced statistically and clinically significant improvements in family functioning and Hb1Ac values in youth with chronically poor glycemic control (Harris, Freeman, & Beers, 2009; Harris & Mertlich, 2003). More recently, preliminary findings of BFST delivered via Skype to youth with poorly controlled diabetes suggest that telehealth delivered BFST shows promise as being as, if not more, effective in improving youth health behaviors and health status compared with BFST delivered face-to-face in the clinic (Harris et al., 2012). Previous studies have also examined the feasibility of adapting

BFST to other populations (e.g., youths with cystic fibrosis; [Quittner, Drotar, Ievers-Landis, Seidner, Slocum, & Jacobsen, 2000](#)). Building on work supporting the efficacy and adaptation of BFST, an investigation of treatment expense found that the cost of BFST is significantly less than one 2–3-day hospitalization ([Harris & Mertlich, 2003](#)). Thus, not only does BFST produce important positive health and psychosocial outcomes, but is also a financially sensible treatment.

### **Nuts and Bolts of NICH: Making Theory and Evidence Work**

To date, NICH has been implemented with a diverse population of youth with various complex medical conditions. As such, the individual characteristics of referred patients, the potential environmental influences on their health, and the treatment regimen associated with their medical condition can vary substantially. Thus, the targets of treatment and specific interventions used can differ from case to case. However, a core set of approaches consistent with the theoretical underpinnings of NICH have been used with each patient to attempt to improve health behaviors and ultimately improve health outcomes.

First, applying systems theory, NICH practitioners have sought to establish a strong understanding of the context in which these youth live, including the identification of key players in a child's life who can support the treatment regimen. When assessing microsystemic factors, the NICH practitioner discovered that Jake's mother had left the family home to live with her boyfriend in another part of the state. As a result, the NICH interventionist identified another family member (maternal aunt) who could care for and monitor Jake. The NICH interventionist arranged for Jake's aunt to be educated in diabetes management and provided a structure for the aunt to support Jake's efforts to manage his diabetes. By engaging Jake's aunt in his life and in his diabetes care, we were able to provide him with appropriate supervision for his diabetes care as well as a supportive and stable living arrangement. Without the involvement from the NICH interventionist, the medical team would have not known about Jake being left on his own and likely would have not seen him again until his next episode of DKA.

Second, NICH providers have placed great importance on clarifying for the youth and family what health care behaviors are necessary and providing a direction for how to remediate poor health behaviors. Regarding the case of Jake, identifying short- and long-term medical goals as well as problem-solving regarding how to reach these goals appeared to reduce barriers to treatment progress. Often, adolescents with chronic health conditions are discouraged as they are pushed for optimal adherence. Unfortunately, such adherence is often unattainable given the many challenges they have in their lives coupled with their current baseline of health behaviors being so far from optimal. The short-term goals allows for immediate success and a sense of accomplishment and self-efficacy. The longer-term goals keeps optimal adherence as something that is always considered.

Third, NICH therapists put an emphasis on building small wins that are attainable and immediate around health care. In Jake's case, this concept was exemplified by working toward a goal of checking his blood glucose level one more time per day, as opposed to a goal of perfect adherence. These small wins allow for a shift away from a completely negative experience around one's health and address the need for establishing control over something that feels uncontrollable. For Jake and his family, achieving this small goal was the first success they had experienced around his medical conditions in more than a year, appearing to result in increased motivation and an improved sense of self efficacy. In addition, the NICH interventionist provided Jake with small incentives to reach his goals in his diabetes care. These incentives presented Jake with immediate reinforcement for his efforts and represented a symbolic acknowledgment of "not giving up" and "caring about his health."

Finally, and possibly the most important, the NICH interventionists serve as the "care ambassador" for the youth and the family, as many of these youth have been marginalized by the health care system and need assistance reengaging in care. For example, when intervening at the mesosystemic level, Jake's interventionist worked to better inform Jake's care providers of the socioeconomic difficulties and other barriers that Jake and his family faced on a daily basis, with the intention of increasing medical provid-

ers' feelings of empathy and motivation to help them succeed. In most cases, NICH interventionists collaborate with medical staff to discuss how to best engage the referred youth and family and establish attainable goals. Thus far, we have found medical providers to be open to working with NICH interventionists, as the medical team has referred these families because of their difficulties with changing health behaviors and had often found themselves frustrated and overwhelmed with patients like Jake and his family.

### Keys to the Success of NICH

Anecdotal observations from our work thus far suggest that there are several lessons to be learned when attempting to implement an evidence-based intervention for youth with complex medical conditions who are repeatedly hospitalized. First, applying a systemic perspective to this population may improve treatment providers' ability to successfully identify and target the multiple factors that can lead to these youth being repeatedly hospitalized (e.g., [Berry et al., 2011](#)). In the cases currently involved in our program, there appear to be a complex set of individual factors, disease-specific demands, family systems issues, economic challenges, parenting difficulties, and academic and social factors all simultaneously directly and indirectly affecting the youth's health. For example, in the case of Jake, successfully addressing the lack of a present caregiver, the need for smaller and more attainable goals, and the interactions between Jake and his family with school and medical personnel appeared to directly or indirectly relate to increased adherence and decreased hospital visits. Hence, our use of systems theory as our guiding theoretical perspective allows for conceptualizing the aforementioned factors and places them in a context in which we can better appreciate and understand why these youth are not able to properly care for their health. Using a systemic framework also helps to direct our interventions at the systems that seem to be having the most significant impact on these youth and their families, and ultimately may facilitate better health behaviors and improved health status.

Second, an effective intervention model for this population would likely benefit from a combination of case management, care coordination, and family-based problem solving being

delivered by the same individual. Just implementing one or two of the intervention strategies does not appear to be enough to make the necessary shifts and changes that are necessary to support the youth in better caring for his or her health. In some cases, there is a greater focus on one of the treatment strategies, but all the cases thus far seem to benefit from utilization of all three strategies to greater or lesser extent. Having the same individual be responsible for all treatment strategies may improve the provision of continuity of care by maximizing engagement from the families and by providing a point person to coordinate care and be a liaison between the family, the medical team, social service agencies, school personnel, and any other key extrafamilial individuals and groups.

Finally, by attempting to create a multitude of small wins for families of youth with complex medical conditions, a population that at times has been written off by the health care system as not prioritizing health, perceptions of futility in both the families and the health care providers may be changed to perceptions of hopefulness. After outlining and reinforcing achievable steps to better health, families appeared to have renewed optimism about managing the many challenges that come with raising a child with a complex medical condition. Hopefully, such optimism results in behavioral changes that better support healthy behaviors. For the health care providers involved in the care of our NICH cases, we have seen a shift in their perception of these families as more information is provided by NICH interventionists about the multitude of daily challenges these young people and their families face beyond health care needs. This change in perception on the part of the medical providers appears to have resulted in care and direction to patients that take into consideration the obstacles to better health behaviors coupled with the daily demands on families.

### NICH: Next Steps

Although our initial observations and anecdotal findings suggest that NICH is a promising intervention for children and adolescents with complex medical conditions, much work must be done before determining whether this program is effective in improving health, improving health behaviors, and reducing costs. Although we estimate

that youths receiving NICH will benefit from between 4 to 12 months of service provision, depending upon the level of case complexity, we do not at this time have the experience and data necessary to draw firm conclusions regarding length of treatment. In addition to determining the ideal length of NICH treatment, next steps include gathering medical utilization data for NICH participants as well as collecting other outcome data such as patient and family health and well-being. The primary outcome of this demonstration project will be the number of hospitalizations and/or emergency room visits any given patient has had within the calendar year. Secondary outcomes will include other health care utilization costs (e.g., visits to subspecialty and primary care physicians), estimates of adherence to prescribed treatment regimen, and general psychosocial, academic, and social functioning. Should we find the results of NICH to promising, we plan to also investigate potential moderators and mediators of NICH outcomes and determine whether NICH is equally effective across patient populations (e.g., T1DM vs. chronic pain). Should future studies continue to support the effectiveness of NICH, disseminating this program to other locations and settings will become a priority.

### Conclusions

Although children and adolescents with complex medical conditions represent a relatively small percentage of the population, their use of health care dollars is quite large. In addition, the impact of having a complex medical condition on these youth, their families, and the system extends beyond the cost of care into academic functioning, family relationships, and nearly all other aspects of their lives. Although NICH was primarily developed to reduce unnecessary hospitalizations and emergency department visits for children and adolescents with complex medical conditions, most of whom are Medicaid recipients, it is hoped that NICH will also lead to improvements for the individual youth, their families, and communities. Anecdotal evidence thus far indicates that those youth involved are evidencing increased adherence to medical regimens, improved overall health, and less hospitalizations and ED visits, suggesting increased quality of life for patients and families as well as possible cost savings. We hope that this promising treatment program can serve as an example of the type of theoretically

grounded and evidence-based model needed to effectively intervene with complex and chronic health conditions.

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Received October 30, 2012

Revision received March 11, 2013

Accepted March 15, 2013 ■