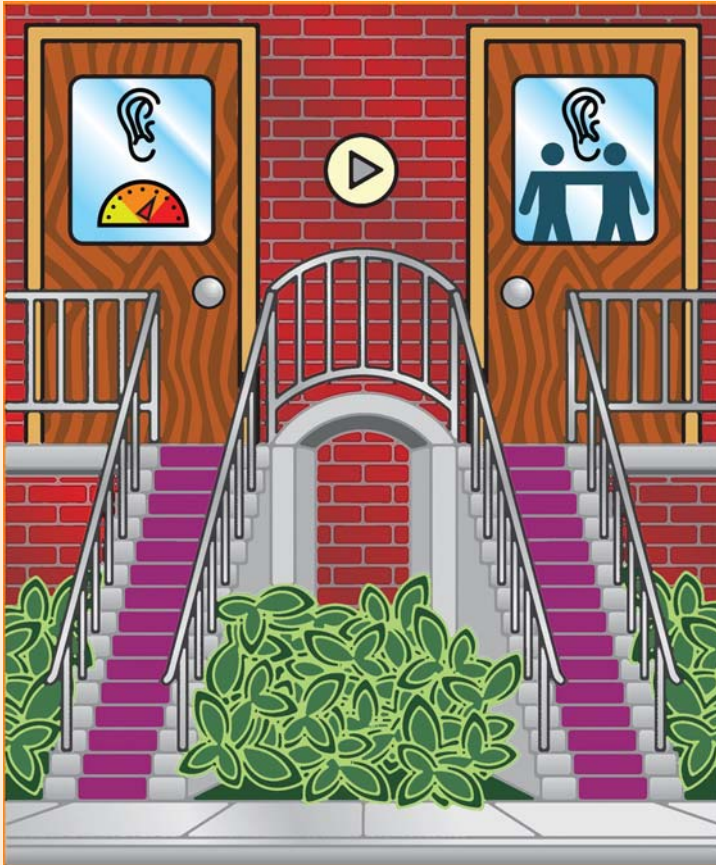


# CJSLPA • RCOA

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## Canadian Journal of Speech-Language Pathology and Audiology

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d'orthophonie et  
d'audiologie*



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- ▶ *Prevention of Reading and Writing Difficulties: A Preliminary Study of the Practices of Canadian Speech-Language Pathologists*  
Pascal Lefebvre, Natacha Trudeau and Ann Sutton
- ▶ *Effects of Sub-Thalamic Deep Brain Stimulation on Speech Production in Parkinson's Disease: A Critical Review of the Literature*  
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Alexandrea K. Gow
- ▶ *Parents' Experiences in a Locally  
Initiated Newborn Hearing Screening  
Program*  
Sarah Kelly and Mary Ann Bibby

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The Canadian Association of Speech-Language Pathologists and Audiologists (CASLPA) is the recognized national professional association of speech-language pathologists and audiologists in Canada. The association was founded in 1964, incorporated under federal charter in 1975 and is committed to fostering the highest quality of service to communicatively impaired individuals and members of their families. It began its periodical publications program in 1973.

The purpose of the Canadian Journal of Speech-Language Pathology and Audiology (CJSLPA) is to disseminate contemporary knowledge pertaining to normal human communication and related disorders of communication that influence speech, language, and hearing processes. The scope of the Journal is broadly defined so as to provide the most inclusive venue for work in human communication and its disorders. CJSLPA publishes both applied and basic research, reports of clinical and laboratory inquiry, as well as educational articles related to normal and disordered speech, language, and hearing in all age groups. Classes of manuscripts suitable for publication consideration in CJSLPA include tutorials, traditional research or review articles, clinical, field, and brief reports, research notes, and letters to the editor (see Information to Contributors). CJSLPA seeks to publish articles that reflect the broad range of interests in speech-language pathology and audiology, speech sciences, hearing science, and that of related professions. The Journal also publishes book reviews, as well as independent reviews of commercially available clinical materials and resources.

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## Objet et Portée

L'Association canadienne des orthophonistes et audiologistes (ACOA) est l'association professionnelle nationale reconnue des orthophonistes et des audiologistes du Canada. L'Association a été fondée en 1964 et incorporée en vertu de la charte fédérale en 1975. L'Association s'engage à favoriser la meilleure qualité de services aux personnes atteintes de troubles de la communication et à leurs familles. Dans ce but, l'Association entend, entre autres, contribuer au corpus de connaissances dans le domaine des communications humaines et des troubles qui s'y rapportent. L'Association a mis sur pied son programme de publications en 1973.

L'objet de la Revue canadienne d'orthophonie et d'audiologie (RCOA) est de diffuser des connaissances relatives à la communication humaine et aux troubles de la communication qui influencent la parole, le langage et l'audition. La portée de la Revue est plutôt générale de manière à offrir un véhicule des plus compréhensifs pour la recherche effectuée sur la communication humaine et les troubles qui s'y rapportent. La RCOA publie à la fois les ouvrages de recherche appliquée et fondamentale, les comptes rendus de recherche clinique et en laboratoire, ainsi que des articles éducatifs portant sur la parole, le langage et l'audition normaux ou désordonnés pour tous les groupes d'âge. Les catégories de manuscrits susceptibles d'être publiés dans la RCOA comprennent les tutoriels, les articles de recherche conventionnelle ou de synthèse, les comptes rendus cliniques, pratiques et sommaires, les notes de recherche, et les courriers des lecteurs (voir Renseignements à l'intention des collaborateurs). La RCOA cherche à publier des articles qui reflètent une vaste gamme d'intérêts en orthophonie et en audiologie, en sciences de la parole, en science de l'audition et en diverses professions connexes. La Revue publie également des critiques de livres ainsi que des critiques indépendantes de matériel et de ressources cliniques offerts commercialement.

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# From the Editor

## Summer Issue



The writer Mark Twain (1835-1910) wrote facetiously that “The time to begin writing an article is when you have finished it to your satisfaction. By that time, you begin to clearly and logically perceive what it is that you really want to say.”

Writing a research paper is not only an effective way of sharing professional knowledge, it is also a great learning experience and a valuable personal achievement. Is now the time for you to start working on the research piece that you have been thinking about?

At the 33rd annual meeting of the *Canadian Association of Speech-Language Pathologist and Audiologists* in Kananaskis, the editorial team of the *Canadian Journal of Speech-Language Pathology and Audiology* held an information meeting about the process of writing and publishing a paper. We were overwhelmed by the number of registrations we received for this event. In the end, not all of those interested could be accommodated. Of those in attendance at the session, most were already working on, or nearing completion of, a specific research project. We are looking forward to receiving these manuscripts when they have been completed. We would also like to invite the readers and conference delegates who could not attend the meeting to share their ideas for papers and projects with us. The editorial team will be happy to give you preliminary feedback and pointers for synopses or manuscript drafts that you are working on. The *Canadian Journal of Speech-Language Pathology and Audiology* strives to provide a nurturing and constructive environment particularly for junior authors. Case in point, two of the contributions in the current issue have novice first authors.

The first paper by Lefebvre, Trudeau and Sutton reports the results of a survey about the current practices of Canadian Speech-Language Pathologists regarding the prevention of reading and writing difficulties in school-aged children. Kelly and Bibby describe a qualitative investigation of the views and experiences of parents whose children were diagnosed with hearing loss in a newborn hearing screening program. The paper by Iulianella, Adams and Gow reviews the literature about the effects of deep brain stimulation of the subthalamic nucleus on speech production. Finally, Mellies reviews a new publication on the education of children with velo-cardiofacial syndrome.

Tim Bressmann  
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# Mot du rédacteur en chef

## Numéro de l'été



L'auteur Mark Twain (1835–1910) a écrit avec humour que “ Le bon moment de commencer à écrire un article, c'est quand on vient juste de le terminer à son goût. C'est à ce moment-là qu'on commence à voir de manière claire et logique ce qu'on voulait vraiment dire. ”

La rédaction d'un article scientifique constitue non seulement un moyen efficace de partager ses connaissances professionnelles, mais aussi une bonne expérience d'apprentissage, sans compter un accomplissement personnel gratifiant. Est-il temps de vous mettre à rédiger un article auquel vous pensiez depuis un moment?

À la 33<sup>e</sup> assemblée générale annuelle de l'*Association canadienne des orthophonistes et audiologistes* à Kananaskis, l'équipe de rédaction de la *Revue canadienne d'orthophonie et d'audiologie* a organisé une rencontre d'information sur les étapes de la rédaction et de la publication d'un article. Nous avons été renversés par le nombre de personnes qui se sont inscrites à cette rencontre nous a submergés. En fin de compte, nous n'avons pas pu recevoir toutes les personnes intéressées. Parmi celles qui ont assisté à la séance, la plupart travaillent déjà à un projet de recherche précis ou sont en voie de l'achever. Nous attendons ces manuscrits une fois qu'ils seront terminés. Nous voulons également inviter les lecteurs et les délégués au congrès qui n'ont pu assister à la rencontre à partager leurs idées d'articles et de projets avec nous. L'équipe de rédaction se fera un plaisir de vous donner leur avis et des conseils sur une ébauche d'un synopsis ou d'un manuscrit auquel vous travaillez. La *Revue canadienne d'orthophonie et d'audiologie* cherche à créer un climat valorisant et constructif, surtout pour les auteurs débutants. D'ailleurs, dans le présent numéro, deux des articles sont rédigés par des premiers auteurs novices.

Le premier article, signé par Lefebvre, Trudeau et Sutton, présente les résultats d'une enquête sur les pratiques actuelles des orthophonistes au Canada en matière des difficultés de lecture et d'écriture chez les enfants d'âge scolaire. Kelly et Bibby décrivent une enquête qualitative sur le point de vue et les expériences des parents dont la perte auditive de leur enfant a été diagnostiquée dans le cadre d'un programme de dépistage auditif chez les nouveau-nés. Quant à l'article d'Iulianella, Adams et Gow, il passe en revue les publications sur les effets de la stimulation cérébrale profonde d'un noyau sous-thalamique sur la production de la parole. Enfin, Mellies fait un compte rendu d'une nouvelle publication sur l'éducation des enfants atteints du syndrome vélocardiofacial.

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■ **Prevention of Reading and Writing Difficulties :  
A Preliminary Study of the Practices of Canadian  
Speech-Language Pathologists**

■ **La prévention des difficultés de lecture et d'écriture :  
une étude préliminaire des pratiques des orthophonistes  
au Canada**

Pascal Lefebvre  
Natacha Trudeau  
Ann Sutton

**Abstract**

This preliminary study surveyed the practices of 151 Canadian speech-language pathologists (S-LPs) regarding the prevention of reading and writing difficulties. Using a questionnaire, the survey addressed the scope of their preventive practice, the nature of the activities they use in prevention, and their perception of their training in this domain. Most of the participants engaged in prevention of reading and writing difficulties in children, but they devoted little of their time to it. They reported that they provided both direct and indirect services. They worked in collaboration with other early childhood practitioners to provide activities targeting a variety of emergent literacy components in children from diverse subgroups of the population. The evaluation of their training was divided, and they actively sought out additional sources of training. The value of addressing emergent literacy components that are less traditional to speech-language pathology and of providing services for at-risk populations is discussed. Specific recommendations for further studies are provided.

**Abrégé**

La présente étude préliminaire a sondé l'opinion de 151 orthophonistes au Canada sur les pratiques de prévention des difficultés de lecture et d'écriture chez les enfants d'âge scolaire. Par le biais d'un questionnaire, cette enquête a porté sur l'étendue de leur pratique en matière de prévention, la nature de leurs activités de prévention, et leur perception de leur formation dans ce domaine. La plupart des participants faisaient de la prévention des difficultés de lecture et d'écriture auprès des enfants, mais ils y consacraient très peu de temps. Ils ont indiqué qu'ils donnaient des services directs et indirects. Ils travaillaient en collaboration avec d'autres intervenants auprès de la petite enfance afin d'offrir des activités ciblant divers aspects de l'éveil à l'écrit chez des enfants de différents sous-groupes de la population. Ils étaient partagés quant à l'évaluation de leur formation et ils cherchaient activement d'autres sources de formation. Cette étude traite de l'intérêt d'aborder les aspects de l'éveil à l'écrit qui sont moins conventionnels en orthophonie et d'offrir des services aux populations à risque. Elle formule des recommandations pour poursuivre la recherche dans ce domaine.

**Key words:** professional practices, survey, prevention, reading and writing, emergent literacy

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In North America, speech-language pathologists (S-LPs) working with children have been aware of the relationship between oral language abilities and reading and writing, but it was only in the early 90s that many of them started to introduce literacy into their clinical practice (Butler, 1999). In Canada, no national guidelines exist about the role of S-LPs in reading and writing for children, even though knowledge and competencies in literacy are now mandatory for certification of clinical competency (CASLPA, 2004). No specific guiding principles are provided with respect to prevention of reading and writing difficulties (R&WD). Because of initial training and clinical expertise in linguistic components that underlie reading and writing, S-LPs have been called upon to play a role in improving prevention efforts in reading and writing, especially in children with oral language impairments (Fey, 1999; Snow, Scarborough, & Burns, 1999). Justice (2006) argues that S-LPs can become more powerful catalysts for prevention of R&WD if they go beyond providing services for children already identified with language impairments. Given the paucity of information about the practices related to prevention of R&WD in Canada, the purpose of this article is to provide a first glimpse of these practices in Canadian speech-language pathologists in order to lay the foundations for a more detailed study.

Several ways of conceptualizing prevention exist in health and education fields. The classic terminology proposed by the Commission of Chronic Illness (1957), includes three levels of prevention: 1) primary, to reduce the number of new cases with problems; 2) secondary, to reduce the number of existing cases with problems; and 3) tertiary, to reduce the impact of an identified problem. More recently, Weisz, Sandler, Durlak, and Anton (2005) make a clearer distinction between prevention and intervention: secondary and tertiary prevention activities should be classified as intervention rather than prevention because they target children with diagnosable problems. The term primary prevention is reserved for efforts that can reduce the incidence of problems before they appear. Weisz et al. also use the same terminology as Gordon (1987) and the Committee on Prevention of Mental Disorders of the Institute of Medicine (Mrazek & Haggerty, 1994), distinguishing between three types of primary preventive strategies: (a) universal prevention to address risk factors in the population at large, (b) selective prevention for subgroups of the population who share a significant risk of developing a problem, and (c) indicated prevention aimed at children who have significant symptoms of a problem, but do not currently meet diagnostic criteria. In addition, Weisz et al.'s framework focuses on health promotion, the goal of which is to strengthen positive behaviours that prevent problems in all populations. These authors also propose that the level of prevention should be proportionate to the level of risk, that is, universal and selective prevention should require less direct and intensive service delivery than indicated prevention or intervention.

The Weisz et al. (2005) framework is highly relevant to R&WD because its conceptualization of prevention

is in line with the report of the U.S. National Research Council's Committee on the Prevention of Reading Difficulties in Young Children (Snow, Burns, & Griffin, 1998). Recognizing that the process of becoming literate begins before formal instruction in school, this committee recommends universal prevention through promotion of oral language and emergent literacy skills in all early childhood environments. Its report also focuses on groups of children from lower income families, from linguistic minorities, or with a familial history of reading and writing problems, who are more likely to develop reading and writing difficulties (Duncan & Brooks-Gunn, 1997). Selective prevention activities would be appropriate for these children, and would include professional, family or preschool-focused programs to improve emergent literacy skills known to be predictors of reading success, such as letter knowledge, phonological awareness, print awareness, and oral language skills (Hammill, 2004). Snow et al. also encourage indicated measures through a more direct and intensive approach targeting children whose symptoms appear prior to the diagnosis of R&WD, for example, children with cognitive, hearing or early language impairments (Catts, Fey, Zhang, & Tomblin, 2001).

Although Canadian S-LPs do not have national guidelines in regard to prevention of R&WD, they may be influenced by the guidelines provided in the United States. In its position statement and guidelines on services in reading and writing for children and adolescents, the American Speech-Language Hearing Association (ASHA) clearly states that S-LPs have a major role to play in the prevention of reading and writing difficulties (ASHA, 2001a, 2001b). According to these guidelines, prevention of R&WD should be accomplished through stimulation of oral language and emergent literacy skills. Adequate skills in vocabulary, syntax, morphology and pragmatics, and development of emergent literacy skills are good predictors of reading and writing development (Hammill, 2004, National Early Literacy Panel, 2004).

ASHA highlights eight components of emergent literacy to be addressed in order to prevent reading and writing problems: (a) joint-book reading: strategies to make reading interactive and pleasurable for children, providing access to books; (b) environmental print awareness: recognition of logos, symbols, or signs; (c) conventions of print: direction of reading, orientation of books, space in between words, and punctuation; (d) phonological awareness and sensitivity: rhymes, alliterations, phoneme and syllable games; (e) alphabetic/letter knowledge: letters, numbers, frequent words, sorting words by letters; (f) sense of story (narrative structure): logical and temporal sequence of events in narratives; (g) adult modeling of literacy activities: examples of real actions related to literacy and the daily use of writing; and (h) experience with writing materials: access to paper and pencils to scribble, copy, and pretend to write.

ASHA supports both direct and indirect service delivery. Along a continuum from indirect to direct service, types of service delivery include: (a) information



for the public, parents, professionals, or preschool practitioners about the development and the stimulation of oral language and emergent literacy skills; (b) coaching of parents or caregivers to provide stimulation of oral language and emergent literacy skills; (c) early stimulation of oral language and emergent literacy skills directly with children. Roth and Baden (2001) proposed direct service delivery for children with known language disorders and indirect service delivery for all children through collaborative consultation and education of professional staff, parents, the community, and policy makers.

ASHA encourages S-LPs to collaborate with other early childhood practitioners in their prevention efforts. In fact, everyone involved in the education of the children, regardless of their area of expertise, must collaborate in order to ensure future reading and writing achievement for as many children as possible (Silliman & Wilkinson, 2004). That way, young children can have many opportunities to develop their oral language and emergent literacy skills in multiple environments.

However, in order for S-LPs to take a role in literacy-related prevention, ASHA (2001a) recommends that university programs should provide students in speech-language pathology with coursework and clinical placements in reading and writing. Snow et al. (1999) highlighted the importance of continuing education programs for S-LPs already working in the field to help them to introduce prevention of R&WD into their current practices. Therefore, university training and continuing education opportunities may influence the extent and the nature of their activities in prevention of R&WD.

Thus, although it is clear that S-LPs have a role to play in prevention of R&WD, little information is available on their current preventive practice with preschoolers and their families. A few studies have examined S-LPs' practices regarding assessment and intervention in reading and writing with school-aged children. In the United States, Staskowski and Zagański (2003) report that the integration of reading and writing in speech-language pathology practice is variable. For a number of years, some have incorporated literacy into their practice, while others are just starting to introduce it. Coe Hammond, Prelock, Roberts, and Lipson (2005) found that S-LPs in Vermont schools felt fairly knowledgeable about literacy and rated their competency as adequate, even though they felt more confident working in more traditional areas of speech-language pathology like phonological awareness and vocabulary. Those working in collaboration with other school staff members and those with more years of experience tended to rate their knowledge and competency in reading and writing higher. In a preliminary study surveying 12 school-based S-LPs from the Midwest and Mid-Atlantic regions of the United States, Katz, Fallon, DiDonato, and Van Der Linden (2006) found that 70% of the participants believed that reading and writing were within their scope of practice. Slightly more than half of the participants worked in collaboration with teachers and used mixed groups (some children receiving speech-language

pathology services and some not) in the classroom. S-LPs reported using a wide range of specific literacy practices for both assessment and intervention. The majority of them targeted phonological awareness, vocabulary, and reading comprehension.

The literature to date concerns the practices of S-LPs in schools for whom intervention with children already showing R&WD represents a main aspect of their mandate, but prevention of these difficulties has not been directly examined. Further, practices in Canada specifically have not been studied. In order to provide an initial portrait of how clinical practices in Canada are consistent with recommendations and guidelines of regulatory agencies in the United States, and to lay the foundations for a more detailed study, a preliminary study on Canadian S-LPs' practices regarding prevention of R&WD was conducted. More precisely, the study pursued four goals: (a) to obtain a first measure of the extent of practices in prevention of literacy difficulties among some Canadian S-LPs, (b) to describe the nature of the preventive activities these S-LPs use according to the type of service delivery they offer, the emergent literacy components and the clientele they target, and the collaborations they establish, (c) to explore the perception of these S-LPs regarding their training in prevention of R&WD, and (d) to identify modifications needed to guide further more detailed studies.

## Method

### Study Design

To address the four goals of the current study, a survey approach was used. Surveys can effectively provide a quick description of the characteristics of a population and examine the distribution of specific attributes within this population (Babbies, 1990).

### Participants

Advertisements inviting S-LPs to participate in the survey were sent by mail or e-mail via provincial and national professional associations and regulatory colleges of Canada.<sup>1</sup> S-LPs working in Canada with preschoolers (0-6 year-olds), including children in kindergarten, were eligible to participate. Participants downloaded the questionnaire and a consent form in either English or French from a website. They filled out both documents and faxed or mailed them back to the first author. This somewhat cumbersome procedure was needed in order to have their signature on the consent form, a condition required to obtain approval from the local ethics board. A total of 154 participants responded to the survey. Three completed surveys were eliminated, because they were unreadable ( $n = 2$ ) or the consent form was not filled out ( $n = 1$ ).

The data from 151 S-LPs were analysed. More than half of the respondents (56.6%) worked in the province of Quebec and most of these participants used only French in their practice. The other respondents (43.4%) came from the other provinces and territories of Canada

and, in most cases, used only English in their practice (10.7% from Ontario, 10.7% from Alberta, 6.0% from New Brunswick, 6.7% from British-Columbia, 4.7% from Newfoundland and Labrador, 1.3% from Nova Scotia, 1.3% from Saskatchewan, 1.3% from Manitoba, and 0.7% from Northwest Territories). This distribution differs from the national distribution of the S-LPs across Canada according to the Canadian Institute for Health Information (CIHI) (2007) (37% from Ontario, 22% from Quebec, 14% from Alberta, 11% from British-Columbia, 4% from Saskatchewan, 4% from Manitoba, 3% from New Brunswick, 3% from Nova Scotia, 1% from Newfoundland and Labrador, and 1% from Prince-Edward Island). In the survey, similar proportions of participants worked in preventive healthcare facilities (36.7%: 33.3% in community health centers and 3.3% in home health care service programs or community organisations) and in curative healthcare facilities whose main mandate is not traditionally oriented towards prevention (36.7%: 15.3% in rehabilitation centers, 14.0% in hospitals, and 7.3% in private practice). Roughly a quarter (26.7%) worked primarily in education facilities. Two-thirds (66.6%) of the participants had graduated before 200 when the ASHA guidelines on the “Roles and responsibilities of speech-language pathologists with respect to reading and writing in children and adolescents” (ASHA, 2001a) were published (6.7% in the 1970s, 16.7% in the 1980s, 42.7% in the 1990s, and 34.4% in the 2000s). Participants’ work status information (i.e. full-time or part-time) was not collected.

### Instrument

Given that questionnaires are recommended for data collection about professional practices (Schivetti & Metz, 2002), the survey was conducted through an electronic questionnaire (Appendix A) developed by the researchers, and modified following preliminary testing. Multiple choice questions were used to facilitate responding and the subsequent analyses as prescribed by Silverman (1998) and Chadwick, Bahr, and Albrecht (1984). The questionnaire included three parts: (a) Demographic Information, (b) Speech-Language Pathology Practice, and (c) Training.

The first part contained questions about the participant’s province and language used in practice. This section also surveyed the participant’s work setting and decade of graduation. This information was collected in order to provide the characteristics of the sample.

The second part contained questions about the amount of time dedicated to prevention and, more specifically, to prevention of R&WD. This information addressed the first goal of the study. Participants who devoted part of their time to the prevention of R&WD then described the preventive activities that they provide. This section included aspects of the activities that were highlighted by ASHA guidelines (2001b) and the U.S. National Research Council’s Committee on the Prevention of Reading Difficulties in Young Children (Snow, Burns, & Griffin, 1998). Preventive activities were classified as one of three types of service

delivery: (a) information for parents and early childhood workers; (b) coaching of parents or caregivers to provide stimulation; and (c) early stimulation directly with children. For each type of service delivery used, participants were asked to identify the components of emergent literacy they targeted. These components were taken from ASHA (2001a), and a “language” component was added in order to take into account the importance of oral language skills in prevention of R&WD in addition to stimulation of emergent literacy skills (ASHA, 2001a). Participants were also asked to indicate the age group of the clientele they served: (a) preschoolers and (b) kindergarteners, and the types of prevention they offered: (a) universal for children from the general population; (b) selective for children from at-risk groups; and (c) indicated for children showing symptoms of future literacy problems (Weisz et al., 2005). Participants also described in this section the type of practitioners with whom they collaborate during their preventive activities. The information related to the types of service delivery, the targeted emergent literacy components, the targeted clientele, and collaboration addressed the second goal of the study.

The last section contained questions concerning the sources of training in the prevention of R&WD, as well as the respondents’ rating of this training from poor to excellent. The training information was gathered to address the third goal of the study.

A glossary (Appendix B) including definitions largely inspired from ASHA (2001b) and Weisz et al. (2005) was available at the end of the questionnaire to ensure that the questions were clear. Both English and French versions of this glossary were field tested by two S-LPs. Following their questions and comments, clarifications were made to the original definitions.

### Procedures

Responses from each survey were entered in a Microsoft Excel table by the first author. Responses to multiple choice questions were given numerical categorical values except for percentage of work time, which was entered as a continuous value. Reliability was established by having a research assistant familiar with the project verify all entered data. This verification showed that the data entry was 100% correct.

### Analyses

Descriptive statistics including proportions for categorical variables and means and standard deviations for continuous variables were used to present the results in each section about S-LPs’ practices in prevention of R&WD. To verify if the difference between proportions of work time dedicated to prevention of R&WD and of oral language difficulties was significant, a paired t test was used because both variables came from the same sample. Each analysis was based on the number of participants responding to the question; if a participant skipped one question, he or she was not included in the analysis for that question only. All statistical analyses were performed using SPSS version 14.0 for Windows (SPSS, 2005).

## Results

Preliminary comparisons of the scope of practice, the nature of the activities, and the training between participants from the province of Quebec and those from the other provinces and territories of Canada were made because almost the half of the participants were from Quebec. There were no statistically significant differences between the two groups for scope of practice and training. The few differences that were identified were related to more detailed aspects of the nature of the activities they provided, but the overall direction of these results remained the same between the two groups. For example, fewer participants from Quebec (70%) than from the other provinces and territories of Canada (94%) targeted joint-book reading, but in both groups, joint-book reading was still one of the emergent literacy components targeted by at least 50% of the participants. Given the preliminary nature of the study and that the differences observed were relatively minor, the analyses presented here included all participants in a single sample.

### Scope of Practice

Prevention is defined in the questionnaire as the set of activities which prevent the emergence of difficulties. It includes activities prior to any evaluation or intervention plan and aims at establishing favourable conditions to support the maximal development in children. The scope of practice in the prevention of R&WD was measured in two ways: percentage of participants engaged in the prevention of R&WD, and percentage of their work time dedicated to it. The participants were asked to provide also the percentage of their work time dedicated to the prevention of oral language difficulties in order to compare these results with those related to the prevention of R&WD. Roughly the same percentage of participants engaged in the prevention of R&WD (81.8%) as in the prevention of oral language difficulties (80.1%). Those who did engage in prevention of R&WD ( $n = 121$ ) spent only a mean of 12.3% ( $SD = 10.5$ ) of their time on it, half the time on average spent on prevention of oral language difficulties ( $M = 23.3\%$ ,  $SD = 24.3$ ). This difference was significant, paired  $t(110) = 4.78$ ,  $p < .01$ .

### Nature of the Activities

The following analyses examined different facets of the activities by the 121 participants engaged in prevention of R&WD.

**Types of service delivery.** The first analysis examined the types of service delivery provided. Participants provided all three types of service delivery, although slightly more offered information (86.0%) and direct stimulation (83.5%) than coaching (71.9%).

**Targeted emergent literacy components.** The second set of analyses examined the emergent literacy components targeted by the activities. At least 50% of the S-LPs engaged in prevention of R&WD engaged in joint-book reading (80.2%), phonological awareness (81.8%), and sense of story (56.2%). The other components were all addressed by less than 30% of the participants: oral language (28.9%), environmental print awareness (27.3%), conventions of print (26.4%), experience with writing material (27.3%), adult modeling of literacy activities (20.7%), and alphabet knowledge (19.0%).

Inspection of Table 1 shows that joint book reading, phonological awareness, and sense of story were still the three top emergent literacy components addressed by the participants across all three types of service delivery. Joint-book reading tended to be addressed indirectly through provision of information, while phonological awareness tended to be addressed directly through stimulation. Sense of story tended to be addressed through stimulation and coaching.

**Table 1**

*Percentage of Participants Using Each Type of Service Delivery to Target Emergent Literacy Components*

Emergent literacy components	Type of service delivery		
	Information ( $n = 105$ )	Coaching ( $n = 87$ )	Stimulation ( $n = 101$ )
Joint-book reading	78.1	65.5	62.4
Phonological awareness	63.8	64.4	75.2
Sense of story	28.6	47.1	46.5
Oral language	23.8	20.7	20.8
Environmental print awareness	23.8	18.4	12.9
Conventions of print	16.2	10.3	20.8
Experience with writing material	10.5	14.9	18.8
Adult modeling of literacy activities	17.1	17.2	5.9
Alphabet knowledge	5.7	11.5	13.9

**Targeted clientele.** The third set of analyses examined the clientele for whom the activities were intended under two different perspectives: their age group and their population subgroup categories. More participants

performed activities targeting preschoolers (81.0%) than kindergarteners (57.0%) independently of their population subgroup category. Inspection of Table 2 shows that more participants targeted preschoolers than kindergarteners regardless of the types of service delivery they provided. Results also showed that more S-LPs targeted children showing symptoms of future written language difficulties (82.6%) than those from the general population (69.4%) or at-risk environments (55.4%) independently of their age group. Inspection of Table 2 also reveals a different distribution across the three types of service delivery. More participants using provision of information targeted children from the general population, compared to those targeting children with symptoms or children from at-risk environments. More participants performing coaching or direct stimulation targeted children with symptoms than those from at-risk environments, or from the general population.

it as fair and 22.1% as insufficient. Roughly a quarter of the participants obtained their training in prevention of R&WD in their initial training as S-LPs (76.8% from initial university training, other university training and clinical training), but a majority of participants obtained supplementary training from continuing education (90.7% from workshops and conferences, personal reading and peer discussions).

## Discussion

There are more than 6,600 S-LPs in Canada (CIHI, 2007) and approximately 65% of them work with young children (CASLPA, 2003). Thus, there are currently approximately 4,290 Canadian S-LPs working with young children. Given that only 151 S-LPs participated to the study (3.5% of all Canadian S-LPs working with young children) and that the S-LPs from Quebec were overrepresented compared to the actual distribution across Canada (CIHI, 2007), results of the current study are not fully representative of the practices of all Canadian S-LPs. However, the results provided initial information concerning the scope of practice and the nature of the activities in prevention of R&WD among the Canadian S-LPs who participated in the survey.

**Scope of Practice in the Prevention of Reading and Writing Difficulties.** A discrepancy was identified between the number of S-LPs engaged in prevention of R&WD and the time they devoted to it. These findings are consistent with those reported by Katz et al. (2006). In their preliminary survey, the participants who believed that literacy was within their scope of practice identified time as a barrier to provision of service.

In the current study, too, time could be a factor limiting prevention of R&WD efforts. The heavy work load that S-LPs experience in Canada (Kaegi, Svitich, Chambers, Bakker, & Schneider, 2002; Lagace & Potter, 1995) may provide an explanation to the small amount of time dedicated to prevention of R&WD in the current study. A survey conducted by CASLPA (2003) revealed that many S-LPs feel they are unable to provide an adequate level of service to clients due to excessive workload. However, given that it is easier to prevent than to treat written language problems (Snow et al., 1998), prevention should nonetheless remain a priority for all early childhood practitioners, including S-LPs. Efficient ways exist to identify at-risk children early on (Justice, Invernizzi, & Meier, 2002) and to offer efficient preventive services to them (Justice & Pullen, 2003).

**Table 2**

*Percentage of Participants Using Each Type of Service Delivery to Target Clientele Groups*

Clientele	Type of service delivery		
	Information (n = 105)	Coaching (n = 87)	Stimulation (n = 101)
Preschoolers	81.9	79.3	81.2
Kindergarteners	48.6	54.0	54.5
Children with symptoms	63.8	79.3	82.2
Children from the general population	74.3	45.3	46.5
Children from at-risk environments	55.2	47.1	45.5

**Collaboration.** The last set of analyses examined the collaborative aspect of S-LPs' work in prevention of R&WD. Three quarters of the participants (74.4%) worked in collaboration. More participants worked with collaborators from the education system (44.6%) than with professionals from the health care system (34.7%) and with collaborators from outside the healthcare or educational systems (community organisations, day cares, preschools, and volunteers, 33.9%).

## Training

Training in prevention of R&WD was examined through participants' rating of their training and the sources of training they used. Half were satisfied with their training: 7.4% rated it as excellent and 38.9% as good. But half were not completely satisfied: 31.5% rated

One may argue that S-LPs who decided to participate might already have had an interest in the prevention of R&WD and may therefore have been more motivated to complete and return the forms. Thus, the results of the current study may have drawn a more positive picture of what is going on in the field than would be obtained with a larger sample. If so, however, recommendations about the increase of work time and training devoted to prevention of literacy difficulties would not only still be appropriate, they would be even more essential.

***Nature of Activities in the Prevention of Reading and Writing Difficulties.*** Many S-LPs generally treat most of the components recommended in the guidelines published by ASHA (2001a), but tend to focus on emergent literacy components that are traditionally part of their field of expertise. This is consistent with the results of Coe Hammond et al. (2005) and Katz et al. (2006) who found that S-LPs were more comfortable integrating the more traditional targets of speech-language pathology like phonological awareness and vocabulary into their practices in reading and writing. It is important to highlight that alphabet knowledge and print conventions are two of the best predictors of reading and writing success (Hammill, 2004; National Early Literacy Panel, 2004), along with phonological awareness and oral language abilities.

The focus on specific emergent literacy components may also reflect an efficient division of labour: the S-LPs may prefer to target components like phonological awareness that are usually less targeted by other early childhood practitioners while these practitioners target components like alphabet knowledge. However, phonological awareness training is known to be effective if it is associated with letter-sound correspondence teaching (Gillon, 2004). Thus, alphabet knowledge and print conventions, although not identified as priorities in the current study, may nonetheless be important to include when phonological awareness training is undertaken by S-LPs.

Another unexpected finding was that the oral language component was not among those targeted most frequently by the S-LPs, although this is their main domain of expertise. Oral language components such as elaborated vocabulary, complex grammar, decontextualized discourse and inferential language are associated with reading and writing success (Dickinson & Snow, 1987; Hammill, 2004; van Kleeck, 2006) and thus also need to be emphasized. However, the definition of the oral language component in the glossary excluded oral language as treated within the context of speech-language therapy sessions with children showing oral language problems. The S-LPs may focus on components they already treat in therapy with children showing oral language difficulties, and may choose not to overload their therapy by adding preventive goals in reading and writing to their curative goals in oral language. They may also be treating relevant language goals directly, which, based on the definition of prevention offered, would preclude them reporting such efforts as prevention of R&WD.

The nature of each emergent literacy component suggests a possible explanation concerning the types of service delivery provided for prevention of R&WD. S-LPs may play a more indirect role for emergent literacy components that lend themselves to implicit teaching, such as joint-book reading. They play a more direct role for more complex components that need explicit teaching, such as phonological awareness and sense of story.

The results suggest that some S-LPs are concerned about early preventive activities, especially for children most likely to develop reading and writing difficulties, as prescribed in the scientific publications and policies in the prevention of R&WD (ASHA, 2001a; Snow et al., 1998). Nevertheless, the children from more vulnerable environments such as linguistic minorities or lower income families still represent a population at risk for later reading and writing underachievement (Snow et al., 1998; Willms, 1999). Given that a majority of these children tend to show problems in reading and writing development that are explainable by environmental factors (access to print material, limited language interaction, lack of adult models involving literacy), prevention could be very effective among this population (Torgesen, 2002) and reduce future reading and writing problems in school.

The high collaboration rate of the participants suggests that the practices of the Canadian S-LPs are consistent with ASHA recommendations (2001a). Canadian S-LPs may consider collaboration an important element in shared responsibilities and roles regarding prevention of R&WD.

***Training in the Prevention of Reading and Writing Difficulties.*** The overall evaluation of training was divided and the S-LPs actively sought out additional sources of information to improve on their initial training. This evaluation is not as positive as the one in Coe Hammond et al.'s study (2005) in which S-LPs felt fairly knowledgeable about literacy. The mitigated opinion about the training in the current study suggests that the participating S-LPs felt that there is room for improvement in this regard. It may also provide additional explanation for the reduced work time dedicated to prevention of R&WD and the low priority given to important emergent literacy components such as alphabet knowledge and print conventions.

***Recommendations for Further Studies.*** In order to provide a wider perspective with regard to prevention of R&WD, the use of an online survey generator may help reach more S-LPs by making the questionnaire faster to complete, without needing to print and fax forms as in the current study. Also, even if the questionnaire used in the current study yielded relevant information about S-LPs' practices in prevention of R&WD, improvements are suggested in order to capture important features more adequately.

The categories used to describe types of service delivery, targeted emergent literacy components and clientele, and collaboration were not optimal. It would be more informative to use fewer but wider categories (e.g. types of service delivery into only two categories: direct

and indirect services). It would also be easier to use the population subgroup categories directly (i.e., children from the general population, children from at-risk environments, and children with symptoms) instead of using the type of preventive measure (universal, selective, and indicated) to identify the targeted clientele. In addition, families as possible collaborators should be included, which was not the case in the current study. Regarding training, more information about the actual training received would be useful, not only about the perception of it. Future studies should also address another important issue often associated with prevention: early identification of children at risk for developing R&WD. The results of the current study may underestimate some of the work done by S-LPs in prevention of literacy difficulties because early identification was not included.

Given that the goal of the current study was not to provide a detailed and extended description, but rather an initial picture of the prevention of R&WD among Canadian S-LPs, systematic validity or reliability analyses of the questionnaire were not performed, although pre-testing was carried out to ensure clarity of the questions and definitions and user-friendliness of the questionnaire. To ensure the soundness of the results of a more detailed inquiry, validity and reliability measures of the questionnaire would be mandatory.

Finally, factors such as the facilities in which S-LPs work, the graduation time, and the work status (i.e. full-time or part-time) may have had an influence on both the scope of the preventive practice and the nature of the activities in prevention of R&WD. These variables may need to be taken in account in future studies to provide a clearer portrait of preventive practices.

## Conclusions

Overall, the results suggest that S-LPs in Canada play a role in prevention of R&WD, but they dedicate a limited amount of time to it. Their activities in prevention of R&WD are generally consistent with the recommendations of ASHA (2001a) and the Committee on the Prevention of Reading Difficulties in Young Children (Snow et al., 1998). However, additional measures may be needed to encourage those S-LPs to address some specific emergent literacy components such as alphabet knowledge and print conventions, and some at-risk sub groups of children. One promising solution may be to better prepare future S-LPs through initial university S-LP training and to provide continuing education to those already working with children. The development of recommendations for practice in the area of prevention of R&WD in Canada may also guide Canadian S-LPs in their endeavor.

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### Footnote

- <sup>1</sup> See author note for a complete list.

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## Appendix A

### Transcript of the Online Survey on Canadian Speech-Language Pathology Practices Regarding Prevention of Reading and Writing Difficulties

If you work with 0-6 year-old preschool children including those in kindergarten, you may participate in this study. Even if you don't work precisely in emergent literacy or in prevention of reading and writing difficulties, you may participate. We need answers from as many speech-language pathologists working with preschoolers as possible to capture a real picture of the situation. Even if you work only part time with preschoolers, you may participate. If you only work with children in 1st grade or higher, adolescents, adults, or the elderly, you cannot participate. This survey takes only 10 minutes to fill out on your computer.

#### Part 1: Demographic Information

1. In which year did you finish your university training in speech-language pathology?

< 1960,  1960–1969,  1970–1979,  1980–1989,  1990–1999,  2000–2005

2. In which language do you practice speech-language pathology? (can check more than one)

English,  French,  other(s): \_\_\_\_\_

3. In which type of establishment do you practice speech-language pathology? (most relevant)

community health center,  hospital,  private practice,  rehabilitation center,  schools including kindergarten,  other(s): \_\_\_\_\_

4. In which province or area do you practice speech-language pathology?

Alberta,  British Columbia,  Manitoba,  New Brunswick,  Newfoundland and Labrador,  Northwest Territories,  Nova Scotia,  Nunavut,  Ontario,  Prince Edward Island,  Quebec,  Saskatchewan,  Yukon

#### Part 2: Speech-Language Pathology Practice

5. What proportion of your work is dedicated to prevention? (see definition in glossary)

a) Oral communication difficulties

0%,  5%,  10%,  15%,  20%,  25%,  30%,  35%,  40%,  45%,  55%,  60%,  65%,  70%,  75%,  80%,  85%,  90%,  95%,  100%

b) Written communication difficulties (If 0%, go to Part 3, question 8)

0%,  5%,  10%,  15%,  20%,  25%,  30%,  35%,  40%,  45%,  55%,  60%,  65%,  70%,  75%,  80%,  85%,  90%,  95%,  100%

6. Check the activity you use to prevent reading and writing difficulties (can check more than one). For each activity, select the letter corresponding to targeted emergent literacy component (see glossary). Select the targeted age group for each activity (see glossary). Specify the type of preventive measure of each activity according to the targeted clientele group (see glossary).

##### Activities

Information for caregivers

Emergent literacy components:  a,  b  c,  d,  e,  f,  g,  h,  i

Age groups:  preschool,  kindergarten,  both

Types of measure:  U,  S,  I,  U/S,  U/I,  S/I,  U/S/I

Coaching of caregivers

Emergent literacy components:  a,  b  c,  d,  e,  f,  g,  h,  i

Age groups:  preschool,  kindergarten,  both

Types of measure:  U,  S,  I,  U/S,  U/I,  S/I,  U/S/I

Early stimulation with children

Emergent literacy components:  a,  b  c,  d,  e,  f,  g,  h,  i

Age groups:  preschool,  kindergarten,  both

Types of measure:  U,  S,  I,  U/S,  U/I,  S/I,  U/S/I

7. In general, do you work in collaboration with other preschool workers for prevention of written language difficulties? If yes, specify with whom (you can check more than one box).

no,  yes.

volunteers,  community organisations,  school staff,  health care staff,  other(s): \_\_\_\_\_

#### Part 3: Training

8. How would you qualify your training in prevention of reading and writing learning difficulties?

excellent,  good,  fair,  insufficient

9. What are your sources of training on this subject? (leave blank if you have none)

university training in speech-language pathology,  workshops and conferences,  clinical training,  personal readings,

other university training,  other(s): \_\_\_\_\_



## Appendix B

### Glossary for the Survey on Canadian Speech-Language Pathology Practices Regarding Prevention of Reading and Writing Difficulties

Prevention in speech-language pathology can be described as: “The set of activities which prevent the emergence of oral and/or written language difficulties.” It includes activities, prior to any evaluation or intervention plan, which aim to establish favourable conditions to support the maximal development of oral and/or written communication of children. In preventive practice, activities include: (a) information for the public, parents, professional or preschool workers about the development and the stimulation of oral and/or written communication; (b) online coaching of parents or caregivers for the stimulation of oral and/or written communication; (c) early stimulation of oral and/or written communication directly with children.

Emergent literacy components: (a) Joint-book reading: strategies to make reading interactive and rewarding for children, access to books if needed, motivation and pleasure of reading; (b) Environmental print awareness: recognition of logos, symbols, or signs; (c) Conventions of print: direction of reading, orientation of books, space in between words, punctuation; (d) Phonological awareness and sensitivity: rhymes, alliterations, phoneme and syllable games; (e) Alphabetic/letter knowledge: letters, numbers, frequent words, sorting words by letters; (f) Sense of story (narrative structure): logical and temporal sequence of events in narratives; (g) Adult modeling of literacy activities: examples of real actions related to literacy and the daily use of writing; (h) Experience with writing materials: access to paper and pencils to scribble, copy and pretend to write; (i) Oral language: components linked with reading and writing which are not within the context of oral speech-language therapy sessions.

Age groups: (a) Preschool: includes children from 0 to 5 year old who are not yet attending kindergarten; (b) Kindergarten: includes 5 or 6 year-old children attending kindergarten, but not 1st grade; (c) Both: includes both groups.

Types of preventive measures: (a) U for universal: activities accessible to the population at large; (b) S for selective: activities adapted for populations who may be vulnerable to written language development problems (e.g.: low socio-economical status families, multi-ethnic groups); (c) I for indicated: activities accessible to children with symptoms indicating predisposition to develop written language problems (e.g. : children with language delays); (d) U/S, U/I, S/I, and U/S/I combinations for parallel activities in more than one type of preventive measures.

## ■ Effects of sub-thalamic deep brain stimulation on speech production in Parkinson's Disease: A Critical Review of the Literature

## ■ Les effets de la stimulation cérébrale profonde d'un noyau sous-thalamique sur la production de la parole chez les personnes atteintes de la maladie de Parkinson : un compte rendu critique des publications

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### Abstract

This critical review examined the effects of subthalamic nucleus deep brain stimulation (STN-DBS) on speech in individuals with Parkinson's disease in eight studies. Study designs included: seven quasi-experimental studies and one case study. Overall, the evidence failed to provide support for the beneficial effects of STN-DBS on speech production in Parkinson's disease. It is suggested that the STN-DBS procedure requires additional refinements in order to be optimized for the treatment of speech symptoms. Additional studies involving more subjects, randomization procedures, control of severity level, and systematic manipulations of stimulation settings and locations are recommended.

### Abrégé

Le présent compte rendu critique porte sur huit études, soit sept recherches quasi expérimentales et une étude de cas, qui traitent des effets de la stimulation cérébrale profonde d'un noyau sous-thalamique (SCP-NST) sur la parole des personnes atteintes de la maladie de Parkinson. Dans l'ensemble, il manque des données probantes pour appuyer les effets bénéfiques de la SCP-NST sur la production de la parole chez les parkinsoniens. Il faudrait améliorer la procédure de SCP-NST pour qu'elle agisse de manière plus optimale lors du traitement des symptômes de la parole. Il est recommandé de mener d'autres études faisant appel à davantage de participants, à des procédures de randomisation, au contrôle du degré de sévérité ainsi qu'à la manipulation systématique des paramètres et des zones de stimulation.

**Key words:** Parkinson's, deep brain stimulation, subthalamic nucleus, speech

### Introduction

Marsden (1994) defined Parkinson's Disease (PD) as "a progressive degeneration of dopamine producing cells in the substantia nigra, resulting in increased inhibitory output of the basal ganglia to the thalamus and the brainstem locomotive center." The subthalamic nucleus (STN) provides excitatory input to the basal ganglia which in turn increases the inhibitory output of the basal ganglia to the thalamus, consequently resulting in more inhibition of the motor cortex. These changes in neural activity ultimately translate into disturbances in gait and facial expression, postural instability, akinesia, bradykinesia, rhythmic tremors, and rigidity of movement, which

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are the hallmarks of PD. In addition to the aforementioned characteristics, disturbances in speech and swallowing can also result and often co-occur in PD. Speech symptoms can include reduced perceptual loudness (hypophonia), a change in voice quality (i.e., breathiness, harshness, or tremor), monopitch, monoloudness, reduced stress, rapid speech rate, short rushes of speech, imprecise consonants, inappropriate silences, and reduced intelligibility overall (Duffy, 2005 p.189; pp.194-198).

Deep Brain Stimulation (DBS) has been documented in the literature to be a relatively recent and successful method of managing the overall gross motor symptoms associated with PD. The National Institute of Neurological Disorders and Stroke (NINDS, 2006) describes DBS as “a surgically implanted, battery operated device called a neurostimulator---similar to a heart pacemaker and approximately the size of a stopwatch---that delivers electrical stimulation to targeted areas of the brain that control movement, blocking the abnormal nerve signals that cause tremor and PD symptoms.” For a number of years, the target areas for DBS treatment of PD symptoms were the thalamus and globus pallidus. The effects of these early surgical procedures on speech have been previously reviewed (Schultz & Grant, 2000; Maruska, Smit, Killer, & Garcia, 2000). Currently, the most common target area for DBS treatment of PD is the subthalamic nucleus (STN). (NINDS deep brain stimulation for PD, 2006). Subthalamic nucleus deep brain stimulation is currently considered superior to globus pallidus DBS because “the anti-akinetic effect seems to be more pronounced, allows a more marked reduction of anti-parkinsonian medication, and requires less stimulation energy.” (Volkman, 2004).

While there are a large number of reports describing the effectiveness of STN-DBS in reducing most motor symptoms associated with PD (i.e., tremors, rigidity, akinesia, and postural instability) (Hamani, Richter, Schwalb, & Lozano, 2005; Rodriguez-Oroz, Obeso, Lang et al., 2005), the number of studies examining the secondary effects of STN-DBS on speech in PD is limited. A critical review of the effects of STN-DBS treatment on speech is considered to be important to the field of speech-language pathology because many individuals with PD who are undergoing or considering STN-DBS treatment are dealing with a speech disorder and are attending a speech-language pathology clinic. These individuals will often seek advice from speech-language pathologists and other health care providers about the potential risks and benefits of STN-DBS treatment. In addition, if a critical review of the literature suggests that STN-DBS treatment is associated with the development of speech symptoms or a worsening of speech symptoms, this information needs to be communicated to speech-language pathologists who are working with individuals with Parkinson's disease.

### Objectives

The primary objective of this paper was to outline and critically evaluate selected studies that have examined the effects of STN-DBS on speech production in patients with

PD. A secondary objective was to evaluate information related hemispheric effects (left or right STN) and stimulation parameter settings on speech production in STN-DBS.

### Methods

**Search Strategy.** Computerized databases, including PubMed, Medline, CINAHL, JNNP (online), Science Direct, CommDisDOME, PsycINFO, and the University libraries search engine were searched using the following search strategy: (Parkinson's Disease) AND (Deep Brain Stimulation) AND (Speech). The search was limited to English language and journal articles or reviews published before February 2007.

**Selection Criteria.** Studies included in this critical review were required to examine the effects of subthalamic deep brain stimulation (STN-DBS) on speech in patients with Parkinson's disease. All patients studied suffered from levodopa-responsive PD. No limits were set on the demographics (age, gender, culture, race, or socioeconomic status) of research participants, or type of speech parameter (e.g., vocal intensity, intelligibility, intonation, respiration, phonation, etc.) investigated. Studies included those conducted in North America, as well as those conducted in Europe and Australia.

**Data Collection.** Results of the literature search yielded eight articles consistent with the selection criteria: One case study and seven group studies involving quasi-experimental designs. Our intention was to review all peer-reviewed articles that have focused on the effect of STN-DBS on speech production in PD.

### Results

**Case-study.** Hoffman-Ruddy, Schultz, Vitek, and Evatt (2001) looked at the effects of bilateral STN-DBS on voice and speech characteristics in a single male PD patient who had been living with PD symptoms for 7 years. The test protocol consisted of four conditions: (1) OFF-stimulation, OFF-medication; (2) ON-stimulation, OFF-medication; (3) OFF-stimulation, ON-medication; and (4) ON-stimulation, ON-medication. Speech tasks were administered by a speech-language pathologist (S-LP) and included three repetitions of maximum sustained vowel phonations, pitch glides, syllable repetition, short consonant-vowel-consonant (CVC) words and oral reading of a standardized passage. All recordings were analyzed using a Computerized Speech Lab (CSL) and Multi-Dimensional Voice Program (MDVP).

The largest changes in speech measures occurred between the ON-stimulation/ON-medication condition and the OFF-stimulation/OFF-medication condition. For the purposes of the present review, a comparison of the effect of stimulation in the OFF medication conditions is of greatest interest. Relative to the OFF-stimulation/OFF-medication condition, the ON-stimulation/OFF-medication condition was associated with the following: increased F0 (+18%), increased pitch range (+40%), increased sound pressure level in sentences (+18%),

decreased jitter and shimmer (-42% and -52%), decreased standard deviation of voice onset time (-65%), and increased rate of syllables/sec (+160%).

Overall, these results suggest that STN stimulation can be associated with improvements in multiple speech and voice acoustic parameters in selected individuals with PD. These positive STN-DBS results need to be interpreted with caution, as they may not generalize to other individuals with PD.

**Group Study #1.** Gentil, Pinto, Pollak and Benabid (2003) examined non-speech oral force control and speech acoustics in 16 individuals who had received bilateral STN-DBS for the treatment of PD. Oral force control and speech acoustics were measured under two conditions: during bilateral STN stimulation and 30 minutes after stopping stimulation. Speech tasks included: (1) sustained /a/ and /i/ vowels; (2) repetition of the phrase “*Le petit chat joue avec la balle*” without stopping for 30 seconds; (3) production of short sentences at a conversational speaking rate; and (4) repetition of the nonsense word “*pataka*” as fast as possible 10 times.

The results for the non-speech oral force tasks indicated that the upper lip, lower lip, and tongue were associated with significantly larger maximal force, more rapid force rise-time and more accurate force tracking during the STN stimulation condition. For these non-speech force results the authors provided appropriate t-values and descriptive statistics. With regard to the results for the speech tasks, the authors state that they obtained significant results for a number of the acoustic measures but they failed to provide the appropriate t-values and descriptive statistics (i.e. standard deviation). The following acoustic measures of speech were reported to be significantly improved during STN stimulation: maximum phonation time (increased), diadochokinetic rate (increased), pause time (decreased), speech intensity (increased), and F0 variability in sustained vowels (decreased). These positive speech results need to be treated cautiously because of the inadequate reporting of statistical results.

**Group Study #2.** Dromei, Kumar, Lang, and Lozano (2000) investigated the effects of STN-DBS on acoustic measures of voice in seven patients with PD who received bilateral STN-DBS. Pre-surgery and 6 month follow-up data were reported. At both time points, speech recordings were made while patients were in an OFF-medication and an ON-medication state. Speech tasks included sustained vowel phonation and a 30 second monologue on a self-selected topic.

Mean and standard deviation of the fundamental frequency and speech intensity during sustained vowels were obtained with acoustic analysis software (Multi Dimensional Voice Program). A series of Wilcoxon signed ranks tests were used to evaluate changes in the acoustic measures across conditions. Intrameasurer reliability was reported (0.9987 to 0.9997).

For the purposes of the present review, the STN stimulation conditions in the unmedicated state were the

most relevant. The comparisons of the stimulator on versus stimulator off conditions (both unmedicated) failed to show significant differences in any of the speech variables examined. In addition, the effects of STN stimulation on the individual patients were reported to be “modest and inconsistent.” For example, four of the seven patients showed a small decrease in speech intensity while the other three patients showed a slight increase in speech intensity during STN stimulation.

Overall, the results of this study fail to provide evidence for an improvement in speech following STN-DBS. The authors acknowledge that the overall impact of these speech results is not substantial and would not represent a functionally useful change in speech performance.

**Group Study #3.** Wang, Verhagen Metman, Bakay, Arzbaeher and Bernard (2003) investigated the effect of unilateral stimulation of the STN on speech production in six right-handed PD patients with mild to moderate dysarthria. Three patients received implantation of the STN-DBS stimulator in the right STN, and three in the left STN. Speech recordings were made in the OFF-medication state (12 hours without medication) during a baseline pre-surgery condition, and at three months post-surgery in stimulator “on” and stimulator “off” conditions. Evaluators were blinded to the stimulator conditions until after the data were analyzed. The speech task included six maximally sustained vowel phonations. Four acoustic measures were obtained from these prolonged vowels: mean intensity, duration, mean F0 and jitter.

A mixed two-factor analysis of variance with repeated measures ( $p < 0.05$ ) was used to evaluate speech performance across the stimulation conditions and the side of stimulation. None of the comparisons involving the STN stimulation “on” versus STN stimulation “off” conditions were associated with a significant change in the four speech variables examined (intensity, duration, mean F0, jitter). A non-significant trend was noted for the comparisons of left versus right STN stimulation effects in the intensity and duration data. Right STN stimulation tended to be associated with an increase in the intensity and duration of the prolonged vowels whereas left STN stimulation tended to be associated with a decrease in the intensity and duration of the prolonged vowels. These potential hemispheric effects need to be examined in future studies that include a greater number of subjects.

Overall, these results do not provide support for a beneficial effect of STN-DBS on speech production in PD.

**Group Study #4.** Subsequent to the above study, Wang, Verhagen Metman, Bakay, Arzbaeher, Bernard, and Corcos (2006) reported the results of a larger study that included the same series of patients plus additional patients. This inclusion of some subjects from the earlier study violates the statistical assumption of independent samples and therefore reduces the potential importance of the results. This study examined the effects of unilateral left versus right STN-DBS in twenty right-handed subjects

with PD. Ten subjects received unilateral left STN-DBS and 10 received right STN-DBS. The side of STN-DBS was selected on the basis of the side of the body with the most severe motor impairments. Subjects were tested in the OFF-medication state (12 hours without medication) at baseline pre-surgery, and 3 months post-surgery with and without stimulation. The speech tasks included fast repetitions of the syllables “*puh*”, “*tuh*” and “*kuh*”. Three trials were obtained for each syllable repetition task. The first 4 seconds of each trial were used in the analysis. Twenty listeners (graduate students in S-LP) rated the samples on articulatory accuracy and speaking rate using a 0-4 rating scale. Acoustic measures obtained for each sample included: syllable rate, syllable duration, vowel duration, voice onset time (VOT), and fundamental frequency (F0). A mixed three-factor analysis of variance with repeated measures ( $p < 0.05$ ) was used to evaluate the side of stimulation, test condition, and syllable type.

One of the main findings was that articulatory accuracy was rated as significantly worse when the STN stimulator was turned on relative to when the stimulator was off or relative to the pre-treatment baseline condition. In addition, left STN stimulation was associated with a significantly greater negative impact on articulatory accuracy than right STN stimulation. Hemispheric effects were also noted for speaking rate. Speech and syllable rates decreased significantly with left STN stimulation but remained unchanged or increased with right STN stimulation. The left and right STN stimulation had no significant effect on VOT or F0.

Overall, the results of this study fail to provide support for a beneficial effect of STN-DBS on speech production. In contrast, these results suggest a negative effect of STN-DBS on speech. The authors of this 4th group study suggest that this negative effect may be greatest in left sided STN-DBS. A major concern with this latter conclusion is that differences in the severity of the initial speech symptoms may have biased these apparent hemispheric effects in DBS. At baseline, the subjects in the left side group had poorer articulatory accuracy and slower speech rates than those in the right side group. It is possible that subjects with more severe speech symptoms respond differently to STN-DBS than those with less severe speech symptoms. If so, the differences observed in this study may have been directly related to the greater severity of speech symptoms in the left side group rather than any real differences in left versus right hemispheric effects of STN-DBS on speech. Future studies of hemispheric effects will need to control for the severity of speech symptoms.

**Group Study #5.** Santens, De Letter, Borsel, De Reuck, and Caemaert (2003) analyzed the effects of left and right STN stimulation separately on different aspects of speech in seven PD patients who had been implanted with a bilateral STN-DBS system. Speech tasks included a 200 word reading passage, and a sustained “*ah*” vowel in four different STN stimulation conditions: (1) left ON, right OFF; (2) right ON, left OFF; (3) bilateral stimulation OFF; and (4) bilateral stimulation ON. The four conditions were

randomized within patients to avoid order effects. All speech samples were video-recorded. The video-taped reading of the passage was randomly presented to 22 S-LPs, blinded to the stimulator conditions, who provided visual analogue ratings for six different aspects of speech production: prosody, articulation, intelligibility, voice quality, loudness and speech rate. Inter-rater reliability was reported (ranging from 0.86 to 0.97). Effects of stimulation conditions on different characteristics were estimated using Friedman’s non-parametric test for related samples ( $p < 0.05$ ). Post-hoc Wilcoxon signed ranks tests were performed.

A primary finding from this study was that the comparison between bilateral stimulation “on” versus bilateral stimulation “off” revealed no significant changes in any of the ratings of the six speech parameters examined. For the comparisons involving the right versus left STN-DBS, only one significant finding was observed. In particular, selective stimulation of the left STN produced a significant negative effect (more abnormal) on the rating of prosody. There was also a non-significant trend for the left STN stimulation to produce negative effects on articulation and intelligibility. The results for the comparison of the right STN stimulation versus no STN stimulation produced no significant effects on any of the six speech parameters. Finally, the results for the duration of the prolonged vowel “*ah*” across the various stimulation conditions produced no significant effects.

In general, this perceptual rating study fails to provide support for a beneficial effect of bilateral STN-DBS on speech production. In contrast, these results suggest that there may be a moderate negative effect of left-sided STN-DBS on speech prosody.

**Group Study #6.** A study by Tornqvist, Schalen, and Rehnroona (2005) examined the effects of different STN-DBS parameter settings on speech performance in PD. Speech recordings were obtained from ten subjects with PD under 11 different parameter settings. The order of the 11 settings was randomized in each subject. For each parameter setting condition, the patients were required to read a standard running text in Swedish and then five syntactically correct nonsense sentences from a dysarthria test. The recorded speech samples were randomized and presented to a panel of ten listeners (including five S-LPs) who were blinded to the experimental conditions. The listeners orthographically transcribed the words in the nonsense sentences. These transcriptions were used to determine the patients’ intelligibility scores. Listeners also used a visual analogue scale to rate the overall intelligibility, precision of articulation, and quality of voice for all reading samples. Rate of speech was calculated as syllables per second using the time counter on the recording instrument.

Intra and inter-rater reliability of the judges were calculated with the Spearman rank correlation coefficient. For each patient and each tested parameter setting, the mean value of the 10 listeners’ evaluations was calculated for further statistical analysis ( $p < 0.05$ ;  $r > 0.70$ ). Effects of stimulation conditions on the different speech characteristics were examined statistically with two non-

parametric tests; the Wilcoxon test for matched pairs and Friedman's test followed by Dunn's procedure for multiple comparisons ( $p < 0.05$ ).

With regard to the objectives of the present review, one of the most important findings of this study was that STN stimulation was associated with a decrease in speech intelligibility scores (-25%) when compared to the no STN stimulation condition. This result approached statistical significance ( $p = 0.058$ ). With regard to the effects of changes in the stimulation parameter settings, two important results were reported. First, an increase in the amplitude of the stimulators, to 25% above usual levels, was found to produce a significant deterioration in the intelligibility and articulation ratings. Second, reducing the frequency of stimulation, from usual levels of about 130Hz down to 70Hz, was found to produce a significant improvement in the intelligibility and articulation ratings ( $p = 0.01$ ).

Overall the results of this study fail to provide support for a beneficial effect of STN-DBS on speech production. In contrast, these results provide weak support for a negative effect of STN-DBS on speech. In addition, this study suggests that adjustments in the amplitude and frequency of the stimulus parameters may reduce the negative consequences of STN-DBS on speech production.

An important limitation of the study was that it included three patients who were previously treated with unilateral ablation neurosurgery (thalamotomy) for PD.

**Group Study #7.** A study by Tripoliti, Dowsey-Limousin, Tisch, Borrell, and Hariz (2006) compared the effects of medication and STN-DBS on speech production in 16 patients with PD. The 16 patients were randomized to two treatment groups: Eight patients continued to receive their regular anti-parkinson medication only and eight patients received bilateral STN-DBS treatment (and a parallel decrease in their anti-parkinson medication). All patients were assessed on and off medication at baseline and 1 year later (post STN-DBS insertion). At the 1 year assessment, the STN-DBS patients were evaluated with the stimulator on and off. The speech tasks included sustained phonation, sentence reading, and one minute of monologue. Speech measures included intelligibility scores (CAIDS), the intensity of sustained phonation, and the long-term average spectrum (LTAS) of the sentences and monologue. Statistical analysis involved matched pairs t-tests to compare the baseline and one year results and independent samples t-tests to compare the medication only and STN-DBS treatments ( $p < 0.05$ ).

One important finding was that, relative to the baseline, there was no significant change in speech intelligibility following the STN-DBS treatment. The authors also note that two patients showed a fairly large (40%) decrease in intelligibility following STN-DBS. The results for the intensity of sustained phonation are difficult to interpret. The intensity of sustained phonation was significantly higher for the STN stimulator "on" (and medicated) condition when compared to the baseline condition. Unfortunately, the study did not report the results for the

comparisons of the stimulator "on" versus "off" conditions or the comparisons involving the unmedicated conditions. These limitations make it difficult to evaluate the effects of STN-DBS on speech in this study. With regard to the results for the long-term average spectra, this study failed to find a significant difference between the baseline condition and the STN-DBS condition.

Overall, the results of this study failed to provide support for the beneficial effects of STN-DBS on selected measures of speech intelligibility and intensity. The results also suggest that STN-DBS can have a substantial negative effect on speech intelligibility in some individuals.

## Discussion

The evidence from these eight studies needs to be interpreted with caution because all of the studies included fairly small sample sizes. The sample sizes for the seven group studies ranged from 6 to 20 subjects and most of these group studies (five out of seven) had less than 10 subjects. In addition, the experimental methodologies used in these studies were quite diverse which made it difficult to make comparisons across studies. For example, the types of speech tasks used across these studies included maximum sustained vowels, pitch glides, syllable repetitions, sentence repetitions, reading aloud, and monologue. One study also included a non-speech oral force task. A diversity of speech measures were obtained from these speech tasks. These included acoustic measures of speech intensity, fundamental frequency, jitter, shimmer, voice onset time, long-term average spectra, and syllable durations. The various perceptual speech measures included listener ratings of articulatory accuracy, speech rate, prosody, intelligibility, voice quality, and loudness. Despite the sample size limitations and the diversity of experimental speech procedures used, some important trends emerged. First, almost all (six out of seven) of the group studies failed to find support for a beneficial effect of bilateral STN-DBS on various measures of speech production. These included both acoustic measures (i.e. SD of F0, intensity of sustained phonation, maximum phonation time (MPT), jitter, long-term average spectra (LTAS)) and perceptual measures (i.e. articulatory accuracy, intelligibility, prosody, voice quality, loudness). Second, four of the seven group studies reported negative effects of STN-DBS on speech production. Speech parameters associated with negative effects included intensity of sustained phonation, MPT, articulatory accuracy, prosody and intelligibility. In addition, three of these studies provided preliminary evidence that left-sided STN stimulation is associated with a greater negative effect on speech production than right-sided STN stimulation. Finally, the two studies that reported positive effects of STN-DBS stimulation included a case study and a group study that failed to provide sufficient statistical information to allow for an accurate evaluation of the experimental evidence. Therefore, the evidence for positive effects of STN-DBS on speech is considered very limited. Although the present review suggests a fairly consistent trend in the evidence across the eight studies, it should be noted that

some of the studies were associated with minor concerns related to their experimental procedures. In order to reduce these concerns, it is recommended that future studies of STN-DBS give consideration to including the following experimental procedures: an evaluation of STN-DBS subjects when they are both on and off their anti-parkinson medications, a detailed reporting of time periods between medication ingestion and experimental testing, a clear and detailed description of perceptual and acoustic speech measurement procedures, an inclusion of connected speech and conversational speech samples, an inclusion of outcome measures based on self-reporting procedures, and a careful and detailed reporting of statistical procedures.

The overall conclusion of this review is that bilateral STN-DBS is not generally associated with a beneficial (positive) effect on speech production in PD. In contrast, several studies report negative effects of STN-DBS on speech. These negative effects may be more apparent for left-sided STN stimulation than right-sided STN stimulation. In addition, there appears to be a fair bit of individual variation in the speech response to STN-DBS. Across the eight studies reviewed, there were several reports of individual subjects showing either a substantial positive or negative effect of STN-DBS. The source of this substantial inter-subject variation needs to be addressed in future STN-DBS studies of speech outcomes. Some potential sources of variation that may need to be evaluated include: the duration and stage of PD, the age of onset of PD (i.e. young onset versus older onset), the severity of dysarthria, the prominence of specific speech deficits (i.e. hypophonia, rapid speech, dysfluency, etc.), the combined effects of STN-DBS and anti-parkinson medications, the effects of previous surgical procedures (i.e. thalamotomy plus STN-DBS), and the duration of time since STN-DBS (i.e. long-term effects of STN-DBS on speech).

The novel results from the study by Tornqvist, et al., (2005) indicate that the STN-DBS parameter settings can have important positive and negative effects on speech production. Additional systematic studies of the effects of parameter settings on speech are required. It is anticipated that the results of these types of studies will lead to important refinements in the STN-DBS procedure and improved outcomes in speech production. Additional refinements may also be achieved through studies that systematically examine the effects of different STN stimulator locations on speech production. Currently, the STN procedure is usually focused on placing the stimulator into STN locations that are most likely to provide maximum benefit to the non-speech limb symptoms. Potential benefits to the speech symptoms do not usually factor into the decision about the final location of the STN stimulator. Additional studies involving the placement of stimulators into new STN locations that are involved in speech production are required. It is anticipated that these STN studies involving targeted speech locations may lead to improved speech outcomes in the STN-DBS procedure. Unfortunately, studies involving focused speech target STN-DBS locations may need to await the

development and regular use of stimulators with the capability of providing multiple sites of STN stimulation. It should be noted that there have been a few preliminary reports involving new multiple site thalamic stimulation electrodes used in the treatment of tremor (Foote & Okun, 2005; Lim, Khandhar, Heath, Ostrem, Ringel, Starr, 2007). Until these multi-location stimulators are developed for placement in the STN, it is unlikely that speech sites will be given priority over the standard non-speech limb sites in STN-DBS treatment.

The conclusion from the present review, that bilateral STN-DBS does not generally produce beneficial effects on speech, is in marked contrast to the numerous reports of significant positive effects of STN-DBS on most of the non-speech, limb symptoms in PD (Hamani, et al., 2005). This finding appears to be consistent with the growing evidence that interventions that lead to fairly consistent improvements in non-speech motor control (especially limb movements) often have neutral or negative outcomes for speech in Parkinson's disease (Kent, 2003). This may be related to the unique genetic, developmental, functional and phenotypical properties of the speech muscles (Kent, 2003) and/or fundamental differences in the role of dopaminergic processes in the regulation of speech and limb movements (Kompolti, Wang, Goetz, Leurgans, and Raman, 2000).

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## ■ Parents' Experiences in a Locally Initiated Newborn Hearing Screening Program

## ■ Un programme d'initiative locale de dépistage auditif chez les nouveau-nés : le point de vue de parents

Sarah Kelly  
Mary Ann Bibby

### Abstract

This exploratory qualitative study presents an in-depth look at the experiences of five parents whose children were diagnosed with a hearing loss through newborn hearing screening. The screening was implemented as part of a research project in four health regions in Alberta. The funding for this project covered only newborn hearing screening, with referral to diagnosis. Program restructuring that allowed seamless transitions from screening to diagnosis and intervention services could not be funded, so parents needed to access already existing support services and programs. The parents in this study shared their experiences pertaining to the screening and diagnostic process and their transition to intervention programs. The following three major themes emerged from the parents' stories as they shared their perspectives: (a) experiencing and dealing with the screening and diagnosis, (b) interacting with professionals, and (c) coping and realizing additional areas of need. The findings of the study indicate that the parents experience significant challenges as they navigate the process. The stories of parents provide valuable insights into their own strengths and how screening services, professional interactions, and the process of empowering parents can be improved.

### Abrégé

La présente étude exploratoire de type qualitatif examine en profondeur l'expérience vécue par cinq parents qui ont appris que leur enfant avait une perte auditive par le biais d'un programme de dépistage auditif chez les nouveau-nés. Ce programme a été mis en œuvre dans le cadre d'un projet de recherche dans quatre régions régionales de la santé de l'Alberta. Le financement de cette étude assurait seulement le dépistage auditif des nouveau-nés, incluant une référence vers les milieux cliniques. Il ne permettait pas de procéder à une restructuration des programmes visant une transition fluide entre les services de dépistage et les services de diagnostic et d'intervention, de sorte que les parents devaient accéder aux services et programmes déjà en place. Les parents de cette étude ont partagé leur expérience par rapport au processus de dépistage et de diagnostic et à la transition vers les programmes d'intervention. Les trois grands thèmes suivants sont ressortis des témoignages des parents : (a) vivre et de gérer l'expérience du dépistage et du diagnostic; (b) interagir avec les professionnels, et (c) s'en sortir et prendre conscience de besoins supplémentaires dans plusieurs sphères. Les observations de cette étude montrent que les parents doivent surmonter des défis considérables pour franchir les étapes de ce processus. Leurs témoignages permettent de poser un regard utile sur leurs propres forces et sur la manière d'améliorer les services de dépistage, les interactions avec les professionnels ainsi que le processus accordant plus de pouvoir aux parents.

**Key words:** parents' perspectives, early hearing detection, hearing loss, locally initiated newborn hearing screening, facilitation to intervention, best practices

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New technological advances are shaping the futures of children born with a hearing loss. The implementation of newborn hearing screening (NHS) for all babies is the first step in a process that moves families from screening to diagnosis and then to referral for intervention. Although screening is a necessary component of a comprehensive early hearing detection and intervention (EHDI) program, to be ultimately successful, research from best practices has indicated that it must also be tightly integrated with diagnostics and intervention services (Hyde & Riko, 2000). In Canada, however, only a few areas have initiated province-wide collaborative EHDI programs. In several provinces, NHS is being implemented and funded through local hospital initiatives. In these cases, there is no comprehensive provincial planning. Parents take advantage of existing services that may or may not be coordinated. Park, Warner, Sturgill, and Alder (2006) indicated that even in comprehensive programs, however, numerous obstacles remain in the way of obtaining timely screening, diagnosis, and treatment. Some families still experience a gap between "the ideal" and the "real." A body of knowledge is building on EHDI programs, but little research has explored the experiences of screening in the more individualized initiatives. This exploratory qualitative study asked parents about their experiences within the context of a non-comprehensive screening procedure and contrasted the findings with recommended practice. Parents' stories provided snapshots of their fears, frustrations, and strengths. They shed light on both the negative and the positive aspects of the system, and provided important signposts for change.

## Background

### The Canadian Context

Over 25 years ago, in the 1980s, a federal task force on childhood hearing impairment surveyed the provinces and territories to document the activities that were in place in the areas of early hearing detection, identification, and intervention. At that time, screening was performed only in high-risk registries. Although technology was advancing, the survey results indicated a lack of standardized screening tools, a lack of audiologists, and other system barriers (Durieux-Smith & Stuart, 2000). In 1999 in another survey, Brown, Dort, and Sauve (2000) found that in spite of more advanced technology, only 10% of Canadian birthing hospitals had any type of hearing screening for newborns. In other North American contexts, research indicated initial concerns about cost recovery, the availability of trained professionals, and the quality of outcomes for children. By 1998, the implementation of hospital screening was determined to be "feasible, beneficial and justified" (Mehl & Thompson, 1998, p. 1).

In 2000, the Canadian Association of Speech Language Pathologists and Audiologists (CASLPA) and the Canadian Academy of Audiologists (CAA) published a position statement that recognized and supported the need for "the establishment of an integrated system" (Durieux-Smith,

Seewald, & Hyde, 2001, p. 140). Durieux-Smith et al. recommended that this system include hearing screening for all babies; seamless transitions through screening, diagnosis, and early intervention; ongoing surveillance; educational components; professional development; and uniform provincial and territorial registries.

At the same time, CASLPA supported the recommendations (see below) of the American Joint Committee on Infant Hearing ([JCIH] 1994, 2000), the American Academy of Pediatrics (1999), and the National Institute of Health (1993). The 2000 JCIH position statement suggested a re-evaluation of existing diagnostic and support services and recommended eight principles to guide the implementation of comprehensive EHDI programs: (a) Infants should be screened before 1 month of age; (b) diagnostics should occur before 3 months; (c) intervention should begin before 6 months; (d) children passing the screening but identified as at risk should be monitored; (e) families should have the right to make informed decisions; (f) the results from the screening should be protected as carefully as any other health information; (g) regions should monitor their programs' effectiveness; and (h) regions should monitor their programs to ensure quality, practicality, and cost effectiveness (JCIH, 2000).

In 2005, the Canadian Working Group on Childhood Hearing (CWGCH) published a document to be used as an "evidence-based resource on early hearing and communication development (EHCD)" (CWGCH, 2005, p.1) for provinces that were implementing EHCD programs. The CWGCH chose the term "Early Hearing and Communication Development programs" to emphasize the goal of communication development.

As of August 2007, the government is offering comprehensive funding for EHDI program development in some provinces such as Ontario, New Brunswick, Nova Scotia, and British Columbia, but in other provinces, hearing screening is still being initiated locally and is not provincially coordinated with other diagnostic and intervention services.

### The Screening Process: The First Step to Support and Intervention

The screening process, whether as part of an EHDI program or as a local initiative, follows well-established guidelines and protocols. The infant is usually first screened in a two-stage process 24 to 48 hours after birth with automated technology that is "objective, physiologic, reasonably accurate, non-invasive, quick, and inexpensive" (Hyde, 2005, p. S72). The screening can be done while the child is sleeping or quiet. A 'refer' result from the screening necessitates follow-up with diagnostic audiology to determine the type of hearing loss, which ear is affected, and the degree of the hearing loss (Widen, Bull, & Folsom, 2003). A common goal is to complete audiometric testing by about 3 months (Hyde, 2005), and an audiologist must interpret the results (Hyde & Riko, 2000). Some parents are also referred to an ear, nose, and throat specialist for a medical diagnosis. The parents' own insights and

observations can contribute to the diagnostic evaluation (Hyde & Riko, 2000).

The goal of a "best practices" EHDI program is to facilitate the child and family's access to the most appropriate follow-up, counselling, and intervention services within the 6-month time frame to support the family's ability to develop their infant's communication and language skills, to enhance the family's understanding of their infant's strengths and needs, and to promote the family's ability to advocate on behalf of their infant (Gracey, 2003). In contrast, a locally initiated screening procedure usually encourages professionals to follow procedures and access services that may be well established but not coordinated.

### The Parents' Context

If a child is diagnosed with hearing loss, this has a significant impact on the whole family. Approximately 90% of infants born with a hearing loss are born to hearing parents (Northern & Downs, 1991). Newborn hearing screening allows children's hearing loss to be detected soon after birth, much earlier than what has historically been the case. This can be a very emotional and vulnerable time, particularly for new parents (Benedict & Raimondo, 2003; Gallagher, Easterbrooks, & Malone, 2006; Sjoblad, Harrison, Roush, & McWilliam, 2001). Not only must parents adjust to the birth of a new family member, but they are also asked to come to terms with the diagnosis and begin to make decisions that will have a significant impact on their child's future development and education. The majority of the parents have little, if any, experience with hearing loss (Vaccari & Marschark, 1997). The parents have "no experiences to draw upon, no expectations to refer to, and often, no close family or personal friend to consult" (McCracken, 2001, p. 121). Families must "face the challenge of trying to visualize the child's future with at best a poorly informed model of what this might look like" (p. 122). The families must also come to terms with the fact that their homes become staging grounds for various counselling, support, or teaching activities on a weekly basis (McCracken, 2001). They have to open their doors to numerous unknown medical professionals and support workers. Where the child is born also determines accessibility to the appropriate diagnostic facilities and support. Families "have little choice in this matter, being subject to the local arrangements and provisions" (McCracken, 2001, p. 122).

### Context of the Study and Objectives

The participants in this study were parents who had experienced NHS in one of four provincial health regions in Alberta. The initiatives in these regional birthing hospitals were part of a research project that had been established specifically to investigate only this initial screening and diagnostic phase. The principal objective of the project was to identify infants with hearing loss by 3 months of age. The project assumed that after the identification of hearing loss, parents would then be referred to intervention

services (Dort, 2000). The aims were to screen a minimum of 95% of all newborns, to establish a tracking system to ensure follow-up, and to diagnose hearing loss. Funding for this project was limited to developing and implementing screening procedures (Alberta Universal Newborn Hearing Screening Project, 2000).

Screening protocols developed in line with well-established guidelines and recommendations for diagnostics and intervention were distributed to appropriate professionals. However, the exact mechanisms for the implementation of the guidelines was left up to the local professionals (Alberta Universal Newborn Hearing Screening Project, 2000).

Little research has been conducted with parents who have experience with locally initiated screening procedures. The present study elicited the stories of five parents, which shed light on factors unique to their experience. Their insights and ideas for improvement are essential to our understanding of the ways in which professional behaviour and system challenges affect the lives of families.

## Methods

### Recruitment and Description of Participants

We used a basic interpretive approach (Merriam, 2002) and an open-ended interview technique (Patton, 2001) to explore the experiences of parents and, ultimately, to gain insight into their needs. The selection of the participants was based on purposeful sampling (Patton, 2001). The criteria for participation specified that the parents would (a) be hearing and (b) have had their infant diagnosed with a hearing loss in the new screening programs. Three of the four health regions agreed to initiate participant recruitment. The coordinators contacted parents, informed them of the study, and asked them whether they were interested in participating. Those who expressed interest were presented with appropriate information about the study. Of seven families who agreed to participate, only four could be interviewed. Three families were unable to participate because of relocation, family death, and medical considerations. In three of the four participating families, the mothers were interviewed. In the fourth family, both the mother and the father were interviewed. The parents provided "thorough, in-depth, powerful and information rich accounts" (Patton, 1990, p. 182) of their experiences.

The age at which the infants were first screened ranged from birth to 3 ½ weeks, and they were officially diagnosed at between 6 weeks and 9 months of age. The age of each child at the time of the interview ranged from 1 year to 3 years. John and Samantha (all names changed) were initially diagnosed with a sensorineural hearing loss. Ella and Joey were diagnosed with a conductive hearing loss. The degree of the children's hearing loss ranged from mild to profound; two children had a health concern in addition to their hearing loss. An introduction to the families is presented further down.

## Procedures and Data Analysis

Following established procedures for facilitating participation and encouraging discussion (Merriam, 1998; Rubin & Rubin, 2004), we collected data through in-depth, open-ended, semistructured interviews that lasted from 60 to 90 minutes. Before the interviews, we developed a guide (Patton, 1990) that was based on issues that were highlighted in the literature as being relevant to the NHS experience. The questions were open-ended to allow other relevant issues and insights to emerge spontaneously. We audiotaped and transcribed the interviews verbatim and sent the transcripts to the parents for feedback. Three different research ethics boards - one from the university faculty in which this research was conducted and the others from the health regions - reviewed and approved the research protocol.

Analysis of the interview data followed procedures appropriate to the identification of themes (DeSantis & Ugarriza, 2000; Merriam, 1998; Miles & Huberman, 1994). We marked or highlighted "interesting" and "significant" issues or quotations in the margin with comments (Barnard, 1997). These highlighted sections were then coded and merged into themes. Following the analysis, we contacted the parents for verification. In addition to their transcript, we sent them a summary that described the topics discussed and identified the themes of the interview so that the parents could "clarify and amplify the themes that had emerged during the first interview" (Corcoran & Stewart, 1998, p. 91). We conducted the follow-up discussions by mail and over the phone.

## Introduction to the Parents and Children

Rachael told us about some very difficult experiences with her son Joey, who was born with a cleft palate and was slightly over 1 year old when the interview took place. She described dealing with the confusion about the screenings, the diagnosis and multiple appointments. She had mixed feelings about her encounters with different professionals. She shared her frustrations with these experiences.

Susan spoke eloquently about the challenges she encountered in not being able to confirm a conductive hearing loss until Ella was 9 months old. Ella was 2 years old at the time of the interview, and since the diagnosis, Susan had been able to obtain "good" information and support from "home-based development coordinators."

Julie's son John was born just before NHS was implemented in her hospital. Julie told us about "being distressed and having to convince" professionals to arrange for screening. After two screenings, John was diagnosed with a profound sensorineural loss at 7 weeks. At the time of the interview, John was about 3 years old. Julie talked about her challenges and successes in accessing a variety of professionals for assessments and service.

Morgan and Paul shared different perspectives on their experiences with Samantha. Paul's perspective was unique in that he himself had a hearing loss. Samantha was 17 months at the time of the interviews. Both parents spoke about difficulties that they encountered during

several screenings and about not receiving confirmation of a permanent conductive hearing loss until Samantha was about 7 months old.

## Findings

### Dealing With the New Procedures

**The screening process.** The screening process itself left the parents with mixed feelings. All of them had "heard something about it" before it was done, through either their doctor or another professional. Morgan had been told by "a hearing screening nurse who explained how it all worked and what they were going to do, [so I was] fine with that information and really appreciated it." Susan said that she "thought that the experience in itself would be cool. I thought it was a great thing."

Getting a 'refer' result, however, precipitated anxious responses from the parents. They received the information from the audiologist, the nurse, or the assistant who had done the screening. All reported that they were "confused" and "uncertain" about what it meant. Julie explained that the terminology caused her concern:

John received a 'refer' on his second testing. *"I said, 'That means he failed.' All she would tell me was, 'Well no, no, that doesn't mean he failed. It just means that we need more information.' So I didn't really get anything from her."*

Rachael felt that she was not provided with adequate information about the screening process:

*"[The screener] just came in, tested, and she just did it again and again and again. She just handed me a little pamphlet . . . but she didn't fill it in. She said, 'He didn't pass. He'll need further testing.' She just didn't know what to say to me."*

All children underwent at least three screenings. The parents recalled being told that the equipment was either "acting up" or "not working properly," and Morgan was told that "we are going to see if we can get a different machine; come back in a couple of weeks again." Susan was told that her infant Ella was either "too mucousy" or "rattly," which would require further screening. It was difficult for the parents to bring their infants for multiple screenings. Susan told us:

*"They did not say Ella might have a hearing loss. I was really, really anxious and frustrated, very frustrated, very hesitant about taking her in again. I just wanted to forgo all the little steps and go for the main testing. I understand that there is a process to follow too, but it was so frustrating as a parent to sit back and hear excuses like my baby was breathing too loud."*

Even Paul, who had personal experience with hearing loss, found that the process of multiple screenings had a big impact upon his hopes and expectations:

*"In my mind, I just kind of ruled it out. It could be a hearing loss, but I bet more on thinking that it was equipment malfunctions [or] environmental factors. Maybe something's just not quite right, but maybe Samantha is really just fine."*

Waiting for a diagnostic referral and then waiting for an appointment with the audiologist put Morgan and the other parents into "a little bit of a no-man's land." Susan reported that "not knowing drove me nuts." The wait time ranged from 2 weeks to 9 months for the parents in this study, but Julie said, "It didn't matter how long it lasted; when you're waiting for something like that, it is forever."

**Receiving the diagnosis.** Receiving the diagnosis meant that the parents had to balance deep emotions with receiving new and distressing information. All of the parents described the shock and stress of the diagnosis of their child's hearing loss.

Susan: "I just thought . . . Oh my God, this is happening to me . . . what does this mean? I have had two healthy children up until now, and now I'm going to have one that is hearing impaired. And of course the panic button's been hit."

Morgan: "Right away I remember thinking . . . I think I should have a multitude of questions to ask, but I just couldn't think any more at that point."

Rachael: "All you're thinking is, Oh my God, my baby is deaf! That's the only thing that I thought: . . . Oh my God, oh my God!"

Paul: "Well, it's like a death; it's really like a death. Sam is still alive, of course, but to have some of your hopes crushed . . . with that comes the experience of loss, and with that comes the experience of grieving."

Julie: "You go back and think, What have I done? What did I do while I was pregnant that would cause that? . . . Oh God, is that what did it?"

**Receiving "too much" or "not enough" information.** Receiving "too much" or "not enough" information was a thread that connected the stories of the parents. They had different experiences, both positive and negative, with the amount and quality of information that they received from the professionals after the diagnosis. Terms such as "profound hearing loss," "deaf," and "hearing impairment" were confusing because, as Julie said, "not knowing anything about hearing loss, [those terms] didn't register for me. I left feeling really uninformed." Julie reported difficulties getting the information and support that she needed at the diagnostic stage:

"I was like, well, what do I do? . . . The hospital that we dealt with in [the city] . . . and the doctor didn't even seem like they had the time to deal with us. They were just so busy. . . . And I know [my husband] got really mad and stormed out because we had been down there for three days, and we didn't really get anywhere with anything. The only thing we found out is the things that we already knew . . . that he had a profound loss and that we should get hearing aids and start sign language."

Rachael, Susan, and Morgan, on the other hand, expressed appreciation for having received "a lot of information up front about . . . options." Rachael found this information helpful, "especially when you are so concerned about it. It's such a shock; you don't know what to expect. As you deal with it, you get more comfortable to a certain extent. That's just the way it is." But the parents also talked

about feeling "overwhelmed" or like "spinning circles" as they strived to keep their emotional balance. Susan and Morgan expressed this as follows:

Susan: "[The home base development coordinator] gave it all to me to the point where I was a little overwhelmed because it was so much. But on the opposite side of things, it calmed my nerves down enough to actually be able to absorb things, and that's what I needed at the time."

Morgan: "My audiologist gave me [a lot of information]. At the time, I felt quite okay with it. . . . There was a lot of information at that point that's thrown at you, and not in a bad way, but just because these are the things you need to do; these are the steps you need to take; here's a folder of information. And you can get online with these organizations and support and that kind of thing. Just with the whole nature of everything that had been going on in our lives, I went home and I put it all away [laughs] because I was just feeling personally overwhelmed with everything, and I needed to just slow down. I felt like, I will take out this book, one piece of paper at a time, when I am ready to take it out and read it, but don't push me right now."

Even though Morgan and Paul knew about the hearing loss, Paul reported:

"We just didn't get on the ball with it partially because we just were so overwhelmed with everything else that had just happened. Looking back, I wish that, at the time, I had pursued that more. . . . I think Morgan had to give me a pep talk, and . . . I had to kick myself in the pants. My ignoring of the issues, the fact of her hearing loss . . . choosing inactivity, that's not helping her at all."

Julie shared a positive experience when her audiologist helped her with the overwhelming information that she received:

"I'll let you go home now, and I'll give you a call tomorrow afternoon. . . . It's a lot for you to deal with right now. I'll just give you a chance to come to terms with it. . . . And that's what she [the audiologist] did."

**Interacting With Professionals.** After describing the screening process, the parents shared their perspectives on interacting with the professionals, which included issues of communication. They felt overwhelmed by the number of professionals who became involved in the care of their child. At the same time, they sometimes felt unsupported as they transitioned from the diagnosis to intervention programs. They were concerned about mistakes that were made, and information that was sometimes inappropriate or inaccurate.

In sharing their stories, Rachael, Susan, and Julie highlighted communication issues. Rachael addressed the frustration that she felt when there appeared to be confusion about Joey's hearing loss. At first his hearing loss was diagnosed as sensorineural, but about six months later, after tube surgery for ear infections, his hearing was found to be normal:

"They figured it was his middle ear or his inner ear and they weren't sure, and it's just, 'He is deaf.' But as it turns out, it wasn't that the test said he was deaf; it was the doctor being too rushed or negligent to look at the chart."

Susan and Julie also talked about difficulties with communication:

Susan: *"I know a lot of professionals nowadays are scared to tell you what they think; they only want to tell you what they know. But I honestly think that, if they think it's a hearing loss, then say it may be. 'Further testing is needed' . . . that's all it would have taken. . . . I think they have to take at least that into consideration: not the testing itself, but how do you convey the results to parents or not convey, in my case?"*

Julie: *"It was almost like, 'We have told you that your child has a hearing loss. We have told you what to do, what more do you want from us?' . . . [Even the doctor] didn't give us any time really."*

At a time when the parents were adjusting to a new member in their family, they had to open their doors to unknown professionals and accommodate numerous medical and home visits within the context of finding out about hearing loss. Members from nine different specialities were involved in the care of the children of the four families in this study. Rachael dealt with seven professionals; Morgan and Paul, as well as Susan, each encountered six; and Julie interacted with 10.

Susan *"had two people from [an intervention service] coming in once a week, and it was just . . . so overwhelming."* Morgan's statement captured the feelings of the other parents:

*"There really was a time when things got really confusing because you are working with so many professionals. Between the speech-language pathologist, the public health nurse, and three different audiologists, after a while I was asking questions like, 'I don't know if I am supposed to contact these people myself or whether they contact each other or whether I am supposed to phone the S-LP, or are they going to make that connection for me?'"*

The parents also commented that at times they felt unsupported, unassisted, and "left to their own devices" in trying to access intervention services. Rachael came across services "just by fluke," and Susan felt very "lucky" when "she caught sight of a poster advertising services." Yet, even though the parents talked about the difficulties that they had in trying to access services, Julie and Susan also reported relief once they were connected with a supportive professional:

Julie: *"You didn't know where to be going and you didn't know what to be doing. . . . You really had nowhere to go and no one to turn to. . . . [But] I've thanked the audiologist there, oh my God, a million times. . . . I used to speak with her every day and found out pretty well everything I needed to know. She set it all up [for appointments] and visits. . . . She was so helpful, and she still keeps in contact with us after 3 years."*

Susan: *"If I needed to know something, I could phone and leave [the home-based development coordinator] a voice mail, and she would get back to me even after hours. . . . There was no waiting for days . . . it was almost immediate. If she wasn't in the office, she'd call me as soon as she got the message. If she didn't know the answer, she'd find out. She*

*was right in there, and had she not been . . . I don't know where we'd be today."*

However, the information that the parents received was mixed. Some was useful and appropriate, but some was not. Paul and Morgan were told that "because Samantha was still a newborn, [intervention] wasn't really pertinent right now." Similarly, a speech pathologist told Rachael that her child was "just too young. . . . We won't come out until he's at least 18 months." Paul said that his own audiologist later admitted not knowing about the best amplification for babies: "It wasn't a fault or oversight . . . they just did not know." In addition, professionals also told these parents that their child would "have no speech; he's going to need hearing aids and sign language." Julie, on the other hand, was informed that "the recommendation is to amplify. His exact words were, 'From our standpoint, we expedite amplification,'" and there was "no mention of alternatives, neither sign nor cochlear implants."

**Coping and Identifying Additional Needs.** After having their child diagnosed with a hearing loss, the parents talked about becoming a "parent of a child who is deaf" and their needs for support in this new role. During the time of finding out, Morgan was grateful for "a lot of family support. 'Both of our families are well aware and very supportive, and there were definitely other Christians from our church around us who were a huge support.'" Susan too said, "I don't know if I would have been able to keep it together had it not been for my mom." Rachael, however, reported that "at first even family didn't want to hold him, didn't want to baby-sit him because of his hearing aids." Julie felt isolated living "away from home. . . . When you don't know anybody, you have nobody to call, and you have nobody to talk to."

When we asked the parents how they were able to obtain additional help, both Rachael and Julie talked about accessing the services of a genetic counsellor when they became pregnant again:

Rachael: *"There was a 25% chance that I could have another child with a hearing loss, but I was like, 'At least I know what I'm dealing with.' But I was still like, 'Phew! That's a lot to deal with!'"*

Julie: *"We did find out it was genetic; it was both on my side and [my husband's] side. Both of us are carriers, but there is no history on either side. . . . It was like winning the lottery that you just got two carriers together. . . . My new baby is 8 months old now, and I've had her tested three times because I am really paranoid, but her hearing is fine."*

Morgan and Paul: *"(We) both would have appreciated the more personal services of a counsellor who can deal with parents of children with a disability . . . just to help us through some of that grieving process and be where we are at and explain how to move on from there. . . . Access to someone who would be up on the latest research and technology and programs, but who can also guide parents through their own thoughts and emotions and help them be the best support they can to their children with disabilities. [That] would be really helpful, really helpful."*

Each one of the parents expressed a need to access “veteran parents” who had been through the process before and who could explain what the experience was like, what to expect, and what the possible outcomes were. Paul wanted to go to “seminars and workshops and start talking to other parents.” Rachael and Morgan concurred:

Rachael: “[It] could have saved a lot of stress, a lot of not knowing, and especially having someone come in who’s dealt with hearing impaired children and who’s taught them or who’s been a mother, or somebody who’s first hand, not somebody who’s read about it, because [those professionals] don’t really understand.”

Morgan: “I think it would have been good for me to have some one-on-one interaction with other parents who have also gone through this same thing. . . . It would have been a comfort at that point.”

Julie, on the other hand, had positive experiences with other parents. She found e-mail communication particularly helpful:

“That was one of the biggest things that I found great down here, was that they put me in touch with everybody that was going through the same thing that I went through. They did it in a way that was helpful, because it’s not that easy to pick up the phone and talk about it when you are first going through it, so they did it through e-mails. I e mailed a lot at 2 or 3 in the morning when you couldn’t sleep, you couldn’t call anybody, and I used to e mail people and ask, ‘How did you get through that?’ or ‘How did you deal with this? What did you find was the best way to go about it?’”

## Discussion

In viewing the parents’ stories as “of-the-moment-evidence” (Young & Tattersall, 2007, p. 216) and as remembered snapshots of their reality, and in discussing the relevance and importance of these findings, readers must be mindful of the context of the parents’ experiences. Funding for this project focussed predominantly on the screening initiative so the referral and intervention procedures relied on existing services in the province. Fitzpatrick, Graham, Durieux-Smith, Angus, and Coyle (2007) noted that in Ontario, local hospitals had begun screening before a province-wide strategic program was developed. Some of the seven children who participated in their study had been “screened through [these] local initiatives” (Fitzpatrick et al., 2007, p. 105). In most provinces such local screening initiatives have been the forerunners of province-wide program development. Where province-wide funding for comprehensive program development is not in place, professionals struggle with decisions such as whether or not to begin a screening program without additional supports in place.

It is interesting to note, however, that even in comprehensive programs, parents still experience difficulties. Mazlan, Hickson, and Driscoll (2006) described these as “service shortfalls” (p. 253). Park et al.’s (2006) survey of 108 families of pediatric patients in a comprehensive program also revealed difficulties that were

experienced as a result of information sharing, multiple screenings, and wait lists for diagnostics. Nonetheless, the parents in the present study highlight the pitfalls of developing local initiatives without comprehensive professional collaboration.

**The Ongoing Need for Education and Training.** The ongoing need for education and training is a thread that ties the experiences of the parents together. Their stories about perceived mistakes and misinformation reveal a critical need to bring professionals up to date in terms of new developments in early identification and intervention. There may be a tendency to believe that because there is an infrastructure for the diagnosis of and intervention for hearing loss, that all of the professionals have current skills and knowledge. The parents have alerted us to the fact that we cannot take this for granted and that education must be ongoing, especially in light of technological advances.

The parents in this study shared their feelings about their interactions with the numerous professionals who had entered their lives. All of the parents would have preferred less ambiguity and more sensitivity in what and how they were told. The professionals conveyed understanding and empathy, or lack thereof, in many ways: through their use of terminology and language, in the amount of time that they spent with the parents, in their ability to listen to the parents’ concerns at the time, and through the growth of trust. This happened at different stages: at the screening where the professionals told the parents about the ‘refer’ result, when the parents received confusing messages about the process itself or about hearing loss, and when they received information about the diagnosis and what would happen after. Professionals have long been aware of the importance of communicating with parents of young children in supportive and empathetic ways. Tattersall and Young (2006) concluded, “In fact, professional communication and manner are the most significant predictors of parents’ experiences in the NHS program” (p. 33). Young and Tattersall (2007) discuss the changes brought about by the implementation of newborn hearing screening, such as institution-initiated detection, a compressed timescale between birth and diagnosis, and the effect of the early diagnosis on the development of the relationship between parent and child. In the context of these circumstances, the parents remind us that education must also include training that allows all professionals to interact in the best possible way with parents as they move through one of the most difficult stages of the process. The parents’ stories illustrated the importance of professionals’ knowledge, impartiality, and ethical conduct in their presentation of information about best practices in intervention.

It is also important to acknowledge that some parents may not always hear what professionals tell them. Parents may pick out parts of a message, or they may get stuck on key words. This underlines that EHDI programs must be structured to allow parents to receive information multiple times and in various formats.

Furthermore, the parents in the present study stressed

the importance of detailed pre-screening information. Weichbold, Welzl-Mueller, and Mussbacher (2001) concluded that parents who are informed about the screening tend to view the process more positively. Other findings indicate that the more informed that parents are about the screening, the higher their acceptance of the screening and the lower the maternal concern about the results (Hergils & Hergils, 2000; Weichbold et al., 2001). However, Davis et al. (2006) found that communication about screening is often limited. For the parents in this study, more detailed information about the screening and the meaning of a 'refer' result might have improved their understanding and alleviated some of their fears.

**New Procedures.** In discussing the importance of the findings, it is important to remember that the parents experienced screening at the beginning of its implementation in birthing hospitals where "seamless transitioning" and "essential supports" had not been the focus. It is possible that some of the procedural difficulties will be resolved.

The parents expressed concern and worry about the need for multiple screenings because of difficult testing circumstances or to rule out faulty equipment. Repeated screening may be a problem unique to NHS procedures. In fact, most protocols recommend a minimum of two screenings to achieve low false-positive rates (Hyde, 2005). Their occurrence, however, and the degree to which they impact parents can be expected to vary. Differences in parents' perspectives on these procedures may depend upon the extent to which each province has been able to implement the guidelines that the JCIH (1994, 2000) has set out, that CASLPA (Durieux-Smith et al., 2001) has supported, and the CWGCH has reinforced and further developed (CWGCH, 2005).

Careful planning for, developing, and organizing "seamless transitions" are part of these best practice guidelines and necessitate comprehensive province-wide collaboration among professionals. The parents described the difficulties that they faced when there was no comprehensive plan in place. The wait time for the parents of these children ranged from two to nine months, but no matter how long it was before the children were diagnosed, the parents felt the stress of "being in a no-man's land." In one case, the diagnosis was not reached until nine months of age, which defeats the purpose of the NHS. In recognition of the importance of developmental milestones, recommendations for EHDI programs call for screening before 1 month of age, diagnosis before 3 months, and intervention before 6 months. Transition protocols should be in place to facilitate the path to intervention. In many locations, a comprehensive program may require restructuring the health care system to allow parents to access intervention services, audiological and medical management, and family counselling immediately (Mencher & DeVoe, 2001). Access may depend on many factors, such as the number and quality of diagnostic and intervention programs that are already in place for infants, the availability of trained professionals, the

geographic location of birthing hospitals and diagnostic centers, the availability of and access to funding, the ability of each province to centralize and share expertise, and the sophistication of "information systems to track and facilitate timely delivery of services" (Hyde, 2005, p. S72). The findings from this study show that although appropriate services were already in place throughout the province, the parents found out about them by luck. Access to appropriate and timely services should be developed and improved.

The need for specialized support was also evident in the interview data. Irrespective of the severity of the hearing loss, all parents were shocked when they found out. Researchers are investigating the effects of the initial shock of the early diagnosis on the parent-child bond (Fitzpatrick et al., 2007; Yoshinaga-Itano, 2001; Young & Tattersall, 2007). The parents also emphasized the importance of access not only to genetic counselling and counsellors, but also to other parents who had gone through similar experiences. Edwards (2003) noted that most human beings "do not invite change into their lives" (p. 4). People function according to the pattern of their lives, and when something unexpected happens, most individuals resist that change. The parents in this study provided evidence of the individual ways in which parents react to the diagnosis. It is evident that the professionals' giving and the parents' receiving of the information were not always compatible. Different families have different coping styles, and professionals should strive to adapt their counselling styles and timing to each family's needs.

The parents also shared the challenges that they faced in dealing with the large numbers of professionals who became part of their lives after the screening. They lamented that they "didn't know what to do and where to go." Several researchers have noted a lack of collaboration in infant hearing programs (Bamford, Davis, Hind, McCracken, & Reeve, 2000; Bodner-Johnson, 2001; Corcoran, Stewart, Glynn, & Woodman, 2000; DesGeorges, 2003; Harrison & Roush, 1996; Luterman & Kurtzer-White, 1999; Russ et al., 2004; Sjoblad et al., 2001). A statement from one of the parents in this study commands our attention: "We need a professional to coordinate the professionals."

## Conclusion

This study offers new insights from parents whose children went through NHS procedures, but who were not part of a comprehensive EHDI program. The parents' experiences were mixed, and they identified a number of areas for improvement. Some of the problems reported stemmed from the fact that the NHS was implemented without a comprehensive strategic plan for the management of congenital hearing loss. As province-wide guidelines for EHDI programs are being established, it is hoped that many of the issues reported by the parents should be resolved. However, no management program will ever be flawless and perfect.

Based on the stories of the parents in this study, one may be tempted to question the wisdom of implementing



screening without comprehensive planning. It is important to appreciate that despite the challenges and struggles, the parents were unanimously grateful for the early diagnosis of their child's hearing loss. The early diagnosis enabled them to take the necessary steps to assist their child.

The interview perspective employed in this study recognizes the parents' stories and opinions as their realities. They offer a snapshot of the challenges that many parents may face. They also highlight the need for professionals to try to understand the context in which they partner with parents to meet the needs of the child with a hearing loss. It is hoped that this study will inspire further research that will broaden our understanding of parents' experiences of the implementation of programs that involve NHS.

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## Material and Resource Review/ Évaluation des ressources

*Educating Children with Velo-Cardio-Facial Syndrome*  
Cutler-Landsman (2007)

**Publisher:** Plural Publishing Inc., San Diego, California  
Available from: [www.pluralpublishing.com](http://www.pluralpublishing.com)  
**Cost:** \$57.95 US, \$66.00 (CAD)  
**Reviewer:** Christie Mellies, M.S., CCC/SLP, Speech-Language Pathologist  
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This book is a guide to educating children and adolescents with Velo-Cardio-Facial Syndrome (VCFS). VCFS is a genetic syndrome involving a microdeletion on the long arm of chromosome 22. Children with VCFS often have developmental and learning difficulties, but there has been a paucity of published information on the educational needs of these children, until this book. Part I of the book was written by the lead author Donna Cutler-Landsman and contributing authors, while part II is written solely by Ms. Cutler-Landsman. Ms. Cutler-Landsman is an educator with 30 years of experience teaching children in grades 5-8. She has also been a cooperating teacher with the School of Education, University of Wisconsin-Madison for 15 years and an educational consultant regarding the special education needs of children with VCFS. Ms. Landsman-Cutler has a child who was diagnosed with VCFS in 1994 when he was in 4th grade, enabling her to share personal experiences and insights as well. Contributing authors include: Robert Shprintzen, PhD; Tony J. Simon, PhD; Wendy Cates, PhD; Bronwyn Glaser, MA; Stephan Eliez, MD; Doron Gothelf, MD; Merav Burg, MA; Karen Golding-Kushner, PhD; and Anne Marie Higgins, RN. All are leading researchers and professionals well versed and published in the topic of VCFS.

The targeted audience for this book includes professionals in the fields of speech-language pathology, psychology, education, genetics, pediatrics and other professionals involved in the care of children with VCFS. Parents will also benefit from the book as it will help them better understand their child and his/her educational needs, as well as help them to advocate on behalf of their child.

The purpose of part I is to provide an overview of the medical, neurocognitive, psychiatric and communication issues that children with VCFS often face. Part II focuses on educational interventions starting in the 0-3 year-old range and extends through the school years and into adolescence. There are three appendices. Appendix A, "Accommodations" lists classroom accommodations for

a variety of issues such as academic delays, organization of assignments, test writing, behavior and more. There are also specific accommodations to consider for children with nonverbal learning disability. A "Teacher Awareness Questionnaire," with answers appearing in Appendix B, is designed to help develop understanding of how VCFS differs from other genetic syndromes including Down Syndrome and Fragile X. Finally, Appendix C has "Exercises for Understanding" that include questions and hypothetical scenarios with the purpose of helping educators discuss and plan for the needs of a child with VCFS.

The book is well organized and while one can access just the chapters that are related to their child's age, information in other chapters can be quite useful regardless of the child's grade in school. Part I will help the reader understand how VCFS is diagnosed, and identifies the characteristics, typical neurocognitive and communication profiles and psychiatric issues associated with VCFS. There is also information about psychoeducational and communication tests. The information is generally clear, concise and provides a comprehensive overview. Parents and professionals will benefit from a better understanding of VCFS and its sequelae.

In Chapter 1 Dr. Shprintzen outlines the history of the nomenclature of VCFS and the various other names it has been called in the past (Di George syndrome, Shprintzen syndrome, conotruncal anomalies face syndrome). While the collective authors have decided to continue with the name "velo-cardio-facial syndrome," perhaps it would be less confusing to use the genetic nomenclature "22q11 deletion syndrome" or "microdeletion 22q11 syndrome," the chromosomal area affected in VCFS. While most of these children do have palate (velo), cardiac (cardio) and typical facial features there are some that may only have 2/3 characteristics. However, they all have the microdeletion.

There are a few lists in Chapter 1 that I thought would be especially helpful for parents when advocating for their child at school and for teachers in planning for a student with VCFS. The first entitled "Learning Issues" lists the relative strengths and weaknesses in learning noted in this population. It is important to identify each child's individual strengths and weaknesses so the teacher can get a sense of what to look for and how to prepare for difficulties before they arise. Another list that is beneficial is a timeline for education-related interventions. This helps parents and teachers to assess the student's current and future needs.

Part I ends with the "Velo-Cardio-Facial Syndrome Specialist Fact Sheet." This lists the 186 anomalies and characteristics that can be associated with VCFS. It also provides incidence and prevalence information. While this information may not be terribly useful for educators as no child will have all of the characteristics and anomalies, it does give them the sense that these children are a complex, heterogeneous group and that many factors may affect their performance in school.

Part I contains a confusing and contradictory passage about the relationship between verbal and performance IQs in children with VCFS. One sentence on page 17 reads “This pattern of performance IQ being significantly higher than verbal IQ, indicative of a nonverbal learning disability, seems to be true for most VCFS children, but not all.” However, the two sentences preceding and the two sentences following this sentence state the opposite, that children with VCFS typically have higher verbal IQs than performance IQs.

Part II is laid out very nicely with the chapters progressing by age/school stage. Parents and educators may benefit from tips in any of the chapters as they are based on children’s strengths and weakness that may affect them at any age. In many of the sections, there are bulleted lists that highlight teaching strategies for a certain academic area. For example in the section “Mathematics”, Chapter 10, there is a list of what an instructional approach should include that combines suggestions for direct instructions and strategy instruction. There are case vignettes to help illustrate some of the difficulties children with VCFS experience at different stages in school. A weakness for Canadian readers is that the educational laws and policies referenced by the author pertain to the American education system. While the laws may not be the same, many of the principles on special education appear to be similar in both countries.

Appendix A is particularly useful in determining which accommodations might help the child with VCFS reach their fullest potential in school. These accommodations will be particularly beneficial to parents when advocating for their child, and for teachers developing a student’s individualized education plan. Many of the accommodations will also be helpful to other professionals such as S-LPs and OTs when planning assessment and therapy sessions with the children.

This is an excellent book to help professionals, educators and parents better understand VCFS and the educational needs of these students. Ms. Landsman-Cutler argues that there is little research available on educational interventions for children with VCFS, but that these children need support today. There is no “cook book” approach to teaching children with VCFS. Ms. Landsman-Cutler and the other authors stress the importance of looking at the child’s individual strengths and weakness and providing support where needed. All intervention approaches should be analyzed as to whether they are benefiting the child and modified as appropriate.



## Information for Contributors

The Canadian Journal of Speech-Language Pathology and Audiology (CJSLPA) welcomes submissions of scholarly manuscripts related to human communication and its disorders broadly defined. This includes submissions relating to normal and disordered processes of speech, language, and hearing. Manuscripts that have not been published previously are invited in English and French. Manuscripts may be tutorial, theoretical, integrative, practical, pedagogic, or empirical. All manuscripts will be evaluated on the basis of the timeliness, importance, and applicability of the submission to the interests of speech–language pathology and audiology as professions, and to communication sciences and disorders as a discipline. Consequently, all manuscripts are assessed in relation to the potential impact of the work on improving our understanding of human communication and its disorders. All categories of manuscripts submitted will undergo peer-review to determine the suitability of the submission for publication in CJSLPA. The Journal recently has established multiple categories of manuscript submission that will permit the broadest opportunity for dissemination of information related to human communication and its disorders. New categories for manuscript submission include:

*Tutorials:* Review articles, treatises, or position papers that address a specific topic within either a theoretical or clinical framework.

*Articles:* Traditional manuscripts addressing applied or basic experimental research on issues related to speech, language, and/or hearing with human participants or animals.

*Clinical Reports:* Reports of new clinical procedures, protocols, or methods with specific focus on direct application to identification, assessment and/or treatment concerns in speech, language, and/or hearing.

*Brief Reports:* Similar to research notes, brief communications concerning preliminary findings, either clinical or experimental (applied or basic), that may lead to additional and more comprehensive study in the future. These reports are typically based on small “*n*” or pilot studies and must address disordered participant populations.

*Research Notes:* Brief communications that focus on experimental work conducted in laboratory settings. These reports will typically address methodological concerns and/or modifications of existing tools or instruments with either normal or disordered populations.

*Field Reports:* Reports that outline the provision of services that are conducted in unique, atypical, or nonstandard settings; manuscripts in this category may include screening, assessment, and/or treatment reports.

*Letters to the Editor:* A forum for presentation of scholarly/clinical differences of opinion concerning work previously published in the Journal. Letters to the Editor may influence our thinking about design considerations, methodological confounds, data analysis and/or data interpretation, etc. As with other categories of submissions, this communication forum is contingent upon peer-review. However, in contrast to other categories of submission, rebuttal from the author(s) will be solicited upon acceptance of a letter to the editor.

## Submission of Manuscripts

Contributors should send a file containing the manuscript, including all tables, figures or illustrations, and references in MS word or WordPerfect format via e-mail to the Editor at: tim.bressmann@utoronto.ca. Sending manuscripts by e-mail is the preferred method of submission. However, manuscripts may still be submitted by sending five (5) hard copies to:

**Tim Bressmann, PhD**  
**Editor in Chief,**  
**Canadian Journal of Speech-Language Pathology and Audiology**  
**Department of Speech-Language Pathology**  
**University of Toronto**  
**160 - 500 University Avenue**  
**Toronto, Ontario M5G 1V**

Along with copies of the manuscript, a cover letter indicating that the manuscript is being submitted for publication consideration should be included. The cover letter must explicitly state that the manuscript is original work, that has not been published previously, and that it is not currently under review elsewhere. Manuscripts are received and peer-reviewed contingent upon this understanding. The author(s) must also provide appropriate confirmation that work conducted with humans or animals has received ethical review and approval.

Failure to provide information on ethical approval will delay the review process. Finally, the cover letter should also indicate the category of submission (i.e., tutorial, clinical report, etc.). If the editorial staff determines that the manuscript should be considered within another category, the contact author will be notified.

All submissions should conform to the publication guidelines of the Publication Manual of the American Psychological Association (APA), 5th Edition. A confirmation of receipt for all manuscripts will be provided to the contact author prior to distribution for peer review. CJSLPA seeks to conduct the review process and respond to authors regarding the outcome of the review within 90 days of receipt. If a manuscript is judged as suitable for publication in CJSLPA, authors will have 30 days to make necessary revisions prior to a secondary review.

The author is responsible for all statements made in his or her manuscript, including changes made by the editorial and/or production staff. Upon final acceptance of a manuscript and immediately prior to publication, the contact author will be permitted to review galley proofs and verify its content to the publication office within 72 hours of receipt of galley proofs.

## Organization of the Manuscript

All copies should be typed, double-spaced, with a standard typeface (12 point, noncompressed font) on high quality 8 ½ X 11 paper. All margins should be at least one (1) inch. An original and four (copies) of the manuscript should be submitted directly to the Editor. Author identification for the review process is optional; if blind-review is desired, three (3) of the copies should be prepared accordingly (cover page and acknowledgments blinded). Responsibility for removing all potential identifying information rests solely with the author(s). All manuscripts should be prepared according to APA guidelines. This manual is available from most university bookstores or is accessible via commercial bookstores. Generally, the following sections should be submitted in the order specified.

**Title Page:** This page should include the full title of the manuscript, the full names of the author(s) with academic degrees, each author's affiliation, and a complete mailing address for the contact author. An electronic mail address also is recommended.

**Abstract:** On a separate sheet of paper, a brief yet informative abstract that does not exceed one page is required. The abstract should include the purpose of the work along with pertinent information relative to the specific manuscript category for which it was submitted.

**Key Words:** Following the abstract and on the same page, the author(s) should supply a list of key words for indexing purposes.

**Tables:** Each table included in the manuscript must be typewritten and double-spaced on a separate sheet of paper. Tables should be numbered consecutively beginning with Table 1. Each table must have a descriptive caption. Tables should serve to expand the information provided in the text of the manuscript, not to duplicate information.

### **Potential Conflicts of Interest and Dual Commitment**

As part of the submission process, the author(s) must explicitly identify if any potential conflict of interest, or dual commitment, exists relative to the manuscript and its author(s). Such disclosure is requested so as to inform C JSLPA that the author or authors have the potential to benefit from publication of the manuscript. Such benefits may be either direct or indirect and may involve financial and/or other nonfinancial benefit(s) to the author(s). Disclosure of potential conflicts of interest or dual commitment may be provided to editorial consultants if it is believed that such a conflict of interest or dual commitment may have had the potential to influence the information provided in the submission or compromise the design, conduct, data collection or analysis, and/or interpretation of the data obtained and reported in the manuscript submitted for review. If the manuscript is accepted for publication, editorial acknowledgement of such potential conflict of interest or dual commitment may occur when publication occurs.

**Illustrations:** All illustrations included as part of the manuscript must be included with each copy of the manuscript. All manuscripts must have clear copies of all illustrations for the review process. High resolution (at least 300 dpi) files in any of the following formats must be submitted for each graphic and image: JPEG, TIFF, AI, PSD, GIF, EPS or PDF. For other types of computerized illustrations, it is recommended that CJSPLA production staff be consulted prior to preparation and submission of the manuscript and associated figures/illustrations.

**Legends for Illustrations:** Legends for all figures and illustrations should be typewritten (double-spaced) on a separate sheet of paper with numbers corresponding to the order in which figures/illustrations appear in the manuscript.

**Page Numbering and Running Head:** The text of the manuscript should be prepared with each page numbered, including tables, figures/illustrations, references, and if appropriate, appendices. A short (30 characters or less) descriptive running title should appear at the top right hand margin of each page of the manuscript.

**Acknowledgments:** Acknowledgments should be typewritten (double-spaced) on a separate sheet of paper. Appropriate acknowledgment for any type of sponsorship, donations, grants, technical assistance, and to professional colleagues who contributed to the work, but are not listed as authors, should be noted.

**References:** References are to be listed consecutively in alphabetical order, then chronologically for each author. Authors should consult the APA publication manual (4th Edition) for methods of citing varied sources of information. Journal names and appropriate volume number should be spelled out and italicized. All literature, tests and assessment tools, and standards (ANSI and ISO) must be listed in the references. All references should be double-spaced.

### **Participants in Research Humans and Animals**

Each manuscript submitted to CJSPLA for peer-review that is based on work conducted with humans or animals must acknowledge appropriate ethical approval. In instances where humans or animals have been used for research, a statement indicating that the research was approved by an institutional review board or other appropriate ethical evaluation body or agency must clearly appear along with the name and affiliation of the research ethics and the ethical approval number. The review process will not begin until this information is formally provided to the Editor.

Similar to research involving human participants, CJSPLA requires that work conducted with animals state that such work has met with ethical evaluation and approval. This includes identification of the name and affiliation of the research ethics evaluation body or agency and the ethical approval number. A statement that all research animals were used and cared for in an established and ethically approved manner is also required. The review process will not begin until this information is formally provided to the Editor.

## Renseignements à l'intention des collaborateurs

La Revue canadienne d'orthophonie et d'audiologie (RCOA) est heureuse de se voir soumettre des manuscrits de recherche portant sur la communication humaine et sur les troubles qui s'y rapportent, dans leur sens large. Cela comprend les manuscrits portant sur les processus normaux et désordonnés de la parole, du langage et de l'audition. Nous recherchons des manuscrits qui n'ont jamais été publiés, en français ou en anglais. Les manuscrits peuvent être tutoriels, théoriques, synthétiques, pratiques, pédagogiques ou empiriques. Tous les manuscrits seront évalués en fonction de leur signification, de leur opportunité et de leur applicabilité aux intérêts de l'orthophonie et de l'audiologie comme professions, et aux sciences et aux troubles de la communication en tant que disciplines. Par conséquent, tous les manuscrits sont évalués en fonction de leur incidence possible sur l'amélioration de notre compréhension de la communication humaine et des troubles qui s'y rapportent. Peu importe la catégorie, tous les manuscrits présentés seront soumis à une révision par des collègues afin de déterminer s'ils peuvent être publiés dans la RCOA. La Revue a récemment établi plusieurs catégories de manuscrits afin de permettre la meilleure diffusion possible de l'information portant sur la communication humaine et les troubles s'y rapportant. Les nouvelles catégories de manuscrits comprennent :

**Tutoriels :** Rapports de synthèse, traités ou exposés de position portant sur un sujet particulier dans un cadre théorique ou clinique.

**Articles :** Manuscrits conventionnels traitant de recherche appliquée ou expérimentale de base sur les questions se rapportant à la parole, au langage ou à l'audition et faisant intervenir des participants humains ou animaux.

**Comptes rendus cliniques :** Comptes rendus de nouvelles

procédures ou méthodes ou de nouveaux protocoles cliniques portant particulièrement sur une application directe par rapport aux questions d'identification, d'évaluation et de traitement relativement à la parole, au langage et à l'audition.

**Comptes rendus sommaires :** Semblables aux notes de recherche, brèves communications portant sur des conclusions préliminaires, soit cliniques soit expérimentales (appliquées ou fondamentales), pouvant mener à une étude plus poussée dans l'avenir. Ces comptes rendus se fondent typiquement sur des études à petit « n » ou pilotes et doivent traiter de populations désordonnées.

**Notes de recherche :** Brèves communications traitant spécifiquement de travaux expérimentaux menés en laboratoire. Ces comptes rendus portent typiquement sur des questions de méthodologie ou des modifications apportées à des outils existants utilisés auprès de populations normales ou désordonnées.

**Comptes rendus d'expérience :** Comptes rendus décrivant sommairement la prestation de services offerts en situations uniques, atypiques ou particulières; les manuscrits de cette catégorie peuvent comprendre des comptes rendus de dépistage, d'évaluation ou de traitement.

**Courrier des lecteurs :** Forum de présentation de divergences de vues scientifiques ou cliniques concernant des ouvrages déjà publiés dans la Revue. Le courrier des lecteurs peut avoir un effet sur notre façon de penser par rapport aux facteurs de conception, aux confusions méthodologiques, à l'analyse ou l'interprétation des données, etc. Comme c'est le cas pour d'autres catégories de présentation, ce forum de communication est soumis à une révision par des collègues. Cependant, contrairement aux autres catégories, on recherchera la réaction des auteurs sur acceptation d'une lettre.

## Présentation de manuscrits

On demande aux collaborateurs de faire parvenir par voie électronique un fichier électronique incluant leurs manuscrits, y compris tous les tableaux, figures ou illustrations et références, en format MS Word ou WordPerfect à : tim.bressmann@utoronto.ca. L'envoi des manuscrits par voie électronique est la méthode préférée pour la soumission, pourtant les manuscrits peuvent toujours être soumis en envoyant 5 copies imprimées à :

**Tim Bressmann, PhD**  
**Rédacteur en chef, Revue canadienne d'orthophonie et d'audiologie**  
**Department of Speech-Language Pathology**  
**University of Toronto**  
**160 - 500 University Avenue**  
**Toronto, Ontario M5G 1V7**

On doit joindre aux exemplaires du manuscrit une lettre d'envoi qui indiquera que le manuscrit est présenté en vue de sa publication. La lettre d'envoi doit préciser que le manuscrit est une œuvre originale, qu'il n'a pas déjà été publié et qu'il ne fait pas actuellement l'objet d'un autre examen en vue d'être publié. Les manuscrits sont reçus et examinés sur acceptation de ces conditions. L'auteur (les auteurs) doit (doivent) aussi fournir une attestation en bonne et due forme que toute recherche impliquant des êtres humains ou des animaux a fait

l'objet de l'agrément d'un comité de révision déontologique. L'absence d'un tel agrément retardera le processus de révision. Enfin, la lettre d'envoi doit également préciser la catégorie de la présentation (i.e. tutoriel, rapport clinique, etc.). Si l'équipe d'examen juge que le manuscrit devrait passer sous une autre catégorie, l'auteur-contact en sera avisé.

Toutes les présentations doivent se conformer aux lignes de conduite présentées dans le publication *Manual of the American Psychological Association (APA)*, 5<sup>e</sup> Édition. Un accusé de réception de chaque manuscrit sera envoyé à l'auteur-contact avant la distribution des exemplaires en vue de la révision. La RCOA cherche à effectuer cette révision et à informer les auteurs des résultats de cette révision dans les 90 jours de la réception. Lorsqu'on juge que le manuscrit convient à la RCOA, on donnera 30 jours aux auteurs pour effectuer les changements nécessaires avant l'examen secondaire.

L'auteur est responsable de toutes les affirmations formulées dans son manuscrit, y compris toutes les modifications effectuées par les rédacteurs et réviseurs. Sur acceptation définitive du manuscrit et immédiatement avant sa publication, on donnera l'occasion à l'auteur-contact de revoir les épreuves et il devra signifier la vérification du contenu dans les 72 heures suivant réception de ces épreuves.

## Organisation du manuscrit

Tous les textes doivent être dactylographiés à double interligne, en caractère standard (police de caractères 12 points, non comprimée) et sur papier 8 ½" X 11" de qualité. Toutes les marges doivent être d'au moins un (1) pouce. L'original et quatre (4) copies du manuscrit doivent être présentés directement au rédacteur en chef. L'identification de l'auteur est facultative pour le processus d'examen : si l'auteur souhaite ne pas être identifié à ce stade, il devra préparer trois (3) copies d'un manuscrit dont la page couverture et les remerciements seront voilés. Seuls les auteurs sont responsables de retirer toute information identificatrice éventuelle. Tous les manuscrits doivent être rédigés en conformité aux lignes de conduite de l'APA. Ce manuel est disponible dans la plupart des librairies universitaires et peut être commandé chez les libraires commerciaux. En général, les sections qui suivent doivent être présentées dans l'ordre chronologique précisé.

**Page titre :** Cette page doit contenir le titre complet du manuscrit, les noms complets des auteurs, y compris les diplômes et affiliations, et l'adresse complète de l'auteur-contact. Une adresse de courriel est également recommandée.

**Abrégé :** Sur une page distincte, produire un abrégé bref mais informateur ne dépassant pas une page. L'abrégé doit indiquer l'objet du travail ainsi que toute information pertinente portant sur la catégorie du manuscrit.

**Mots clés :** Immédiatement suivant l'abrégé et sur la même page, les auteurs doivent présenter une liste de mots clés aux fins de constitution d'un index.

**Tableaux :** Tous les tableaux compris dans un même manuscrit doivent être dactylographiés à double interligne sur une page distincte. Les tableaux doivent être numérotés consécutivement, en commençant par le Tableau 1. Chaque tableau doit être accompagné d'une légende et doit servir à compléter les renseignements fournis dans le texte du manuscrit plutôt qu'à reprendre l'information contenue dans le texte ou dans les tableaux.

### **Conflits d'intérêts possibles et engagement double**

Dans le processus de présentation, les auteurs doivent déclarer clairement l'existence de tout conflit d'intérêts possibles ou engagement double relativement au manuscrit et de ses auteurs. Cette déclaration est nécessaire afin d'informer la RCOA que l'auteur ou les auteurs peuvent tirer avantage de la publication du manuscrit. Ces avantages pour les auteurs, directs ou indirects, peuvent être de nature financière ou non financière. La déclaration de conflit d'intérêts possibles ou d'engagement double peut être transmise à des conseillers en matière de publication lorsqu'on estime qu'un tel conflit d'intérêts ou engagement double aurait pu influencer l'information fournie dans la présentation ou compromettre la conception, la conduite, la collecte ou l'analyse des données, ou l'interprétation des données recueillies et présentées dans le manuscrit soumis à l'examen. Si le manuscrit est accepté en vue de sa publication, la rédaction se réserve le droit de reconnaître l'existence possible d'un tel conflit d'intérêts ou engagement double.

### **Participants à la recherche – êtres humains et animaux**

Chaque manuscrit présenté à la RCOA en vue d'un examen par des pairs et qui se fonde sur une recherche effectuée avec la

**Illustrations :** Toutes les illustrations faisant partie du manuscrit doivent être incluses avec chaque exemplaire du manuscrit. Chaque manuscrit doit contenir des copies claires de toutes les illustrations pour le processus de révision. Il faut envoyer un fichier électronique pour chaque image et graphique en format JPEG, TIFF, AI, PSD, GIF, EPS ou PDF, compression minimale 300 ppp. Pour les autres types d'illustrations informatisées, il est recommandé de consulter le personnel de production de la RCOA avant la préparation et la présentation du manuscrit et des figures et illustrations s'y rattachant.

**Légendes des illustrations :** Les légendes accompagnant chaque figure et illustration doivent être dactylographiées à double interligne sur une feuille distincte et identifiées à l'aide d'un numéro qui correspond à la séquence de parution des figures et illustrations dans le manuscrit.

**Numérotation des pages et titre courant :** Chaque page du manuscrit doit être numérotée, y compris les tableaux, figures, illustrations, références et, le cas échéant, les annexes. Un bref (30 caractères ou moins) titre courant descriptif doit apparaître dans la marge supérieure droite de chaque page du manuscrit.

**Remerciements :** Les remerciements doivent être dactylographiés à double interligne sur une feuille distincte. L'auteur doit reconnaître toute forme de parrainage, don, bourse ou d'aide technique, ainsi que tout collègue professionnel qui ont contribué à l'ouvrage mais qui n'est pas cité à titre d'auteur.

**Références :** Les références sont énumérées les unes après les autres, en ordre alphabétique, suivi de l'ordre chronologique sous le nom de chaque auteur. Les auteurs doivent consulter le manuel de l'APA (5<sup>e</sup> Édition) pour obtenir la façon exacte de rédiger une citation. Les noms de revues scientifiques et autres doivent être rédigés au long et imprimés en italiques. Tous les ouvrages, outils d'essais et d'évaluation ainsi que les normes (ANSI et ISO) doivent figurer dans la liste de références. Les références doivent être dactylographiées à double interligne.

participation d'êtres humains ou d'animaux doit faire état d'un agrément déontologique approprié. Dans les cas où des êtres humains ou des animaux ont servi à des fins de recherche, on doit joindre une attestation indiquant que la recherche a été approuvée par un comité d'examen reconnu ou par tout autre organisme d'évaluation déontologique, comportant le nom et l'affiliation de l'éthique de recherche ainsi que le numéro de l'approbation. Le processus d'examen ne sera pas amorcé avant que cette information ne soit formellement fournie au rédacteur en chef.

Tout comme pour la recherche effectuée avec la participation d'êtres humains, la RCOA exige que toute recherche effectuée avec des animaux soit accompagnée d'une attestation à l'effet que cette recherche a été évaluée et approuvée par les autorités déontologiques compétentes. Cela comporte le nom et l'affiliation de l'organisme d'évaluation de l'éthique en recherche ainsi que le numéro de l'approbation correspondante. On exige également une attestation à l'effet que tous les animaux de recherche ont été utilisés et soignés d'une manière reconnue et éthique. Le processus d'examen ne sera pas amorcé avant que cette information ne soit formellement fournie au rédacteur en chef.





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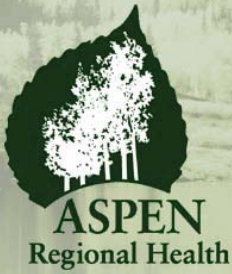
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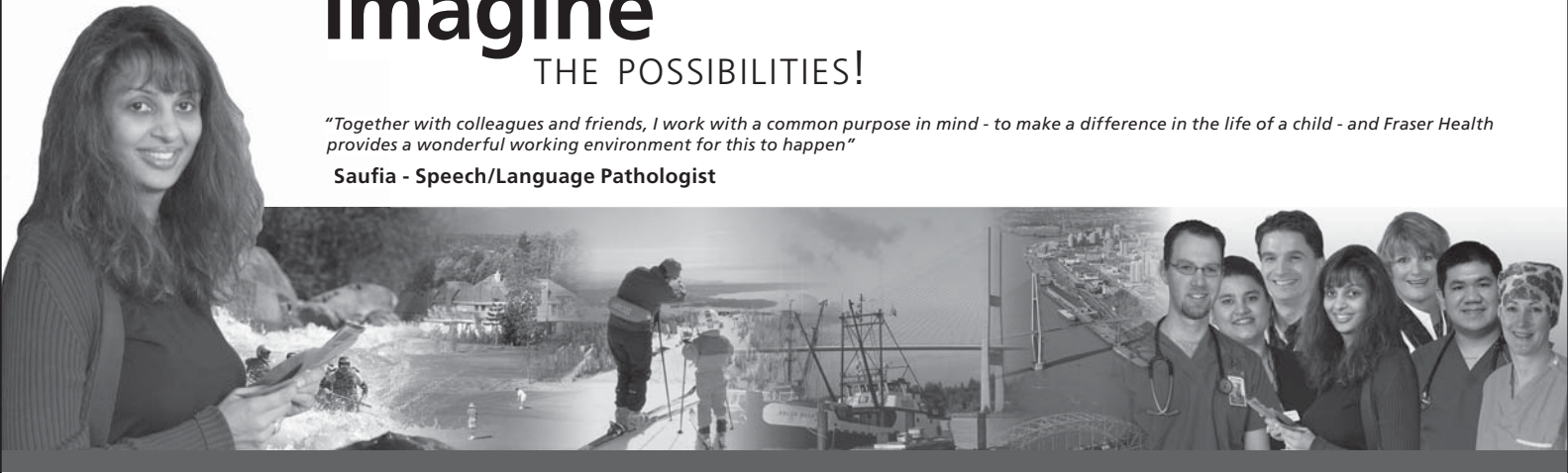
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