Nurse-Led Service Models: Lessons Learned Over 25 Years

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Overview of Past and Ongoing Nurse-Led Healthcare Transition Models of Care

This chapter is designed to provide an overview of programmatic efforts that were generated over a period of 25 years pertaining to the care of adolescents and emerging adults (AEA) with a variety of long-term conditions[1] as it pertained to healthcare transition planning. In this chapter, decades of nurse-led efforts related to healthcare transition services will be memorialized with the intent of providing a chronology of programmatic efforts that were developed, implemented, and refined based upon nursing model of care that was adapted in a variety of clinical and community-based settings. The intent of this chapter is to share with the reader the evolution of model development and implementation that occurred over time in response to changing circumstances that required adaptations of the nurse-led model.

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[1] In the United States, the terminology varies as to the designation of AEA with chronic conditions/illnesses. Authors use the following terms to denote classification of AEA that convey varied meanings: special healthcare needs, complex chronic conditions, intellectual disabilities, and developmental disabilities. For the purposes of this chapter, the terminology, long-term conditions will be used as well in addition to other commonly used designations identified in this chapter.

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Early Beginnings

Our initial nurse-led healthcare transition programmatic efforts were influenced by our first extramural grant support from the Maternal Child Health Bureau, United States Department of Health and Human Services, entitled, *UCLA University Affiliated Program/School to Work Interagency Transition Program Southern California Transition Coalition/Healthy and Ready to Work Project* and later named *California Healthy and Ready to Work (CA-HRTW)* Project. This project was developed and implemented in collaboration with the Southern California Transition Coalition (SCTC) of the School to Work Interagency Transition Program located in West San Gabriel Valley, a suburb of Los Angeles to create an interagency transition coalition. SCTC was one of four local interagency transition coalitions that had received funding from the California School to Work Interagency Partnership (SWITP). SWITP had been established with grant support from the federal government, as a joint initiative of Departments of Education and Labor through the School-to-Work Opportunities Act of 1994 (National Transition Network 1994). The intent of this legislation was to promote "…major restructuring and significant systemic changes that facilitate the creation of a universal, high-quality, school-to-work transition system that enables all students in the United States to successfully enter the workplace" (National Transition Network 1994).

SCTC had formed an interagency coalition that worked with community-based partners from a number of organizations and agencies to improve transition services for adolescents with special healthcare needs and disabilities. Representatives from education, employment, disability-focus agencies, self-advocacy and family organizations, rehabilitation, social security and job training, transportation, community colleges, and regional occupational programs participated in SCTC. Our team joined in partnership with SCTC to introduce health issues as a component of transition planning. *CA-HRTW* facilitated the inclusion of healthcare representatives from state-funded programs for children with special healthcare needs and pediatric healthcare settings. The goals of the *CA Healthy and Ready to Work* project were to support adolescents with special healthcare needs in making the successful transition to the adult healthcare system, enrolling in an adult health insurance plan, competently managing their own special healthcare needs and obtaining the needed health-related accommodations for work, school, and living as independently as possible in the community. Programmatic efforts were also directed to providing referrals to community-based transition and adult support services for postsecondary education and training, job development and employment, and community living.

The partnership with SCTC was formative and innovative as it ushered in the opportunity to create a nurse-led model of healthcare transition that embodied an interagency approach. We recognized the importance of embracing an integrated model of care that incorporated the health, psychosocial, and developmental concerns of AEA with long-term conditions and their families as they transferred their care to the adult system of care and transition to adulthood. Given this framework of care, our approach addressed not only health-related concerns pertaining to condition self-management, their health literacy, and transfer of care issues but

examined the impact of living with a long-term condition where AEA lived, worked, and played.

Based upon this holistic HCT approach, efforts were directed to developing and implementing a nurse-led transition program over 20 years ago, called *Creating Healthy Futures* (Betz and Redcay 2003). This pilot program consisted of an advanced practice nurse whose role was to assess transition-related needs for services and an interagency team who served as consultants. A diverse group of AEA with long-term conditions and their families were served; it was a pivotal opportunity to experiment with a new approach to HCT. Our team generated a number of publications based upon our *Creating Healthy Futures* program (Betz and Redcay 2002, 2005a); one of our early publications was on the role of the transition service coordinator (Betz and Redcay 2005b)

During this early period as well, the team with the input of interagency partners and interdisciplinary colleagues gathered collective input for the development of the *CA-HRTW* Transition Assessment (CA THCA) that was used in our early clinical work. This HCT assessment tool consisted of 73 items that comprehensively assessed knowledge and skills related to healthcare self-management, including those pertaining to health prevention, emergency measures/care, reproductive counseling, and safety behaviors. Other areas assessed included the use of transportation, health-related and academic accommodations at school, and understanding legal rights and protections (Betz et al. 2003). At the time, this pilot program was not sustainable beyond the grant funding project period, which was disappointing. However, the knowledge gained from this pilot program was later applied to our subsequent clinical, educational, and research efforts.

Movin' On Up

An opportunity arose in 2011 to replicate the original *Creating Healthy Futures* model into an outpatient clinical setting at Children's Hospital Los Angeles for youth and young adults with spina bifida. Replication of this model required modifications given the clinical setting wherein this model was implemented. Our model required changes in the service delivery model in order to adapt to the clinical services arrangements, needs of the youth and families, and reimbursement options for services. This nurse-led model of healthcare transition services has been sustainable for over 10 years.

Initially, it was envisioned to schedule the HCT clinic separately from the usual clinic schedule. This arrangement was found to be not feasible for several mitigating factors. The staffing needed to support a stand-alone clinic was not feasible fiscally and logistically. Administrative staffing was not available, and availability of conference rooms was limited. However, of primary consideration was the burden that would be imposed on families for coming to another clinic on another day of the week. The reality of that arrangement meant that families with limited resources would be required to spend additional funds for travel. Hosting the clinic at another time would cause considerable inconvenience for families who would have to get

their child and other siblings ready to come to the hospital or make other arrangements for childcare. Another significant issue that deterred the proposed scheduling was the youth would be missing part or all of a school day, which was not in their best interests.

Given the aforementioned constraints, it was decided that HCT services would be integrated within the flow of the usual spina bifida clinic services. A revised plan for the implementation of the HCT was devised that accommodated the clinic logistics, staffing availability, and be responsive to the needs of youth and families. It was determined that the most feasible approach would be to have weekly team conferences that could be reimbursed according to the payer's code and provide direct HCT services that would be integrated into the clinic weekly schedule. Both of these service components were integrated components of the *Movin' On Up* HCT service program (Betz et al. 2015).

Movin' On Up weekly conferences consist of interdisciplinary team members who provide discipline-specific input regarding the HCT progress of youth and their families. Typically, the team conferences involve the HCT service coordinator who organizes the conference meetings and reviews current HCT status as it pertains to condition self-management, coordination for service referrals, needs for durable medical equipment, supplies, braces, and assistive devices. Other issues reviewed are the needs for scheduling/updating annual and, as needed, specialty service evaluations (i.e., urology, physical therapy), current status and needs for academic and health-related accommodations, as well as engagement in social and recreational activities. Our team also reviews future planning needs as it pertains to postsecondary education and training, living arrangements, and employment.

Team meeting members include the spina bifida nurse care manager, social worker, physical therapist, and pediatrician/spina bifida specialist. Other members of the spina bifida clinic team are accessed on an as needed consultative basis. Team conferences enable review, monitoring, and revision of healthcare transition planning goals. At the conclusion of each team conference meeting, the revised set of goals are generated until the next conference team meeting. Generally speaking, conferencing on youth occur approximately twice a year. For youth whose needs are of pressing concern (i.e., postoperative needs for in-home schooling, social challenges) and for those who are approaching age 21 and the termination of pediatric care, they may require additional conferences.

Direct HCT nursing consultation services are provided during the weekly half-day morning spina bifida clinics. During these clinics, the HCT specialist meets with youth and their families to review the current status of issues pertaining to healthcare transition planning. Issues addressed during direct consultation encounters are highly dependent upon the current needs the youth and/or families identified. It is not unusual that issues previously identified as pressing are no longer an issue as it has been resolved or another priority is now identified by the youth and family. Examples of issues that are discussed include the status of CIC self-management, school bullying, obtaining academic and health-related

accommodations needed at school, review of job training options, and accessing community-based recreational programs. It is also an opportunity to meet with new patients who meet eligibility criteria for HCT services, which are provided to all youth who are 10 years and older regardless of insurance status.

Involvement in the *Movin' On Up* program has enabled our team to explore issues relevant to healthcare transition planning that are not often explored in the literature. The theoretical framework of our transition program is based upon a comprehensive healthcare transition planning approach that addresses health-related concerns that are not only relegated to chronic care management and illness concerns. Having a chronic condition impacts every aspect of an individual's life. For children and youth, their chronic condition can affect their school performance, peer relationships, and involvement in sports and recreational activities and their aspirations for the future. Therefore, we have been and continue to be interested in learning more about the lived experiences of transition-aged youth with the ultimate aim of improving their quality of life and lived experiences.

To that end, we conducted several studies pertaining to the student's school experiences. Our team investigated youth's understanding of their individualized education plan (IEP), which is an academic plan of instruction support and services for students who qualify for special education services (Betz et al. 2019). An IEP is an individualized plan based upon the needs of each student to assist him/her to achieve academic goals for the school year. Our team was interested in obtaining empirical data to better understand the extent to which students enrolled in our study understood what an IEP is and how an IEP can be helpful to them academically. Findings revealed that students had limited understanding of the purpose of an IEP and its relevance to their own academic activities.

We conducted another study to explore the types of academic and health-related accommodations students with spina bifida received in the school settings (Betz et al. 2022a). Our interest in exploring this phenomenon in the school setting was not only to gather empirical data but to raise this issue as a relevant to the provision of comprehensive healthcare transition services. Our findings revealed that the most frequently identified educational accommodation was enrollment in special education and the most frequently identified health-related accommodations students with spina bifida received was assistance with clean intermittent catheterization. Other academic accommodations that were most often reported were adaptive physical education, tutoring, and home schooling.

These studies illustrate that there are relevant and important areas of assessment and intervention that need to be considered with the provision of healthcare transition planning services. In order to support the AEAs transfer of care to adult healthcare services and transition to adulthood, assisting the AEA to learn to manage their chronic care needs in a variety of settings wherein they work, live, and play is essential. Learning to self-manage their needs in diverse settings is necessary to promote optimal health and quality-of-life outcomes and the AEA aspirations for adulthood.

Future Development in Intellectual Disabilities and Developmental Disabilities

More recently in 2021, our team was awarded a grant *Community-Based Transition Pilot Program* by the Administration on Community Living to generate a pilot plan for the transition program for individuals with intellectual disabilities and developmental disabilities (ID/DD). This project has enabled our team to undertake new efforts to develop and implement programmatic efforts for individuals with intellectual disabilities and developmental disabilities (ID/DD). These efforts include hosting Transition Summits for professionals and family members, production of white papers that address policy-related topics relevant to transition for ID/DD, and constructing a blueprint for a transition pilot program for youth and young adults with ID/DD.

As well, our team is involved with program development efforts in designing a pilot HCT program for transition-aged youth with ID/DD and co-occurring mental health conditions as this is an underserved group of AEA with ID/DD. Our goal is to obtain extramural support for this pilot program. To that end, our team conducted a survey of three major groups of stakeholders (i.e., providers, community-based organization/resource representatives, and disabilities advocates) to elicit their perceptions about the need for HCT services for this group of AEA with ID/DD with co-occurring mental health conditions. This data will be used in our grant proposal to demonstrate the need for this model of care. As well, our team is currently working on generating publications based upon the survey data that we collected from 277 respondents (Betz et al. 2022b).

As has been recounted with our team efforts in providing nurse-led healthcare transition services, there have been varied opportunities that presented themselves to enable our service model to be implemented and be sustainable. We have discovered over the years that sustainability of nurse-led service models can be a challenge. However, having administrative and institutional support for programmatic efforts are foremost factors to ensure sustainability. Our team has been fortunate to have continued support for our *Movin' On Up* nurse-led HCT program. It is our fervent hope and desire that our program continues in the spina bifida clinic in the years to come and that we are able to leverage our efforts into other programs for AEA with ID/DD and those with ID/DD and co-occurring mental health conditions.

Based upon our decades of clinical efforts, our team has acquired insights and understandings with the development and implementation of nurse-led programs. Nurse-led service models involve considerable time, effort, resources, creativity, and institutional support. Nurse-led service models are not developed and implemented in a vacuum; these service programs require the collaboration of a network of support. The following portion of this chapter provides readers with the "lessons learned" with nurse-led service model development.

Lessons Learned

In this chapter section, lessons our team learned with the development and implementation of nurse-led healthcare transition model of care are presented. Many of the "lessons learned" as described below are applicable to nurse-led efforts undertaken by nurse innovators whose practice involved different age groups of children with a variety of needs and is embedded within traditional healthcare settings or conducted in settings with full practice authority (American Nurses Association 2020; Bosse et al. 2017; Stucky et al. 2020). As ANA asserts, Full Practice Authority refers to the "…APRN's ability to utilize knowledge, skills and judgment to practice to the full extent of his or her training." The "lessons learned" that are presented include timing is pivotal, partnerships are essential, measuring outcomes are needed, infrastructure support, HCT services need to be individualized, flexibility not rigidity is needed, referral support is needed, and dissemination is important.

Timing Is Pivotal The timing of a nurse-led service model is a key factor in its development and implementation. In the early 1990s, our team had received extramural funding to create a nurse-led community-based primary care clinic for individuals with intellectual and developmental disabilities. A nurse-practitioner staffed this early project. This project encountered a number of challenges in terms of staffing issues, outreach and recruitment of individuals for care, logistical support, and a clearly defined plan of operation. This innovation was created long before other similar programs were established. Although the model was not sustainable beyond the project period, it did provide the impetus for the development of other programs similar to this original model. Nevertheless, this early model of care served as a precursor to the development of our later nurse-led models of care.

Partnerships Are Essential Throughout the span of more than 25 years of service development, research, and policy-making, partnerships have been essential to supporting and influencing our collective efforts. With our early efforts, partnerships and collaborative efforts helped to shape the development of our model of care that was unique and innovative at a time wherein the focus of state of practice and research was primarily focused on the transfer of care. As we described previously, our partnership with SCTC was hugely influential with the conceptual development of our nurse-led healthcare transition service model. As reflective of our comprehensive nursing approach with the provision of healthcare transition services, our publications have reflected our involvement and interest with AEA lived HCT experience such as exploring issues associated with school-related services and accessing community resources (Betz et al. 2019; Betz and Redcay 2005a). Over the past many years, our team has been involved with a HCT network, the International and Interdisciplinary Health Care Transition Research Consortium (HCTRC) (Ferris et al. 2011). Through collaboration with HCTRC, we have shared HCT knowledge

and clinical acumen that have enhanced our own programmatic efforts. These collaborations have led to other projects that have resulted in joint publications, projects, and hosting of monthly HCTRC zoom meetings and the Annual HCTRC Research Symposiums (Betz et al. 2014; Fair et al. 2015). Currently, members of the *Community-Based Transition Pilot Program* Partnership Advisory Team are advising our team with pilot HCT planning efforts. Their recommendations and assistance with these program development efforts have been invaluable in moving forward with the development of this nurse-led service model.

Measuring Outcomes Is Needed   The effectiveness of services can only be verified with measurement of outcomes. The primary focus of measuring outcomes has been on the transfer of care. That is, researchers have engaged in limited tracking of AEA following their transfer of care to adult providers. Generally, in the current literature, indicators of a successful HCT outcome have been the first appointment with the adult provider and care coordination between pediatric and adult providers (Suris and Akre 2015). A significant challenge with tracking pediatric patients into another system of care is the lack of resources available to continue monitoring. Longitudinal studies require allocation of resources for staffing support to conduct the follow-up. Staffing for a project of this type likely extends beyond the resources available within the program needed for a longitudinal study that include staff with statistical, research, and database development expertise. Another widespread challenge for longitudinal research is that lack of connectivity/linkages among service systems in some countries. In the United States, there are few states that designate an identifier to the user across systems of care. Most often, when a pediatric patient exits pediatric care, the identifier within the insurance plan is discarded and replaced with a new identifier for the new service system, thereby making tracking a challenge.

Some issues have been raised as to what HCT outcomes should be considered for measurement (Coyne et al. 2017). In a recent review of transition outcomes, authors noted that standardization of transition outcomes are needed as currently there is lack of uniformity in the conceptual meaning and measurement of transition outcomes (Coyne et al. 2017). Several Delphi studies were conducted that resulted in a list of indicators that should be considered for outcomes measurement (Fair et al. 2015; Suris and Akre 2015). More recently, discussions have been raised that it is timely to revisit this topic given the advances and developments in HCT research and practice.

Infrastructure Support   Key to the development of any nurse-led model is infrastructure support. This form of support is invaluable and contributes greatly to the sustainability of the project. Infrastructure support comes in the form of intramural or extramural support. The types of intramural support our project team has encountered over the years have not always been quantifiable as financial support. Our team has been fortunate to create collaborations and partnerships with other transition and adult-related agencies that served as referral sources and informational resources that enabled our team to be more informed and adept HCT service provid-

ers to the AEA and families we served which we have described previously in the section on Partnerships Are Essential.

As well, our collaborations and partnerships created new opportunities for joint programming and projects. For example, in one of our transition projects, our Partnership Advisory Team was instrumental in supporting our efforts to host two Transition Summit meetings, one for professionals and another for families and self-advocates. Our advisory members were key to the success of our Transition Summits as they volunteered as speakers or provided introductions to other speakers with the subject matter expertise. Our team would not have been able to host these Transition Summits if not for their support and involvement with this effort.

We have learned over the years that extramural support is certainly an ideal opportunity to create and pilot a program, but it is not sustainable. Other sources of financial support are needed and essential for programmatic sustainability. In our own experience, seeking extramural programmatic support can be challenging, particularly as the field of healthcare transition expands and grows. Therefore, other avenues of sustainable support need to be explored. Fortunately, for our program, we were able to access one of the financial advisors to assist the team in accessing funding support through a government program to enable sustainable funding. This individual was a pivotal resource in enabling the continuation of services.

More recently, we have discovered through a collaboration with one of our advisory board members that we may be able to create a training program that heretofore would not have been possible without this collaborative effort. As well, we have been advised by colleagues over the years of smaller and larger pockets of funding support for ancillary projects that contribute to the overall mission of our HCT efforts.

HCT Services Need to Be Individualized We discovered in our programs that the life course of AEA does not follow predictable patterns. During a HCT planning encounter, the adolescent may identify a self-management priority such as working on developing competence with a daily condition-related management task such as weight management. That priority may not be as evident with a subsequent encounter as other factors intervened such as undergoing major surgery based on medical necessity resulting in decreased physical activity level. Other developmentally related events such as changing schools, access to after-school activities, and friendships can affect HCT planning. Individualization of care is the bedrock of providing services that are based on an adolescent-centered and family-centered framework of care. That is, services are predicated on the AEA and family's interests, needs, and preferences.

Flexibility not Rigidity Is Needed Being adaptable is essential to any long-term programmatic effort, particularly those that are nurse-led. Having an attitude that is open to recommendations and opportunities that present themselves enables new pathways to programmatic development. A new opportunity for service development may initially seem undesirable; however, upon further reflection and consider-

ation with the team, this new venue can and very often lead to growth of not only the program itself but contributes to the professional development of the team members as well.

Importantly, in the burgeoning field of healthcare transition, innovations are being introduced that impact service development, policymaking and research. For example, in the early days when the concept of healthcare transition was first introduced, the age range suggested for initiating transition service was in late adolescence and more narrowly focused. The early literature and to a certain extent even today, HCT planning tends to be focused on the transfer of care (Chu et al. 2015; Hart et al. 2019). More recently published articles describe models of care that are more comprehensive in approach that include other components of services such as an emphasis on learning self-management and navigation skills, service referrals to transition, and adult services and coordination of care (Betz and Coyne 2020).

Nursing models of HCT have become more evident in the literature and in service settings. Evidence of the influential role of nurses in the field of HCT is to peruse the literature for examples of nursing HCT models and scholarly papers (Betz and Coyne 2020; Grady et al. 2021). In 2020, the National Institute of Nursing Research in conjunction with the National Association of Pediatric Nurse Practitioners sponsored a 2-day meeting at NINR, National Institutes of Health: Research Roundtable: Care Transitions from Pediatric to Adult Care: Planning and Interventions for Adolescents and Young Adults with Chronic Illness (Betz 2021; Grady et al. 2021). Later that same year, Lost in Transition Workshop was hosted by National Institute of Child Health and Human Development and National Institute of Health, signifying the recognition of this important area for research development.

Referral Support Is Needed   Our team has learned that providing referral information is not always a sufficient strategy, particularly for AEA. A foremost consideration is the extent to which AEA have had previous experience in making a "cold call" to a transition-related or adult service agency. We have observed that this can be a very intimidating experience, especially when the AEA has not previously called an agency independently. Our team discovered that several strategies can be used to assist AEA in reaching out to an agency for assistance.

We begin with role playing and coaching the script and actions needed to make the call. This is a necessary precursor step before the AEA actually makes the call. Following that preliminary step, the AEA makes the call, while we are in the room preferably on speaker phone so that we can provide assistance with the conversation/request being made. These strategies have been found to be more effective in supporting AEA to make the call with staff assistance.

There are relevant sources for consideration to be made when providing referrals. Many of the agencies have phone trees that can be challenging to navigate.

Assisting an AEA through the phone tree can be very helpful. In today's world, technology reigns supreme for younger generations as evidenced with characterizations of Generations X, Y, Z and the Alpha Generation. Integrating technology into providing referrals is effective and efficient. During the appointment, accessing the websites of referral agencies enables having a screenshot to be taken. This is a more lasting and convenient method for obtaining and retrieving information when needed.

Dissemination Is Important The field of HCT will only advance with the sharing of ideas, evidence, model development, and research. Our team realized early on the importance of sharing our work in practice, service, scholarship, and policy-making as a means of contributing to the literature that provides understanding and knowledge of the science and practice. Colleagues will only learn of others work through dissemination opportunities whether it be at conferences, involvement in practice, and research networks as has been mentioned previously, engagement in institutionally led efforts for HCT activities, participation in professional associations' HCT policy-making, and through publishing efforts ranging from newsletters to peer-reviewed publications.

Our team published several clinically oriented articles that were generated from our work with our first grant funded by the Maternal Child Health Bureau, United States Department of Health and Human Services. These early papers focused on introducing the concept of healthcare transition to pediatric nurses (Betz 1998a, b). As well, we published papers on our nurse-led HCT program, the role of the transition service coordinator, and our interagency approach to HCT that have been referred to in this chapter. As mentioned previously, our team has published several research studies including a randomized control trial (Betz et al. 2010) and systematic reviews. Through these publishing efforts, we have been able to communicate with colleagues our findings and experiences as well as contribute to the expanding HCT literature.

Conclusion

This chapter has provided the reader with an overview of collective experience with the development and implementation of nurse-led healthcare transition models of care. As has been discussed in this chapter, over the period of many years, nurse-led models originally developed can and do evolve in response to changing situations, emergence of new evidence to shape HCT practice, and scope of nursing practice developments such as authorization of Full Practice Authority for nurse practitioners in states across the United States. Based upon our experience, a selection of "lessons learned" gained with the development and implementation of nurse-led models of care is offered.

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