ABSTRACT
The transition to adulthood for youth born with spina bifida (SB), as for any chronic disability, is challenging. Despite extensive and centralized services offered to this population in childhood, desired outcomes of adulthood are seldom achieved. Adolescents and young adults with SB have lower than expected rates of independence, employment, and attendance in post-secondary education, and are more isolated socially. Because the factors that affect “success” in adulthood are uncertain, programs to optimize the transition of disabled adolescents to adulthood and to support them as disabled adults within the community remain theoretical. In Montreal, a Spina Bifida Continuum Program (SBCP) was created to optimize the continuity of medical care during the transition from childhood to adulthood and to promote social integration for people living with SB. In order to assess the effectiveness of the SBCP, this project will develop a questionnaire based on a set of evidence-based and consensus-based indicators of the essential aspects of services required for the successful transition of youth with SB from childhood to adulthood. A literature review identified 4 major barriers to transition: 1) autonomy and social development; 2) health care management (e.g. coordination of care and access to services); 3) social integration 4) employment/employability issues. These four barriers matched the themes that stemmed from issues raised in three focus groups: 1) young adults with SB, 2) parents, 3) clinicians/administrators. From these barriers, indicators were formulated as questions in a questionnaire that will be administered to clients and families in the SBCP to evaluate the services actually offered to this clientele during the transition to adulthood.