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Improving Access for Pediatric and Adult Cochlear Implant Candidates in Ontario

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Abstract

In 2011, the Ontario Ministry of Health and Long-Term Care (MOHLTC) announced the one-time allocation of $5.9 million to be shared by cochlear implant programs at five Ontario hospitals. The primary goal of this reform was to address cochlear implant wait times. More specifically, this funding was aimed at reducing adult wait times by 50% and to completely eliminate pediatric waiting lists. Prior to this funding, wait times for pediatric and adult cochlear implants were known to exceed four years. The funding was provided in response to a growing body of research that demonstrates increased speech perception and vocabulary among pediatric recipients, and pressure from parents of children on cochlear implant waiting lists, surgeons and other involved healthcare providers (e.g., auditory verbal therapists, audiologists, and speech language pathologists). The decision to increase funding was also influenced by government stakeholders who believed this one-time investment would be returned as pediatric patients reach adulthood and are better equipped to participate in mainstream (i.e., hearing) society. While this one-time funding model has the potential to eliminate wait times for pediatric patients, thereby ensuring these children can access therapeutic services as early as possible, it does not address the future of cochlear implant waiting lists or the capacity of health human resources to absorb this sudden and unprecedented influx of pediatric patients.

Le Ministère de la Santé et des Soins de Longue Durée (MSSLD) de l'Ontario a annoncé en 2011 le déblocage d'un budget de $5.9 million à partager entre les programmes d'implants cochléaires dans cinq hôpitaux de la province. La réforme visait avant tout à diminuer les temps d'attente pour les implants cochléaires. Plus particulièrement, cet apport budgétaire avait pour but de diminuer les délais de 50% pour les adultes et de les éliminer complètement pour les enfants. Les délais d'attente pour les adultes et les enfants confondus étaient considérés comme supérieurs à quatre ans. Le coup de pouce budgétaire était en réaction à des résultats de recherche démontrant une amélioration de la compréhension du discours et du vocabulaire chez les enfants recevant l'implant, et de la pression de la part des parents des enfants sur liste d'attente d'implants cochléaires, des chirurgiens et des autres producteurs de soins impliqués (par exemple les thérapeutes de la communication auditivo-verbale, les audiologistes, ou les orthophonistes). La décision de donner un coup de pouce budgétaire a aussi été influencée par les conseillers du gouvernement qui pensaient que cet investissement ponctuel serait rentabilisé quand les enfants traités atteindraient l'âge adulte mieux équipés pour la vie en société. Si cet apport ponctuel peut éliminer les délais d'attente pour les enfants, leur assurant ainsi l'accès aux services thérapeutiques aussi tôt que possible, il ne résoud en rien le problème des listes futures ni la capacité des ressources humaines sanitaires à absorber un tel afflux soudain de patients pédiatriques.

Key Messages

- In 2011, the Ontario government introduced a one-time allocation of $5.9 million to be shared by the cochlear implant programs at five Ontario hospitals (i.e., Toronto Hospital for Sick Children, The Ottawa Hospital, Children's Hospital of Eastern Ontario, London Health Sciences Centre, and Sunnybrook Health Sciences Centre).
- The lump sum funding represented a policy response to building pressure from several stakeholders in the hearing community (e.g., surgeons, parents of children on cochlear implant waiting lists, researchers, and advocacy groups) to address cochlear implant wait times.
- Policy responses focused on eliminating the pediatric cochlear implant waiting list have the potential to support improved speech perception, vocabulary, and access to mainstream education among children and yield long-term societal returns. This particular reform does not, however, address the implications in terms of available health human resources, as an unprecedented number of children begin to seek therapeutic services, nor does it address the efficacy of pediatric implantation.

Messages-clés

- *Le gouvernement de l'Ontario a débloqué un budget de $5.9 million en 2011 à partager entre les programmes d'implants cochléaires de cinq hôpitaux en Ontario (à savoir l'Hôpital des Enfants Malades de Toronto, l'Hôpital d'Ottawa, l'Hôpital pour Enfants de l'Est Ontario, le Centre de Sciences de Santé de Londres, et le Centre de Sciences de Santé de Sunnybrook).*
- *Ce forfait de financement était une réponse politique à la pression accentuée exercée par plusieurs groupes au sein de la communauté des entendants (par exemple, les chirurgiens, les parents d'enfants en liste d'attente pour un implant cochléaire, les chercheurs et divers groupes de pression) pour régler le problème des délais d'accès aux implants cochléaires.*
- *Les politiques visant à éliminer les listes d'attente pour implants cochléaires peuvent avoir pour effet d'améliorer la perception du discours, le vocabulaire et l'accès au système éducatif des enfants et peuvent donc générer des bénéfices sociaux sur le long terme. Cette réforme particulière ne permet cependant pas de*

résoudre les problèmes de disponibilité de ressources humaines pour répondre à l'afflux soudain de demande de soins par les enfants, ni d'améliorer l'efficacité de l'implant pédiatrique.

1 BRIEF DESCRIPTION OF THE HEALTH POLICY REFORM

In 2011, the Ontario Ministry of Health and Long-Term Care (MOHLTC) announced that it would provide $5.9 million in funding to be shared by the cochlear implant programs at five Ontario hospitals (i.e., Toronto Hospital for Sick Children, The Ottawa Hospital, Children's Hospital of Eastern Ontario, London Health Sciences Centre, and Sunnybrook Health Sciences Centre). Through the provision of funding to provide an additional 184 unilateral implants between 2011 and 2012, the reform aimed to reduce the wait time for cochlear implants among adults by 50% and to eliminate the pediatric waiting list altogether. The funding was introduced as part of the government's *Open Ontario Plan* to provide more access to health care services while improving quality and accountability for patients.

2 HISTORY AND CONTEXT

The advancement of cochlear implant technology has had a dramatic impact on the lives of children and adults with severe to profound hearing loss in Canada. The history and context of cochlear implant technology in Ontario is a narrative framed within two distinct communities—the hearing community and the Deaf community. Some members of the Deaf community opposed the provision of funding to develop a more robust pediatric cochlear implant program, while those in the hearing community who had advocated for such an expansion (e.g., surgeons, speech-language pathologists, auditory verbal therapists, the government, and hearing parents of deaf children) celebrated the reform. A cochlear implant is a medical device that is surgically implanted to "improve hearing in children and adults with severe to profound hearing impairments" (Hanrahan 2011, 1). It operates electronically using a receiver/stimulator that is embedded in the bone of the skull, and an electrode array that is inserted in the cochlea. A speech processor is worn behind the ear and a microphone is worn on the head above the ear. Health Canada approved cochlear implants for use in children in 1990.

Cochlear implants are insured under the Ontario provincial health care system. This means that the candidacy assessment process, the surgery itself, post-surgery follow-up, and rehabilitation (i.e., auditory verbal therapy and speech-language pathology) are available free-of-charge to patients. However, that does not mean there are no barriers to access or unequal access for the same level of need, because of current policy and practice.

First, a variety of assessment tools are used in Ontario to determine cochlear implant candidacy. For example, the Hospital for Sick Children in Toronto uses the Children's Implant Profile, the London Health Sciences Centre uses the Multisyllabic Lexical Neighbourhood Test or the Lexical Neighbourhood Test, and the Canadian Consensus statement on bi-lateral implants is the primary reference and assessment tool used by the Children's

Hospital of Eastern Ontario. At present, there exists no means of standardizing cochlear implant candidacy assessment tools and protocols. The lack of standardized cochlear implant candidacy assessment tools and protocols is primarily due to a lack of policy coordination among and between Ontario hospitals. The lack of provincial coordination has meant that each hospital is responsible for building and implementing their own policies regarding cochlear implant candidacy. As a result, individual hospitals have developed teams that carry out these assessments and determine candidacy on a case-by-case basis.

Also, provincial coverage leaves substantial out-of-pocket expenses to be born by patients (or their family): these include travel to and from the implant hospital, which can be exacerbated for rural or out-of-town patients due to the current concentration of cochlear implant programs in urban centres, replacement batteries for speech processors, as well as the cost of repairing or replacing components (i.e., the speech processor, coil, and battery) in the event of loss, damage, or theft. There is also the issue of technological advancements, which can render the speech processor relatively obsolete in a short period of time. In Ontario, unlike other jurisdictions, the MOHLTC makes a financial contribution of up to 75% of the cost of a new processor, to a maximum of $5,444 through the Assisted Devices Program. Unfortunately, program eligibility requires that current equipment is not functioning or a new processor demonstrates significant additional benefits to the patient. The problem here lies in the fact that if a patient waits until her/his processor is not working, s/he must go without the technology on which s/he has come to rely in order to function in the hearing world. At the same time, the ability to demonstrate the significant additional benefits of an upgraded speech processor is subject to interpretation by a patient's audiologist due to the lack of standardization in this area. Indeed, financial and geographical barriers to accessing cochlear implants are exacerbated by current policy and practice which have failed to standardize processes surrounding maintenance and replacement of the implant.

These issues have been exacerbated in recent years by an increase in demand for implants. Technological advances and scientific innovations have brought about the expansion of cochlear implant criteria, in effect making these devices suitable for a wider range of patients. Also, in 2006 the Canadian Association of Speech-Language Pathologists and Audiologists (CASLPA) released a position paper advocating for pediatric implantation in light of the growing body of evidence demonstrating superior outcomes with regard to speech perception and vocabulary associated with early implantation. Additionally, the implementation of the Ontario newborn hearing screening program in 2008 has led to the identification of children with hearing loss earlier than ever before (Argintaru, Hamidi, Allen 2011). Together these factors have contributed to increased demand and consequent wait times for cochlear implants in Ontario.

The growing pool of possible cochlear implant candidates meant that provincial resources could not keep pace with the increasing demand for these medical devices; wait times for adult and pediatric implants grew to be years in length (Fitzpatrick and Brewster 2008; Hearing Foundation of Canada 2003). Concurrently, a public debate began to crystallize in response to wait times. In particular, the trend that has seen hearing parents of deaf children opt for early implantation and speech therapy as opposed to American Sign Language (ASL) has prompted a fervent and polarized public debate between hearing and Deaf communities. Certainly, the expansion of cochlear implant programs has not always been met with open arms. From a cultural standpoint, the Deaf community challenges the efficacy of pediatric implants. Criticism of the pediatric cochlear implant program emanating from the Deaf community has revolved around issues related to bilingualism and biculturalism. The opportunity for children who are born deaf and subsequently implanted at an early age to become proficient in ASL is severely curtailed by early implantation and a focus on spoken language. The Deaf community has advocated for bilingualism (i.e., proficiency in both ASL and spoken language) as well as biculturalism (i.e., understanding and acceptance of implanted children in both the hearing and Deaf communities). Opposition to pediatric cochlear implants was almost entirely overshadowed, however, by the growing chorus of hearing parents of deaf children on cochlear implant waiting lists. In addition, the provincial government has remained resolute in its categorization of deafness as a disability.

To summarize, the provision of one-time, increased funding for cochlear implant programs in 2011 was introduced by the MOHLTC without consultation with specific community stakeholders (i.e., the Deaf community). The funding came in response to a series of activities that transpired between 1990 and 2010 in the domains of research, policy implementation, and public advocacy. These activities eventually culminated in the movement of cochlear implantation into the policy area. More specifically, the Ontario government's one-time funding followed: *1*) the expansion of cochlear implant criteria, *2*) research advocating for pediatric implants, *3*) the medical community's support of early implantation, *4*) introduction of the Ontario provincial hearing screening program, and *5*) mounting pressure from hearing parents of deaf children on cochlear implant waiting lists. Some members of the Deaf community opposed the provision of funding to develop a more robust pediatric cochlear implant program, while those in the hearing community who had advocated for such an expansion (e.g., surgeons, speech-language pathologists, auditory verbal therapists, the government, and hearing parents of deaf children) celebrated the reform.

3 GOALS OF THE REFORM

The primary goal of the reform was to address wait time for cochlear implants in Ontario. By providing a one-time allocation of $5.9 million, the reform intended to equip Ontario's five existing cochlear implant programs with the resources required to provide an additional 184 unilateral implants across the province. Priority was given to pediatric implants, with the goal to provide implants to all children on a waiting list at that time (the average wait time for pediatric cochlear implant being over four years in Ontario in 2011). Early implantation in children can make a big difference in outcomes later in life, as research has indicated that implantation in children under two years old with bilateral severe-to-profound sensorineural hearing loss contributes to significant improvement in language perception and vocabulary (Svirsky, Teoh, Neuburger 2004). The reform was meant to make it easier for recipients of cochlear implant, who have accessed speech and auditory verbal therapy since childhood, to integrate into hearing society; early implantation has allowed many children to enter first grade with language skills comparable to children with normal hearing (Argintaru, Hamidi, Allen 2011). Furthermore, this reform may decrease demand for therapeutic speech and auditory services provided to cochlear implant recipients in their adulthood, thereby redirecting these resources to children. In the short term, however, this reform may create pressure on audiology, speech-language pathology, auditory verbal therapy, and educational resources as these professions adjust to an unprecedented increase in demand for their services.

4 FACTORS THAT INFLUENCED HOW AND WHY

4.1 The issue came onto the government's decision agenda

According to Kingdon's (2003) policy window model, three components—problems, politics, and policy—must come together for a matter to be addressed in the public policy arena. The problem in the case of pediatric cochlear implants was the wait time associated with accessing these devices. Indeed, cochlear implantation is often a time sensitive intervention and wait times have the effect of pushing children outside this ideal window of opportunity (i.e., between 12-24 months of age) that has been correlated with better speech perception and language outcomes.

The politics that surround this issue are extremely polarized and have been characterized by a rigid hearing/deaf divide. Support in favour of expanding pediatric cochlear implant programs primarily came from the hearing community and hearing parents of children who were waiting for cochlear implants, as well as surgeons, who met with their members of provincial parliament to address the wait time issue (Hinmann 2011). Moreover, several hospital representatives approached their Local Health Integration Network, and VOICE for Hearing Impaired Children (a Toronto-based non-profit organization that offers support to parents with children who are deaf or hard of hearing) was also strongly involved in advocating for increased funding to improve access for young children who may reap the therapeutic benefits of early implantation. Opposition to this reform has been led by the Canadian Association of the Deaf (CAD), an organization that has advocated against the expansion of pediatric programs, asserting that there is insufficient empirical research and evidence to support the efficacy of cochlear implantation in deaf children. CAD also disputed the government's decision to exempt implanted children from resources that would have allowed them to learn ASL (CAD 2012).

The policy response has been exclusively focused on meeting the demands of those in the hearing community (i.e., surgeons, hospitals, and hearing parents of children on cochlear implant waiting lists). As research continues to mount in favour of early implantation, children are being implanted as young as eight months old. The Ontario government's one-time increased funding to the pediatric cochlear implant program has worked to eliminate pediatric wait times and provide timely access to cochlear implants for children. However, this reform and the current policy have not been concerned with whether or not Ontario's health workforce (i.e., auditory verbal therapists, speech-language pathologists, and audiologists) can manage the influx of children seeking services after the implantation.

5 HOW THE REFORM WAS ACHIEVED

The Ontario government's introduction of a one-time funding envelope of $5.9 million was led by advocacy efforts mounted by parents of children on cochlear implant waiting lists and surgeons struggling to compile resources to provide this time sensitive intervention to their pediatric patients. The government policy response was directed by Deb Matthews, the Minister of Health at that time, who pushed the funding initiative forward within the MOHLTC. Matthews advocated for the increased funding when she became aware of the wait times associated with cochlear implants for children and the effects that timely access may have on long-term speech and language development (Ferguson 2011). Despite grappling with an $18.7 billion deficit the year that the funding was introduced, experts in the field advised the MOHLTC that their investment in pediatric cochlear implants would be returned in the long run. Early recipients of cochlear implants (i.e., infants under two years of age) are more aptly equipped to participate in hearing society as adults having participated in speech and language therapy since infancy and developed age-appropriate language skills. Despite widespread government support, the MOHLTC did not give the cochlear implant programs *carte blanche* (CASLPA 2006). Funding was divided according to the need and capacity of each hospital and was only for the devices, not for the health human resources required to perform the surgery or to follow up with the patient to perform device activation.

6 EVALUATION

At present, there have been no formal evaluations of Ontario cochlear implant programs. A proper evaluation of cochlear implant programs will necessitate a transdisciplinary approach. Future evaluations need to be sensitive to the socio-cultural implications of such evaluations, especially when evaluations necessitate using the Deaf community as a marker for comparison of social and economic success. Evaluations need to equally consider the policy outcomes of cochlear implant programs, including whether or not timely access to the desired medical devices was achieved. Finally, prospective evaluations should aim to report formally on the intended objectives of early cochlear implantation (e.g., integration of implanted children into mainstream school and full participation as adults in society). Indeed, the outcomes of early implantation are only recently coming to the fore in Canadian research and have yet to be formally reported, but they hold significant potential for future policy-making in the area.

7 STRENGTHS, WEAKNESSES, OPPORTUNITIES AND THREATS

Table 1 summarizes strengths, weaknesses, opportunities, and threats to the introduction of one-time funding in the amount of $5.9 million to cochlear implant programs in Ontario from the perspective of diverse stakeholders (e.g., health care workers, government, cochlear recipients, hearing parents of children with cochlear implants, the Deaf community, the hearing community, and educational institutions).

Table 1: SWOT Analysis

Strengths	Weaknesses
• The provision of an additional 184 cochlear implants has the potential to reduce adult wait time and completely eliminate pediatric waiting lists. • Research has shown that pediatric implantation extensively improves speech perception and vocabulary.	• Lump sum funding does not address the future of cochlear implant waiting lists. • As children are given implantation priority, adults may experience unchanged or even longer wait times.
Opportunities	Threats
• This funding model has the potential to empower health care providers in audiology teams to allocate funding to patients they think require the surgery most. • This funding presents the opportunity to cultivate and foster technological innovation in Canada's already extensive and internationally renowned cochlear implant research program.	• The trend in pediatrics (as well as, more recently, adult care) towards bilateral implantation versus unilateral implantation may undermine the potential impact of the funding and prove less cost-effective. • Children and adult cochlear implant recipients are no longer eligible to receive deaf resources (e.g., ASL or access to deaf education), which may be especially threatening to the implanted children of deaf parents.

OPPORTUNITIES (CONT'D)	THREATS (CONT'D)
• This reform creates opportunities for children who were implanted as infants to access mainstream education with little to no assistance by Grade 1.	• There may be a critical lack of capacity among auditory verbal therapists, speech-language pathologists, and audiologists as they try to absorb a wave of recently implanted children, which could threaten these children's long-term speech and language outcomes.

8 CONCLUSION

In summary, the provision of $5.9 million by the MOHLTC to fund cochlear implants in five Ontario hospitals represents a policy mechanism embraced by various stakeholders to help reduce adult wait times and to completely eliminate the pediatric wait times for cochlear implants. Increased funding to cochlear implant programs represents one facet within a complex and long-term rehabilitative process. This funding model signifies the Ontario government's commitment to provide timely access to these medical devices for children, which have been proven to aid in the development of better speech perception and vocabulary with early implantation. The one-time funding allocation does not address the potential impact on available health human resources nor the future of cochlear implant waiting lists and is perceived as a threat to Deaf culture by many of those in the Deaf community.

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