THE ONTARIO MOBILITY DEVICES SECTOR

A THIRD PARTY REVIEW

SPINAL CORD INJURY ONTARIO | LÉSIONS MÉDULLAIRES ONTARIO

public good initiative

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Introduction

Spinal cord injuries, whether traumatic or not, lead to a lifelong physical disability and restricted mobility for those who are affected. Access to mobility and other assistive devices is therefore critically important to the wellbeing of people who have suffered a spinal cord injury. A large body of research demonstrates that improving people's mobility leads to improved physical and mental wellbeing, and an overall higher quality of life. This is caused by a number of factors, including through enabling individuals to participate in the workforce, providing greater access to opportunities for socialization, allowing individuals to live independently and therefore develop a sense of personal independence, and creating opportunities for physical activity[1][2][3][4]. When provision of mobility devices is inadequate, people with spinal cord injuries and other disabilities may not have access to the variety and quality of devices that they require. In turn, they are more likely to be excluded from the labour market, have impaired access to education and health services, suffer from social exclusion and struggle to move and live within their own home. Given the importance of access to mobility devices in promoting this population's wellbeing, government should therefore aspire to meet the mobility device needs of all Canadians.

There are also considerable financial costs associated with spinal cord injuries that are shared by those living with the injury and society as a whole. Research finds that the average lifetime economic cost of an individual living with a spinal cord injury is as high as $3 million, and the total economic cost of all new cases annually is $2,67 billion[5]. These costs are derived from the direct costs of acute and long-term healthcare needs, as well as the lost labour market participation. Indeed, as of 2010, there were an estimated 85,556 people living in Canada with a spinal cord injury, with an average of 4,259 new cases each year. By 2030, this number is expected to grow to 121,000

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[1] Davis, Jennifer C., Stirling Bryan, Linda C. Li, John R. Best, Chun Liang Hsu, Caitlin Gomez, Kelly A. Vertes, and Teresa Liu-Ambrose. "Mobility and cognition are associated with wellbeing and health related quality of life among older adults: a cross-sectional analysis of the Vancouver Falls Prevention Cohort." BMC geriatrics 15, no. 1 (2015): 75.

[2] Samuelsson, Kersti, and Ewa Wressle. "User satisfaction with mobility assistive devices: An important element in the rehabilitation process." Disability and rehabilitation 30, no. 7 (2008): 551-558.

[3] Brandt, Åse. Outcomes of Rollator and Powered Wheelchair Interventions-User Satisfaction and Participation. Division of Occupational Therapy, Faculty of Medicine, Lund University, Sweden, 2005.

[4] Valtonen, Kirsi, Ann-Katrin Karlsson, Hannu Alaranta, and Eira Viikari-Juntura. "Work participation among persons with traumatic spinal cord injury and meningomyelocele1." Journal of rehabilitation medicine 38, no. 3 (2006): 192-200.

[5] Krueger, H., V. K. Noonan, L. M. Trenaman, P. Joshi, and Carly S. Rivers. "The economic burden of traumatic spinal cord injury in Canada." Chronic diseases and injuries in Canada 33, no. 3 (2013).

Canadians living with spinal cord injuries[6]. Given this expected growth in the number of spinal cord injuries in Canada, and their associated economic costs, governments should take action to ensure that mobility devices are easily accessible, reducing the associated long-term healthcare and economic costs.

The Ontario Assistive Devices Program (ADP) is Government of Ontario's primary program for supporting persons with disabilities in acquiring an assistive device. The program provides funding to assist in the purchase of a variety of devices, including visual and communication aids, orthotics, prostheses, and mobility devices, with the latter type being the focus of this review and of particular importance to people with spinal cord injuries. The ADP funds up to 75% of the costs of a new device, with the remaining 25% paid by the consumer. Individuals seeking to access the ADP for a mobility device must receive medical authorization from a program authorizer, typically an occupational therapist or physiotherapist. Once medical authorization has been received, the consumer can seek out an ADP-authorized mobility device vendor from which they can purchase their device. Given that the ADP is the primary funding source for mobility devices, virtually all Ontarians accessing a device undertake these steps.

Members of these three groups; the consumers, authorizers and vendors, frequently voice their concerns with this process. In an effort to better understand and qualify these concerns, Spinal Cord Injury Ontario has sought the services of the Public Good Initiative to undertake a review of this process and the mobility device sector as whole. The following report, prepared over the course of the previous 8 months, seeks to identify and describe the current challenges within Ontario's mobility device sector. In the sections that follow, it will first describe the methodology of the research undertaken and, based on this research, identify seven key themes which describe the various challenges facing the sector. In each section, we describe the challenges and concerns, how they undermine the principles of a strong mobility device sector, and propose recommendations for addressing the underlying issues affecting the sector.

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[6] Noonan, Vanessa K., Matthew Fingas, Angela Farry, David Baxter, Anoushka Singh, Michael G. Fehlings, and Marcel F. Dvorak. "Incidence and prevalence of spinal cord injury in Canada: a national perspective." Neuroepidemiology 38, no. 4 (2012): 219-226.

Methodology

The following section describes the methods employed in conducting the review of Ontario's mobility device sector. Our overall strategy was guided by two principles. The first principle was that we wanted to include the views of the three primary stakeholder groups within the ADP and the mobility device sector as a whole; ADP authorizers, ADP-authorized mobility device vendors, and consumers of mobility devices. The second principle was that we wanted to hear first-hand accounts from these stakeholder groups to ensure that the review reflected the varied and nuanced opinions that exist within the sector which cannot be described through data alone. In doing so, we feel that we have constructed an accurate and detailed picture of the sector on which we have based our evaluation.

Given the principles described above, we adopted three methods to complete this review; a jurisdictional scan, focus groups, and surveys. The details of these methods are described below.

Jurisdictional Scan

The jurisdictional scan was performed to identify and describe mobility device provision systems across Canada, as well as in the UK, Australia and New Zealand. We specifically sought to identify the current government programs that exist for the funding of mobility devices, the role of the not-for-profit and charity sectors, the types of devices were qualify for funding, the presence of short-term loan and recycling programs, and the regulation of program authorizers and vendors.

Focus Groups

Focus groups were conducted separately for authorizers, vendors, and persons with disabilities. These focus groups were semi-structured, allowing us to ask questions about specific areas of interest while ensuring that participants were able to expand on their own and each other's answers as they wished. The focus groups took place remotely with a maximum of 6 participants, and typically lasted between one and two hours.

Surveys

Surveys were circulated to mobility device vendor and authorizer representatives through key stakeholder representative SCIO channels. They were designed to include both Likert-scale questions and open-ended questions, and required approximately 20 minutes to complete.

The results of the surveys and focus groups allowed us to identify the key challenges facing Ontario's mobility device sector, while the jurisdictional scan was ultimately used as a tool to assist in identifying potential policy options to overcome these challenges. Both challenges and solutions are discussed in the subsequent sections of the report.

Theme 1: Inpatient and Outpatient Healthcare

***Principle**: People with spinal cord injuries and other physical disabilities should always be provided with the highest quality of healthcare. This includes access to expert-run seating clinics, short-term access to high quality mobility devices, and authorizers who are adequately trained and are knowledgeable in the progression of spinal cord injuries.*

***Principle**: No patient should be discharged from inpatient care prior to having received a high quality mobility device which matches their needs.*

***Concern**: People with spinal cord injuries are being assessed and discharged from inpatient care far too quickly for them to have received an appropriate and personalized mobility device.*

***Concern**: Early discharge from inpatient care negatively influences the way in which authorizers assess and interact with patients when prescribing a mobility device.*

***Concern**: When authorizers observe that their patients can only afford one device, they tend to prescribe a power chair which allows greater long-distance mobility but can harm the individual's recovery period.*

***Concern**: When authorizers lack opportunities for mentorship and education from experienced professionals, they are less able to properly anticipate changes in the patient's condition and prescribe appropriate devices.*

***Policy Recommendation 1.1**: The Government of Ontario should explore opportunities to provide greater access to tertiary rehabilitation services for individuals recovering from spinal cord injuries.*

***Policy Recommendation 1.2**: The Government of Ontario should expand opportunities for occupational and physical therapists to follow-up with their patients at home or in the community and ensure that the prescribed device is appropriate.*

Following an injury or other condition which leads to a spinal cord injury, patients find themselves in inpatient care facilities which provide them with diagnosis, assessment, rehabilitation and ultimately mobility device authorization services.

Authorizers we spoke to describe the evaluation and authorization of mobility devices in the inpatient care as a multi-factored problem. The first factor contributing to this problem is that, due to increasing pressures on the healthcare system, patients recovering from a spinal cord injury are increasingly discharged from inpatient care

facilities before their injury has finished progressing. This means that they are prescribed a device that may soon no longer suit their needs as their rehabilitation and treatment continue. Furthermore, according to some of the authorizers interviewed during our review, advances in medicine and rehabilitation has meant that less than 20% of inpatients go on to require wheelchairs in the long term, despite all requiring one initially[7]. Together, these two factors contribute to a situation in which patients progress beyond the need of their ADP-funded mobility device after being discharged from inpatient care. This is evidently problematic for patients, as they may be required to purchase multiple mobility devices as their condition progresses which creates unnecessary financial duress.

We also learned from speaking with occupational and physical therapists that assessing how a spinal cord injury will progress over a three or four month period is simply a difficult estimation, and can lead to under- and over-prescription of mobility devices, both of which were reported by authorizers to be a significant issue[8]. Under-prescription can result in harmful effects to the person with physical disabilities when their prescribed device limits their essential mobility. Over-prescription can result in harmful effects to the patient if, progression in their physical condition increases their mobility, their device is unable to assist in their mobility and provide better recovery. This happens when a patient is forced to choose a power chair as an alternative to a manual chair because ADP covers only one option. When the physical condition progresses, reliance on the power chair worsens their condition. The problem is further exacerbated if authorizers are not adequately trained in both complex physical disabilities and the mechanics of specialized wheelchairs, and this can lead to situations in which therapists modify their device assessment if injury progression is different from what they had originally anticipated. Providing training in this regard is therefore an important part of providing the best possible acute and inpatient care, and this issue is further discussed in Theme 3 of this report.

Finally, we found that some authorizers feel pressured to decide between prescribing a patient with the optimal device, or one which the patient could reasonable afford to pay for. Authorizers made it clear that their goal was always to provide patients with the best possible healthcare outcomes, but acknowledged that, ultimately, the patient's financial status must be taken into consideration. This issue of device affordability is explored in more detail in Theme 5 of this report.

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[7] Authorizer Focus Group

[8] Ibid

With these concerns in mind, we propose two recommendations that can ensure that patients are prescribed with a mobility device that will meet their needs for years to come. First, we recommend that the MOHLTC explore opportunities to provide greater access to tertiary rehabilitation services for individuals recovering from spinal cord injuries. During our interviews with people with spinal cord injuries, we found that those who had undergone rehabilitation in specialized centres, such as the Lyndhurst Rehabilitation Centre in Toronto, reported very high levels of satisfaction with their inpatient care and mobility device prescription. Second, we recommend that the MOHLTC work with rehabilitation healthcare professionals and ADP program authorizers to expand the delivery of in-home follow-up appointments for patients who have been prescribed a mobility device through the ADP. During our interviews, authorizers stated that they are currently limited in their ability to visit patients in their home to follow-up on the progression of their condition and assess whether or not their mobility device remained appropriate. Further, they stated that assessing their patients at home is critical to understanding how a mobility device is being used by the patient in day-to-day situations.

We also note that some stakeholders expressed interest in building a short-term mobility device rental pool which would allow patients to loan or rent a mobility device for short periods of time following discharge from inpatient care. In doing so, it would ensure that patients could borrow a mobility device until their authorizer was certain that their condition had finished progressing, and therefore be prescribed with a mobility device through the ADP which would meet their needs for years to come. While we find this strategy appealing, we note that many authorizers expressed concerns that mobility devices must be personalized and adjusted to meet the needs of a specific patient. Therefore, a rental pool of devices may not provide the level of variation needed to meet the healthcare needs of patients[9].

[9] Ibid

Theme 2: The ADP Application Process

Principle: *The application process for ADP should never impact an applicant's rehabilitation progress in any way, shape or form.*

Principle: *The application process should ensure minimal room for error and should be approved or denied within a reasonable amount of time allowing the applicant and their medical team to plan accordingly.*

Principle: *The application process should only be submitted when the authorizer has full confidence that their assessment has been appropriately completed and have been given the requisite skills, resources and time to complete the initial assessment.*

Concern: *The application process takes too long after submission to receive approval or denial, causing vendors and/or community members to shoulder the financial burden.*

Concern: *Feedback with respect to the reason for why an application is denied is not given in a reasonable amount of time, resulting in long delays for approval.*

Concern: *The length of the application period itself can result in long periods of time for the community member without access to an appropriate assistive device, making it difficult to participate in daily life, attain and/or continue employment and maintain physical and mental health.*

Concern: *The authorizer community has indicated dissatisfaction with some industry representatives pushing authorizers to complete the assessment and submit an application before they feel comfortable .*

Procedural recommendation 2.1: *The ADP application process should be moved to a fully-digital, online submission portal where applicants can save, share and review applications between authorizers, industry and the Ministry of Health and Long Term Care ADP application review team.*

Procedural recommendation 2.2: *The ADP application system should have the functionality to automatically identify areas that could result in application denial and inform authorizers prior to submission, eliminating significant delays between applications.*

Procedural recommendation 2.3: *The ADP application system should have the functionality to ensure that when an application is denied, reviewers at MOHLTC can provide feedback directly on the original application which then can be edited by authorizers / industry for re-submission.*

Procedural recommendation 2.4: *Reapplication following application rejection due to error should be flagged and fast-tracked through the system.*

Procedural recommendation 2.5*: Appropriate regulations and licensing requirements for vendors should be established to ensure the authorizer community has professional freedom and an appropriate complaint mechanism for delinquent industry representatives.*

Procedural recommendation 2.6*: Applications submitted without authorization by both ADP authorizers and industry representative providing the device should be disqualified.*

Procedural recommendation 2.7*: Vendors should not place restrictions on the number of times someone can try a piece of equipment.*

Procedural recommendation 2.8*: The MOHLTC should provide webinars and/or readily accessible online education materials such that all parties can be educated and informed of the application system to eliminate errors in transition to the new system.*

All stakeholders agree that in principle, the way the application process for ADP itself is designed shouldn't have a negative impact on the person requiring the device. The reality of the situation however doesn't substantiate this principle. After convening focus groups with industry representatives, authorizers and persons with disabilities, it was clear that the application process is much too slow, burdensome and potentially costly to patient rehabilitation[10]. In particular individuals from the authorizer community highlighted multiple instances of applications that fell through the cracks and took upwards of 6 months for approval - worsening what could have been a better outcome with respect to their rehabilitation[11]. This extended waiting period is harmful to the physical and mental health of the patient[12]. Furthermore, this long delay in approval is not limited to the patient themselves, but also to the vendor who may be required to make expensive orders for equipment. Finally, the Ministry itself has a vested interest in ensuring this extended waiting period is reduced as spillover effects of not having the appropriate equipment in place may lead to high hospital admission rates and greater negative impact on patients' physical and mental health[13].

This problem can be largely solved by transitioning the manual processes and mail-in submission system currently used by ADP into a digital online submission that evaluates applicants on base criteria and uses technology such as automation, artificial

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[10] Authorizer Focus Group

[11] Authorizer Focus Group

[12] Warren, Narelle, Karin Walford, Annisha Susilo, and Peter Wayne New. "Emotional Consequences of Delays in Spinal Rehabilitation Unit Admission or Discharge: A Qualitative Study on the Importance of Communication." Topics in Spinal Cord Injury Rehabilitation (2017).

[13] Burns, Anthony S., Ralph J. Marino, Sukhvinder Kalsi-Ryan, James W. Middleton, Lindsay A. Tetreault, Joseph R. Dettori, Kathryn E. Mihalovich, and Michael G. Fehlings. "Type and timing of rehabilitation following acute and subacute spinal cord injury: a systematic review." Global spine journal 7, no. 3_suppl (2017): 175S-194S.

intelligence or machine learning to limit the necessity of inspection by ministry staff, instead allowing for staff to oversee the process and expedite and track applications where necessary. The Government of Ontario should aggressively pursue these technologies to increase capacity and expediency when processing ADP applications and should model technology off of existing plans as highlighted by firms such as Deloitte[14] and KPMG[15] and already utilized by countries such as Estonia[16]. Regardless of the degree to which innovative technologies can be implemented in the near-term, it is clear that an expedited, digital process could significantly enhance the experience for all stakeholders and reduce instances of manual error.

Through our evaluation it was noted that tens of thousands of applications are processed by ADP manually, many of which are re-submitted applications after an error was found in processing[17]. There are simple remedies that can be made to find solutions to these problems including instantaneous evaluations for clerical errors, a transferable saveable format for applications where both authorizers, vendors and patients can review the application and creating feedback mechanisms that can provide comments by reviewers so similar errors are not made again. Furthermore, if an application is rejected, the relevant stakeholders should be immediately notified and applications should be flagged to fast track if the patient is reapplying after a previous failed application, ensuring that the extended process itself does not negatively impact their rehabilitation.

Following discussion with the authorizer community, it became clear that there is a gap in mandated professional responsibility on behalf of the vendors. While brands such as Motion Specialties may have customer service standards that the vendors are expected to uphold, there are few ways for authorizer to hold vendors accountable should they act irresponsibly or try to fast-track a sale prior to the completion of a full and complete assessment. We would advise that the government investigate the creation of a professional body and regulate a clear code of conduct for vendor behavior where consequences could be felt if an individual acts nefariously or not in the best interests of the patient. The intention of this is not to punish vendors for acting in their own best interest, but rather to establish a stronger professional responsibility and to establish a

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[14] Deloitte: AI Augmented Government, using cognitive techniques to redesign public sector work (2016) Retrieved: https://www2.deloitte.com/content/dam/insights/us/articles/3832_AI-augmented-government/DUP_AI-augmented-government.pdf

[15] KPMG: Demystifying Intelligent Automation, the lament guide to the spectrum of robotics and automation in government (2017) https://cdn2.hubspot.net/hubfs/407136/PDFs/KPMG/KPMG_demystifying-intelligent-automation.pdf

[16] Margetts, Helen, and Andre Naumann. Government as a platform: What can Estonia show the world. Research Report. Available at: https://www. politics. ox. ac. uk/publications/government-as-a-platform-what-canestonia-show-the-world. html (28.04. 2017), 2017.

[17] Authorizer focus group

complaint mechanism for authorizers to use should they feel uncomfortable with how a situation is playing out. We would also recommend that regulations are developed to ensure that appropriate product trial is an option for all patients. These pieces of equipment cost thousands of dollars and it is important for all parties that the patient is satisfied. During our focus groups with both persons with disabilities and authorizers it was clear that there were inconsistencies with respect to vendor policy on how long an individual can test a product before purchasing[18].

Another area that should be highlighted when talking about the application in terms of vendor-authorizer interaction is the need for both the authorizer and the vendor to have a role in submitting the application from a patient care perspective and to eliminate potential errors. This was highlighted as a major piece of feedback in the vendor focus group.[19] Our recommendation is to build the online application system in such a way that it requires authentication from both parties before being processed and does not place the burden of review on either party.

Finally, this report will touch on the importance of education in another section, but it should be noted that additional resources should be prepared for the ADP application system, especially if the intention is to move it online. Right now, there is dis-satisfaction among the authorizer community about the availability of resources with respect to dealing with complex cases or clerical questions[20]. By developing webinars and digital resources that can be accessed at any time and by any one, this may considerably benefit the effectiveness of medical professionals and limit errors in the application system, while simultaneously increasing efficiency.

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[18] Authorizer focus group, Persons with disabilities focus group

[19] Vendor focus group.

[20] Authorizer focus group.

Theme 3 - Education and Licensing

***Principle**: People with spinal cord injuries and other disabilities should always have access to well-trained, knowledgeable and qualified healthcare professionals when they are being prescribed a mobility device.*

***Principle**: ADP-authorized mobility device authorizers should not struggle to find learning opportunities for the proper assessment and prescription of mobility devices.*

***Principle**: People with spinal cord injuries and other disabilities should always have access to well-trained, knowledgeable and qualified vendors when they are purchasing a mobility device.*

***Concern**: Patients lack access to highly-qualified medical authorizers. This problem is especially prevalent in rural and other regions lacking specialized seating clinics.*

***Concern**: Newly-graduated occupational therapists lack access to training resources for building proficiency in the assessment and prescription of mobility devices.*

***Concern**: There is a lack of training opportunities in the vendor community to ensure that vendors possess proper knowledge and skills required to prescribe mobility devices.*

***Concern**: There are inadequate regulatory requirements in place to ensure that mobility device vendors in Ontario are knowledgeable of the mobility devices.*

***Policy recommendation 3.1**: The Government of Ontario should consult with the College of Occupational Therapists Ontario (COTO), the Ontario Society for Occupational Therapists (OSOT), and any other relevant professional bodies to identify opportunities to expand mentoring opportunities to members wishing to become mobility device authorizers within the ADP.*

***Policy recommendation 3.2**: The Government of Ontario should consult with Ontario's universities currently offering occupational therapy and physiotherapy degree programs to explore the opportunities to expand the attention provided to mobility devices within the program curricula.*

***Policy recommendation 3.3:** The Government of Ontario should explore opportunities to increase the credentials required to become an ADP-authorized mobility device vendor, as is currently the case for other assistive device categories.*

Assessing a patient's mobility device needs, prescribing the appropriate device and ultimately providing the prescribed device requires a considerable and specialized degree of knowledge and expertise. However, throughout our consultation with Ontario ADP mobility device authorizers, vendors, and people with disabilities, we heard that

this knowledge and skill is becoming increasingly rare. Furthermore, this is perceived to be the case both for program authorizers who may lack the skills required to assess and prescribe mobility devices, and for vendors who may lack the required skills to fill these prescriptions. In this section, we explore the causes, implications, and potential remedies for these concerns.

A great deal of skill and knowledge is required to assess a patient with a spinal cord injury or other disability, and to prescribe them with the correct mobility device. Not only must the healthcare professional identify how a mobility device will meet the patient's current healthcare needs, but they must also attempt to predict how the device will meet their future needs as their condition progresses. Interviews with members of the ADP authorizer community reveal that, following graduation from a provincially-recognized occupational therapy or physiotherapy degree program, opportunities to be trained in the assessment and prescription process for mobility devices are limited. As a result, a considerable number of these professionals, especially those early in their careers, may be lacking the training required to perform these difficult and nuanced procedures. They also note that this has become a pressing over time, with Ontario's aging population requiring the provision of more mobility devices than ever before. This growing trend has left the ADP with little choice but to register more program authorizers despite adequate experience working with assessing patients' mobility device needs.

Throughout our interviews and focus groups, members of the authorizer community and persons with physical disabilities also noted that compared to urban areas, obtaining access to highly-qualified authorizers was particularly problematic in more rural and remote regions of the province. While the major urban centres offer access to well-staffed and specialized mobility device seating clinics, this is typically not the case in rural regions. As a result, individuals seeking a mobility device in these areas may receive a poorer quality of service than someone with access to an urban centre seating clinic.

The failure to prescribe the appropriate device may have significant and deleterious consequences on the patient's health, leading to pressure sores and ulcers, decreased user function and an overall decreased quality of life[21][22][23]. Furthermore, health issues are not the only risk to patients in prescribing an inadequate mobility device. If the

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[21]Krouskop, T. A., P. C. Noble, S. L. Garber, and W. A. Spencer. "The effectiveness of preventive management in reducing the occurrence of pressure sores." Journal of rehabilitation R&D 20, no. 1 (1983): 74-83.

[22]Bergen, Adrienne Falk, Jessica J. Presperin, and Travis Tallman. Positioning for function: Wheelchairs and other assistive technologies. Valhalla Rehabilitation Publications, 1990.

[23]Rosen, L. E. "Fit to function. Four areas where function can be improved by selecting the proper fit of the manual wheelchair." Rehab management 23, no. 10 (2010): 14.

patient's condition progresses to the point that their original device is no longer usable, the financial costs associated with requiring a new mobility device can still be in the thousands of dollars, even after accounting for the ADP's device subsidy. Getting the prescription right the first time is critical to both the health and financial wellbeing of the patient, and the MOHLTC should therefore ensure that the system works to provide this outcome.

To ensure that all ADP mobility device authorizers possess the required skills to prescribe the best mobility device for the patient, we have identified a few potential options for the MOHLTC to explore. First, the ministry should work with relevant stakeholders to develop additional professional development opportunities for occupational therapists and physiotherapists who intend to work as mobility device authorizers within the ADP program. For example, we recommend that the ministry consult with the College of Occupational Therapists Ontario (COTO) and the Ontario Society for Occupational Therapists (OSOT) to identify opportunities to expand mentoring opportunities. Currently, the OSOT offers a mentorship program which connects occupational therapists across Ontario seeking mentorship experience in specific areas of occupational therapy practice[24]. There may be opportunity to expand this program, specifically with an eye towards creating more mentorship opportunities for specialization in mobility device assessment and prescription, with financial assistance from the provincial government. This may be accomplished through financial-based incentives for participating mentors and mentees, ensuring that each party is remunerated for undertaking activities which otherwise would not be paid for. Particular emphasis should be placed creating mentorship opportunities for therapists working in rural and remote locations to address the skills gap in these regions.

A second approach to addressing this concern is to consult with Ontario universities currently offering occupational therapy and physiotherapy degree programs and to explore the opportunities to expand the presence of mobility devices within the program curricula. While we do recommend the ministry pursue this route, we do note that the authorizers interviewed stressed the importance of receiving training through hands-on, experiential learning opportunities like mentorship programs.

Throughout our interviews and focus groups, members of the authorizer and vendor communities suggested that a lack of regulation of the vendor sector may contribute to the unsatisfactory customer service experienced when purchasing a mobility device. Often, individuals purchasing their mobility device require technical advice when making their purchases and setting up their chair. Without highly-knowledgeable and skilled

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[24] Ontario Society of Occupational Therapists (OSOT). OSOT Mentorship Program. http://www.osot.on.ca/OSOT/Practice_Resources_Pages/OSOT_Mentorship_Program.aspx.

vendors, patients may find themselves receiving limited or harmful advice. In reviewing the ADP Guide to Vendor Registration Requirements for New Vendors[25], it is notable that while a number of assistive device vendors (including vendors of hearing aids, visual aids, orthotic devices and many prostheses) require the staffing of professionals with device-specific credentials, mobility device vendors do not. Based on this observation and our conversations with authorizer and vendor representatives, we recommend that the ministry explore opportunities to increase the credential requirements of mobility device vendors; similar to what is required for the sale of other assistive devices. Some authorizers specifically recommended that increased mobility device vendor credentials could be required based on the relative complexity of the devices being offered. While the exact devices that should be considered “complex” is beyond the scope of this report, we strongly recommend that the ministry consult with the authorizer and vendor communities to determine which mobility devices should require greater regulation to be sold.

[25] MOHLTC. “Guide to Vendor Registration Requirements for New Vendors.” May 2015. http://www.health.gov.on.ca/en/pro/programs/adp/docs/vendor_registration_guide_en.pdf.

Theme 4: Customer Service & Care

***Principle**: Persons with spinal cord injuries and other disabilities should always be provided with the highest level respect and customer service as they are being prescribed and are purchasing their mobility device.*

***Principle**: Persons with spinal cord injuries and other disabilities should have the opportunity to ensure that a potential mobility device will be a good fit for them, their home and their lifestyle before purchasing the device.*

***Concern**: The level of customer service provided by mobility device vendors has noticeably declined in recent years.*

***Concern**: Clients often do not receive adequate opportunity to trial a potential mobility device in their home.*

***Concern**: Mobility device vendors, especially those located in rural and remote areas with no competition, have the opportunity to overcharge for devices based on the prices approved by the ADP.*

***Procedural recommendation 4.1**: The Government of Ontario should expand, strengthen, and enforce a new set of standards for service delivery, beginning the with specific recommendations described below.*

***Procedural recommendation 4.2**: The Government of Ontario should continue to conduct regular pricing reviews of mobility devices offered and funded through the ADP.*

The process of purchasing a mobility device funded through ADP, especially for the first time, can be stressful, confusing, time-consuming and costly. Prospective clients must find a device to meet some of their most fundamental mobility needs and that is expected to last for five years or longer. Given this confluence of factors, there is no question that individuals purchasing a device should be provided with the highest level of customer service when acquiring their device.

Unfortunately, during our interviews with both people with spinal cord injuries and other disabilities, as well as with ADP authorizers, we learned that patients often feel that they are receiving inadequate customer service from the vendors issuing their mobility device[26] [27]. In particular, they noted the gradual growth in ancillary fees (*eg.* assembly,

[26] Authorizer Focus Groups

[27] Persons with Disabilities Focus Groups

delivery, and repair fees), increased prevalence of up-selling additional mobility device features, and reduced access to trial their chosen devices for the amount of time required to ensure that it is the right choice for them. Another point that was frequently brought up by individuals who had purchased a device through an authorized vendor was that the receipts provided to them were complicated, unintuitive, and they had trouble understanding which parts of their device were covered by the ADP and which were not. People with spinal cord injuries and other disabilities, as well as ADP authorizers also suggested that, especially in rural and remote regions, a lack of ADP-authorized vendors may result in monopoly-like incentives which only cause further deterioration in the quality of customer service.

Solving these issues will not be easy. However, we believe that the MOHLTC can make significant progress in this area by expanding, strengthening, and ultimately enforcing vendors' standards of service delivery. We recommend specifically that the following measures be included in these expanded standards:

- All receipts of purchases provided by mobility device vendors to consumers should clearly outline what each addition or piece of the mobility device cost, and whether or not each aspect is covered by the ADP. This will ensure that consumers can make well-informed decisions when purchasing their device.

- Vendors must allow customers to trial a potential mobility device for an appropriate amount of time in the comfort of their own homes. This will ensure that the consumer's mobility device is appropriate for their body and is compatible with their own home. What qualifies as an "appropriate amount of time" may vary on a case-by-case basis, and we recommend that the authorizer have discretion in determining this timeframe.

We recognize that, because used devices are ineligible for funding through the ADP, there is an economic disincentive for vendors to provide trial devices. Once a trial device has been used by a prospective customer, it cannot be resold if the customer chooses not to purchase it. As a result, there is often a lack of trial devices available and a reluctance from vendors to supply them for the amount of time required for the customer. However, since requiring vendors to provide greater access to trial devices may not be financially feasible for many vendors, in order to ensure that this recommendation is enforced, the MOHLTC may have to provide some financial assistance to vendors so that they can keep a stock of trial devices on-hand.

Finally, to ensure that prices charged to consumers accurately reflect the market rates for mobility devices, we recommend that the ministry continue to undertake regular

pricing reviews of devices for sale. This is particularly important to ensure price equity between rural and remote regions where consumers only have access to a single vendor. To our knowledge, the most recent pricing review was completed in 2015.

Theme 5: Financing

***Principle**: The cost of a device should never be a determining factor in ensuring the community member is receiving the most beneficial assistive device.*

***Principle**: People with disabilities deserve the right to interact with society in the same way that an able-bodied individual may be able to.*

***Concern**: At the 75% funding level, significant and burdensome costs may apply to acquire the best assistive device for an individuals needs, especially when it comes to custom electric-powered devices.*

***Concern**: For many individuals, secondary devices, specifically for at home use are a requirement for people with spinal cord injuries and can be incredibly costly.*

***Concern**: For individuals who may want to participate in athletic activities or seek employment opportunities that may require additional physical capacity, secondary or even tertiary devices may be necessary.*

***Policy recommendation 5.1**: The Government of Ontario should increase base funding for ADP to 90% of the costs of a primary device.*

***Policy recommendation 5.2**: The Government of Ontario should increase base funding for ADP to fund 75% of the cost of a secondary device in situations where medical professionals deem it necessary.*

***Policy recommendation 5.3**: The Government of Ontario should increase base funding for ADP to include 25% of the cost of a tertiary device which may promote better community integration, employment outcomes and/or promote physical health.*

***Policy recommendation 5.4**: The Government of Ontario should establish a ADP loans program such that the cost of the device the community member is responsible for paying would be made through a government-backed loan program.*

Persons with disabilities should be able to interact with society in the same way that able-bodied individuals can without having to accept significant physical, mental or financial harm. This principle is what has guided generations of disability legislation and is integral to the implementation of the Accessibility for Ontarians with Disabilities Act (AODA)[28]. While Ontario has made significant strides in improving physical accessibility

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[28] Beer, Charles. *Charting a path forward: Report of the Independent Review of the Accessibility for Ontarians with Disabilities Act, 2005*. Government of Ontario, 2010.

with respect to regulatory requirements for ramps, lifts, elevators *etc.*, financial accessibility is something that also needs to be considered further. After completing our review, it became clear that compared with other jurisdictions the ADP program does an adequate job with respect to prioritizing affordability. However, this does not mean that ADP does not create significant financial barriers for participants and that improvements cannot be made.

In Ontario, the median after-tax income is $34,306[29] and a person working full time for minimum wage brings in $22,665[30]. Given the 25% copayment required for ADP equipment, this places a significant financial burden on an average person, especially if they require and assistive device to function effectively in society. The full cost of an electric custom chair starts at $1,200-$1,500[31] and can be as expensive as $30,000[32] with an average cost of approximately $7,132[33]. At the 25% copayment of the average cost, this means that the ADP program expects ADP recipients to contribute $1,783 or between 5-8% of their annual take home income. Given the existing high burden of cost placed on persons with disabilities, this price differential is unreasonable and leads to situations where ADP recipients must choose between incurring debt or choosing a sub-optimal device[34]. This burden is especially problematic for a device that the government should consider an essential medical device to assist with appropriate patient care. Therefore, our recommendation is to increase base funding for ADP to 90% of the costs of a primary device, significantly reducing this cost burden while still establishing a sense of ownership over the device for users and maintaining financial penalties if they misuse or do not properly care for their device.

Secondly, it should be noted that ADP does not fund additional devices that are required for appropriate care should someone have a catastrophic injury. Devices such as bathroom commodes, lifts and other necessary items should be funded at a subsidized rate. Looking at this sector with an equity lens, we do not charge an able-bodied person to have good hygiene, nor to get out of bed in the morning, but for those with disabilities there is an argument to be made that we do by forcing them to pay for essential equipment. Expanding the ADP program to include secondary devices deemed medically necessary by professionals is important to fairly and equitably support those

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[29] Statistics Canada

[30] Ibid

[31] ADP List

[32] Ibid

[33] Ibid

[34] Authorizer Focus Group

with spinal cord injuries and other disabilities. We therefore recommend that the Government of Ontario increase base funding for the program to establish a 75% subsidy for these secondary yet essential devices, given that they do not represent as significant a cost as a primary mobility device like an electric chair.

Thirdly, the government of Ontario has historically pursued policy and programs that promote physical and mental fitness, activity and socialization for the public good. Subsidized athletic programs and public health campaigns encourage individuals to get out and be active. While the disability community receives grants to promote these athletics pursuits, funding for the necessary personal equipment must also be considered. Therefore, we recommend the government consider funding secondary sports wheelchairs and/or appropriate athletic devices that promote physical fitness. Research supports that physical fitness has significant spillover benefits for those requiring mobility devices and as such there is a strong argument to be made for why this should be funded[35]. Furthermore, secondary or tertiary devices should be considered available for funding if they improve employability. For example, for those with low-grade spinal cord injuries, robotic devices may be able to assist individuals in lifting heavy objects that they would otherwise not be able to.

Finally, after completing our review, ability to pay was identified as a major gap during discussions with stakeholder groups. For many in Ontario, they do not have the readily-available savings to be able to pay for a several-thousand dollar copayment for an expensive chair[36]. When faced with extenuating circumstances this may cause individuals to sacrifice their physical health or choose to pursue high-risk loans. Given this insight, we recommend the government establish an ADP loans program for those unable to make the immediate co-payment. This will relieve the pressure placed on vendors to establish a payment plan without any guarantee and could piggy back off of existing infrastructure from government-backed loan programs such as the Ontario Student Assistance Program[37].

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[35] Hutzter, Yeshayahu, and Michael Bar-Eli. "Psychological benefits of sports for disabled people: A review." Scandinavian Journal of Medicine & Science in Sports 3, no. 4 (1993): 217-228.

[36] “BMO Financial Group: Canadians Withdrawing More from their RRSPs for Everyday Expenses (2018) Retrieved: https://newsroom.bmo.com/2018-02-15-Canadians-Withdrawing-More-From-Their-RRSPs-For-Everyday-Expenses-BMO-Study

[37] Ontario Student Assistance Program: www.osap.ca

Theme 6: Device Variety & Flexibility

***Principle**: People who suffer from spinal cord injuries and other disabilities should always have access to mobility devices and other products that facilitate their daily lives and promote a higher standard of living.*

***Concern**: The ADP program only covers one mobility device. The ADP program funds either a manual chair or a power chair, but not both.*

***Concern**: Getting through snow is difficult for wheelchairs in winter, especially in Northern Ontario. A winter tire or an all-terrain wheelchair is needed, considering the weather conditions in some remote areas.*

***Concern**: Interviews with the SCI community members suggest that the ADP program covers mobility devices only. However, other accessibility products, such as lifting chairs, bath lifts and pressure relief mattresses are also essential to ensure the safety at home and the living standards.*

***Policy recommendation 6.1**: The Government of Ontario should increase base funding for ADP to fund the cost of a secondary device in situations where medical professionals deem it necessary.*

***Policy recommendation 6.2**: The Government of Ontario should expand the list of accessibility devices currently funded through the ADP to include more devices which assist with daily living.*

While the ADP program covers one mobility device, individuals with with spinal cord injuries found the program limiting. Through our focus group interviews, people with spinal cord injuries indicated that in many cases both power chairs and manual chairs are needed to sustain daily life and activities. Most people use power chair for travelling longer distances, while manual chairs were reportedly more likely to be used in an indoor environment[38]. Due to the ADP only providing funding for a single mobility device, those in need of two devices typically choose to apply their ADP funding towards covering the costs of a power chair only, as it is the more expensive and versatile option. However, this can lead to over-usage of the power chair, accelerating the depreciation of the device and resulting in greater costs of repair[39]. For people with spinal cord injuries, this can create a sense of reliance and exclusive dependency on power chairs, resulting in gradual physical deterioration due to lack of exercise.

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[38] Persons with Disabilities Focus Group

[39] Vendor Focus Group

Other accessibility devices are also essential to ensure that people with spinal cord injuries and their caregivers enjoy a greater quality of life. Many of these accessibility devices ensure the safety and prevent risk of injuries and other physical and mental medical challenges[40]. For example, supplementary products such as the pressure-relieving mattresses prevent secondary health complications like pressure sores and ulcers[41]. Similarly, lifts and slings are a key part of home independence to overcome mobility difficulties for many people with spinal cord injuries who need assistance transferring between bed, wheelchair or bathroom[42]. With the assistance of lifts and slings, individuals are less likely to fall down and are able to move more safely and independently within their own homes. Additionally, people with spinal cord injuries and other disabilities can also benefit significantly from improved access to specialized fitness devices, which are recommended to improve and maintain physical and mental wellbeing by facilitating regular exercise.

However, during our interviews with people with spinal cord injuries, it was discovered that many people are loaning these accessibility devices from community groups or other charitable organizations, or are experiencing considerable financial hardship when it comes to affording the devices that support their independence and ensure their safety at home[43]. Both of these situations are far from ideal. Often, these devices must be designed and optimized for specific individual's body and condition, so borrowing used devices through a loaner program may result in people receiving suboptimal devices. As the ADP continues to fund the patient's mobility devices to support their mobility, the list of products funded by the program should be expanded to include a greater diversity of assistive devices which would improve the patient's safety, independence, and overall health at home.

Recognizing the importance of the accessibility devices, we recommend that the Government of Ontario to expand the list of devices currently funded by the ADP to include these other types of assistive devices. The details of our recommendations on the process for funding these devices can be found in Theme 5: Financing.

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[40] Westgren, N., & Levi, R. (1998). Quality of life and traumatic spinal cord injury. Archives of physical medicine and rehabilitation, 79(11), 1433-1439.

[41] Gefen, A., & Santamaria, N. (2017). Comment on 'Effectiveness of a multi-layer foam dressing in preventing sacral pressure ulcers for the early acute care of patients with a traumatic spinal cord injury: comparison with the use of a gel mattress'. International wound journal, 14(5), 882-884.

[42] Florio, J., Arnet, U., Gemperli, A., Hinrichs, T., & for the SwiSCI study group. (2016). Need and use of assistive devices for personal mobility by individuals with spinal cord injury. The Journal of Spinal Cord Medicine, 39(4), 461–470. http://doi.org/10.1080/10790268.2015.1114228

[43] Person with Disabilities Focus Group

Theme 7: Repairs & Maintenance

***Principle**: People with spinal cord injuries and other physical disabilities should not be financially penalized when accidental damage or anticipated wear and tear occurs to their mobility device.*

***Principle**: Damage to an individual's device should not have deleterious consequences for the individual's health.*

***Concern**: The costs of repairing and maintaining mobility devices have been increasing without any additions to assistance to cover these costs.*

***Concern**: Avoiding or refusing to repair a device because of financial considerations is harmful to the health of the device owner.*

***Policy recommendation 7.1**: The ADP should be provide funding for regular upkeep, inspections and parts replacement, rather than simply emergency maintenance.*

When speaking with industry representatives, we found that most repairs requested by ADP clients concerned issues of wear and tear and a lack of diligent and frequent preventative maintenance[44]. Currently, there is no funding provided through the ADP to assist in financing or facilitating repairs and maintenance of ADP devices. This is an important gap that must be addressed. As it currently stands, only the device user has any responsibility for ensuring effective maintenance. Drawing on an earlier example: physicians uphold a professional responsibility to ensure that their patients are progressing regularly, but when this extends to a device that is medically necessary there is no oversight or mechanism to ensure accountability or financing this cost. Speaking to stakeholder groups, we were also made aware that the costs of these repairs are growing and are becoming increasingly prohibitive - undermining the health and safety of mobility device users. Therefore, it is becoming increasingly important to provide funding for these repairs, as it is dangerous and harmful to a person's health if they avoid or refuse to repair their device for financial reasons.

This issue is exacerbated by the fact that product support and repair requirements are highly variable. Whereas some manufacturers provide warranty on parts, others do not. For example, power chairs are able to provide greater mobility in challenging weather, but require more repairs with greater use. It is important to note that if a device is well-

[44] Vendor Focus Groups

maintained, it can last longer than the five year ADP cycle. Wheelchairs are designed to be low maintenance but require regular inspection[45].

Through the ADP, the Government of Ontario should provide funding for the regular maintenance of mobility devices to ensure that persons with physical disabilities maintain the integrity of the mobility device through the five-year device funding cycle. Industry representatives note that if a device is well-maintained, it can last much longer than its standard five-year cycle. Therefore, by providing funding for repairs and maintenance, the ADP can ensure that persons with physical disabilities maintain the integrity of their devices and limit the number of new devices required every five years, ultimately reducing program costs in the long-run.

[45] Cook, Albert M., and Janice Miller Polgar. Assistive Technologies-E-Book: Principles and Practice. Elsevier Health Sciences, 2014.