

# What Do We Really Know About the Transition to Adult-Centered Health Care? A Focus on Cerebral Palsy and Spina Bifida

Jessie A. Binks, MSc, Wendy S. Barden, MSc, Tricia A. Burke, BA, Nancy L. Young, PhD

**ABSTRACT.** Binks JA, Barden WS, Burke TA, Young NL. What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. *Arch Phys Med Rehabil* 2007;88:1064-73.

**Objectives:** To address the lack of synthesis regarding the factors, processes, and outcomes specific to the transition from child-centered to adult-centered health care for people with cerebral palsy (CP) and spina bifida (SB); more specifically, to identify barriers, to outline key elements, to review empirical studies, and to make clinical and research recommendations.

**Data Sources:** We searched Medline and CINAHL databases from 1990 to 2006 using the key words: *transition, health care transition, pediatric health care, adult health care, health care access, health care use, chronic illness, special health care needs, and physical disability*. The resulting studies were reviewed with a specific focus on clinical transition for persons with CP and SB, and were supplemented with key information from other diagnostic groups.

**Study Selection:** All studies meeting the inclusion criteria were included.

**Data Extraction:** Each article classified according to 5 criteria: methodology, diagnostic group, country of study, age group, and sample size.

**Data Synthesis:** We identified 149 articles: 54 discussion, 21 case series, 28 database or register, 25 qualitative, and 34 survey articles (some included multiple methods). We identified 5 key elements that support a positive transition to adult-centered health care: preparation, flexible timing, care coordination, transition clinic visits, and interested adult-centered health care providers. There was, however, limited empirical evidence to support the impact of these elements.

**Conclusions:** This review summarizes key factors that must be considered to support this critical clinical transition and sets the foundation for future research. It is time to apply prospective study designs to evaluate transition interventions and determine long-term health outcomes.

**Key Words:** Cerebral palsy; Disabled children; Health care systems; Rehabilitation; Spinal dysraphism.

## See commentary p 1080.

From Laurentian University, Sudbury, ON, Canada (Binks, Burke, Young); The Hospital for Sick Children, Toronto, ON, Canada (Barden, Young); Institute for Clinical Evaluative Sciences, Toronto, ON, Canada (Young); and University of Toronto, Toronto, ON, Canada (Barden, Young).

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Reprint requests to Nancy L. Young, PhD, Laurentian University, NOSM Bldg, 935 Ramsey Lake Rd, Sudbury, ON P3E 2C6, Canada, e-mail: [nyoung@laurentian.ca](mailto:nyoung@laurentian.ca).

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**T**HERE HAVE BEEN IMPRESSIVE increases in the life expectancy of children with cerebral palsy (CP) and spina bifida (SB) in the last 2 decades as a result of improvements in clinical care.<sup>1-5</sup> These gains in life expectancy present new challenges, including the transition to adult-centered health care,<sup>6</sup> that often occurs between 16 and 21 years of age, when the subjects become ineligible for children's services. Adults must move beyond child-centered health care to preserve these limited resources for children,<sup>7-11</sup> and to ensure that adults receive age-appropriate services such as routine health promotion and screening.

The challenge of this transition, for youths with a variety of chronic health conditions, received international attention in the United States at the 1989 Surgeon General's conference on "Growing up and Getting Medical Care: Youth with Special Health Care Needs."<sup>12</sup> Other groups have also recognized this challenge.<sup>9,13</sup> Because of this attention, transition programs are being developed to bridge the gap between child and adult-centered health care.<sup>1,5,9,14-16</sup> These programs are meant to give youths the knowledge and skills required to negotiate the adult health care system independently,<sup>17-21</sup> to minimize or prevent secondary illnesses,<sup>19,22</sup> to promote autonomy, and facilitate their maximum potential.<sup>11,22-24</sup> They are also intended to plan for long-term needs, to give youths hope and focus,<sup>7,25,26</sup> and to teach them that leaving pediatric care is not a precursor to drastic declines in health.<sup>27,28</sup>

The transition to adult-centered health care is uniquely challenging for people with CP<sup>4,29,30</sup> and SB<sup>31,32</sup> because their complex health care needs become superimposed on an adult health care system with fragmented services.<sup>4</sup> The adult system is often lacking in expertise specific to chronic conditions of childhood, and rarely includes multidisciplinary teams that are central to the care of people with CP and SB.<sup>18,31,33-36</sup> Because the health and well-being of these vulnerable adults hinges on uninterrupted access to health care,<sup>37</sup> a successful clinical transition is critical.<sup>38</sup>

Although some key elements essential to transition services have been proposed in the literature, a synthesis of this information as it relates to CP and SB is not available to guide clinicians in the development of evidence-based programs. Furthermore, few standardized programs have been implemented and empirical studies have rarely evaluated the effectiveness of such programs.<sup>26,39</sup> The purpose of this comprehensive review was to synthesize the key issues, to facilitate the development of clinical programs, and to direct future empirical research specific to CP and SB.

Our objectives in this review were (1) to identify barriers associated with the transition to adult-centered health care for CP and SB patients; (2) to outline key elements that should be included in transition programs for these groups; and (3) to

review the empirical evidence related to the process and outcomes of that transition. This information will be useful in guiding and encouraging future research to empirically evaluate the impact of transition on health outcomes among adults with CP and SB.

## METHODS

We conducted a comprehensive review of the clinical literature, using Medline and CINAHL databases, encompassing the period 1990 to 2006. We limited our review to English-language studies published in the peer-reviewed literature and we applied the following 4 search strategies.

First, in our database search we used the following key words: *transition, health care transition, pediatric health care, adult health care, health care access, health care use, chronic illness, special health care needs, and physical disability*. The results were combined (using the and command) with the terms cerebral palsy or spina bifida.

Second, we used an author name search of the same databases to find additional studies by authors identified through the primary search strategy. These articles were only included if they were focused on the transition to adult-centered health care for people with CP and SB.

Third, the reference lists from all articles found resulting from the first 2 strategies were reviewed. We did this to identify key articles not found in the original search.

Fourth, studies related to health care transitions of people with other conditions previously experienced only in childhood, but now common in adulthood, were also identified. These included: diabetes, respiratory disease, renal impairment, juvenile idiopathic arthritis (JIA), inflammatory bowel disease (IBD), cystic fibrosis (CF), congenital heart disease (CHD), celiac disease, cancer, organ transplant, and epilepsy. These articles were included to augment the limited literature with a focus on CP and SB. Studies focused on conditions other than CP or SB (ie, articles identified by strategies 2, 3, and 4), were included in this review only if they provided key information related to clinical transition that was considered relevant to CP or SB.

All studies that met the inclusion criteria specified above were reviewed jointly by 2 reviewers and labeled according to the reviewers' consensus on 5 criteria that described the nature of each study: methodology, diagnostic group, country of study, age group, and sample size. The labels were generated based on the themes that were common in the articles reviewed. Some studies included multiple methods, diagnoses, or age groups. In such cases, the study was included in all relevant groupings. This information was compiled in table format to describe the sample of articles used in this review.

The main review process included all articles, which were coded according to their main messages. Articles with similar main messages were placed together in common themes. Again, many articles contributed to more than 1 theme. Article themes were organized under the main objectives and identified a priori: barriers, key program elements, and empirical evidence. Details regarding the main themes were synthesized and are presented in table 1.

## RESULTS

Our review of the literature identified 149 articles that were published between 1990 and that were relevant to the transition to adult-centered health care. (The reference list includes 150 references because of the inclusion of reference 12, which is a conference proceeding that was a keystone in the transition literature, but that was not peer-reviewed. Peer review was a

**Table 1: Number of Articles per Theme**

Theme	No. of Articles Cited
Child-centered health care providers	22
Youth	16
Parents	23
Adult-centered health care providers	18
Total no. of articles contributing to objective 1 (barriers to transition)	30*
Timing	19
Preparation	33
Coordinated approach	33
Transition clinics	27
Interested adult-centered health care providers	23
Total no. of articles contributing to objective 2 (key elements suggested for transition programs)	42*
Introduction	56
Empirical evidence based on other chronic conditions of childhood	41
Why does evidence from other populations not apply to CP and SB?	42
Total no. of articles contributing to objective 3 (empirical evidence re: process and outcomes of transition)	123*

NOTE: Only 11 (7%) articles were original research specific to persons with CP and SB.

\*The total number of articles contributing to each objective is less than the sum of the parts because some articles contributed to more than 1 part and were counted only once in the total.

criterion for inclusion in the results.) Of the 149 articles, 36% were discussion studies, 17% reported the results of qualitative interviews, 23% reported survey results, 19% reported on secondary analyses of pre-existing databases or registers, and 14% were case series reports. Most of the studies were conducted in the United States, the bulk of the remainder were done in the United Kingdom, Canada, and Australia. Table 2 summarizes the articles included in this review.

Several categories appeared consistently across the articles. These were organized under each of the objectives set a priori. The common themes and the number of articles that contributed to each theme are presented in table 1.

### Objective 1: Barriers to Transition

Many barriers to transition for people with CP and SB were identified; most were similar to those experienced by adults with other complex chronic illnesses. Barriers were reported from several perspectives, including providers of child-centered health care, youths in transition, parents of these youths, and providers of adult-centered health care.

**Child-centered health care providers.** One of the greatest barriers to an effective transition was reported to be the inability of child-centered health care professionals (eg, pediatricians) to "let go" of their long-standing relationships with patients,<sup>1,3,10,11,14,15,18,20,23,25,27,28,31,40-45</sup> and their distrust of adult-centered health services.<sup>1,10,14,20,23,25,26,31,41,46</sup> This often results in a lack of planning and a critical delay in readiness to transfer.<sup>20,45,46</sup> The literature, however, underscores the importance of leaving the child-centered health care system because child-centered providers may not be best suited to care for young adults.<sup>10</sup> For example, pediatricians often find it difficult to discuss adult issues,<sup>26,40,47</sup> and may be inexperienced in dealing with changes in childhood diseases during adulthood.<sup>15</sup>

Table 2: Summary of Articles Used in the Literature Review, With Emphasis on CP and SB

Descriptor	Discussion Articles (n=54)		Database Analyses (n=28)		Case Series* (n=21)		Quantitative Methods* (n=34)		Qualitative Methods* (n=25)	
Country	United States	34	United States	11	United States	7	United States	15	United States	9
	United Kingdom	13	United Kingdom	11	United Kingdom	8	United Kingdom	5	United Kingdom	7
	Canada	4	Canada	3	Canada	1	Canada	2	Canada	4
	Australia	3	Australia	3			Australia	3	Australia	3
					Sweden	1	Sweden	2	Sweden	1
					Italy	3	Italy	2		
							Germany/Netherlands	2	Germany	1
					Japan	1	Japan	1		
							Norway	1		
							New Zealand	1		
Diagnostic group	<b>CP</b>	<b>6</b>	<b>CP</b>	<b>13</b>	<b>CP</b>	<b>7</b>	<b>CP</b>	<b>11</b>	<b>CP</b>	<b>10</b>
	<b>SB</b>	<b>3</b>	<b>SB</b>	<b>2</b>	<b>SB</b>	<b>11</b>	<b>SB</b>	<b>7</b>	<b>SB</b>	<b>5</b>
	Ill-defined conditions	31	Ill-defined conditions	12	Ill-defined conditions	1	Ill-defined conditions	5	Ill-defined conditions	5
	CF	6					CF	7	CF	4
	JIA	1			Diabetes	1	Diabetes	1	Diabetes	2
	Cancer	1					JIA	2	JIA	1
			CHD	1			Cancer	1		
	Other chronic conditions (IBD, organ transplant, renal and respiratory conditions)	5			Other chronic conditions (celiac disease)	1	CHD	1	Other chronic conditions (epilepsy)	1
Age group*	Children	13	Children	7	Children	3	Children	5	Children	2
	Youth and young adults	45	Youth and young adults	21	Youth and young adults	15	Youth and young adults	29	Youth and young adults	24
Sample size	Adults	8	Adults	20	Adults	13	Adults	18	Adults	13
	0-30	NA	0-30	0	0-30	4	0-30	5	0-30	8
	31-100	NA	31-100	1	31-100	7	31-100	13	31-100	11
	101-200	NA	101-200	0	101-200	3	101-200	6	101-200	3
	201-300	NA	201-300	3	201-300	4	201-300	3	201-300	3
	>300	NA	>300	24	>300	3	>300	7	>300	0

NOTE. Items in bold indicate articles specific to CP and SB.

Abbreviation: NA, not applicable.

\*Some articles had methods and/or age ranges that overlapped, and therefore were included in all relevant categories.

**Youth.** Obstacles may also arise from youths themselves. There is often little incentive for them to move on from providers who have supported them very well for a long period. Young adults may be reluctant to leave the safety and familiarity of family-centered care.<sup>1,15,18,25,27,28,46</sup> This philosophy is common practice in health care for children, but is rarely applied to adult-centered services. Some patients feel rejected or isolated after years of commitment by a multidisciplinary group of health professionals.<sup>3,11,14,18,20,26-28,41,43,44,48</sup> Moving to adult services may also be perceived by some as a "step closer to disease complications and even death."<sup>3(p2)</sup>

**Parents.** Parents display their own distinct forms of resistance to their child's clinical transition. Adult-centered services rarely engage with families in the same way as do child-centered services.<sup>3,14</sup> and, as a result, parents may interfere with the transition because they feel excluded from the decision-making process.<sup>3,23,25,42,49</sup> Although parents should be involved in planning, their inability to relinquish control over their child's health and health care decisions may impede their child's autonomy.<sup>11,15,18,20,27,28,31,41,43-47,50-52</sup>

**Adult-centered health care providers.** According to the literature, adult-centered health care providers may present obstacles to successful transition. Adult-centered physicians may have limited training and experience with childhood chronic illnesses, and therefore have limited knowledge or interest in caring for these young adults.<sup>1,3,6,11,15,18,23,25-28,31,35,43,44,52</sup> In addition, they may have insufficient resources to support the patient's complex needs.<sup>23,53</sup> For example, some patients noted in qualitative interviews that their physician was uncomfortable or ambivalent about some topics, had difficulty discussing bad news, and lacked specific training.<sup>15</sup> Adult-centered providers also have a tendency to conduct a complete reassessment at the first appointment, which can be unsettling, exhausting, and frustrating for the young disabled person.<sup>3</sup> The challenges of transition may be further complicated by poor communication between adult-centered providers and patients. Additionally, these clinicians often become overly focused on the patient's chronic illness,<sup>41</sup> and may fail to address the primary medical issues that prompted the visit, or fail to assess routine health and health promotion issues.

## Objective 2: Key Elements Suggested for Transition Programs

Reducing or eliminating these transition barriers has been the impetus for a multitude of discussion articles suggesting essential components for successful transition programs. It is important to recognize that although these elements have been identified in the literature, most of the information is based on theory and has not been subjected to empirical evaluation.

**Timing.** The timing of the transfer should be established by both the pediatric provider and the family.<sup>23</sup> Timing should be flexible, and should depend on the youth's cognitive development, physical abilities, environment, and family support.<sup>1,3,7,11,14,15,17,18,23,25-28,41,43,45,48,50,52</sup> Although no definitive time has been identified for actual transfer, a target age range is helpful in preparing for transition (the most commonly suggested age range is 14 to 16 years). Some clinics use a chronologic cutoff, whereas others use social transitions such as leaving school.<sup>3,25,45</sup> Because many services may be unable to delay the age of transition, they may need to consider beginning the process earlier to align with an externally imposed transition deadline.

**Preparation.** There should be a long preparation period before leaving child-centered care. It is recommended that the transition process should be initiated years before the

official transfer,<sup>1,3,6,7,11,14,18,19,25,28,40,45,46,48,50,54</sup> and some suggest that it should begin at diagnosis.<sup>1,8,13,22,45,55</sup> Patients must understand their condition and its daily management<sup>1,3,6-8,14,21-23,28,43,47,51</sup> and acquire basic skills to independently care for themselves.<sup>1,8,13,17,22,23,52</sup> Nevertheless, independence does not mean "without assistance," only that the young adult must take responsibility for the direction of his/her care, which may include directing an attendant to assist with specific activities. Continuous support and encouragement from family is also essential for the youth to attain autonomy and alter his/her self-perception from being "disabled" to being "competent."<sup>15,17,20,21,27,31,41,42,46,47,52</sup>

**Coordinated approach.** Transition planning for each patient should be a coordinated approach that includes feedback from the youth and his/her family, pediatrician, primary care physician, and adult specialist(s).<sup>1,3,7-11,14,15,18,20,21,27,28,41,43,44,46,50,52,56</sup> The child-centered team should also prepare an up-to-date medical summary to be given to the adult-centered providers,<sup>14,45,48,52,55</sup> including details of current treatment regimes and recommendations.<sup>9,20,25,49,55</sup> Planning should also include the development of a clinical transition plan,<sup>1,6,9,18,20,27,54,57</sup> and, at a minimum, include the services required and identify who will provide them.<sup>9,20</sup> Youths with more severe functional limitations may require a plan developed over a longer period of time.<sup>17</sup> Financial planning (ie, estate details), education, and vocational training<sup>8,10,13,17,18,20,22,42,46,49,55</sup> should also begin before adulthood.

**Transition clinics.** The transition process may be improved with several visits to a transition clinic before the actual transfer, and include a consult with both the child and adult-centered health care providers.<sup>1,6,7,10,20,31,43,45,48,49,52,57</sup> Clinics can provide the patient and family with an overview of the general differences between the 2 sectors of care.<sup>6,23</sup> They also serve as an avenue to provide ongoing support and resources to the family,<sup>1,3,6,13,20,23,46,58</sup> such as contact with a mentor or peer group who have been through the process.<sup>13,20,46,48,54,58</sup> Young adults are encouraged to actively participate in decision making and to direct their own health care.<sup>1,6,13-15,18-20,22,24,28,45,50,56</sup>

**Interested adult-centered health care providers.** For all people involved, transition should be a gradual process, not an event, from child to adult-centered health care. There must be interested adult-centered health care providers on the receiving side of the transition.<sup>1,3,10,14,20,26,43,45,57</sup> Adult-centered providers should not only care for the chronic condition, but also address basic issues such as independence, social interactions, body image, sexual health, alcohol and drugs, and anxiety.<sup>1,6,15,18,20,23,24,27,46,49</sup> Transition planning must involve primary care physicians,<sup>17,55</sup> who may provide the only medical continuity for young people and their families during a time of discontinuities.<sup>43</sup> The child-centered team may need to find an adult-centered provider willing to accept the patient, and become a health care coordinator.<sup>31,46</sup> Increasing ties between child and adult-centered departments may also promote confidence in the adult service.<sup>10</sup> As the transition process unfolds, it should be monitored and evaluated<sup>1,7,11,26-28,57</sup> to help guide the development of best practice.<sup>1</sup>

The key limitation of many of these studies is that the elements have not been implemented consistently in transition programs, nor formally evaluated. Therefore, they are based on theory and clinical experience and are not evidence-based. The volume of discussion articles over the past decade, however, has stimulated an interest in evaluation and, as a result, some qualitative and quantitative studies on clinical transition are now being done.

### Objective 3: Empirical Evidence Related to the Process and Outcomes of Transition

Very few empirical studies addressed the specific issue of clinical transition to adult-centered health care for CP and SB patients.<sup>59-65</sup> Among these was a study by Stevenson et al<sup>61</sup> who assessed the use of health services, welfare, and social functioning before and after leaving school for youths and adults with CP. They identified fragmentation of services after adolescence. General health was considered poor in 21% of their "older" group (20 and 22 years of age), and in 9% of their "younger" group (15 to 18 years of age). Their "older" group also felt more socially isolated than the "younger" group. Morgan et al<sup>59</sup> assessed the decline in contact with health and social service departments for young adults with SB. It was clear from their evaluation that more than half of the young people had unmet medical needs and were grateful for the offer of an annual assessment in the adult setting.

Perceptions about clinical transition have been studied using qualitative methods.<sup>38,66-68</sup> For example, Sawyer et al<sup>38</sup> described the planning and implementation of the transfer of 10 young people (mean age, 22y) with SB to an adult health care facility. They found that most participants had already transferred informally to an adult facility, but with little or no communication between the 2 systems. Darrach et al<sup>67</sup> found that families continued to experience dissatisfaction and frustration with service delivery. The consistent messages from these qualitative studies were that patients and caregivers were unprepared for their roles in the next health care setting, did not understand the essential steps in managing a chronic illness, and had limited access to appropriate health care practitioners for guidance. Effective clinical transitions must bridge the gap between health care institutions that often function in isolation.<sup>69</sup> New models of "cooperative care" that link primary care providers and local services to regionalized adult-centered specialty services may make it possible to offer a meaningful transition experience to young people with chronic conditions.<sup>52</sup>

Overall, there is limited empirical evidence related to the process and outcomes of the transition to adult-centered health care for CP and SB patients. Most of the empirical evidence relates to the functional status (ie, mobility) and social status (ie, living arrangements) of these populations,<sup>70-97</sup> and their life expectancy and causes of death.<sup>32,98-111</sup>

**Empirical evidence based on other chronic conditions of childhood.** Because of limited empirical evidence about transition for CP and SB patients, we elected to supplement the information with data related to transition from other populations with complex and chronic conditions of childhood. Empirical studies on the transition to adult-centered health care have most often focused on young people with CF, cancer, CHD, arthritis, and diabetes, where there are similar conditions in adult populations and therefore have pre-existing adult specialists.<sup>31,112</sup> A series of quantitative articles reported experiences of clinical transition, perceptions about the process from patient, parent, and physician perspectives, and identified issues associated with transition.<sup>5,37,39,53,113-128</sup>

Examples from other populations that enrich our understanding of the clinical transition include a study conducted by Flume et al,<sup>124</sup> in CF clinics across the United States. They assessed health care team members' (ie, nurses') perceptions of clinical transition. The authors stated that only 11% of team members agreed with an introduction to the idea of transfer at diagnosis, and many outlined valid criteria for transfer (ie, 27% cited pregnancy). Shaw et al<sup>128</sup> surveyed 17-year-old patients with JIA and their families, who had been transferred to adult

care. They reported several ongoing transitional issues: 55% were still seeing the rheumatologist with a parent, 20% were not taking their medication independently, and 14% had not received career counseling.

Other studies used pre-existing databases to assess service use and the health status of populations with a chronic condition or special health care needs.<sup>112,129-135</sup> For example, Lotstein et al<sup>37</sup> conducted a study to assess the proportion of youths with special health care needs who received services for medical transitions. Overall, 50% of parents had discussed their child's changing needs with their child's physicians, and 59% had developed a plan to address these needs. Other studies focused on transition to adult-centered health care, while others only addressed transition as an afterthought. Some studies evaluated follow-up procedures for patients who were discharged from a pediatric facility,<sup>136,137</sup> and found that few programs focused on the long-term health needs of adults.<sup>136</sup> Also, several qualitative studies assessed patient perspectives and experiences during their clinical transition,<sup>2,16,29,138-144</sup> and their findings supported those of the quantitative papers cited above.

Why does evidence from other populations not apply to CP and SB patients? Although studies on other diagnoses provide useful information, they are limited in their generalizability to multidomain illnesses such as CP and SB. For example, CP or SB patients may present with limitations in communication,<sup>4,65,85,145</sup> problem solving,<sup>4,77</sup> learning,<sup>30,47</sup> mobility,<sup>4,30,47</sup> and feeding,<sup>4,30,71</sup> and therefore require extensive health care support.<sup>9</sup> The cumulative effect of these complex disorders makes transition difficult,<sup>17,38,47,85</sup> and limits the patients' ability to utilize the adult-centered health care system in the traditional patient-physician relationship.<sup>18,33,45,138,146</sup>

The challenges of clinical transition in the CP and SB groups are also exacerbated by several factors, including the lack of multidisciplinary comprehensive health services for adults with a chronic illness,<sup>23,52,60,73</sup> a dearth of adult providers with interest in chronic illnesses of childhood,<sup>1,3,25,43,44,52</sup> and a lack of specialized training in the proper care of adults with CP and SB.<sup>16</sup> Consequently, these adults are often left to navigate an unfamiliar and often ill-equipped health care system.<sup>38,52</sup> Many adults with CP and SB continue to attempt to access pediatric health care services despite their age and changing needs.<sup>14,26,35,133</sup> Others struggle to connect to appropriate adult-centered health care resources. The remainder stop seeking medical attention,<sup>7,11,13,26,43,117</sup> either out of frustration or rebellion. Clearly, there is a need for ongoing care because of ongoing health issues,<sup>71,147,148</sup> coupled with the development of new health issues in adulthood.<sup>78,81,83,89,145,148-150</sup>

## DISCUSSION

We found sufficient discussion literature about clinical transitions. Currently, the need is to step beyond the concepts and into evidence-based research. This research must begin by defining the concept of success, as related to clinical transition, and how it can be effectively measured. Once this is achieved, suggested research questions include: (1) What is the distribution of health outcomes in adults with CP and SB? (2) What characteristics of transition are associated with better health in adults with CP and SB? (3) What patterns in health care utilization are associated with health and well-being of adults with CP and SB?

These questions may be best addressed by intervention studies that assess the population before and after clinical transition. Now is the time to measure health and well-being, when there are few standardized transition programs in place. Long-term studies will enable us to assess natural variation in the

population, and to tease apart patterns in health associated with the transition to adult-centered health care. People who are at the extremes of the health outcomes distributions, for example, the successes and failures, should be studied further to dissect the nuances of their transition process. Also, multiple methods should be combined within studies to generate a more comprehensive picture of the dynamics associated with transition. For example, qualitative methods enhance and add context to other data collection methods. This type of research will aid in the development of effective transition programs, inform policies on health care for these populations, and help secure funding for specialized services.

Future research must also pay attention to the full spectrum of impairment. Differences in severity (eg, mild vs severe) may cause very different responses to transition and create different needs for clinical transition programs. While we recognize that the strongest studies will include the full range of severity and will use exploratory subanalyses to examine the impact of severity, the sample sizes necessary to accomplish this are often not feasible. The distribution of severity within study samples, however, should be clearly articulated in the sampling frames of future studies.

### Clinical Practice Implications

Several provisions are needed to support adult subjects with CP and SB during the transition process. Adequate funding and resources must be allocated for patients with complex and chronic health care needs (ie, government funding for specialized programs). Furthermore, clinicians must foster the autonomy of physically challenged young people in developing skills for clinician-patient communication. Clinicians should also create a complete discharge summary for both the patient and the adult-centered health care provider that serves as a health care "passport." This will help empower young adults with knowledge about themselves and their disease, help them communicate with their new providers, and help reduce the time required during the reassessment phase. A basic health care passport may have the potential to address several key components of the transition to adult-centered health care described previously in this review.

### Educational Implications for Health Care Providers

The key concepts regarding clinical transition, as well as the emerging empirical research on this topic, must also be translated into the curricula of nursing, rehabilitation, and medical schools. Programs should incorporate information on the unique challenges and special health care needs of CP and SB patients, including changes in the expression of childhood diseases with age. Curricula must also promote the development of skills in working with people who have cognitive and communication challenges, and foster an appreciation of the value and importance of having an advocate in attendance at clinical appointments. This may require clinicians to set aside their concept of the traditional clinician-patient relationship and to learn to include a third party. Seeing beyond the disability is critical in creating a culture of acceptance and instilling a sense of worth in these populations. Finally, providers must learn to balance the concurrent demands of chronic health care conditions with generic health promotion and screening needs.

### Study Limitations

The primary limitation of this review is related to the source materials. The methods and data analysis sections of the source articles reviewed were often unclear (ie, may not have specified

the measurement properties of their data collection tools). The different sampling strategies used in the source articles limited our ability to make comparisons across studies. We had difficulty applying standardized age groupings, because the source materials included variable age ranges and lacked details on the sample characteristics. The lack of detail regarding age within the source articles made it impossible to examine age-specific differences that are key to studying the impact of transition (see table 1). The lack of detail on sample characteristics such as education, ethnicity, employment status, marital status, living arrangement, illness severity, and health status further limit cross-study comparisons.

### CONCLUSIONS

The delivery of care to adults with conditions that have historically been limited to childhood presents new challenges to the health care system.<sup>42</sup> There are many discussion studies on the transition to adult-centered health services that suggest key components for planning and designing successful clinical transition programs. Most studies, however, discuss key factors in isolation, without considering the multifaceted nature of several factors that have a concurrent impact. Furthermore, very few studies have applied and evaluated these concepts in practice, or assessed the direct impact of the transition to adult-centered health care on health outcomes. Moreover, empirical studies specific to CP and SB are rare and have been limited to a few health care systems, making it difficult to compare outcomes across systems.

Clearly, there is a clinical problem that must be addressed by the health care system to ensure that adults with CP and SB receive continuous, age-appropriate health care. The challenge now is to develop high quality, multidisciplinary care comparable to that available for children.<sup>6,7,23</sup> A smooth and easy transition to adult-centered health care should be an expected and desired outcome of child-centered health care.

This review offers a significant step toward that goal by identifying key factors that must be considered in the planning of care for children and adults, and specifically for transition programs. It is time to use emerging theoretical models to develop transition interventions and to evaluate them using controlled trial methods that consider both medium and long-term health outcomes. This review shifts the focus to populations with conditions that require complex care and may have the most difficulty with clinical transition. The greatest opportunities for substantial improvement are found in these vulnerable populations.

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