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Transitioning adolescents and young adults with a chronic health condition to adult healthcare - an exemplar program

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Over the last generation, pediatric specialists have successfully improved the longevity and quality of life of many children with chronic health conditions (CHC) Betz (2004); Bowman, McLone, Grant, Tomita, & Ito (2001); Clarizia et al. (2009); Sawin, Cox, & Metzger (2010). Important points of focus for this population include age-related tasks of developing self-sufficiency, pursuing independence and planning for their futures – including the transition of healthcare to adult facilities. Transitioning is important for both medical and social reasons. As adolescents reach adulthood, they may encounter other concomitant medical problems more commonly treated in adult facilities. Furthermore, the transition to adult healthcare facilities allows adolescents and young adults (AYAs) to grow their independence. Our experience and the experiences of others (Boyle, Farukhi, & Nosky (2001); Flume, Taylor, Anderson, Gray, & Turner (2004); Giarelli, Bernhardt, Mack &

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Pyeritz (2008) indicate that AYAs and their parents often are reluctant to transfer care to a new adult healthcare team and facility. Therefore, it is important for the transition team to help the family feel comfortable with, and confident in, both the transition process and the new healthcare team/facility.

This article describes the experiences of the Children's Hospital of Wisconsin Spina Bifida Program Team working with select adult healthcare providers at Froedtert Memorial Lutheran Hospital and the Medical College of Wisconsin in developing and implementing a formalized pediatric to adult Spina Bifida Transition Program. Suggestions and resources are offered to guide success during the development, implementation and evaluation of a transition program. The processes and tools used to develop our program are likely to be useful to other healthcare professionals in their development of pediatric to adult healthcare transition programs for AYAs with a variety of CHC.

Background

Published literature delineates a large gap in adult healthcare for AYAs born with CHC (USDHHS Healthy People (2010) and (2020); Sawin et al. (2010). A comprehensive analysis of the literature identified a lack of: effective transition programs, theoretical frameworks to guide programs, valid and reliable instruments to measure outcomes, data on readiness for transition, and evidence of factors associated with successful transition outcomes (Betz, 2004). Multiple authors have identified physical and psychosocial barriers to an effective transition. These include culture differences, limited adult health care providers with condition specific expertise, and lack of sensitivity to family issues (AAP) (2002); HRTW (1989).

The American Academy of Pediatrics (AAP) (2002) identified multiple benefits of transitioning to adult care and strongly recommended the development of transition programs from pediatric to adult care for all children with CHC. Specifically, the AAP proposed that such programs would provide AYAs with access to sub-specialists for on-going care, promote competence, independence and social/emotional development, and allow a sense of security for support of long term healthcare planning and life goals.

In an effort to remedy service gaps, the AAP (2002) identified critical "First Steps" needed to transition. These "First Steps" included engaging the Pediatric Health Care Provider in the transition process, preparation of a portable, accessible medical summary, and other responsibilities. Others have identified vital components of successful transition programs as including: working directly with the AYA, focusing on the development of self-management behaviors and readiness for transition (Greenen, Powers, & Sells (2003); Reiss, Gibson, & Walker (2005), and training adult providers. Coordination of transition services has also been identified as important. Coordination includes transfer of clinical information, patient follow up (McLaughlin et al. (2008), nurse oversight of the transition experience (Patterson & Lanier (1999), and program evaluation (McLaughlin et al. (2008). Recently, the AAP (2011) published a general guide/algorithm intended to help pediatric and adult healthcare providers implement transition processes for individuals with CHC, beginning early in adolescence. With this overview of what all AYAs with CHC need to prepare them and their families to enter the world of adult healthcare, our pediatric team proceeded to identify additional areas that required services that would meet the needs of AYAs with spina bifida.

Focus on Adolescents and Young Adults with Spina Bifida

While embracing the above general recommendations, our pediatric team recognized that AYAs with spina bifida (SB) have been identified as having additional specific healthcare needs that require attention in the transition process (Betz, et al. (2010); Sawyer & Macnee (2010). These include awareness of their wide diversity in intellectual, physical, social, emotional and independent functionality. Lipak (2009) described key characteristics of successful SB transition as: (a) specific training/mentorship of AYAs; (b) pediatric and adult healthcare provider collaboration; (c) family education and support; and (d) a dedicated transition coordinator to set developmentally appropriate goals, manage transportation and transfer health information from one team to the other. Yet, to date, few programs have been developed that include these characteristics.

Due to medical advances in the specialty areas of neurosurgery, urology, orthopedics and rehabilitation, children born with SB in recent years are expected to live well into middle age and beyond (Bowman et al. (2001); Dicianno, et al. (2008). Following discharge from the newborn nursery, the child and their family see specialists and members of the SB healthcare team on a regular basis. Families frequently forge a strong “connectedness” with the pediatric health care team (Wang, McGrath, & Watts (2010), possibly explaining a family’s reluctance to embrace transition.

Many adults with SB receive care in pediatric settings. In a study of 63 SB programs in the United States, 41% provided care in a pediatric setting to both children and adults with SB (Delmarva Foundation (2006). It is unknown if these programs use a conceptual framework as suggested by Betz (2004). This practice of providing care to adults in pediatric settings raises several challenging questions. Does a pediatric environment promote self-advocacy, autonomy and self-management? How are inpatient hospitalizations affected? Are appropriate specialists available (e.g., Rheumatology, Sexual Health, Women’s Health)? We propose that a better approach is to partner with an adult healthcare facility to provide optimal care for this population.

Conceptual Framework

The development of our SB Transition Program was guided by the Transition Care Model and the Ecological Model of Secondary Conditions and Adaptation in Spina Bifida (Sawin, Buran, Brei, & Fastenau (2003); Sawin & Thompson (2009). The Transition Care Model (see Figure 1) provides a bridge between pediatric and adult healthcare providers in their respective facilities and served as a framework for the overall development and evaluation of our transition program. Using all domains of this model, both pediatric and adult transition visits were created to: (a) inform the AYA and family of a different system of care delivery; (b) orient the AYA and family to the adult care model; (c) focus on promoting AYA autonomy and encouraging their self-advocacy; (d) help coordinate the transition care visits; and (e) enhance the AYA’s skill in coordinating their own care.

Ecological theory is particularly useful in our program as it describes a system of factors that surround an individual and influence the experiences and behaviors of that individual (Wang et al. (2010). Our second model, Ecological Model of Secondary Conditions and Adaptations in SB, was used to guide the assessment of AYA in transition. This model identifies two types of risk factors (SB-specific factors and neuropsychological factors) and three categories of protective processes (adolescent resiliency, family resourcefulness and health care adequacy) that influence four outcomes (i.e., physical health, mental health, academic competency and health related quality of life) (Sawin, et al. (2003); Sawin, et al. (2009). We used the categories of protective processes and the related outcomes to develop tools used during and after the transition visit. They are discussed in detail later on in this article.

A Pediatric To Adult Healthcare Exemplar Spina Bifida Transition Program

It is important to acknowledge from the outset that a systematic process (planned meetings, follow-through, on-going evaluation) is needed to successfully establish a pediatric to adult healthcare service. Key questions to ask concerning any specialty population include: (a) Who are the adult healthcare providers most likely to take interest in providing care and how can they become engaged in the transition process? (b) What services are essential to care continuity? (c) Which services are the adult healthcare providers willing to offer? (d) Are grant monies available to help establish a pilot transition program? (e) How best can the transition process be facilitated and evaluated?

Although the literature emphasizes the need for pediatric to adult healthcare transition programs for youth with CHC, exemplar transition programs are rare. When the Children’s Hospital of Wisconsin SB team entered the planning stages to transition AYA to adult healthcare, no other adult specific SB clinics existed in the region and very few models existed across the country. Our goal was to collaborate with appropriate staff from Froedtert Hospital, the adult facility located on the same Regional Medical Campus as our Children’s Hospital. Physicians from both the pediatric and adult facilities were faculty of the Medical College of Wisconsin and often knew one another within their specialty areas. The Advance Practice Nurse (APN) and Medical Director of the Children’s SB Program worked together to plan the first meeting. Medical College Department Chairmen of Neurosurgery, Orthopedics, Urology and Physical Medicine and Rehabilitation (PM&R) were invited to the meeting because they represented the physician specialists on the Children’s Spina Bifida Team. They also were chosen because they had the power to make decisions – a key to success.

Another key to building a successful program was a carefully planned first meeting. We implemented the following essential activities: (a) invite people who can champion your cause, be a stakeholder, or can make decisions; (b) ask the questions “who,” “where,” “when,” “how” and “why”; (c) be willing to meet at the facility you want to be involved with the project; (d) always have an agenda and summarize the key points at the end of the meeting; (e) bring relevant documentation and research summaries to the meeting; (f) listen and learn; (g) prepare and distribute a timely, written meeting summary; (h) follow-up on assigned tasks to ensure progress and identify any unresolved issues; (i) include affected staff when appropriate; (j) recognize that “stumbling stones” do not have to become barriers; and (k) commit to facilitate positive outcomes through cooperation, collaboration and accommodation. Many of our essential program development activities (see Table 1) were also recommended by Sheehan & Zeigler (2010) in their description of developing an outpatient wound care clinic in an acute rehabilitation setting.

The pediatric Spina Bifida Program Medical Director convened our first joint meeting with the following agenda prepared by the APN: Welcome, Introductions, Potential Customers and Volume, Services Needed, Mutual Benefits, Insurance Payment, Feasibility, and Next Steps. Consensus was that interest in establishing an Adult Spina Bifida Clinic existed and the timing was appropriate. The next step in the process was critical. Stakeholders from each institution needed to come forward and help plan the second meeting. Even with the best intentions, a new program will not materialize unless someone is willing to put in the time and effort necessary to advance the discussion ideas. In our case, it was the Pediatric APN and PM&R physician joined by the Clinical Director of PM&R and a Neurourologist from the adult setting who assumed key leadership roles. The APN served as the main project coordinator/facilitator and worked with the other leaders to plan the second meeting. This core group of leaders, joined later by the principal research investigator, continued to work together to plan future meetings, advance program goals and pilot the first Adult Spina Bifida Clinic. Anticipated potential problem areas in transitioning to adult care included changes in care delivery focus by providers, environment, and systems (e.g., registration/scheduling). As each issue surfaced, the planning team worked toward mutually agreeable decisions.

The adult partners identified through this process were the Spinal Cord Injury (SCI) Program in the PM&R Department and the Urology Department neurourologists. The SCI Program emerged as a strong partner because it served a parallel population that had acquired (i.e., SCI) rather than congenital (i.e., SB) spinal cord dysfunction. The SCI Program had appropriate physical facilities to accommodate wheelchair users, including electric exam tables, wheelchair scales, trained staff familiar with spinal cord dysfunction issues (skin breakdown, incontinence, depression) and leadership committed to a partnership. Additionally, the SCI Program was developing a long term care model that included primary care. This model would seemingly benefit AYAs with SB as well as expand the SCI Program.

An additional asset was the SCI Program’s accreditation by the Accreditation of Rehabilitation Facilities. As adult inpatient rehabilitation admissions have become shorter and harder to justify, this accrediting agency has mandated that an outpatient component be added to maintain accreditation of a SCI Program and that the program have a “spinal cord system of care.” This system of care is intended to identify the various components of life-long care and services for people with spinal cord dysfunction besides the mandatory inpatient rehabilitation unit. Thus, because of their skill level in this population across adulthood, sub-specialty training in spinal cord injury, and focus on patient-family centered primary and secondary care, the adult SCI Program was a good “transition fit” with the needs of our young adults with SB. While serving as home base, the SCI Program can also appropriately provide primary care and coordinate health care and disability related needs (i.e., orthotics, durable medical equipment, home health, etc.).

The timing for developing an AYA to adult transition program for those with SB was also good for the adult Urology Department. Having recently hired physicians with expertise in the neurogenic bladder (neurourologists), the Urology Department staff was well prepared to continue quality urological care of AYAs with SB.

Effective Communication Systems Approach

Building trust and “letting go” are key elements in developing and maintaining a positive relationship among providers of different institutions. As regular planning meetings continued, it became increasingly clear that changes from the Pediatric Model to the Adult Model of healthcare delivery had to be made for program development to continue. For pediatric leaders, this meant “letting go” of the “pediatric way” and embracing the “adult way.” Changes included which specialties would be available during the adult clinic, where patients would be seen and how referrals would occur.

It is important for the pediatric transition leader, in our case the APN, to be familiar with the adult care environment (clinics). Our patients needed a latex-safe environment as well as physical accessibility. People with SB are in a high risk category for developing latex allergy, and limiting exposure helps prevent its occurrence. With the APN’s guidance, latex related equipment changes were made in the adult clinics. This is just one example of the type of cooperation, collaboration and accommodation that is required to establish a successful pediatric to adult transition program.

As collaboration continued, the adult leaders made it clear that on the first clinic day the adult patients would need to see Urology and PM&R specialists in two separate specialty clinics of the hospital. This concept differed greatly from the pediatric model, where all specialists were seen in a single clinic. However, the adult providers’ requirement was reality-based, and insisting otherwise could have stopped program development and rendered it not feasible. Accommodation was necessary. Another important accommodation was made with respect to Orthopedic and Neurosurgery visits. At the pediatric clinic, those specialty visits were included in the patient’s clinic day schedule. In the new adult program, visits with those specialists would be made on an “as needed” referral basis only by the PM&R providers. The Pediatric Neurosurgery Department Medical Director met with PM&R providers to discuss potential problem areas in AYAs with SB (e.g., signs of shunt malfunction, Chiari II, symptomatic cord tethering) and tests to be ordered to help determine the need for a neurosurgery referral.

As meetings continued, it became apparent that a mutually satisfying, collaborative style of working together toward common goals was the way to successfully build a transition program. Discussions during subsequent planning meetings included: Pediatric Transition Visit protocol development (described in the next section of this article); letter preparation to families of transition candidates, informing them of the new adult SB services; promotional methods to inform the SB community of the adult clinic; preparation and transfer of relevant information from pediatric to adult healthcare providers; formal and informal follow-up; and a start date to pilot the new Adult SB Clinics.

A central component of developing a new program is designing the program evaluation. After several meetings, a research opportunity was presented to the core group of leaders that would allow us to formalize and scientifically evaluate the strengths and development needs of our pediatric to adult healthcare SB Transition Program. This research project was to be a multi-phased evaluation that would address the processes and outcomes of the transition to adult care, and include the needs and experiences of the AYAs and their families in the broader transition to adulthood. The research proposal was readily embraced by the core leaders and became an optional part of the SB Transition Program. We recommend that transition program planning include a strong evaluation component.

Program Implementation: Pediatric Transition Visit

The purposes of the patient/family pediatric transition visit, convened by the SB Program APN, were to: (a) discuss the adult SB services and the adult setting; (b) conduct a transition-focused history and brief physical examination; (c) provide and orient the AYA to an excellent transition resource, *Adult Healthcare Manual* published by the National Spina Bifida Association (2005); and (d) discuss scheduling the patient's first visit at the Adult SB Clinics on a designated day, in reserved clinic visit time slots. A checklist (see Figure 2) was developed as a guide to essential visit components and to facilitate documentation. During this visit, the AYA and their parents also were offered the opportunity to participate in our Transition Research Project. When they volunteered to participate, research staff obtained consent and administered the baseline study instruments during the same visit. The pediatric transition visit ended with a tour of the adult hospital's Urology and PM&R clinics, viewing the parking options and identifying food services locations. The tour was designed to help patients and their families feel confident and comfortable as they prepared for their first visit to the Adult SB Clinics.

Following the patient's pediatric transition visit, the APN prepared the Spina Bifida Brief Clinical Summary for the patient's new adult healthcare providers (see Table 2 for outline). The summary was based on the information gathered during the transition visit and relevant medical records. The patient also received a copy of the summary. In addition, the patient's most recent radiological studies were taken to the adult hospital for copying into their radiology system, facilitating immediate availability to the adult providers.

Although the pediatric transition visit addressed the specifics of making appointments, the adult with SB was responsible for calling Froedtert's registration staff to make the visit appointments in the Urology and PM&R clinics. For many adults, it was the first time they made their own healthcare appointment. It gave them a sense of responsibility, independence and accomplishment. They also had to make transportation arrangements. Their first SB clinic day was coordinated so that they would see Urology in the morning and PM&R in the afternoon, as close together as feasible.

Program Implementation: Adult Transition Visit

All new AYAs with SB are scheduled for a 75 minute visit in the SCI clinic. After a brief welcome and introduction, considerable time is spent on establishing a rapport with the patient (and family if present), by engaging in a discussion about family, social and functional history, as well as vocational goals and health concerns. This discussion is followed by a complete and detailed physical exam. Key elements of the examination include evaluation of shunt placement, neuromuscular condition and skin inspection. The remaining time focuses on explaining the triage model of care found in adult clinics and how that differs from the pediatric model of care. Key contact information is provided, including a nurse staffed triage line. The availability of clinic visit time slots reserved daily for urgent medical concerns is emphasized. If the AYA's family is present, the AYA is informed that it is their decision to have or not have the family present for subsequent visits. We share our health care goals and work with them toward mutuality. Unless problems or concerns exist, PM&R will see the AYA annually. If indicated, referrals are made (e.g., outpatient Physical Therapy for a wheelchair evaluation). Additionally, a dedicated SCI inpatient unit that focuses on collaborative care among rehabilitation nursing, PM&R, and internal medicine is available as needed.

Patients and families are often most concerned about shunt malfunction. We assure them that their concerns will be addressed and, if indicated, they will be seen in the clinic on an urgent basis or in the Emergency Department after clinic hours. In both cases, patients will be evaluated, appropriate tests ordered, and a neurosurgery consult initiated as indicated.

In the Adult Urology Clinic, the initial visit is 30 minutes. A fellowship trained neurourologist performs a detailed medical/surgical history and physical examination. Careful attention is paid to the patient's bladder management techniques, current use of genitourinary medications, urinary tract issues (incontinence, infection, etc.), bowel program utilized, previous genitourinary surgeries and sexual function. The results of past urinary tract imaging/testing (urodynamic testing, renal ultrasound, cystoscopy) and the necessity of future studies are discussed. Contact telephone numbers for future urinary tract issues and testing are provided. Throughout the visit, establishing a rapport with the patient and his/her family is a priority.

It took 16 months for the SB Transition Program to be fully implemented and the first adult with SB seen in the adult SB Clinics. Some patient/family challenges were resistance to transfer care (change), lack of readiness to transfer care and the fear of leaving healthcare providers that had cared for them over many years. Through informal discussions, we learned that talking about transition earlier with tools such as adult provider information flyers (photo, education, practice) and possibly a tour of the adult facility a year or more before the actual transfer (and again during the Pediatric Transition Visit) may be helpful to some patients and families getting ready to transfer their care. The time spent in careful planning enriched the quality of the transition program and its sustainability. To further develop and improve the program, informal discussions with patients and families will be considered. The opportunity to include the Transition Research Project will provide ongoing evaluation data for evidence based quality improvement initiatives.

Conclusions

While there is urgency in the literature to develop pediatric to adult healthcare transition programs for AYAs with CHC, few exemplar programs exist that demonstrate how this can successfully be achieved. Through the pioneering efforts of a core group of dedicated pediatric and adult healthcare providers, an exemplar transition program for AYAs with SB was developed, implemented and is in the process of being evaluated. The SB Transition Program can serve as a model for other pediatric CHC. Likewise, the adult SCI Program expansion to include SB and focus on long term care can serve as a model for other disability populations.

Based on what we learned throughout the program development process, we recommend: (a) Identification of leaders (stakeholders) from both healthcare settings (pediatric and adult) committed to developing a specific program; (b) Involvement of staff who have the authority to make decisions; (c) Thorough planning while using effective communication systems and keeping to realistic time lines; (d) Accommodation of necessary practice changes (pediatric environment to adult environment) by building trust and “letting go;” (e) Pilot implementation on a small group of patients to evaluate processes, determine patient/family perceptions and make changes where indicated; and (f) Involvement of ongoing program evaluation. Use of these recommendations to develop pediatric to adult healthcare programs for AYAs with CHC is likely to facilitate a successful transition program.

With respect to the above, the emphasis still needs to be on what works in a particular environment for patients, their families and the healthcare providers (pediatric and adult). The “take home” message is that there is more than one way to successfully develop a transition program. While an approach of coordination, collaboration and accommodation are vital, the key is to identify the approach that will work best in your specific environment.

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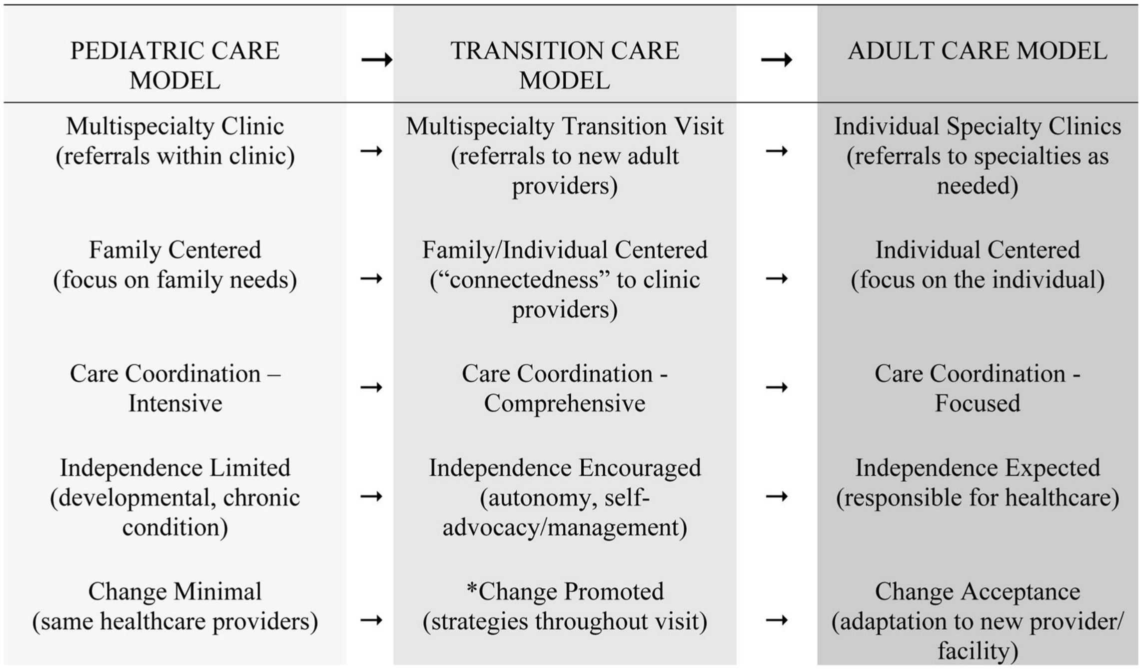
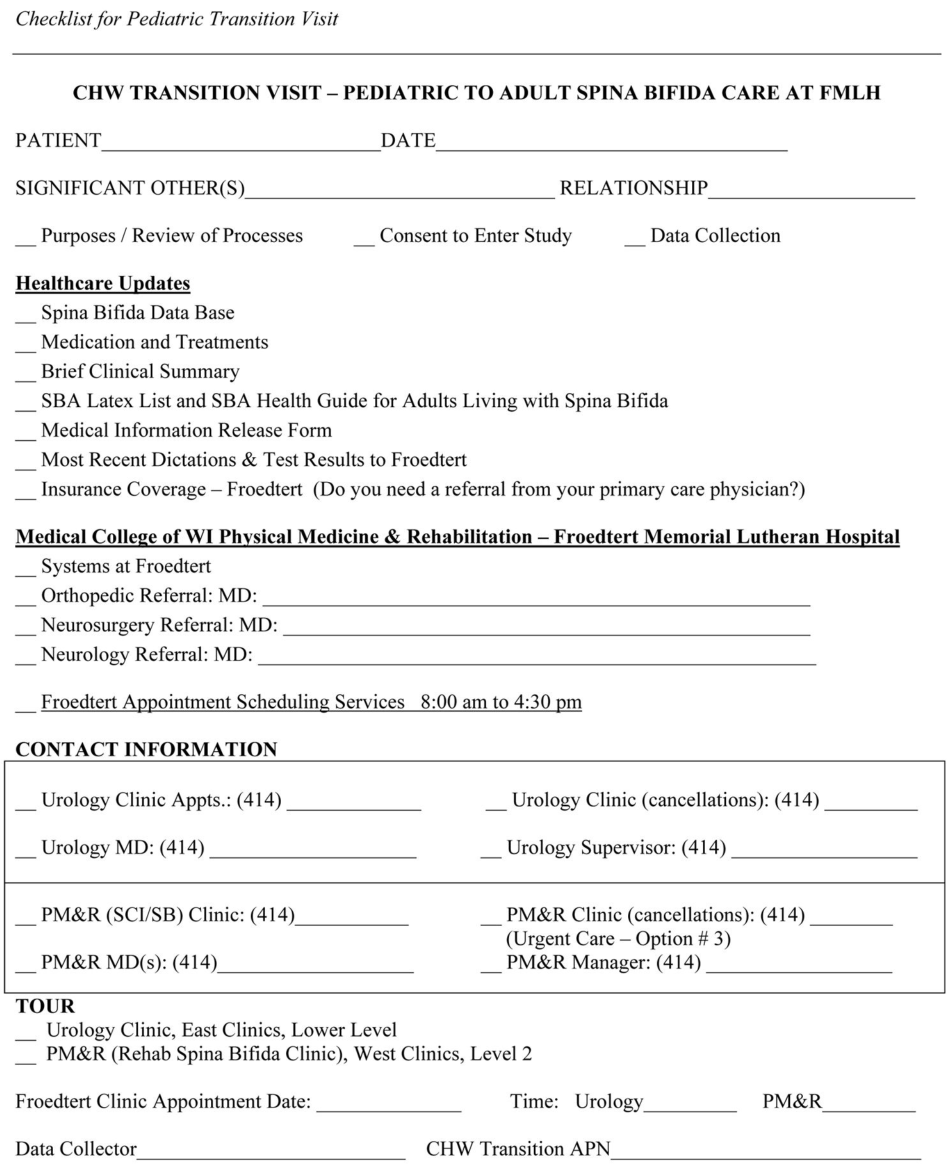


PEDIATRIC CARE MODEL	→	TRANSITION CARE MODEL	→	ADULT CARE MODEL
Multispecialty Clinic (referrals within clinic)	→	Multispecialty Transition Visit (referrals to new adult providers)	→	Individual Specialty Clinics (referrals to specialties as needed)
Family Centered (focus on family needs)	→	Family/Individual Centered ("connectedness" to clinic providers)	→	Individual Centered (focus on the individual)
Care Coordination – Intensive	→	Care Coordination - Comprehensive	→	Care Coordination - Focused
Independence Limited (developmental, chronic condition)	→	Independence Encouraged (autonomy, self-advocacy/management)	→	Independence Expected (responsible for healthcare)
Change Minimal (same healthcare providers)	→	*Change Promoted (strategies throughout visit)	→	Change Acceptance (adaptation to new provider/ facility)

Figure 1. Comparison of Pediatric, Transition and Adult Care Models for Spina Bifida

*Change Strategies: Informing, updating, discussing, touring facility, detailing "why?" and 'how?" and providing written material, including a copy of the Brief Clinical Summary



Checklist for Pediatric Transition Visit

CHW TRANSITION VISIT – PEDIATRIC TO ADULT SPINA BIFIDA CARE AT FMLH

PATIENT__________________________DATE_________________________________

SIGNIFICANT OTHER(S)_____________________________ RELATIONSHIP___________________

__ Purposes / Review of Processes __ Consent to Enter Study __ Data Collection

Healthcare Updates

__ Spina Bifida Data Base
__ Medication and Treatments
__ Brief Clinical Summary
__ SBA Latex List and SBA Health Guide for Adults Living with Spina Bifida
__ Medical Information Release Form
__ Most Recent Dictations & Test Results to Froedtert
__ Insurance Coverage – Froedtert (Do you need a referral from your primary care physician?)

Medical College of WI Physical Medicine & Rehabilitation – Froedtert Memorial Lutheran Hospital

__ Systems at Froedtert
__ Orthopedic Referral: MD: ____
__ Neurosurgery Referral: MD: ____
__ Neurology Referral: MD: ____

__ Froedtert Appointment Scheduling Services 8:00 am to 4:30 pm

CONTACT INFORMATION

__ Urology Clinic Appts.: (414) _____________
__ Urology MD: (414) ____________________
__ Urology Clinic (cancellations): (414) _________
__ Urology Supervisor: (414) __________________

__ PM&R (SCI/SB) Clinic: (414)___________
__ PM&R MD(s): (414)___________________
__ PM&R Clinic (cancellations): (414) ________
(Urgent Care – Option # 3)
__ PM&R Manager: (414) __________________

TOUR

__ Urology Clinic, East Clinics, Lower Level
__ PM&R (Rehab Spina Bifida Clinic), West Clinics, Level 2

Froedtert Clinic Appointment Date: ______________ Time: Urology_________ PM&R_________

Data Collector__________________________ CHW Transition APN_____________________________

Figure 2. Checklist for Pediatric Transition Visit

Table 1

Essential Activities in Successful Program Development

1. Involve people who have the power to make decisions
2. Plan a good “first meeting”
    - Distribute an agenda
    - Invite staff who can champion the cause
    - Be willing to meet a the adult facility
    - Bring relevant documents/ research findings
    - Listen and learn
3. After the meeting follow-up
    - Designate a program coordinator/facilitator
    - Distribute a timely summary of the meeting
    - Check to see that assigned tasks are being done
    - Include staff as appropriate
    - Recognize that stumbling stones are not barriers
    - Commit to cooperation, collaboration and accommodation
4. Establish the next meeting
5. Identify and verify a core group of leaders to advance program goals

Table 2
Outline of Brief Clinical Summary

Patient Name/DOB/Phone:

<u>Contact Information</u> (Name, Phone Numbers)

Primary Care Provider

Pharmacy

Spina Bifida Pediatric Specialists:

Agencies working with patient, including employer

Durable Medical Equipment Supplier

History

Chronic Diagnoses

Past Surgical History

Active Problems with Plan, who is responsible and expected outcome

Patient / Family Goals – Functional, Medical Personal

Emergency Plan / Code Status

Allergies

Medications

Current Functional Status: Cognitive, Behavioral, Mobility, Self-care, Communication, Vision, Hearing, Bowel function, Bladder function, Sexuality, Patient adjustment to disability

Physical Exam

Recent Laboratory / Imaging findings

Assessment

Future recommendations

Other

Clinical Summary provided by ____(insert name/ date)