

Einer Boberg's Contribution to the Self-Help Movement

La contribution d'Einer Boberg au mouvement d'entraide

by • par

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ABSTRACT

Einer Boberg developed a stuttering treatment program based on continuous improvement of the program's features and scientifically rigorous, data-based research into treatment outcomes. In addition, he made significant contributions to the self-help movement. By establishing contacts among Canadian self-help groups during the organizing of the first Canadian conference for people who stutter staged in Banff, Alberta in 1991, Einer Boberg played a key role in the development of the Canadian Association for People Who Stutter. As the first president of the International Fluency Association, he actively encouraged Canadians who stutter to play leadership roles in the development of international networks bringing together self-help groups, researchers, and clinicians. This article addresses the role of self-help groups for people who stutter and the relationship between self-help groups and speech-language pathologists.

ABRÉGÉ

Einer Boberg a produit un programme de traitement du bégaiement fondé sur l'amélioration constante de ses attributs ainsi que sur une recherche scientifiquement rigoureuse et riche en données sur les résultats du traitement. En outre, il a apporté d'importantes contributions au mouvement d'entraide. En établissant des contacts auprès de groupes d'entraide canadiens au cours de l'organisation de la première conférence pour personnes qui bégaiant, tenue à Banff (Alberta) en 1991, Einer Boberg a joué un rôle clé dans la mise sur pied de l'Association des bégues du Canada. À titre de premier président de l'*International Fluency Association*, il encouragea activement les bégues canadiens à jouer des rôles clés dans le développement de réseaux réunissant groupes d'entraide, chercheurs et cliniciens. Cet article se penche également sur le rôle des groupes d'entraide vis-à-vis des bégues et sur les rapports entre les groupes d'entraide et les orthophonistes.

KEY WORDS: stuttering • intensive therapy • therapy outcome • self-help groups

I first met Einer Boberg in July 1987 when I participated in a three-week intensive stuttering treatment program at the Institute for Stuttering Treatment and Research (ISTAR). To illustrate his contributions to treatment and to worldwide self-help networks for people who stutter, I will share my personal journey in dealing with stuttering and my involvement with the self-help movement.

Treatment

The Comprehensive Stuttering Program (CSP), developed and updated by Einer Boberg and Deborah Kully (1985, 1995) and Kully and Langevin (in press), integrates fluency-shaping techniques with cognitive-behavioural strategies to modify attitudes and reduce avoidances. In my experience, it is helpful to define clearly what is meant by fluency skills or fluency shaping as a treatment component. Some fluency-shaping programs produce a relatively natural sounding speech pattern by teaching clients to prolong syllables differentially while others may produce unnatural prosody by teaching clients to prolong each syllable for the same length of time. Although many have discussed the unnaturalness of some posttreatment speech pat-

terns (Franken, Boves, Peters, & Webster, 1995; Franken, Konst, Boves, & Rietveld, 1995; Franken, Peters, & Tettero, 1989; Kalinowski, Noble, Armson, & Stuart, 1994; Martin, Haroldson, & Triden, 1984), my posttreatment speech sounded relatively natural from the outset. In the CSP, speech rate management is achieved through differential prolongation of syllables. I learned to prolong stressed syllables slightly longer than unstressed syllables, while maintaining natural pitch, loudness, and intonation. These features of the CSP promote a natural sounding speech pattern.

Other fluency skills addressed breathing for speech, voice initiation, blending of syllables, and alteration of articulatory processes to reduce tension. In a process akin to learning a second language, I learned to approach speech as the linking of syllables within breath groups. Each time I spoke a phrase, I would link syllables together as if they formed one long word.

The cognitive-behavioural strategies taught in the CSP deal with acceptance of stuttering, openness about being a person who stutters, avoidance reduction, and alteration of self-talk related to speaking situations (Webster & Poulos, 1997). Altering self-talk involves systematically substituting what cog-



nitive therapists have termed "alternative thoughts" in place of "automatic negative thoughts." For example, if I had a recurring negative thought about an upcoming speaking situation, I would take an index card and draw a line down the middle of it. On one side, I would write the automatic negative thought — which might be: "I'm really worried that I won't do well in this upcoming presentation." Then on the other side of the line I would write an alternative positive thought such as: "This upcoming presentation offers me a wonderful opportunity to see how close I can get to speaking at 210 syllables per minute." In time I learned to alter self-talk without first writing down the two competing thoughts. Altering self-talk has been a central feature of my transfer and maintenance program.

Transfer is the application of fluency skills in situations where environmental cues have, through past experiences, become associated with stuttering. Maintenance refers to the process of consistently applying fluency skills in everyday speaking situations after acquisition in a clinical setting. Throughout his career, Einer Boberg had a strong interest in issues related to transfer and maintenance of fluency (Boberg, 1981, 1983, 1986; Boberg, Howie, & Woods, 1979; Boberg & Kully, 1989; Boberg & Sawyer, 1977), stemming in part from his personal experiences with relapse after treatment. Having also experienced a relapse after treatment elsewhere a decade earlier, I was aware that transfer and maintenance of fluency skills would not be an automatic process (Pill, 1988). In my experience, a structured transfer and maintenance program is essential for long-term maintenance.

Upon returning to Toronto from ISTAR, I spoke in many settings that I had previously avoided. I was comfortable with the fact that at first, my level of physical tension in these situations might be high enough to occasion some dysfluencies. Dysfluencies did occur, but on such occasions I would congratulate myself for having entered into previously avoided situations. On subsequent occasions, I found the going easier. I was consistently aware of Boberg's comment that avoidance, rather than overt stuttering, is the most salient feature of stuttering. My transfer experiences are similar to those described by Tunbridge (1994) and Klassen (1995), who have successfully applied fluency skills in everyday situations.

It has been suggested that it is difficult or impossible to transfer fluency skills from a clinical setting to previous difficult speech situations because of a need to concentrate on the process of speech production (Perkins, 1992; Starkweather & Givens-Ackerman, 1997). I initially addressed this issue by consciously keeping the information content of my messages simple and undemanding during the first year after treatment. This was a strategy I developed on my own, after attending ISTAR.

In the CSP approach to maintenance, a transfer is not complete until it has been analyzed. During the first four years and

four months after my time at the clinic, from July 1987 until December 1991, I regularly and consistently tape-recorded and analyzed transfers. As well, I regularly analyzed unrecorded transfers during this period. When analyzing transfers, I used a structured format to evaluate application of the fluency skills. In addition to continuing to carry out transfers, my maintenance activities also included focused speech practice and awareness and alteration of self-talk. In the years following my treatment program, I practised different speaking rates daily, graphed actual rates achieved weekly, and practised specific skills.

By applying the skills and strategies learned at ISTAR, I have maintained ongoing control of my stuttering for over 11 years. Using a scientifically rigorous, data-based approach, Einer Boberg and his colleagues (Boberg & Kully, 1994; Langevin & Boberg, 1991) collected treatment outcome data indicating that about 70% of clients maintained satisfactory levels of fluency based on stringent criteria and 80% reported satisfactory levels of fluency up to two years after therapy. Maintenance and treatment outcomes continue to command strong interest among researchers (Craig, 1998).

My experiences with maintenance motivated my initial involvement with the self-help movement. A year after attending ISTAR, I became aware that I would need help in adjusting to the fact that I could now consistently engage in fluent presentations to large audiences. This motivated me to start a self-help group where I could compare notes with other individuals who stutter. In September 1988 I formed the Stuttering Association of Toronto. This group works closely with clinicians but is independent of them, offering an impartial forum for exchange of information about stuttering. While we run the group without direct input from speech professionals, we welcome speech-language pathologists who want to attend meetings as observers, or wish to collaborate with members in organizing the group's optional speech-skills practice sessions. Within a year, the Toronto group enabled me to adjust to the markedly enhanced fluency I was experiencing after having stuttered severely for almost 40 years.

Self-Help Networks for People Who Stutter

In discussing self-help groups, it will be useful to establish clarity about the characteristics of such groups. The following definition concerns self-help groups of all kinds, not solely those that address stuttering. The definition is adapted from ones offered by the American Self-Help Clearinghouse and by Self Help Nottingham, both of which have Web sites. A self-help group consists of people who have personal experience of a similar problem or life situation. Four things make them what they are. First, they involve mutual help. They involve people helping one another and helping themselves in the process. Secondly, their members typically run the groups. If profes-



sionals are involved, they serve in supplemental roles. Third, they are composed of peers. Fourth, they are voluntary non-profit organizations.

Einer Boberg encouraged, supported, and made significant contributions to the self-help movement. He understood the importance of establishing networks of self-help groups and was instrumental in fostering contacts between the Stuttering Association of Toronto and the Alberta Stuttering Association which led to the first national conference for Canadians who stutter, staged in Banff, Alberta in August 1991. This successful conference led to the founding of the Canadian Association for People Who Stutter (CAPS), a national network of individuals and autonomous Canadian self-help groups. CAPS cooperates and collaborates with speech professionals but is independent of them.

Since its inception, CAPS has hosted three equally successful national conferences — CAPS 93 in Ottawa, CAPS 95 in Toronto, and CAPS 97 in Vancouver — and will cohost with the *Association des bègues du Québec* the next conference, to be staged in Montreal on August 19 to 21, 1999. In addition to strengthening ties between CAPS and the *Association des bègues du Québec*, this conference will also strengthen links with the *Association des jeunes bègues du Québec*, and the *Association des jeunes bègues du Nouveau-Brunswick*. Each conference strengthens the network. For example, the award winning Web site at caps.webcon.net was one of several significant outcomes of CAPS 95. Speech-language pathologists have used this site to educate school teachers about stuttering. CAPS 97 resulted in enhanced communication between CAPS and the regional British Columbia Association of People Who Stutter.

CAPS has also assisted in forming new self-help groups in Sudbury and Kapuskasing, Ontario. Other regional autonomous self-help groups (not all directly associated with CAPS) exist in Halifax, London, Belleville, Toronto, Ottawa, Hamilton, Montreal, Calgary, Winnipeg, Yellowknife, Vancouver, Victoria, and several other locations. Many groups are open to anyone who wants to join. Others are restricted to graduates of specific treatment programs. Some had restrictions early on, but subsequently evolved to attract a wider membership (Jezer, 1997).

CAPS was also involved in organizing presentations on self-help themes at the International Fluency Association First World Congress on Fluency Disorders in Munich in 1994 (Starkweather & Peters, 1995) and the Second World Congress on Fluency Disorders in San Francisco in 1997 (Healey & Peters, 1998). The Stuttering Home Page, accessible from the CAPS Web site, features papers from the 1997 World Congress in San Francisco and from the first International Stuttering Awareness Day Online Conference. The next World Congress will be held in Copenhagen in 2000 and the next International Stuttering Association World Congress will be in Belgium in 2001.

CAPS is built upon the volunteer efforts of many individuals who have played key leadership roles (many of whom are ISTAR graduates) and those who have provided support in other ways. CAPS has also benefited from sizeable grants from many sources, including the Harmonize for Speech Fund of the Ontario District Association of Chapters of the Society for the Preservation and Encouragement of Barbershop Quartet Singing in America.

In his role as first president of the International Fluency Association (IFA), which brings together speech professionals, researchers, and people who stutter, Einer Boberg actively encouraged CAPS members to play leadership roles in the development of international networks. In 1995, CAPS leaders assisted in the founding of the International Stuttering Association — a network of 35 national self-help associations for people who stutter. IFA and the International Stuttering Association collaborate with each other and with the European League of Stuttering Associations — a network of 15 European self-help associations which in 1998 organized a seminar in Dublin on schoolchildren who stutter (Heite, Griffin, Farr, & Schäfers, 1998). Recent collaborations resulted in designation of October 22 as International Stuttering Awareness Day and deliberations are also under way to announce an International Year of the Child Who Stutters.

Self-Help Groups and Speech Professionals

When discussing self-help groups specifically for people who stutter, it is again useful to define terms clearly. Pill (1995) suggested that a group, whether called a self-help group, maintenance group, or therapy group, be defined by specifying whether the group is run by members or by a speech professional. A group can be either client-driven or clinician-driven depending on who runs it, and depending on the role that person plays. It is also useful to speak of a continuum. At one end of the continuum are self-help groups that are heavily influenced by speech professionals. At the other end are groups that explicitly exclude clinicians. Most groups are somewhere in the middle.

Extensive research has been conducted on self-help groups for many conditions. Web sites for the National Self-Help Clearinghouse and the Mental Health Net offer overviews of research issues related to self-help topics, including selection of subjects, and design of studies collaboratively conducted by self-help members and professionals. Rather than contacting groups solely for the purpose of data gathering, researchers can assist self-help groups by sharing results once data is analyzed. CAPS members frequently receive and respond to requests for assistance in finding participants for research projects. But to date CAPS has infrequently received copies of final project or thesis reports. The results of such research are indeed of interest to us.



Collaboration between speech-language pathologists and self-help groups has been the topic of a number of panel discussions around the world. One was at the IFA's World Congress in Munich in 1994 (Pill & St. Louis, 1995). A similar panel discussion was presented at the Canadian Association of Speech-Language Pathologists and Audiologists conference in Halifax in 1998 (Armson et al., 1998). In Munich, Einer Boberg proposed that self-help can, if one wishes, be viewed as an extension of professional therapy because it provides extra opportunities to practise fluency skills and attitudes learned in therapy. As well, it affords the opportunity to meet new people with different views of the world and different experiences and successes in dealing with stuttering. Participating in a self-help group can keep the momentum of therapy going and can lead to all kinds of new experiences. Boberg also noted that change takes time; and changes that begin in therapy need to proceed with the best vehicle being a self-help group (Pill & St. Louis, 1995). In Halifax, Joy Armson (Armson, Pill, & Oliver, 1998) suggested that self-help groups are essential to the therapeutic process. She recommended that clinicians play a consultative role, providing helpful input without being intrusive. Similarly, Gregory (1997) has recommended that speech professionals relate as consultants to the self-help movement for people who stutter. Luteran (1996) has offered a useful overview of the role of clinicians working with clinician-driven groups for conditions other than stuttering.

How does one go about initiating and running a self-help group? Suggestions are available from the National Stuttering Project and the British Stammering Association, which have links from the CAPS Web site. The CAPS site also offers suggestions. One rule of thumb (applicable to self-help groups of all kinds) is that on average about one-third of total membership will attend a typical meeting. A key recommendation is that members should have a strong sense of ownership of the group, with speaking time shared about equally at meetings, and with each member (who wants to) leading two or three meetings in a row.

Einer Boberg occasionally spoke about membership qualifications for self-help groups. He argued that groups should welcome all people who stutter, including the 20% of clients who do not achieve lasting gains from even the best treatment programs. He believed that neuropsychological functioning — how a person's brain is wired for speech production (Boberg & Kully, 1994; De Nil, in press; Webster, 1997) — may be a factor. It was not a matter, he argued, of a person "not trying hard enough" to maintain fluency skills. CAPS supports the position that all individuals who stutter, regardless of level of fluency, are equally welcome in self-help groups as members and leaders.

Many Canadians worked with Einer Boberg in setting the stage for development of worldwide networks of clinicians,

researchers, and self-help groups. Many individuals around the world continue to be inspired by the vision, integrity, and commitment to renewal and change that were characteristic of Einer's career as a speech-language pathologist and researcher. It is highly significant that the Comprehensive Stuttering Program that Einer Boberg and Deborah Kully (1985) developed has been consistently updated (Boberg & Kully, 1995; Kully & Langevin, in press) in response to client feedback, clinical experience, and worldwide research.

Not all stuttering treatment programs that one may encounter — as a speech-language pathology student seeking training in clinical skills, as a researcher seeking subjects, as an official involved with funding of programs, or as a consumer of treatment services — share this labour-intensive, time-intensive, and results-oriented approach to program development. The strategy of constant improvement is the most powerful concept that I learned from Einer Boberg. Whenever I encounter growth and renewal of any kind, I see a reflection of the inspiring and empowering qualities and strategies that he shared with a worldwide network of people and groups in the course of a lifetime.

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