Perspectives of Adolescents and Young Adults with Cerebral Palsy on the Ethical and Social Challenges Encountered in Healthcare Services

Danaë Larivière-Bastien[1], Annette Majnemer[2], Michael Shevell[2], and Eric Racine[1]*

1) Institut de recherches cliniques de Montréal, 2)McGill University
*Correspondence concerning this article should be addressed to Eric Racine, Institut de recherches cliniques de Montréal, 110 avenue des Pins Ouest, Montréal, QC H2W IR7.
Email: eric.racine@ircm.qc.ca

Abstract. Healthcare is a context where individuals with disability confront important ethical and social challenges. Adolescents and young adults with cerebral palsy (CP) seem to face additional challenges but we have little insight into their perspectives. This qualitative study aimed to identify and better understand such challenges. We interviewed 14 participants with CP aged 18 to 25. Participants described a range of challenges experienced when using health services, including: lack of long-term follow-up, shortcomings in physical access to infrastructures, and situations of injustice. Challenges specific to medical consultations were reported (e.g., rude attitudes, belittlement, inadequate communication, lack of consideration). We discuss and explain further that: (1) the ethical principle of respect for persons needs to be concretely specified to improve current practices; (2) respect for autonomy calls for further direct empowerment of individuals with CP and, (3) gaps in dedicated healthcare resources for CP and the long-term needs associated should be addressed.

Keywords. Cerebral palsy, disability, neuroethics, qualitative research, transition

Healthcare can be a context where individuals with disability are confronted with diverse important ethical and social challenges, including communication issues (Balandin, Hemsley, Sigafoos, & Green, 2007; Beresford & Sloper, 2003; Britto, DeVellis, Hornung, DeFriese, Atherton, & Slap, 2004), inequalities in access to basic services (e.g., preventive and routine care) (Doostan & Wilkes, 1999; Michaud, Suris, & Viner, 2004) and infringement of their rights to confiden-tiality and autonomy (Beresford & Sloper, 2003; Britto, Slap, DeVellis, Hornung, Atherton, Knopf, et al., 2007). Adolescents and young adults with cerebral palsy seem to face additional issues specific to their condition and their age. For example, research has shown that access of young individuals with CP to health services drops dramatically with the end of school attendance (Andersson & Mattsson, 2001; Ng, Dinesh, Tay, & Lee, 2003). The transition from the pediatric to the adult milieu is a period in which

"fair" access to services may be particularly compromised (Bailey, O'Connell, & Pearce, 2003; Binks, Barden, Burke, & Young, 2007). Young individuals with CP also experience negative attitudes in healthcare services and can be confronted with disrespect towards their person and their dignity (Blumberg, 1993) or to stereotypes that undermine respect for their autonomy and their right to decision-making (Doostan & Wilkes, 1999). While some of these issues (especially pediatric-adult transition efforts) are the subject of a growing number of studies, the perspectives and opinions of young people with cerebral palsy on their experiences in healthcare are poorly understood. With respect to the qualitative research that has been conducted, few have directly targeted adolescents and young adults, even fewer have focused on young people with CP, despite the high prevalence of cerebral palsy in our population and the increasing number of young individuals with this condition entering adulthood. Cerebral palsy presents some particularities (e.g., speech difficulties, motor and sensory deficits with cognitive capacities often intact, spasticity) that make the experiences of individuals living with this condition different from those of individuals living with other disabilities or chronic medical conditions. However, we currently have little insight into the perspectives of young individuals with CP regarding the ethical and social aspects of their care. This information would likely help to improve care tailored for individuals with CP. However, if little is known about these individuals' healthcare experiences, much less is known on the ethical and social challenges they face. Accordingly, this research aims to identify and better understand ethical and social issues that adolescents and young adults with CP face.

Method

The sample population for this study consisted of young adults aged 18 to 25 with cerebral palsy. The inclusion criteria were a diagnosis of cerebral palsy and acceptance of the terms of the study as delineated in the informed consent form. Participants also needed to be able to understand and answer questions from the interview and to make

a free and informed consent. We offered a modest compensation ($ 50) for participation in the study. Participants were recruited in the community, from educational, medical, sporting and social support groups for individuals with cerebral palsy and their families. Although the qualitative research principle of theoretical saturation prevented identifying a preset number of participants, we expected that interviews with approximately 15 participants would allow us to characterize key features of the experience of participants.

This study was based on a short questionnaire followed by a semi-structured qualitative interview. The questionnaire was designed by our team and aimed solely to build basic participant profiles, identify characteristics of their CP, and survey participants on ethical issues. The first section of the questionnaire included demographic questions about the participants (e.g., name (which would be assigned a code), age, living arrangements) as well as characteristics of the disability of the participants (level of mobility and communication), schooling and medical background (type and frequency of medical services received, type of healthcare professionals involved with the participants). The second section examined the ethical issues experienced by the participants related to three main categories: 1) access to healthcare, 2) transition from the pediatric healthcare system to the adult healthcare system and, 3) communication with healthcare professionals. These ethical issues were identified by a previous literature review on the issues experienced by people living with CP and other disabilities and feedback provided by our own research team. Finally, we asked the participants about any suggestions they would have in order to improve the healthcare system and the way in which they were and are treated (i.e., characterization of the needs for ethics in the provision of health services).

The second phase of the study included a semi-structured qualitative interview with participants. Interviews were conducted in person to ensure a climate of confidence and trust and they were scheduled at the convenience of the participants at a location chosen by them. The goal of the interviews was to further characterize the challenges

encountered by participants when using healthcare services. The interview grid included many different themes based on the goals of this study and the range of ethical issues reported in the literature (Racine & Lariviere-Bastien, 2011) : (1) background of the participant (this included questions such as the description of their experience of living with a disability, type and frequency of medical services received); (2) the transition from the pediatric healthcare system to the adult healthcare system (this included questions regarding what the participants felt about their experience of the transition, about the support and monitoring they received, their idea of the quality of care in the adult care system compared to the pediatric system, etc.) and (3) the ethical and social issues encountered (this included questions regarding issues or difficulties that may be encountered by the participants in their experiences of healthcare services (e.g., communication, access to healthcare, autonomy, privacy and relationship between participants and healthcare professionals)).

The interviews were conducted in French or in English. The audio-taped interviews were first transcribed *verbatim* and then analyzed ("coded") based on a conventional thematic qualitative content analysis approach (Hsieh, 2005). Prior to coding, a coding guide was elaborated to support the coding process. This guide was first drafted on the basis of the analysis of a diversified sample of interviews where open nodes were generated in an open-coding phase (open nodes (or free nodes) and *open coding* allow capturing content inductively based on the content of the material in contrast to *axial coding* where codes are applied deductively once the meaning of coding has been defined and typically organized in a "tree" structure). The coding guide was developed based on several rounds of piloting and open coding to ensure validity and consistency. Preliminary versions of the coding guide (drafted by the first author) and of the overall coding were formally reviewed and discussed (by the last author) to capture fully the content of the interviews. This open coding led to the final development of the coding guide and to axial coding. The coding guide identified and defined the primary, second-ary and tertiary level codes and included implicit (upper boundary) and explicit (lower boundary) examples. It also included definitions and rules for the application of each code to ensure rigor and thoroughness.

The final coding structure included 8 major topics: (1) the experience of living with CP, (2) the use and access to healthcare services, (3) the description of problematic situations experienced in healthcare, (4) the description of challenges encountered in medical consultations, (5) the challenges experienced in the transition from pediatric to adult healthcare, (6) perspectives on autonomy, (7) improvements suggested by participants, and (8) perspectives of participants on life in society. The coding strategy was rich, not implying the exclusivity of codes in order to maximize the depth of analysis. Excerpts of interviews were translated from French by bilingual team members. Coding of the material was conducted by one team member (first author) and then reviewed by another (last author). Disagreements between the coder and the reviewer were discussed to achieve consensus. When consensus was not achieved, another member of the team was involved to arbitrate and resolve disagreement through consensus (Forman & Dam-schroder, 2008). Coding was supported by the use of the QSR Nvivo 8 qualitative analysis software package (Doncaster, Australia). In the tables and qualitative data, participants are identified simply by the letter P followed by a number. In this paper, we report data on general challenges encountered in healthcare services, issues experienced in medical consultations, as well as recommendations put forward by participants. Future publications will report more detailed data on respect for autonomy and the challenges of the transition from pediatric to adult healthcare services.

Research ethics approvals were obtained prior to the beginning of this study. Participants had to complete the informed consent before being able to complete the questionnaire and prior to being interviewed.

When reporting qualitative content we used the following annotations: "(. . .)" when we removed a portion of a sentence; "[. . .]" when more than one

full sentence separated the quotation we presented, and square brackets "[]" to indicate that we are using a quote that was the start of a sentence. If the latter are not used, it means that a portion was cut at the beginning of the sentence. We used qualitative examples to illustrate salient or illustrative features of the qualitative data.

Results

Participant profiles

We recruited a total of 14 participants from the community. Participants were aged 18 to 25 years old, had different backgrounds of care and education. All were French speaking. Seven participants were male. Mean age of participants was 20.9 years old. Three participants were 18 or 19 years old, six were 20 or 21 years old, three were 22 or 23 years old and two were 24 or 25 years old. Eight participants mainly used a wheelchair, two walked without any aid and the last four used another type of mobility aid (e.g., crutches, walker). Three participants had mild speech difficulties and three had moderate speech difficulties. Consistent with qualitative methodology, we sought to diversify the sample and included participants who used healthcare services of different institutions. Participants were also completing or had completed their schooling in different institutions (specialized or non-specialized) and had different living arrangements (See Tables 1 and 2).

Qualitative data

Our interview data allowed the identification of a range of ethical issues experienced by young adults with CP as well as recommendations suggested by participants in order to improve healthcare services and delivery. Accordingly, we will first present (1) challenges encountered when using healthcare and health services followed by (2) challenges encountered during medical consultations, and finally (3) recommendations suggested by participants.

Challenges encountered when using healthcare and health services

Participants described a range of challenges they experienced when using healthcare and health services. Challenges are listed in Table 3 and for several items (marked by an asterisk), detailed qualitative data is presented in separate paragraphs below to further clarify these challenges that have particularly rich content.

Shortcomings in the physical access to infrastructure and medical equipment

The gaps in the access to medical equipment mentioned by some participants were mainly related to equipment that are not appropriated by healthcare professionals ("I have seen orderlies who . . ., they didn't even use the lever to lift the bed when they helped me . . ., because, they didn't even know how it worked because usually, they don't really use it" (P1), "[e]ven when I come into a physician's room and that I have to climb on the table, and the table is too high, I am not able to climb on a table, you know, this is complex, there is nothing adapted, they have small steps but if you're not able to lift your leg on the step, you're not better off!" (P6)). Other reports concerned toilet sizes (too small) and insufficient numbers of elevators.

Difficulties experienced during surgery or hospitalization

Our participants reported unpleasant and difficult surgery and hospitalization experiences. One participant said that, "I was so fed-up I was considering signing the famous little paper that says 'refusal of treatment'" (P10) and another mentioned "these are things that I would never want to live through again. One would offer me a surgery for my own good and I would say no . . ." (P2)). Participants reported various basic needs that were not being met during surgeries or hospitalization periods ("[a]lso at the level of hygiene care, they didn't know necessarily that I could little or almost not wash myself alone" (P1), "I was not able to eat alone, I was in the hospital for a while, I was force-

Table 1.

Participants According to their Living Arrangements

Living arrangements	N	Participants
With a parent or a family member	9	P2, P4, P7, P8, P9, P11, P12, P13, P14
Alone or with a friend in an apartment	3	P3, P5, P6
In a supervised apartment	1	P1
With a caregiver (other than parents or family member)	1	P10

Table 2.

Participants According to their Education*

Type and level of education	N	Participants
Attends or attended public specialized school	7	P1, P2, P7, P9, P12, P13, P14
Attends or attended public non-specialized school	4	P6, P8, P10, P14
Attends or attended "Cégep",**	5	P1, P3, P5, P6, P14
Attends or attended university	2	P1, P6

*In some cases, more than one category applied to a single individual

**Cégep : Collège d'enseignement général et professionnel (public post-secondary education collegiate institution exclusive to the province of Québec)

fed and this, it is like . . ., it was not fun for me" (P12)). Several participants explained that the support of relatives or family members was necessary in these situations for their basic needs to be met.

Difficulties related to being unaccompanied to a hospital

Some participants faced significant challenges when coming to the hospital unaccompanied by their parents or a caregiver. They had first to deal with the lack of staff available to help them: "there is nobody to help you even to push your wheelchair; you're 'stuck'" (P6). Participants who needed help had to wait long before a staff member could come: "it took one hour and a half I think before they could find me a nurse to help me to put on the hospital gown, so, I found it a little, uh, I don't know, I found it was tactless" (P6). Then they often had to undergo the frustration of healthcare professionals who, while not equipped to care for them, can make patients feel their disapproval ("people reprimanded me

because I was not with someone that day (...)" (P6)). However, participants explained having had no choice but to come alone ("well, nurses who assess the file, they were outraged because I was alone, not accompanied, but you know in the rush, I took a taxi, I left, I didn't think to take somebody with me, I said to myself: 'this is a hospital, it is normal, there's going to have people to help me' (...)" (P6)). When participants don't have family members or friends available to come with them to the hospital, the only option left may be to hire someone to accompany them. However, this can become very complicated and expensive if the appointment is outside working hours, or if the participant does not know how long he will have to wait before the appointment.

Difficulties experienced during participation in research

Some participants had participated in research studies and a few reported experiencing difficulties. For example one participant had a negative

Table 3.

Challenges Encountered when Using Healthcare and Health Services

Participants' Responses

Waiting too long for health services
Lack of human, financial, and material resources
Lack of long-term follow-up and consistency in health services
Lack of interest, research or public recognition of cerebral palsy
Lack of services tailored for people with cerebral palsy
Lack of communication between healthcare professionals
Shortcomings in the physical access to infrastructure and medical equipment*
Administrative difficulties, lack of flexibility, complexity in the administrative aspects of care
Difficulties experienced during surgery or hospitalization*
Difficulties related to being unaccompanied to a hospital*
Difficulties experienced during participation in research*
Difficulties in finding a physician or healthcare professional
Feelings of having to struggle, ask or even "beg" for healthcare services*
Feelings of injustice and inequality in healthcare services*
Feeling left out, abandoned by healthcare providers*

* See text for detailed qualitative description of challenge marked by an asterisk.

experience: "[t]he guinea pig, that I don't want to be anymore, I don't want to be the guinea pig of anybody. I don't want to be the tester, neither . . ., of anybody . . ., to try a new drug . . . if it has not been proven before, you won't get me on this (. . .)" (P6). Two other participants said having suffered a deterioration of their physical condition resulting from the participation in research ("I developed a much more severe lordosis, because the hyperbaric chambers are made in the shape of a submarine." (. . .) "So I didn't get all the space that I needed and then I developed a more pronounced lordosis" (P1), "[a]nd what it was supposed to do, it was supposed to help people to walk, and there is one on which it didn't work . . ., I lost all my strength and . . ., I am the unlucky one" (P3)).

Feelings of having to struggle, ask or even "beg" for services

Several participants reported events that made them feel they constantly had to struggle for the services they needed. They repeatedly used phrases such as: "I really struggled to find a physiatrist who

wanted to do it [giving him a follow-up for his lordosis]" (P1), "the hardest is just that you really have to run after people, after the physicians and the O.T. [occupational therapist] (. . .)" (P4), "you really have to delve to find resources (. . .)" (P6), "it is when you complain that you get the services but otherwise . . ., they don't really tell you what you can get (. . .)" (P6), "[b]ut if you don't ask for a service, you won't get any" (P1). Participants described situations in which they had to undertake a lengthy process (e.g., "a year of battles, a year of paperwork in addition to going to school, a year of missing school because of the appointments (. . .)" (P10), "[I]'ve been applying for three years, trying to get those services" (P11)). Participants reported having to make a "little crisis (. . .)" (P11) and to "explain [their] life (. . .)" (P13) to have adequate services.

Feelings of injustice and inequality

Many participants described several situations that left them with a deep sense of injustice or inequality. One participant deplored the fact that other persons were receiving adaptations or medical equipment

faster than him, another that society seems more inclined to make donations for all other causes, rather than a leading cause of disability like CP. One participant was particularly outraged and insulted by the fact that she was denied certain services (housekeeping), because she earned a living independently, while others who were unemployed received such services that she would need to be more independent. Another participant reported having lost her job because the orderlies who were supposed to come to her house to help her dress didn't show up on time and therefore she was late for work. Participants found it unfair when they perceived that others (e.g., friends, more affluent individuals, individuals living in other regions, well-known individuals, and individuals still using pediatric services) were getting more services than they are.

Feeling left out, abandoned

On many occasions (especially during the transition to adult health services), participants felt abandoned or set aside by the healthcare system. Some felt that all people with CP were disenfranchised ("that's one thing I noticed, chronic cases, such as cerebral palsy, are left aside a lot. Because it is not worth investing any money, let's say it bluntly, in us, because anyway, it will always have to be repeated" (P1), "[i]t seems like we are forgotten somewhere in the world. I don't know. But, you know, not forgotten, but we are . . ., it looks like we are set aside, I found" (4)) while others feel abandoned personally ("but I don't know if you can count on your fingers how many places we went to seek help (. . .)" (P10)).

Challenges encountered during medical consultations

Participants described specific challenges they encountered during medical consultations, with physicians such as pediatricians, other specialty physicians, as well as other healthcare professionals (e.g., physiotherapist, occupational therapist). These included wide-ranging challenges such as rude attitudes and offensive comments, belittle-

ment, inadequate communication, and a lack of knowledge of CP (Table 4).

Suggestions offered by participants

We asked our participants what could be improved in healthcare service delivery in order to help them feel more respected and supported. Their suggestions were related: (1) to characteristics they would like to see in an ideal physician (e.g., honesty, compassion), and (2) to the healthcare system in general (e.g., more research on CP, more specialized services for CP) (See Table 5).

Discussion

This study has identified salient ethical and social aspects of the experience of young adults with CP in healthcare based on their testimonials captured in semi-structured interviews. Through these interviews, we gathered insights on the perceptions of young adults with CP that showed that ethical aspects permeate care and health services delivered to individuals with CP (Table 3). These included several challenges related to perceived unfairness in services delivered and consequent feelings of injustice, shortages of adequate health resources, as well as difficulties related to access to health facilities and inadequate preparation to receive young individuals with CP unaccompanied to their medical appointments. A range of ethically-salient challenges were reported in medical consultations. These included conflation of motor and cognitive disability, impersonal attitudes, and lack of empathic and active listening (Table 4). Finally, participants suggested ways to optimize ethics in healthcare delivery by highlighting desirable attributes of physicians, as well as non-physician specific improvements such as increasing research on different aspects of CP and better support for individuals with CP (Table 5).

This qualitative study has several limitations that need to be explicitly acknowledged. First, our data suggest important ethical and social aspects to consider in the care of individuals with CP but they merit broader scale replication and examina-

Table 4.

Challenges Encountered during Medical Consultations

Participants' Responses

Lack of tact, respect or politeness
Belittling the patient (treating adult patients like children)
Conflating motor disability with cognitive disability*
Impersonal attitude and lack of consideration for the patient*
Lack of optimism, hope and willingness to find new solutions
Lack of listening*
Lack of trust of the physician in the patient*
Lack of time
Disinvestment or lack of interest in the patient
Being uncomfortable with the patient or displaying attitudes creating discomfort
Stereotypes, misconceptions or negative judgments
Lack of knowledge, experience or expertise with cerebral palsy*
To attribute a symptom to CP without justification
Infringements of privacy
Poor relationship with a physician or specialty physician
Use of jargon and technical language
Difficult communication with a healthcare professional or a physician
Healthcare professionals who speak mostly to the parents or the caregiver*
Feeling that professionals do not disclose all the information
Need to discuss health and non-health related matters

Note: See text for detailed qualitative description of challenge marked by an asterisk.

tion. Second, it is possible that some participants may have hesitated to speak about sensitive topics. Third, other limitations concern the content of our sample. For reasons of study design, we did not recruit participants with severe intellectual challenges or severe speech difficulties or participants who communicate non-verbally. Accordingly, we did not include the potentially unique experiences of young individuals with more severe forms of CP or substantial co-morbidities. Further, our participants may not be fully representative of the broader population of individuals with CP. Possible differences between young people of different ages and backgrounds in the experience of ethical and social challenges would need to be further assessed quantitatively. Finally, for this article, we focused on the challenges and difficulties encountered. It is important to highlight that there were many very

positive experiences and respectful relationships with clinicians reported by participants.

Nonetheless, and in spite of its limitations, this qualitative study points to the need for further investigation of ethical aspects of service delivery for individuals with CP given the scant literature on this facet of their healthcare experience. The data suggest, as we discuss below that: (1) the ethical principle of respect for persons needs to be concretely specified in meaningful ways to improve current practices; (2) respect for autonomy calls for further direct empowerment of individuals with CP and further training of healthcare providers and, finally, (3) that the gap between, on one hand, the prevalence and long term needs of individuals with CP, with on the other hand, the lack of dedicated healthcare resources should be addressed.

Table 5.

Improvements Proposed by Participants

Physician and Non-Physician Specific Suggestions	
Physician-specific	Listens and communicates well
	Honesty
	Competency
	Interested in the patient as a person
	Takes into account the view of the patient
	Gets involved and takes more time for patients when needed
	Enthusiastic, optimistic and dynamic
	Acts with kindness, empathy, compassion, and respect
Non-physician specific	More research on CP
	Better monitoring and support during the transition from pediatric to adult care
	Better communication and collaboration between healthcare professionals
	More specialized and specific services for CP
	Improved knowledge and training on CP
	More monitoring and follow-up, support, and encouragement
	More responsive (i.e., expedient) medical services
	Better adapted infrastructure and medical equipment
	More human, material and financial resources

Respect for persons

Our results show that some young people with CP are experiencing negative feelings in response to shortcomings in provision of respectful care. For example, participants spoke about being infantilized or not being talked to directly by healthcare providers. Such shortcomings were also exemplified by the lack of physician's trust in them, disinvestment of some physicians, lack of interest in them as distinct individuals, stereotypes, misconceptions or negative judgments, being misperceived as cognitively impaired, or the discomfort they felt amongst healthcare professionals. Participants reported situations in which they experienced feelings of injustice, inequality, abandonment, and exclusion. These reports concur to suggest that participants experienced feelings of inferiority or disempowerment in their interactions with healthcare providers. Also, some events (e.g., lack of listening, minimal time spent with the patient, lack of respect or politeness) experienced by participants that may actually have nothing to do with their disability were felt by

them as a lack of consideration for them personally or as not being treated like other patients.

These findings confirm other studies that have reported significant challenges for individuals with CP or other neurodevelopmental disorders. For example, Buzio et al. (Buzio, Morgan, & Blount, 2002) reported issues similar to those related by our participants, regarding difficulties experienced during a period of hospitalization (basic needs, like hygiene and meals not always being adequately met, limited access in bathrooms). The complexities in the communication with healthcare professionals that were highlighted by some of our participants were also reported in a another study (Balandin, Hemsley, Sigafoos, & Green, 2007), although this study was conducted on adults with cerebral palsy and complex communication needs. One issue that our participants emphasized was that healthcare professionals often communicated primarily with their parents instead of with them. This issue has been reported in other studies (Beresford & Sloper, 2003; Britto, DeVellis, Hornung, DeFriese,

Atherton, & Slap, 2004; Doostan & Wilkes, 1999; Michaud, Suris, & Viner, 2004), although in most instances these studies were conducted with young individuals with a variety of chronic conditions or developmental disabilities, not specifically cerebral palsy. Another issue that our participants expressed being very affected by is the fact of being misperceived as cognitively impaired. Again, this issue has been identified in the literature (Doostan & Wilkes, 1999), but not necessarily by young individuals with CP themselves. On the other hand, some studies have highlighted issues related to confidentiality (Beresford & Sloper, 2003), and shortcomings in the provision of preventive and routine care (Binks, Barden, Burke, & Young, 2007; Kroll & Neri, 2003; Tiffreau, Schill, Popielarz, Herbau, Blanchard, & Thevenon, 2006), but these issues were not specifically discussed by our participants.

Overall, the reports of our participants strongly suggest that the non-medical dimensions of healthcare (e.g., judgments and attitudes of healthcare professionals, feeling of disempowerment) potentially have great significance and a major impact in the lives of young people with CP. This again concurs with the literature, especially on social models of disability whereby environmental factors may increase the burden of the disability. For example, negative attitudes toward young people with disability can lead to negative personal feelings that complicate provider-patient communications and erode mutual respect and trust. These attitudes, when held by healthcare professionals, may have detrimental consequences for young people with CP and other disabilities (Martin, Rowell, Reid, Marks, & Reddihough, 2005). Furthermore, the feeling of disempowerment and inferiority that can arise in response to these negatives attitudes may impact the self-esteem and independence of young adults and may prevent them from developing their full intrinsic potential. Attitudes toward young individuals with disabilities can have direct implications for their care, influencing for example resource allocation decisions and time spent with the patient (Martin, Rowell, Reid, Marks, & Reddihough, 2005). Beresford and colleagues have shown that the failure to provide care that is appropriate

to the condition of young people with disabilities and in respect for their persons may reduce their trust and satisfaction with healthcare (Beresford & Sloper, 2003). As a consequence, young people with disabilities may diminish their use of the healthcare services they need, and this may lead to a deterioration of their overall health status (Bjornson, Belza, Kartin, Logsdon, & McLaughlin, 2008; Cathels & Reddihough, 1993; Ng, Dinesh, Tay, & Lee, 2003). More specifically, the non-respect of the person may have a detrimental impact on relationships and possibly on the health of the individual and future use of healthcare services. From this standpoint, respect for the person becomes a crucial and valuable goal of both ethics and clinical care.

Respect for autonomy

It became apparent in our study that the environmental and social context in healthcare delivery does not always foster the autonomy of young people with CP. Participants reported experiencing over-protection, infantilization, and paternalism. Also, because of the lack of resources, healthcare services are not organized optimally to promote the autonomy of young individuals with CP. Participants reported that it was hard for them to go to the hospital unaccompanied (e.g., not enough staff to help them and to communicate with them, basic needs not being met during hospitalization if family members were not there to help out). They mentioned that they could not always meet physicians without their parents, their medical decisions weren't always respected, and that they were not sufficiently involved in their treatment plan due to a lack of direct communication with healthcare providers and the fact that they don't receive all the medical information related to their disability. These situations clearly indicate barriers in promoting the decision-making autonomy of young individuals with CP. In addition to these barriers to decision-making autonomy, participants reported challenges with physical and communication autonomy (e.g., accessing some services, gaps in the physical accessibility of infrastructures, lack of resources and time to meet their special needs). Combined, these chal-

lenges can seriously jeopardize the independence of individuals with CP to become more involved in making decisions for their health and also becoming responsible for their healthcare.

Our findings challenge literature that has demonstrated that the promotion of autonomy in childhood helps young adults to take charge of their own health. An environment promoting autonomy helps them feel more involved and will help enhance a sense of competency. As a consequence, this will make them less dependent and there could be better chances that they will continue to subscribe to services like occupational therapy and physiotherapy and to follow their treatment with compliance, all characteristics that increase the chances of having good health and well-being (Michaud, Suris, & Viner, 2004). We can also suppose that for those whose autonomy has been promoted, they will have a better experience with the transition between pediatric and adult healthcare services (e.g., less fear of the unknown, less difficulties of managing the appointments and the characteristics of the adult health system) (Binks, Barden, Burke, & Young, 2007). The situation reported by our participants appears far from optimal in regards to the promotion of their autonomy.

Justice, access, and the place of cerebral palsy in the healthcare system

A third set of observations emerging from our data is that CP is neglected within the general healthcare system. Participants highlighted this gap through several experienced events. They noted gaps in CP specific healthcare services, in the knowledge, experience and expertise on CP, in the healthcare professionals' training on CP, and in the public recognition and awareness of CP. They felt a lack of dynamism, optimism and hope when it came time to propose new solutions or treatments. Our results show that participants had to struggle to get some services related to their condition and that some general gaps of the healthcare system affect young people with CP in a more acute and specific way. Finally, we have seen in our study that the transition from pediatric to adult systems is plagued with

challenges and that it is generally ill-fit for young individuals with CP.

These findings showing a lack of dedicated health resources for CP are in stark opposition with the significant prevalence and implications of CP. In addition to being the leading cause of physical disability in children, CP has significant and lifelong consequences and there is a growing number of young people with CP reaching adulthood (Tator, Bray, & Morin, 2007). Many persons living with CP rely heavily and chronically on health services. Eventually, all children with CP will have to go through the transition to the adult health system. Young individuals with CP experience the transition period a in way that is specific to their condition (e.g., lifelong condition with important physical comorbidities, speech difficulties and physical disability that make their autonomy more difficult to enact), but this specificity is not well recognized within the healthcare system (Binks, Barden, Burke, & Young, 2007; Young, 2007). The subsequent difficulties experienced by these young adults lead to direct tangible impacts: loss of confidence in healthcare, decreased frequency of use of healthcare services and compliance with treatment, deterioration of physical condition, social opportunities, etc. From an ethics standpoint, the gaps in the provision of care highlight problems of social justice and fairness with respect to young individuals with CP. Clearly, individuals with neurodevelopmental disorders can benefit from health systems that rely on solidarity but, for example, in the Canadian context there is still a notable gap between funds allocated for acute care versus funds allocated for the care of chronic conditions over the lifespan (NeuroScience Canada, 2006). The prevalence of CP and its consequences should make it the subject of more attention and dedicated resources. Our study shows that individuals with CP can be active partners in identifying gaps in the provision of healthcare services, and also in suggesting concrete ways to improve ethical and social aspects of the care and services offered to them to ultimately improve their quality of life.

References

Andersson, C., & Mattsson, E. (2001). Adults with cerebral palsy: A survey describing problems, needs, and resources, with special emphasis on locomotion. *Developmental Medicine and Child Neurology, 43*(2), 76–82.

Bailey, S., O'Connell, B., & Pearce, J. (2003). The transition from paediatric to adult health care services for young adults with a disability: An ethical perspective. *Australian Health Review, 26*(1), 64–9.

Balandin, S., Hemsley, B., Sigafoos, J., & Green, V. (2007). Communicating with nurses: The experiences of 10 adults with cerebral palsy and complex communication needs. *Applied Nursing Research, 20*(2), 56–62.

Beresford, B. A., & Sloper, P. (2003). Chronically ill adolescents' experiences of communicating with doctors: A qualitative study. *Journal of Adolescent Health, 33*(3), 172–9.

Binks, J. A., Barden, W. S., Burke, T. A., & Young, N. L. (2007). What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. *Archives of Physical Medicine and Rehabilitation, 88*(8), 1064–73.

Bjornson, K. F., Belza, B., Kartin, D., Logsdon, R. G., & McLaughlin, J. (2008). Self-reported health status and quality of life in youth with cerebral palsy and typically developing youth. *Archives of Physical Medicine and Rehabilitation, 89*(1), 121–7.

Blumberg, L. (1993). The personal and the political. Medical attitudes toward disability. *Health PAC Bulletin, 23*(2), 35–7.

Britto, M. T., DeVellis, R. F., Hornung, R. W., DeFriese, G. H., Atherton, H. D., & Slap, G. B. (2004). Health care preferences and priorities of adolescents with chronic illnesses. *Pediatrics, 114*(5), 1272–80.

Britto, M. T., Slap, G. B., DeVellis, R. F., Hornung, R. W., Atherton, H. D., Knopf, J. M., & DeFriese, G. H. (2007). Specialists understanding of the health care preferences of chronically ill adolescents. *Journal of Adolescent Health, 40*(4), 334–41.

Buzio, A., Morgan, J., & Blount, D. (2002). The experiences of adults with cerebral palsy during periods of hospitalisation. *Australian Journal of Advanced Nursing, 19*(4), 8–14.

Cathels, B. A., & Reddihough, D. S. (1993). The health care of young adults with cerebral palsy. *The Medical Journal of Australia, 159*(7), 444–6.

Doostan, D., & Wilkes, M. (1999). Treating the developmentally disabled. *The Western Journal of Medicine, 171*(2), 92–6.

Forman, J., & Damschroder, L. (2008). Qualitative content analysis. *Advances in Bioethics, 11*(9), 39–63.

Hsieh, H.-F., Shannon, Sarah E., . (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277–88.

Kroll, T., & Neri, M. T. (2003). Experiences with care coordination among people with cerebral palsy, multiple sclerosis, or spinal cord injury. *Disability and Rehabilitation, 25*(19), 1106–14.

Lariviere-Bastien, D. & Racine, E. (2011). Ethics in health care services for young persons with neurodevelopmental disabilities: A focus on cerebral palsy. *Journal of Child Neurology, 26*(10), 1220–8.

Martin, H. L., Rowell, M. M., Reid, S. M., Marks, M. K., & Reddihough, D. S. (2005). Cerebral palsy: What do medical students know and believe? *Journal of Paediatrics and Child Health, 41*(1–2), 43–7.

Michaud, P. A., Suris, J. C., & Viner, R. (2004). The adolescent with a chronic condition. Part II: Healthcare provision. *Archives of Disease in Childhood, 89*(10), 943–9.

Ng, S. Y., Dinesh, S. K., Tay, S. K., & Lee, E. H. (2003). Decreased access to health care and social isolation among young adults with cerebral palsy after leaving school. *Journal of Orthopaedic Surgery, 11*(1), 80–9.

Tator, C. Bray, G., & Morin, D. (2007). The CBANCH report—The burden of neurological diseases, disorders, and injuries in Canada. *Canadian Journal of Neurological Sciences, 34*(3), 268–9.

Tiffreau, V., Schill, A., Popielarz, S., Herbau, C., Blanchard, A., & Thevenon, A. (2006). [Transition in health care from youth to adulthood for disabled people]. *Annales de Réadaptation et de Médecine Physique, 49*(9), 652–8.

Young, N. L. (2007). The transition to adulthood for children with cerebral palsy: What do we know about their health care needs? *Journal of Pediatric Orthopedics, 27*(4), 476–9.