

# Creating Healthy Futures: An Innovative Nurse-Managed Transition Clinic for Adolescents and Young Adults with Special Health Care Needs

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The Creating Healthy Futures (CHF) clinic is an innovative, nurse-managed service model that provides comprehensive transition services to youth and young adults with special health care needs. Unlike other transition service models reported in the literature that are medically based, comprehensive transition services were coordinated by a family nurse practitioner who worked in close collaboration with an interagency team of pediatric and adult service providers. The Creating Healthy Futures (CHF) service model was originally developed for use in educational settings but was adapted for use in health care settings. The components of the service model are described in detail as a model for replication in other health care settings.

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There is growing concern regarding the preparation of adolescents with special health care needs for the transfer from pediatric to adult health care services. Ninety percent of adolescents diagnosed with chronic illnesses survive into adulthood. This statistic underscores the pressing demands for developing and implementing services and programs whose primary goals are to facilitate the transfer of adolescents to adult health care providers, their access to health insurance, and the acquisition of self-care skills to manage their health care needs (Betz, 1998a, 1998b, 1999; Newacheck & Halfon, 1998; Sawyer et al., 1998). This article will describe the development and implementation of CHF, an innovative, nurse-managed transition clinic for youth and young adults with special health care needs.

## Background

Transition service models in health care settings are in the seminal stages of development, with most programs created within the past decade (Callahan, Winitzer, Keenan, 2001; Nasr, Campbell, & Howatt, 1992; Sawyer et al., 1998). Until now, primarily colleagues in education, rehabilitation, social service, and job preparation have generated the evidence-based literature. These advancements are due in large measure to the passage of legislation such as the Individuals with Disabilities Education Act (IDEA) and its subsequent amendments (1997). The regulations require the implementation of transition programs in educational settings to assure special education students are adequately prepared for their departure from high school to assume

new postsecondary roles as students, workers, heads of households, and community citizens.

There is scant health care literature available describing transition services available for youth with special health care needs in health care settings. To date, program descriptions are to be found primarily in the medical literature with emphasis on the medical services transfer from pediatric to adult care physicians (Cappelli et al., 1989; Nasr et al., 1992; Salmi et al., 1986; Sawyer et al., 1998; Schidlow & Fiel, 1990). A recent survey of 120 programs described as health care transition programs or services conducted by the National Center for Youth with Disabilities found 62% located in pediatric subspecialty settings (Scal, Evans, Blozis, Okinow, & Blum, 1999). Services provided most frequently were medical specialty care, health education, and individualized planning for independent living. Nearly 50% of these programs focused on the medical component of transition services. Nurses (66%), medical subspecialists (61%), and social workers (56%) were identified most frequently as transition service providers.

## CHF Model

The CHF transition clinic is a significantly different transition service model compared to those reported in the health care literature to date. CHF is a nurse-managed transition clinic staffed by a family nurse practitioner who serves as the transition coordinator and works in close consultation with an interagency team of child and adult service providers. The adult providers are from community-based education, job preparation, housing and community agencies, and organizations who meet monthly with the

**Table 1. Differences between the SWITP and CHF Service Models**

<b>SWITP</b>	<b>CHF</b>
Educator serves as service coordinator.	Family nurse practitioner serves as service coordinator.
Education planning is primary focus of team that addresses the five IDEA requirements.	Health care planning for the transfer to adult health care providers, access to health insurance, and development of skills for long-term disability management.
Transition planning is mandated in IDEA.	Health care transition planning is identified as a standard of practice by American Academy of Pediatrics (2000); National Association of Pediatric Nurse Practitioners (2001).
Transition planning begins at age 14.	No age is specified although 14 is specified as optimal age to correspond with IEP transition planning.
Interagency team planning corresponds with IEP planning.	Interagency team meets on a monthly basis to provide consultation.

FNP to provide input on the development of a comprehensive transition service plan that addresses the individualized needs of youth with special health care needs for these services. Based upon the team recommendations, the FNP works with the youth/young adult to implement the plan, which involves coordinating access and referrals to community resources and programs. The primary mission of the CHF clinic is to assist adolescents with special health care needs in meeting their goals for adulthood.

The CHF transition clinic is based upon a service model originally developed by the California School-to-Work Interagency Transition Partnership (CA SWITP) of the California Department of Education, Special Education Division (1998). CA SWITP was funded by a School to Work system change grant obtained by the California Department of Education, Division of Special Education from the U.S. Department of Education.

The CA SWITP model, composed of an interagency transition team of child and adult service providers, has been used in school settings for Individualized Educational Planning (IEP) transition planning for students in special education (CA SWITP, 1998). Members of the SWITP team include the special education teacher, who serves as the transition coordinator;

the school nurse; rehabilitation and job preparation specialists (Workforce Investment Agency provider); and representatives from the Social Security Administration, Disabled Student Services, mental health and disabilities advocacy, and support agencies. These interagency team members work with special education students and their families in devising an individualized transition plan according to the five requirements specified in IDEA (IDEA, P.L. 105-17). These program requirements include classroom instruction, related services, community-based experiences, development of employment and other post-school adult living objectives, and, as appropriate, the acquisition of daily living skills and functional vocational evaluation (IDEA, 1997). The United States General Accounting Office (1996) recognized the potential of this model by referring to SWITP as an innovative interagency service approach that facilitated the coordination and provision of services between local agencies involved with transition planning.

The CHF team included the SWITP membership composition, but expanded the model to include members of the youth's specialized health care team located in hospital settings. Unlike the SWITP team, members of the CHF interagency team address a different set of service priorities, primarily, health care transition services.

Health care transition services include locating available adult providers for primary and specialty medical services and therapeutics, ensuring access to health care insurance once eligibility terminates for pediatric coverage, and facilitating the acquisition of self-sufficiency skills in managing long-term disability. Other services provided by the CHF clinic include coordination and referral to educational and/or vocational training, community living, and job preparation programs. Differences between the transition services offered through the CHF clinic and those provided by the SWITP transition team are summarized in Table 1.

The CHF clinic is comprised of several components: service intake; preliminary screening, which includes identification of the youth's goals and needs; presentation of each youth's needs resulting in service recommendations; and long-term follow-up to facilitate the achievement of the youth's developmental tasks for adulthood.

The CHF has been pilot tested for more than 3 years with 38 youth and young adults (13 years to 40 years) with special health care needs. During this time, a total of 59 youth and young adults were referred to the clinic for transition services. Eighteen referrals were not interested in transition services or did not respond to phone calls or letters, four consumers lived out of the area and were interested in health care referrals only, one youth wanted input into his current transition plan in another county, and another asked how to obtain respite care from a community-based disabilities agency. The framework of the clinic procedure is outlined in Table 2.

### **Criteria for Clinic Enrollment**

Initially, the CHF clinic enrollment criteria had specified a more narrowly-defined age range from 14 to 22 years of age. This age range corresponds with the age bracket of transition services provided to special education youth in school settings as specified in the IDEA. The age criteria was modified to accommodate the broad age range of adults, primarily in their twenties and early thirties, referred to the CHF clinic by pediatric providers working in hospitals, clinics, and public health programs and from non-profit agencies. The unexpected referrals of older adults occurred due to their unmet needs for transition services. For these adults, the CHF clinic provided opportunities for services previously not available to them. Several adults requested assistance with job

**Table 2. Creating Healthy Futures Clinic Procedures**

**I. Referral Process/Intake**

*Sources of referrals.*

1. Private individuals.
2. Health care agencies (pediatric tertiary care hospitals, outpatient clinics).
3. Non profit agencies.

*Generation of referrals.*

1. Periodic dissemination of materials to potential referral sources.
2. California Healthy and Ready to Work (CAHRTW) outreach training sessions with health care, social service and educational agencies.
3. Word of mouth.

*Intake questions form completed by transition services coordinator or administrative assistant.*

*Referral screened by CAHRTW group members.*

1. Appointment set up for meeting with transition service coordinator.
2. Brochure, project information and contact information sent to patient
3. Release of information sent to referral or parent, if under 18 years of age.

*Folder assembled for client to include:*

1. Completed release of information.
2. Health Care Assessment Form.
3. "What Are my Goals and Dreams?"
4. Follow up survey.
5. Progress notes.
6. Name, address, and phone number of client.
7. Referral source.
8. Intake questionnaire.

*Letter sent to referral source.*

1. Thank you for referring.
2. Outline of anticipated follow-up.

**II. Preliminary Screening**

*Transition team coordinator meets with consumer (and family, as indicated )*

1. Explanation of interagency team and team process emphasizing that client is a part of the team process.
2. Packet of materials reviewed.
3. CAHRTW brochure.
4. Transition team members and participating agencies.
5. Phone numbers and address for CAHRTW contacts.
6. Release of information obtained.
7. Health assessment filled out with client.

8. "What Are My Goals and Dreams?" filled out with client including goals for health care, education, independent living, employment, and leisure.
9. Follow-up survey filled out with client.
10. Key participants to transition plans identified by client (family members, friends, health care providers, teachers, case manager, if any).

*Requests for information sent to appropriate agencies and entered in folder.*

1. Previous transition plan.
2. IEP/ITP and secondary school records.
3. College records.
4. Medical records.
5. California Children's Services.
6. Department of Rehabilitation.
7. Regional Centers (developmental disability agencies).
8. Disabled Student Services.
9. Social Security Administration.
10. Center for Independent Living.

*Complete written summary of consumer's goals and needs , planned interventions and outcomes.*

1. Enter in folder.
2. One copy to consumer.

**III. Team Presentation**

*Introduction*

1. Presentation of transition issues by transition service coordinator.
2. Referral to appropriate agency(ies) and case manager.
3. Transition planning meeting set up with appropriate agency members and consumer.
  - Summary of transition team recommendations.
  - Copy provided to adolescent/other as directed by adolescent.
  - Copy to key personnel at team agencies.

**IV. Follow-up**

*Weekly by transition services coordinator for 1-2 months.*

1. Monthly for 1 year.
2. Follow-up calls to consumer; family, if indicated; and agency to which consumer referred.
3. Provide transition recommendations to health care provider and/or other referring agencies as indicated.
4. Utilize health professional students and volunteers to assist with follow-up.

**V. Evaluation of Outcomes**

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training and finding jobs. Other admission criteria included diagnosis of special health care needs, mental health problems and/or developmental disabilities, and English or Spanish speaking.

### **Preliminary Screening**

After enrollment in the CHF clinic, an intake appointment was scheduled to gather information on the consumer's transition service needs. A packet containing an appointment confirmation letter, a consent form for release of information, and project information was sent to each enrollee prior to the initial meeting. The preliminary screening meeting was conducted by the CHF service coordinator with the youth/young adult and, as appropriate in accordance with the consumer's request, with a family member, usually the parent. During this initial meeting, the service coordinator provided an explanation of the interagency team and team processes emphasizing the youth's/young adult's role in the team process and their participation as an active partner. The CHF service packet was reviewed and included identification of available services, community transition resources, and the signed release of information consent. Next, a comprehensive transition assessment, entitled "What are My Goals and Dreams," was conducted with the youth/young adult. This assessment was administered to identify his or her needs and goals for health care, education, community living, employment, and social and leisure activities.

The first question asked of the consumer is, "What is your most important goal for the future?" This very broadly worded, open-ended question enabled the youth or young adult to articulate important and very personal dreams for the future. Very often, the hope embedded in their statements concealed the reality of the current life situation; however, it did provide insight into the individual's life priorities and aspirations. Their responses rarely referred to changes in their physical status. All indicated their goals to live as independently as possible and be self-supporting. They expressed desires for intimate relationships, such as for a husband or wife, and vocational ambitions enabling them to be self-sufficient.

The assessment then proceeded with a series of questions pertaining to five broad areas of functioning: health care, education, community living, employment, and social and leisure. Data were gathered from the consumer

about their past experience and current level of involvement in each of these areas. For example, questioning about health care concerns elicited information about recent medical history, level of responsibility assumed for managing special health care needs, names of primary and specialty care physicians and therapists, and current type of health insurance coverage. The youth/young adult were also queried about their engagement in health care transition planning, such as contacting adult health and dental care providers and plans they had made for obtaining health insurance coverage once their current insurance eligibility terminated. Information was also gathered to determine the extent to which the consumer was willing and able to participate in this aspect of transition planning. These questions were included from the California Health and Ready to Work Transition Health Care Assessment Tool that comprise the health care section of "What are My Goals and Dreams" assessment (Betz, 1998a).

Key participants for transition planning (e.g., family members, friends, teachers, health care professionals, teachers, and case managers) were identified by the youth/young adult. Requests for information were sent to appropriate agencies as identified by the youth/young adult. Records obtained included previous transition plans, high school and college records, medical records, and agency records. This information provided a thorough and comprehensive source of data for transition planning.

### **Interagency Team Planning**

Based upon this comprehensive assessment, the goals and needs for transition services and resources, together with a preliminary listing of planned interventions, were identified. This transition plan summary was then presented to the interagency team by the transition service coordinator for review and recommendations for service referrals and coordination. Recommendations included referral to job-training programs in the consumer's community of choice, the suggestion of an adult medicine specialist for services, or strategies for enrollment in an insurance program. Recommendations were coupled with the identification of specific resource personnel, such as a case manager, associated with each recommendation to ensure goal attainment with follow-up. All of the youth/young adults were given the choice to attend team meetings. None of the consumers chose to

participate in the meetings and instead reviewed the recommendations of the team at subsequent meetings with the transition service coordinator.

During the meeting with the transition service coordinator and youth, the team recommendations were thoroughly reviewed. The rationale for each of the recommendations were discussed, including how it could be useful to meeting their needs and realizing their particular goal. For example, one young person with mild developmental delays, organizational problems, and memory lapses, a long-term effect of her chronic condition, wanted to work in a retail store. However, she had experienced anxiety issues during her limited previous retail experience. The transition team recommended a referral to the Department of Vocational Rehabilitation for job training and linkage with a supported employment agency for job coaching. The team also recommended weekly counseling with a psychological intern and quarterly visits to a psychiatrist to help her deal with anxiety. A subgroup of the team consisting of a psychologist, a Department of Rehabilitation counselor, a representative of the Center for Independent Living, and a nurse practitioner met with this individual to obtain her input and engage her in following the recommendations.

All youth were encouraged to engage in exploring and questioning as these recommendations were reviewed. The plan was concerned with meeting his or her individualized needs, not those of the team. It was essential that the consumer felt the necessary level of ownership with the plan to optimize the potential for successful implementation. This meeting was the initial and important opportunity for the transition service coordinator to emphasize the plan as a roadmap for meeting their newly formulated goals for the future. The consumer then explored with the coordinator what steps were needed to reach their long-term goals. Many youth who were referred to the CHF transition clinic stated they want to be employed, relinquish Supplemental Security Income (SSI), move out, and eventually have their own families. A significant, albeit legitimate concern, was the fear of losing their health insurance coverage if they no longer received SSI. The team emphasized that working with the Department of Rehabilitation and the Center for Independent Living were concrete ways to start achieving goals and addressing their concerns about health insurance coverage.

## Follow-up Services and Coordination

The most critical service component to ensuring the youth's/young adult's progression to meeting their stated goals was the long-term follow-up by the transition service coordinator. Initially, this CHF service component was conceptualized as a well-defined and structured follow-up with specific time frames of weekly contacts for 1-2 months and then monthly for 1 year with flexibility for more communication as appropriate. However, this plan proved to be inadequate to the needs of the youth/young adults served by the CHF clinic, as more intensive follow-up was apparently needed. Generally, the modified follow-up services consisted of weekly or biweekly contacts primarily by phone and, in some instances, in person. There were a number of reasons to account for this restructuring of follow-up services.

The foremost reason for providing more intensive follow-up services was the significant needs consumers had for ongoing support and encouragement. Many of the consumers referred to CHF had not achieved comparable developmental levels milestones as would have been expected for their age. Their life experiences had been significantly impacted by their special health care need/disability, thereby limiting their opportunities to learn developmentally-appropriate personal and social competencies. For example, one youth had dropped out of school at age 14 when diagnosed with a chronic condition. Four years later when he was enrolled in the CHF clinic, he presented with significant needs for learning, developing age-appropriate social relationships, and acquiring more sophisticated coping skills. Emphasis on developmentally-appropriate skill building, including long-term chronic and primary care management, was an essential feature of his transition planning to ensure progress toward achievement of his stated life goals, which included the desire to be married and have a family.

In other instances, parents were concerned about their children's ability to achieve their goals (Betz & Redcay, 2002). For example, a youth's desire to obtain a summer part-time job would be influenced by the parent's belief that having a job would be problematic. Parental reasons given included the youth's lack of skills, the special health care needs/disability itself, competing family demands, and the lack of available transportation resources. Many parents were tremendous partners and advocates for their children in providing needed support

and encouragement such as assisting with filling out application forms and providing transportation to meetings. The transition service coordinator was available to provide support, advocacy, and serve as a resource as needed under these circumstances.

In many cases, the service systems necessitated consistent monitoring by the transition service coordinator. Numerous situations arose during the processing of service referrals and coordination between service systems. For many youth, the process of contacting a service agency was an intimidating experience. Very often, service personnel responded to their questions in bureaucratic fashion, as they were accustomed to dealing with older beneficiaries. The philosophic orientation of adult service systems is not oriented to the developmental needs of adolescents. Hence, the transition service coordinator was needed to provide encouragement, assist with problem solving, and enact simplified forms of role-playing for ongoing teaching and support to the consumer.

In other instances, phone calls to service agencies made by either the consumer or transition service coordinator were not returned requiring persistent efforts to elicit a return call. It would not be unusual for a youth to cease any additional attempts to contact the agency if initial calls were not returned. Under the best of circumstances, making phone calls to agencies to request services is difficult for the most seasoned of professionals let alone for a young person whose use of the telephone has been mainly for social purposes. Ongoing follow-up by the transition service coordinator enabled her to address these circumstances and provide coaching to the youth as to the next course of action, such as calling to enroll in a local health care clinic. The challenge was to bolster the youth's plan of action and commitment in the face of these systemic frustrations and use these situations as a learning opportunity for dealing with community resources.

Many of the youth and young adults referred to the CHF clinic had limited, personal, successful experiences with educational, vocational, or social achievements. Many would become discouraged with perceived setbacks in achieving their goals and dreams for the future (Betz & Redcay, 2002). Others had not learned to initiate actions on their own behalf, such as making contact with their agency case manager or simply expressing a personal preference. One young man experienced mild cognitive delays as

one of the long-term outcomes of his medical treatment. He was enrolled with the Department of Rehabilitation but was unsure of his career goals and lacked the self-confidence to believe he could achieve success in school or employment. He did not respond to repeated phone calls and letters from his rehabilitation counselor. Eventually he was dropped from the Department of Rehabilitation services and felt that he was unfairly rejected. Through the coordination of services provided by CHF, he has now been referred to the Client Assistance Project at the Center for Independent Living with the intent of reapplying to the Department of Rehabilitation and improving his self-advocacy skills.

## Nursing Implications

CHF demonstrated the potential of this nurse-managed clinic as a transition service model. This model, originally designed for application in educational settings was utilized to primarily address health care concerns associated with this period of transition. It is possible that this service model could be replicated in a number of health care settings ranging from regional tertiary centers to community- and school-based clinics. CHF used a non-categorical approach for enrolling consumers; however, this model could be easily adapted for condition-specific populations. This service model differed from more commonly reported transition models in several ways. Transition services were comprehensive in scope, addressing the youth's/young adult's needs for adult health services, education and training, employment, housing, and community living, unlike more conventional programs that focused solely on medical services.

This model relied on leveraging resources currently available in the community to meet the individualized needs for transition services. This transition clinic made use of available community resources to avoid duplication of services. Numerous public service programs are funded at the local, state, and federal levels to provide the very services for training, job preparation, and community living that youth and young adults with special health care needs require to successfully make the transition to adulthood (Betz, 1999). For example, the recently passed Workforce Investment Act now provides for year round youth programs that include job training, leadership, and mentoring activities to assist all youth, including those with special health care needs, to develop job

preparation skills.

Additionally, lessons were learned about the process of providing transition services beginning with the assessment of needs and continuing with ongoing monitoring of service coordination and referral (Betz & Redcay, 2002). The process of assessing the youth's/young adult's transition needs is more involved and comprehensive than previously described (Betz, 1998a). As a result, service needs were more complex, dynamic, and long-term in scope. Most of the youth and young adults referred for services required ongoing support and monitoring not only to assure adherence with the transition plan but to respond to their ever-changing needs. For example, one youth was reluctant to assume more independence for his transportation needs, as he had relied heavily upon his parent for transportation. However, his attitude and behavior changed swiftly when his parent unexpectedly died, as he was now compelled to learn to drive. As circumstances changed, the youths/young adults changed themselves during a very dynamic period of their lives. A job preference for summer employment could be the catalyst for an entirely new career or vocational choice. All of these circumstances require continual monitoring and intervention by the transition service coordinator.

Another insight gained from this experience was the need for all professionals and providers in health care and other interagency systems to adopt a lifespan approach in providing services to youth with special health care needs. That is, professionals need to make reference to and about the child's future as an adult. This perspective needs to be as pervasive and expectant as it is for healthy children. Role modeling and mentoring of youth and young adults by adults with special health care needs fosters positive expectations for the future. Encouraging peer support and leadership activities is an avenue for fostering positive attitudes and learning strategies for every day living that are essential for meeting goals for adulthood. Peer support groups such as Kids as Self-Advocates (a program of Family Voices) enable youth to network and learn from their peers.

This experience demonstrated the role nurses could assume in providing transition services to youth with special health care needs. Nurses are ideally suited to function as transition service coordinators given their understanding of the comprehensive biopsychosocial needs adolescents with spe-

cial health care needs have as they transition to adulthood. Their experience in applying the nursing process within their scope of nursing practice can be applied to this new area of service need. Nurses can take the leadership in developing and implementing programs within their health care settings as has been done with this experience.

### Summary

The CHF service model is innovative and characteristically different from those previously described in the literature that are primarily medically-based. The clinic is based upon a model originally developed for educational settings but that was adapted for a health care setting using a family nurse practitioner in consultation with an interagency team of child and adult providers. A strength of this model is its use of available community resources to avoid service duplication and costs. Transition planning is an important role for pediatric nurses and pediatric nurse practitioners, as they possess the knowledge and understanding of living with a special health care need. Nurses can work with youth, young adults, families, pediatric and adult professionals, and service providers in assessing and identifying health care needs that affect the achievement of lifetime goals such as having the needed workplace accommodations or access to health insurance coverage. Youth-centered and asset-oriented plans developed in coordination with interagency partners will assist youth in achieving their goals for the future.

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