

Social circus program (Cirque du Soleil) promoting social participation of young people living with physical disabilities in transition to adulthood: A qualitative pilot study

Running head: Social circus to promote participation in youth

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ABSTRACT

Purpose: To explore the perceived impact of a social circus program on the participation level of young adults' living with physical disabilities from their own and their parents' perspective.

Method: Exploratory phenomenological qualitative design. A social circus program was offered for nine months. Perceived participation level was documented through pre and post semi-structured interviews. A pretested interview guide was used. Interviews were transcribed and coded by two independent researchers.

Results: The average age of the participants (n=9) was 20.0 ± 1.4 years with 2/9 being female. Participation was perceived as being improved after the intervention from both perspectives (participants and parents) mainly for communication, mobility, relationships, community life and responsibilities. The intervention was perceived as strengthening self-perception and self-efficacy, which in turn enhanced participation level and decreased parents' bounding.

Conclusion: The results show promises for social circus as a new approach in adult physical rehabilitation for this population in transition.

KEYWORDS: Circus, art-based (art therapy), participation, young adult (youth-adolescents) physically disabled (handicapped), transition to adulthood

INTRODUCTION

It is estimated that over half a million Canadian children and adolescents are living with physical disabilities that may limit their physical, psychological, and social development and later challenge their subsequent integration into society as adults ¹. With medical advances in the last quarter-century, there is an increasing number of young adults living with all types of physical disabilities transitioning to adulthood ^{2,3}. Around seventy percent of young adults living with physical disabilities (aged 15-24 years) have more than one type of disability ^{4,5}. Associated neurological and cognitive disorders are often present and, when progressive, can make care and services more complex ⁶.

Young adults living with physical disabilities' transition to adulthood is burdened by the transfer-related challenges from a family focused paediatric services to an adult scattered and patient-centered health ones ¹⁻³. The 'falling off a cliff' metaphor is widely used by young adults living with severe physical disabilities' families to describe the great turmoil associated with this key period of life ⁷⁻⁹. Age, health condition, psychosocial environments, and personal life experiences also greatly influence the duration of this period of life and the challenges related to it ^{10,11}. Social participation is a recognized health-promoting outcome for youth and a measurement of success in rehabilitation science ^{5,12}. Compared to any other population of young adults with disabilities, ones with physical limitations (such as orthopedic, neurological or sensory deficits) and associated conditions (such as mental health issues, autism or learning disability) present the lowest level of social participation ^{5,12}. They appear to have poorer outcomes in the areas such as having friends, leisure, sexuality, employment, finding a living environment, community life, financial autonomy, access to quality services and academic success ^{10,13}. Furthermore, specifically relating to the potential influence of the social

environment, parents may provide too much assistance, which may hinder young adults living with physical disabilities' sense of empowerment. Parents may feel confused by the sudden change in their new roles and responsibilities that are partly imposed by adult services and also by their child's desire for greater independency and participation ^{3,10}.

In their study describing the level of participation and enjoyment in leisure activities of young individuals with cerebral palsy (N=175, mean age: 15.3 ± 2.2 years), Shikako-Thomas and colleagues ¹⁴ reached similar conclusions that concurred with previous studies with cerebral palsy (CP) children. Young adults living with physical disabilities are the least involved in formal social and physical activities, especially community-based ones, which are known to be more beneficial for their overall health, self-improvement, social skills and well-being. Instead, they spend more time at home in informal passive leisure activities. Activities are less varied and are accomplished alone or with parents rather than with peer ¹³⁻¹⁵. However, although these studies are quite recent (< 10 years), this may change in the years to come with a rapidly increasing use of social networking using online platforms; community-based activities may become less required to achieve a satisfactory participation level as youth are not necessarily completely isolated even if they spend most of their time at home (although learning to use those tools may remain a challenge for a proportion of them).

The challenge for healthcare professionals working in adult rehabilitation programs is now greater because, in addition to the complex medical profile and specialized needs of this population, a large majority of young adults living with physical disabilities are pursuing their rehabilitation path started in early childhood and require different services and supports to match their changing needs. Experts agree that innovation is needed to enhance traditional ways of doing things with original, more stimulating, meaningful and holistic approaches that will further

engage young adults living with physical disabilities in adult rehabilitation objectives ^{2,10,14,16,17}. New program strategies should be geared toward participation-based, real-life and goal-oriented experiences linked to young adults' prioritized needs. The focus should be on the group and community-based (ecological) programs that enable young adults living with physical disabilities to acquire and generalize new skills and competencies leading to better social participation and inclusion in the community ^{2,10,18,19}.

Arts-Based Rehabilitation Programs

The benefits of arts-based programs have increasingly been documented in the past two decades in the growing field of research classified under the Art & Health paradigm ²⁰⁻²². Scientific articles have been published in the past few years about young people living with physical disabilities transitioning to adulthood and presenting, for the most, explorative studies predominantly documenting drama-based programs²³⁻²⁵.

Compared to most arts or drama-based programs, circus-based programming, although not developed to be 'transition program' per se, offers a wider repertoire of specialties such as circus art, drama, dance, clowning, or music. They may vary from active and more physically challenging ones often associated with sports, to more passive and creative ones, if not offstage and more technical ²⁶. There has been a recent blooming of grey literature publications on circus-based programs including specifically social circus approaches (circus art activities combine with social work to promote community integration) and a greater interest from various academic disciplines for its' many positive societal and pleasurable qualities; it is popular and fun, it promotes social and community inclusiveness, and a positive lifestyle ²⁷⁻³⁰. The social perspective of what a circus approach consists of and also of what living with disabilities represent has greatly changed since 1932, when the movie *Freaks* was first released ³¹. The release of that

movie, which was rejected by the public as too offensive, probably contributed to showing *that people with different bodies had the same sensual bodily experiences as everyone else* ³¹ (page 165). More than 80 years later, surprisingly, even though many therapeutic benefits are being shared about social circus programs, there is not yet, to our knowledge, rigorous research documenting its impact on youth's social participation or well-being ²². Available evidence about the Cirque du Soleil's social circus describes a broader social ethnographic humanitarian perceptive ³²⁻³⁴.

OBJECTIVE

The objective of this qualitative pilot study was to describe the perceived impact of a social circus program (Cirque du Soleil), on social participation of young adults' living with physical disabilities in transition to adulthood from their perspectives as well as the perspective of one of their parents.

METHOD

Study design

An exploratory phenomenological qualitative design was chosen for this pilot study ^{35,36}. The phenomenon of interest was the experience of young adults with physical disabilities and the perceived impact of the social circus educational program on their social participation from their own and their parents' perspective. Any subtle changes (in life habits realization, personal and environmental factors) witnessed by the participants and shared during the interviews were transposed into narrative form (verbatim), then, participant perspectives were interpreted. We chose a qualitative rather than a quantitative approach as this was a pilot study with a small sample size and we wanted to make sure we documented relevant, albeit subtle, perceived

changes and the process meaningful to the young participants and their parents, which we may not have been able to capture using a standardized quantitative outcome measure of participation.

Conceptual Model

The Human Development Model-Disability Creation Process (HDM-DCP2) was used³⁷. It was chosen because it is an interdisciplinary and anthropological model of human development that applies to all (<http://ripph.qc.ca/en/hdm-dcp/hdm-dcp>). It is relevant to document the perceived changes in daily activities (six categories) and social roles (six categories) that are influenced by the young adult's personal factors (intrinsic characteristics) and environmental factors (extrinsic characteristics) as well the parent's views regarding their child's social participation before and after the social circus program. The engagement of the participant in the social circus program could act as a lever to change the dynamics between the different components of the model. It could, for example, enhance positive changes in some personal and environmental factors thus promote better social participation and integration and thus facilitate the transition to adulthood. As such, as we are looking to the data collected using a rehabilitation lens; we did not use another theoretical framework beside the HDM-DCP2.

Sampling and Recruitment

Through a convenience sampling strategy, participants were recruited from local rehabilitation centers and schools using advertisements and networking. For rehabilitation professionals and school partners, the program was perceived as a first community work-type experience where basic pre-vocational and life skills were promoted. The target sample size was twelve young adults with physical disabilities, along with one of their parents (dyads). We aimed to recruit only one parent to increase feasibility and minimize potential burden. To be included, young adults had to be aged between 18 and 25, have physical disabilities, currently use or have

previously used rehabilitation services and live with the parent also participating into the study. Both had to speak French and be available over the year the intervention was offered, free of cost and integrated in as a regular adult rehabilitation group program services. Excluded were individuals with phasic or cognitive impairments that could have affected their informed consent, data collection (interviews) and their active involvement in the program's discussion periods. There were no other exclusion criteria for the parents. The Ethics Committee of the establishments where recruitment took place and the participating school boards approved this study. All participants were given detailed information about the study and program enrolment beforehand, and all gave their formal written consent.

Context and Social Circus Program (Intervention)

The social circus program which combines circus art and social work to promote community integration developed worldwide by the humanitarian division of the Cirque du Soleil, Cirque du Monde was offered through a dedicated service for young adults transitioning from childhood to adulthood at a tertiary-level adult physical rehabilitation center in partnership with a community-based organization. The program consisted of two 2-hour workshops per week over two 12-week sessions, totalling more than 100 hours of intervention including three public presentations^{38,39}. Specific schedules were chosen to reflect real-life situations, i.e., Wednesday mornings (8:00-10:00 am) representing a typical morning work schedule, and Friday nights (7:30-9:30 pm) characterizing a weekend outing or formal type of social recreational activity with peers. The workshops were held in a community-training center (partnership with a community-based organization) dedicated to circus arts in order to provide a non-institutional, unique and interesting context. Two circus instructors (artists) were paired up with one rehabilitation trained kinesiologist who played the community worker's role. All three ran every workshop together.

The circus instructor assured the artistic exploration and circus skills' development. The health professional focused on social and life skills' acquisition and their generalization in youth daily lives as well as answering health related specific needs (assistance, safety and individual follow-up, if needed, with associated external rehabilitation team). The school-year program was divided into five blocks of 2 to 5 weeks. Bloc I consisted of circus repertoire (activities) exploration, knowing each other and group/individual's responsibilities; Bloc II focused on global circus skills' acquisition and group cohesion; Bloc III included personalized circus discipline training and common creative process (scenario and casting); Bloc IV consisted of the show rehearsal, peer/group support and greater shared responsibilities; and finally, Bloc V was about sharing feedback on their stage experience and perceived outcomes on their personal life. For each block, the overall objectives were divided into two categories. The first one, called the *circus lessons* refers to the technical objectives which includes five types of circus-based activities: warm-up games, acrobatics, aerials (trapeze and aerial silk), manipulation (juggling and other objects handling) and balance-based activities ^{26,39}. Some dramatic theater-based activities (masks, improvisation, clowning, role playing) and other performing art disciplines were also included in the program (dancing, percussion, music). The second category called *life lessons* refers to the social objectives and targets social skills, group dynamics and discussion of a variety of topics such as the participants' experience in the program, society and community integration. Each workshop was strategically planned. Approximately 70% of its content was related to circus activities, the rest focused more on life skills. The basic workshop's structure was: greeting period, symbolic beginning ritual, warm-up session, various periods of organized and free games where circus disciplines were taught and practised. Breaks, feedback sessions and a departure

ritual, were also included. Planned educative and thematic discussion periods were held, especially on Friday nights.

Throughout the program, participants had to abide by a code of behavior emphasizing societal values of respect, inclusion, fairness, collaboration and cooperation as they would do in a real work context. Also, meaningful opportunities linked to real life situations were used by the rehabilitation professional to enhance the understanding and the acquisition of personalized essential skills related to adulthood. They also had to respect rules regarding safety and cleanliness, and inform the program director when anyone was late or absent.

Data Collection

The perceived level and quality of the young adult's social participation was documented through three rounds of semi-structured interviews held prior to (T0), at the mid-point (T1) and at the end (T2) of the program with the young adult and separately with his/her parent. Socio-demographic characteristics for the sample description were collected at the first interview. The young adults and parents were thus seen individually for an average of 45 to 90 minutes each time. All interviews were conducted and digitally recorded by the main author (FL), a senior occupational therapist with a vast experience in interviewing. Previously, an interview guide based on the underlying conceptual model (HDM-DCP2) was developed and adapted for each round, mainly to cover every domain associated to the concept of social participation and possible interacting associated personal and environmental factors. The draft interview guide was developed by expert consultations (occupational therapists and experienced researchers) and pretested with three families presenting similar characteristics to those selected for this study. Upon each interview, every young adult was asked to chronologically detail his/her typical daily routine and to share his/her perceptions about the program. A focus was given on his/her level of

functioning (performance) and satisfaction when carrying out his/her life habits. The young adults were also invited to share more precisely any perceived changes in the past 2-3 weeks, and the ones related to their personal and environmental factors that could have influenced (*ability-disability; facilitator-obstacle*) their level of participation and if and how, they perceived the program had influenced these changes from his/her own perspective and interpretation. In parallel, each parent was also questioned about their child's social participation, according to their perspective and perceptions. For example, participants were asked these types of questions:

1. Detail to me, in your own words, a typical weekday, describing me right out of bed, your (his/her) daily activities and social roles:

- a. Detail your (his/her) level of difficulty or needs for assistance? What would you (he/she) like to do more? What are the obstacles? Facilitators?
- b. Any changes during the weekend or during holidays?
- c. Detail any subtle changes since you (he/she) enrolled in the program? In the last 2-3 weeks? How do you feel about it?

2. According to your (his/her) experience in the program, what do you (he and you) think about it? Likes and dislikes? Is it helpful for you (him/her) during this transition? Does it influence your (his/her) adult's life? Personal projects? Future aspirations, in any way? How and why? Any examples?

The interviewer wrote a summary of the interview immediately after each interview. From one interview to the next, the interviewer was then able to appraise the perceived changes with the participant by referring to his/her summary of the previous interview. This process of going back and forth is a method for enhancing the credibility of the data ³⁵.

Data analysis

All audio content was transcribed entirely in verbatim. Content was categorized and each interview analyzed separately through a comprehensive mixed coding process, using NVivo 9 software to structure and categorized the coded material. An initial closed coding process was completed using a preformatted coding grid based on the HDM-DCP2 model's key components as predetermined categories (*nodes or scheme*); its twelve participation domains which were sub-categorized in order to specify the participant's perceived level of achievement (performance) and needs for assistance at the time of the interview. Thereafter, transcripts were revisited a second time using an iterative approach strongly based on the phenomenological principles. This allowed the development of new thematic descriptive categories which allowed inductively an overall picture detailing the experience and the possible effects of the social circus program to emerge. The personal and environmental factors along with their perceptions about the program and its possible outcome represented the opened processed categories in which different and larger themes emerged and were later condensed into analysable and precise thematic subcategories. Although the procedure of analysis may seem rigid, the coding structure remained flexible and new codes could emerge at any steps of the process.

The process of analysis comprised the following steps:

1. A preformatted coding grid was initially elaborated (FL) and stabilized after it was upgraded with new categories that emerged as mixed coding and condensation analysis of 22% of the entire corpus progressed (*3 dyads in pre and post rounds*). A lexicon was elaborated and reviewed by experts and second coder to describe each category and ensure consistency.

2. Further fine-tuning of the grid and lexicon was achieved when a second coder and co-author (JB), an occupational therapist who was familiar with the conceptual model and who had previous coding experience in another study using a qualitative design, joined in and recoded the same initial corpus. This exercise of co-coding comparison reinforced the robustness (strength, stability and solidity) of the coding tools and limited possible researcher's interpretative bias as the main author completed all the interviews and assured a participatory observation throughout the entire program activity³⁵.
3. Further along, as the second coder's content analysis progressed, the newly coded data underwent some regular verification (reverse-coding) by the first author, again to ensure rigor.
4. The coding analysis process and results were discussed with co-authors (AR, ST), both experienced occupational therapy university professors and qualitative researchers.

RESULTS

Eleven dyads met our inclusion criteria, attended the initial interview and started the social circus workshops. Two dropped out in the first three weeks for medical reasons; one of them also had transportation problems. Their data were retrieved from this study. Finally, nine familial dyads (9 young adults and 9 parents) were interviewed three times over a period of nine months for a total of fifty-four interviews analyzed. The young adults' mean age was 20.0 ± 1.4 years and 2/9 was female (see Table 1). Seven of them (7/9) had communication disorders from which five (5/7) had dysarthria, and four (4/7) had hearing aids, including three (3/7) who had both problems and one whose mother tongue was Russian. Eight (8/9) had neurological (dysphasia) or intellectual disorders affecting their comprehension but all, however, met the study inclusion criteria.

The parent's mean age was 51.0 ± 3.6 years and 7/9 was female. Family income was all over \$45,000/year. (See table 1, for more socio-demographic characteristics). The prefixes T0, T1 and T2 mean that the transcript extracts came from the first (T0: before the intervention), second (T1: mid-intervention) or third (T2: after the intervention) round of interviews. The letter 'P' designates a parent, 'Y' a young adult, and 'I' the interviewer. Dyad refers to 'P' and 'Y' of a same family (PY).

(Insert Table 1 about here)

Perceived changes in the young adults level of social participation

Two themes relating to daily activities emerged from the data: communication and mobility whereas there were three themes relating to social roles: interpersonal relationships, responsibilities and community life, all five of which were perceived by both members of the dyads as having improved after the social circus program as compared to before.

Daily activities domains

Communication

Communication skills were reported as optimized by all nine dyads. Six dyads (PY1-2-4-7-8-9) and one young adult (Y6) stated they were better able and more interested in initiating conversation and talking to others. Two dyads (PY5-7) and three other parents alone (P1-4-8) said they shared with more ease opinions, seven dyads (PY1-2-4-5-6-7-9) specified their personal and assistance needs, for three dyads (PY1-7-9), two parents (P2-8) and one youth (Y6) their emotions and for three dyads (PY1-5-9) and two young adults (Y3-7), their personal life experiences. These improvements were observed not only with their family and friends, but also with their peers and strangers, in new situations associated with various community and health services.

T2P7: “He is being monitored for deafness at school and even in the last assessment...

She wrote that he was talking more about his emotions. He sometimes managed to resolve ‘minor’ conflicts he had with others. That too was a change from being stubborn and saying: ‘No, I don’t want to!’ like he did before. I think it’s not as bad. -I: *More willing to discuss, talk to and listen to others?* “Yes, more able also to express what he feels and to say: ‘I don’t like that’.”

All those with comprehension (deafness, dysphasia) or expression disorders (7/9) shared being more inclined to use strategies such as verifying what they did not understand, sharing their difficulties, changing the speed at which they spoke, and modulating their voice.

T2Y2: “They talk too fast” -I: *Were you more able to express that at the end? To say ‘Hey, slow down, I don’t understand’?* “Yes. I do that since I’ve been with you guys. I never did that in my life before. I was always afraid of what everyone thought of me.”

Subsequently, one parent (P1) and four young adults (Y2-5-6-7) expressed being better able and more comfortable speaking in a group and in public.

T2Y2: “But the others began to listen to me... because I had a lot of difficulty with that. With talking... you have to let me talk because I don’t speak otherwise. And, I swear to you, before the circus I never spoke.”

T2Y4: “I’m more at ease. I want more to say nice things! I’m less shy about talking... I’m braver. I want more to speak.”

Eight dyads (PY1-2-3-4-5-6-7-9) stated that the program enhanced their use of communication technologies and devices (phones, tablets, and computers) better and more often. Their devices were also more useful for communicating with others and managing their lives (services, transportation, agenda), especially with applications such as texts, Messenger or Facebook.

T2P3: “Sometimes he’d call twenty times an hour. Yes, he learned to leave messages.

And now he knows I can get texts. I’d say that he has understood at what time he should call.”

All young adults reported improved social communication skills, six dyads (PY2-3-6-7-8-9) and one young adult (Y1) also found that they listened more to others and showed more respect for the group’s rules of conduct.

T2Y3: *I: Discussions?* “I really liked that. Also, there were people before who didn’t listen to others. Then, just like that, in the middle, he listened to us. After that, they’d wait for their turn to speak. I still have to work on that a bit!”

Mobility

All young adults perceived having optimized how they got around town and went out alone more often and to more places. Of the seven participants with mobility aids, at T0 (baseline) one (Y1) already used paratransit without assistance, another (Y2) used it on a weekly basis but with assistance, two (Y5-6) rarely used it, while the remaining three (Y4-7-9) never or almost never used it. All perceived having made progress at the mid-point (T1) and by the end of the intervention (T2), all were getting around alone without human assistance while six of the seven managed all their own trips (schedule, reservations, itineraries, unforeseen events). These perceived benefits also applied to trips (walks) in the neighborhood.

T0Y9: *I: Do you take paratransit to go there?* “Loisirs Soleil (*leisure centre, on Saturday*)” -*I: Who reserves it?* “Dad does.”

T0P9: *I: Do you reserve it or does he manage his transportation?* “No, it’s done by Loisirs Soleil... eventually, he’ll do it... we didn’t use it a lot because we’re together most of the time.”

T1Y9: "... I take paratransit more... but I don't manage it myself."

T2Y9: *I: You make phone calls?* "Yes, to call my paratransit."

T2P9: "He does that alone." -*I: Initially, he didn't take it?* "No, no! He started to take it.

After that, the reservations. Now he's the one who makes them."

Social role domains

Interpersonal relationships

All dyads perceived they were more invested and open socially to enhance their network of relationships. Their social and relationship life became more active after the social circus program.

T2P2: "...it's since the circus. He's willing to go out and make contacts. He talks about doing something more. He spoke to his special educator to find an activity where there'll be social interactions."

With their peers, five dyads (PY1-3-4-8-9) and three young adults (Y2-6-9) said they were more comfortable with initiating and maintaining relationships. Five dyads (PY1-2-4-5-7) and one parent (P8) perceived less social isolation.

T2Y5: "I feel less lonely. If I'm with my group (circus)... with them, I can do everything."

T2P7: "So I liked the show... but I also liked what I saw afterwards. To see him with others. I said: 'Great, bye, have a nice party!' He forgot my existence when I left. So much the better!"

Four dyads (PY3-4-5-9) and one parent (P1) perceived them readier to develop meaningful intimate relationships.

T2P5: “Before, I don’t know if she would have let someone, apart from her friends, get inside her bubble... she let him in (new boyfriend), let him help her with everything.”

Two dyads (PY2-6), three parents (P1-3-8) and one young adult (Y6) perceived their familial relationships improved during the intervention although they had been reported as being more difficult at baseline.

T2P1: “It worked. He (Y1) is a bit less rigid mentally and emotionally. Sometimes he says (to his father) it’s you who’s in charge. I was helping him, he recognized that I gave him some suggestions and he quickly made some good decisions... He was committed... It was positive, it was fun!”

T2P8: “He greatly improved his relationships with others. Here, around the table, at some point... Christmas passed, he stayed in his bubble more... Now he talks... I’m beginning to forget that whole phase when I worried a lot because I thought he was going to isolate that he was going to get depressed and all that.”

Responsibilities

The topic of young adults taking initiatives and responsibilities in everyday life also emerged as an essential theme throughout the interviews. At the personal level, eight dyads (PY1-3-4-5-6-7-8-9) reported that this led to more effective and satisfactory management of their schedules (punctuality), commitments and greater decision-making and organizational skills. All participants assured a sustained attendance throughout the social circus program.

T2Y4: “Yes, the social circus helped me because, when I have an appointment, sometimes I go to new ones, to have a scan (medical appointment) or things like that, now I can go all by myself in paratransit. They (parents) let me.” -I: *Are you happy with that?*

“Yes! I’m happy!” -I: *Is it new?* “Yes.”

T2Y9: "I get up without help... I set the alarm."

T2P9: *-I: You used to get up to wake him up. "He usually gets up by himself now."*

Another perceived change from before and after the social circus program is relating to the parent's confidence (PY3-7-8 and P6) in their youth to stay home on their own.

T0P7: "Sometimes I go out (of the house) for an hour. I know that after 90 minutes, he'll start to get a bit agitated-because he found it too long"

T2P7: "..., I'm not worried that he's alone at home either. That's a big deal too! He can spend a day alone now."

Four dyads (PY1-3-8-9) one parent (P4) and three young adults (Y5-6-7) reported a greater civil responsibility by adopting respectful social behaviors in the community and all parents mentioned an improvement in awareness and initiative.

T2Y6: "... I think it's important to have meetings, to push ahead, to say, I'm here and I'm a person in my own right, even if I'm different from you. It's these little things that I will always have to fight for; to get services. To get what I want and am entitled to..."

T2P9: "... he still calls me but he calls to see if I have any errands to run (laughs)" *-I: So it's more initiative? "Definitely!"*

T2Y9: "Yes, sometimes I run errands for Dad. I call him to see if he wants me to go get cheese, stuff like that." *-I: It's you who calls him to see if he needs something? "Yes, because Dad isn't used to asking me to do things for him."*

Five dyads (PY1-2-3-5-6), one parent (P7) and one youth (Y8) perceived taking more responsibilities in regards to their finance; managing more efficiently their budget and payments (e.g. monthly bills, rent, food and loans).

T2Y3: “Window shopping! I cut down on clubs because I have a budget to respect. When I get some money, things to pay, I respect the budget. For example, they (friends) invited me to go out at the weekend and I said : ‘No, I’m not going out...’.”

T1P3: “I find that it’s good because he leaves with his card, he looks at prices, he compares... I find that he’s grown up. He’s more independent. -I: ...*less impulsive?*”

“Much less.”

Two dyads (PY7-9) and three young adults (Y1-5-8) noted increased awareness of the impacts of their actions on themselves and others (self-regulation).

T0Y5: “... I haven’t slept for two days! (Laughs)... Yesterday with my friends, we drank some rum and went to bed late.”

T2Y5: “I’m trying to be more serious. Before, I used to drink to relieve boredom, but if I’ve got something else... I know I can have fun without drinking. ... the show we did... I really enjoyed it... and there was no alcohol.” -I: *You had some great ‘highs’?* “It was fun!”

Community Life

All young adults said that at the end of the program they used various services and resources in the community more often, more easily and without assistance. Seven dyads (PY1-2-5-6-7-8-9) and one young adult (Y5) reported that they visited more often the library, the gym, running errands or using restaurants more.

T2Y6: “... I started going to my integrated dance classes again, once a week on Monday evening. And I’m going to have a summer session that’ll be twice a week...”

T2P7: “Oh! I went to get something at Subway...”, he said (Y7). He went out with his dog... he came back and he’d never done that, or probably even had the idea to do that. So it was a big new thing for him!”

Four dyads (PY3-4-5-6) specified that they have just started managing their home care and services alone or going to their medical appointments around the city.

T2Y4: -I: ...you now go to your medical appointments... alone? “Yes.” -I: Are you happy about that? “Yes, really happy. It’s something that I changed!”

Emerging Themes Relating to Personal and Environmental Factors

Psychological abilities are the essential themes emerging from the interviews and relating to personal factors. All participants perceived a change in their self-perception and in their confidence toward their own capacities. The group was perceived as a source of motivation, perseverance and improved performance.

T2Y6: “... Pride in showing people, society, everything we have accomplished after 8 months of work. All the assurance we have gained... At the beginning, I was a bit scared that it would be very demanding physically ...I came out of it like a new young woman. I think this experience really made us grow”.

T2Y9: “... I'm more aware because... I see that I can control my attitude (impulsivity/hyperactivity)... That they applaud me for what I've done, not for what I went through when I was a child.”

T2Y3: “... people who have a more visible and bigger disability than me, I couldn't believe that they were capable of doing that. For me, it was, I think it was exceptional.”

Physical benefits were also perceived. Everyone felt more fit. Four dyads (PY1-2-3-4-6) and three young adults (Y5-7-9) stated some global physical improvements perceived in their every day and leisure activities (strength, endurance, balance).

In a lesser extent, positive changes were also perceived in relation to their environmental factors. At a micro level, participants mentioned that their friends now perceive them more positively, especially concerning their participation potential.

T2Y4: “The social circus helped me because when I have an appointment... I can really go alone now in paratransit. They (parents) let me.”

T2Y6: “The confidence that others have in me. That's what mainly surprised me more than other things.”

At a meso level, mainly with the positive feedback after the public presentations at the end of the program, they strongly perceived that the community members, the audience, had a more positive perception about disabled individuals. This opportunity has also nurtured, among young adults, a sense of advocacy.

T2Y6: -I... the way “ordinary” people look ... Can it change? *“Yes, because ... Some people sobbed...some yelled... cried. They were thrilled... they got shivers down their spine... They wondered: Oh! Is he going to fall... That enabled us not only to gain assurance, despite our disabilities, it also enabled us to show society that we can do what we want, despite our conditions, that nothing prevents us doing what we want in life. ...To get people to know us too”.*

DISCUSSION

The aim of this study was to explore the perceived benefit of a social circus program on the participation of nine young adults with physical disabilities transiting to adulthood, and from

their parent's perspective. According to all familial dyads, the life habits domains that were more strongly reported as being enhanced by the circus-based intervention were communication, mobility, interpersonal relationships, community life and responsibilities. These results match many of the clinical targets recommended by experts working with this population^{2,12,13,17,40}. These domains of participation, particularly communication and mobility, are recognized as hierarchical prerequisites leading to the realization of other life habits⁴¹⁻⁴³. Their optimization promotes the acquisition of desired essential life skills known to foster an easier transition and a better social participation. Examples of those valued skills are to experience the consequences of their choices in real-life situations and to problem-solve daily life's challenges. Although we know of no other study that documents this type of circus-based approach in an adult rehabilitation context with this transiting population living with various physical disabilities, our results are consistent with those of Agnihotri and colleagues^{23,24}, who studied a theatrical approach with few circus elements in it. Their multiple case studies (N=2; N=5 with control) using a mixed design (battery of standardized measures) with adolescents with acquired brain injuries and physical limitations supported the feasibility of their program. They documented clinically significant improvements from pre-post program in the areas of social skills, in making friends (interpersonal relationships) and pragmatic conversation (communication), in performance and satisfaction for problem areas related to participation and leisure which were maintained or further increased at follow-up.

As reported in many reviews^{20-22,44,45} and pilot studies^{25,46-48} documenting the use of arts-based programs in physical rehabilitation contexts, marked positive changes were reported in personal factors domains. As global physical benefits were reported by our participants, the personal factors that stemmed out more strongly were predominantly psychological. The group's

generalized initial negative self-perception (image, esteem, confidence) and related social difficulties (shyness) which are identified as being major obstacles to participation and transition (7, 12), were progressively enhanced along with a stronger feeling of self-determination which is also a determinant clinical outcome for this population ^{1,11,13,17,40}. This greater sense of control over their lives was nourished, according to them, greatly by their supporting peers. The risk-taking and decision-making processes combined with the strong group dynamics, promoted by the program although not aiming to be a 'transition program' per se, encouraged various types of learning that fostered social recognition, emulation and vicarious learning. In turn, this led them to new explorations and unexpected accomplishments. As described by Bandura, this intrinsic transformation seems to have led them to a greater feeling of self-efficacy ⁴⁹. This positive perception of their capacities (physical, emotional and cognitive) triggered actions previously conceived as too difficult for them or simply unattainable. The acclaimed public performances, which were beyond their comprehension, are one example of this. The perceived greater empowerment and pride that won over everyone subsequently seemed to have notable positive benefits, which had a ripple effect on participants' various other factors (personal, environmental) and life habits. This motivated the young adults to open up even more to the outside world and to new opportunities, to explore various types of friendships and activities, to seek new responsibilities while understanding and integrating societal values such as mutual aid, fairness, and respect of self and others. Knowing that a sedentary lifestyle awaits this young population and that a program focusing on physical activity and mobility is recommended ^{14,50,51}, it is interesting to observe that the young participants perceived themselves as being fitter and more active physically. Some of them even reported losing weight and testified some striking physical

gains that had a major impact on the performance of meaningful essential activities, such as walking and transfers from floor to standing without assistance.

Furthermore, their sustained commitment throughout the school year-round program, their greater daily independency combined with the acclaimed public performances promoted a reported change in perception and attitude among family, friends and the community which is identified by some experts as being a possible important obstacle for their participation and community integration^{12,13}. Parents' view of the participatory potential of their children improved. This was reflected by a positive change in perception, attitude and supervision. These perceived changes even nurtured a reinforced feeling of security and confidence in the dyads' relationship.

Strengths and Limitations of the Study

Although this was a qualitative and exploratory study, and the number of participants was small, it showed a sustained level of trustworthiness. Its design made it possible to identify a variety of perceived impacts and many notable subtleties both in the quality of the performance of life habits (amount, number, frequency of assistance) and in the change process, which would not have been possible using quantitative measures. However, we do acknowledge that using a phenomenological approach limits us to the documentation of perception which may be an over or under estimation of actual functioning. This descriptive exploratory phenomenological approach was particularly relevant as it was an innovative study (39, 55). The data collection and analysis' tools used were reviewed by experts, and potential observers, social desirability and interviewer-interviewee relationship biases were lessened by confirmation of the perceived changes from one round of interviews to the next with the participants (Y;P) and by triangulation throughout the program with third parties associated with the project^{35,52}. No discrepancy was

identified in the results between participants, or among members of a same dyad. The therapeutic engagement and integration of individuals with limitations acquired late in life, into a group where the majority of participants have developmental or acquired disabilities from a very young age, can be seen as a limitation. For some of these participants, it can be personally and socially confronting. This situation could jeopardize the development of a sense of belonging to the group, which is an essential and integral part of this approach. However, all of the gains documented in this study cannot be attributed solely to the program. The necessary implementation in a rehabilitation context by the lead author and his frequent presence (observations, debriefings) may have influenced the attainment of some clinical objectives; this does not, however, diminish the potential of this rehabilitation approach.

CONCLUSION

This exploratory study documents for the first time the social circus approach developed more than twenty years ago by the Cirque du Soleil's humanitarian division. It sheds light on its possible use in physical rehabilitation in recommended partnerships with schools, the community, paediatric and adult's services. It highlights the clinical potential to accommodate this challenged and growing young population in transition to adult rehabilitation care. What makes this approach particularly promising is that it's inclusive, participatory and community-based which are all consistent with the evidence, as are its target objectives and perceived benefits^{13,17,40}. This circus-based program in a rehabilitation context combining formal and social activities through meaningful real life situations promotes a healthy (nutrition, physical fitness, personal care) and active lifestyle appreciated by everyone. It enabled the acquisition of a range of varied essential life skills, also linked to their rights (advocacy) and work life habit^{1,2,53}. All of the study participants would recommend this approach to their peers. The participants associated

numerous therapeutic strengths with it as a clinical approach but they did not perceive it as if they were engaged in rehabilitation services or a program. Furthermore, given the ongoing and perceived important needs to adapt the intervention according to the group or individual clinical needs such as schedules, life habits related assistance needs, circus accessories, games or activity analysis, the occupational therapist remains the health professional of choice to ensure the therapeutic and medical responsibilities of such a program in a community context. The holistic and graded skill-based approach, psychosocial issues and group dynamics are necessary to promote the inclusion of all as well as the physical and mental integrity of the participants and the artists in their functions.

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Table 1. Participants' characteristics (young adults and parents)

ID	Gender	Age (years)	Diagnosis / Parental status	Main associated conditions	Technical aids	Main occupation (T0)
Y1	Male	18	Cerebral palsy	Spastic quadriplegia. Hydrocephaly. PDD, Asperger's syndrome. Mental health issues. Cognitive learning disabilities.	Wheeled walker	Student (specialized school, adapted program)
P1	Female	50	Married, mother of 2 children			College degree / Self employed (contract)
Y2	Male	21	Leukodystrophy	Muscle and nervous system progressive damage. Bilateral deafness. Chronic pain	Hearing aid. Canadian crutches, manual wheelchair.	Volunteer (adapted workshop)

				syndrome. Fatigue. Mild intellectual disability.		
P2	Female	55	Divorced, single mother of 3 children			B.Sc. degree/ Working full time
Y3	Male	21	Steiner's syndrome	Neuromuscular functional progressive damage . Expressive communication difficulties. Fatigue. Cognitive learning disabilities.	None	Student (specialized adult institute, adapted program)
P3	Female	52	Married mother of 3 children			Master's degree) / Working full time

Y4	Male	20	Childhood callosotomy sequelae for uncontrolled epilepsy	Severe left hemiparesis with surgically repaired wrist in non-functional flexion. Left peripheral vision problems. Cognitive learning disabilities.	Unilateral tibial orthotic	Student (specialized high school, adapted program)
P4	Male	50	Married father of 2 children			Ph.D. degree / Working full time
Y5	Female	22	Friedrich's Ataxia	Cardiovascular and progressive joint damage, severe neuromotor disabilities in all limbs. Expressive communication difficulties (dysarthria).	Manual and motorized wheelchair	At home without an occupation

P5	Female	50	Separated, single mother of 2 children			High school degree / Working full time
Y6	Female	19	Cerebral palsy	Left double spastic hemiplegia (bilaterally very limited upper limb function). Moderate to profound bilateral deafness. Expressive communication difficulties (dysarthria). Cognitive learning disabilities.	Hearing aids. Motorized wheelchair for long distances only	Student (specialized high school, adapted program)
P6	Female	54	Married, mother of 2 children			College degree / Working full time

Y7	Male	21	Cerebral palsy	Spastic diplegia. Bilateral deafness. Expressive communication difficulties (pitch, dysarthria). Mild intellectual disability.	Glasses. Hearing aids. Walking with assistive dog.	Student (specialized high school, adapted program)
P7	Female	45	Married, mother of 2 children			University degree / Working full time
Y8	Male	20	Acquired traumatic brain injury	No major physical limitation. Diminished overall reactions. Mild cognitive and learning disabilities. Fatigue.	None	At home without an occupation
P8	Female	47	Married, mother of 6 children			Master's degree / Working full time

Y9	Male	18	Severe burns in infancy	Multiple skin grafts. Bilateral tibial and finger amputations. Severe psychological disability (affective, anxiety). Deafness. Communication difficulties. ADHD. Borderline intellectual disability	Manual and motorized wheelchair and cart	Student (specialized high school, adapted program)
P9	Male	55	Widower, father of 2 children			High school degree / Working full time