A Sociological Analysis of Stuttering: From Clinical Conceptions to Self-Help/Mutual Aid/Advocacy

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With the exception of sporadic and disconnected writings (Lemert, 1951, 1970; Petrunik, 1982, 1983, 1988, 2000; Klassen, 1995) stuttering has not been systematically or extensively examined from a sociological perspective. In this paper, we use a sociological (symbolic interactionist/social constructionist) perspective to analyze the development of the stuttering self-help/mutual aid/advocacy movement that persons who stutter have developed to deal with the problems they experience in everyday life. In particular, we study the differences in the perspectives on deviance and social problems of professional experts and those experiencing a condition (Scott, 1970; Gusfield 1996; Loseke, 1999; Fox, 2002). By comparing the conceptions of stuttering and persons who stutter and approaches to stuttering management in the two approaches, we aim not only to present fresh insights to professionals working with fluency disorders, but also, by looking at a phenomenon that has been largely ignored by sociologists, to make a contribution to the study of deviance and social problems.

The data for the paper consist of a review of published materials on major clinical (professional) approaches to stuttering (non-avoidance and controlled fluency) and documents produced by a variety of self-help organizations. In addition, interviews were conducted with key individuals representing both the clinical and self-help perspectives, including speech therapists and leaders of self-help groups. Finally, participant observation data on both professional and self-help/mutual aid/ advocacy approaches is employed. As professional sociologists, we incorporate experiential knowledge as persons who stutter, consumers of the services of professional experts, and members of various local, national and international self-help/mutual aid advocacy approaches to the management of stuttering (Klassen, 2001; Petrunik, 1982, 1983, 1988, 2000). In examining self-help organizations, we pay particular attention to newsletters published by self-help/mutual aid/advocacy organizations including the Council of Adult Stutterers, the National Stuttering Association, Speak Easy and the Canadian Association of People Who Stutter.

The Social Construction of Stuttering: From Clinical Model to Self-help/Mutual Aid/Advocacy

Stuttering is a curious phenomenon of speech characterized by involuntary disruptions of the spoken word in the form of blocks, repetitions or prolongations. These disruptions are shaped significantly by the individual’s anticipation that such disruptions are likely or certain to occur and by his/her efforts to prevent, mask, or strategically avoid them. The awareness of the individual of his/her own stuttering behaviour and how he/she reacts to the experience of stuttering are major features of the phenomenon and the particular form that it takes.

Sociologically, stuttering is a form of deviance from situational and cultural norms that define appropriate ways of speaking. Although people who stutter are committed to maintaining the flow of communication, and understand the social norms, they often deviate dramatically in a non-intentional and self-aware manner from the norms (Klassen, 2002; Petrunik, 1982, 1983, 1988). Such deviance is defined by lay people in terms of folk or common-sense categories or by professionals in terms of categories that are part of the diagnostic systems used by disciplines such as speech pathology or psychiatry (Petrunik, 2000:477).

Stuttering has been constructed by professionals as a form of pathology or disorder and is considered an impediment or disability because it impedes communication in general and the ability to effectively play various occupational and social roles where oral communication is important. Unlike many phenomena considered as disorders and/or disabilities, however, stuttering has received relatively little attention from practitioners of medicine, whether physical or psychiatric. Folk remedies have abounded and some non-medical experts (notably teachers of elocution and those who have "cured" their own stuttering) have claimed to be able to provide appropriate interventions.

Clinically, stuttering became the object of a special non-medical profession, speech pathology during the early to middle decades of the 20th century, grouped with other speech and language disorders. Some of these disorders, like stuttering, are largely developmental while others, like aphasia, usually the result of damage to the brain or speech mechanism (Wingate, 1977). As a paramedical discipline, speech pathologists have generally conceived of stuttering in terms of a medical or clinical model. Thus, stuttering is assumed to be "a chronic disease that the person who stutters must learn to deal with effectively and responsibly" typically via treatment provided by a certified speech therapist (American Speech and Hearing Association, 1993).

One version of this model views stuttering as primarily an objective deficit (a pathology of one or more systems of the human organism that results in mechanical failure in speech). In this model, all psychological features and many behavioural features are secondary, in other words adaptive responses to the primary objective pathology. The other version of this model views the very existence of a primary objective deficit as either questionable or of lesser importance than psychological or behavioral factors shaped by socio-cultural and situational expectations. Interventions arising from those two major models have varied in terms of their emphasis on pharmacological or mechanical interventions, individual or group psychotherapy, and behavior modification regimes. With regard to the latter, one of the most influential types of approach (Webster, 1982; Boberg, 1981; Boberg and Kully, 1985) has been behavioural self-management therapy. This involves the "over-learning" of behavioral speech targets in a clinical setting, transfer of these behaviors to other settings, the use of positive self-talk strategies, and an emphasis on relapse prevention (the identification of sequences of thoughts, feelings and behaviours that can lead to a breakdown and a heightened focus on speech targets).

An interesting phenomenon in the development of twentieth century theory, research and practice with regard to stuttering has been the influential role of persons who stutter. Among the most prominent are C.S. Bluemel, the originator of the distinction between primary and secondary stuttering (1932), Wendell Johnson (1944), Charles Van Riper (1937, 1939), Joseph Sheehan (1970), Oliver Bloodstein (1993), Barry Guitar (1998) and Einer Boberg (Boberg, 1981; Boberg and Kully, 1985).

Significantly, some therapists and researchers who stutter played a major role in the development of a societal reaction/labeling conception of deviance that conceptualized stuttering as largely a problem of secondary deviance. Secondary deviance is an adaptation to the experience, and recognition of stuttering that exacerbates whatever primary problems exist and results in a host of secondary problems of stigmatized identity and limitations on one's lifestyle, socio-economic opportunities, and relationships (Petrunik, 2000).

The roots of labeling theory, also known as the societal reaction perspective, lie in the symbolic interactionist social psychology of G.H. Mead (1932), C.H. Cooley (1902), Herbert Blumer and Alfred Lindesmith, in Harold Garfinkel's ethnomethodology, and in the writings of Edwin M. Lemert. Other important contributions were made by Howard Becker, John Kitsuse, and Erving Goffman (Petrunik, 1980; Rubington and Weinberg, 2002).

Labeling / societal reaction theory focussed attention on the processes by which individuals become defined as deviant, the nature of that definition, and both society's and the deviant's response to that definition (Schur, 1971). The labeling/societal reaction perspective toward deviance became in the 1960's a major alternative way of conceptualizing a variety of phenomena previously grouped under various clinical models. These phenomena included mental disorder, alcoholism and drug addiction, homosexuality, and physical and mental disability (Gove, 1975; Petrunik, 1980).

Another influential perspective, built partially on labeling theory, was the social constructionist theory of social problems (Spector and Kitsuse, 1977; Loseke, 1999). Of key importance now, for both labeling theory and social constructionism, was not the putative objective condition but rather how that "condition" was constructed or typified whether in terms of folk categories by laypersons or in the specialized clinical discourse of various professional experts. The proponents of the labeling/social constructionist paradigm began to focus less on whatever inherent limitations might be posed by a particular condition than on negative definitions of that condition (the phenomenon of stigma) which had to be managed individually and collectively in everyday life.

Labeling theory, and the larger social model of disability that derived from it, focused explicitly on socio-cultural rather than biological factors in understanding disability (Oliver, 1990; Shakespeare, 1998). Part of the critique that emerged out of this body of work was a scrutiny of the role of various professional experts in the construction and maintenance of stigmatizing definitions. The notion that one suffered from a disorder that required diagnosis and treatment by professional experts came to be seen as placing limits on the capacity of persons with various life problems to interpret their own experience and develop their own individual and collective remedies. There have been three major challenges to clinical dominance: the alcoholics anonymous movement, the civil rights movement, and the consumers rights movement (Sagarin, 1969, 1971; Oka and Borkman, 2000).

An early pioneer in the challenge of the dominance of professional experts in dealing with deviance was Alcoholics Anonymous (AA) which began in 1935 out of the recognition that medicine was unable to solve the puzzle of a treatment for the disease entity of alcoholism that it had created. AA stressed that while alcoholism was at its roots a medical disorder, it could not be effectively managed through medicine alone. In one part, this was because medical experts not themselves afflicted lacked the requisite experiential knowledge to do so and in another part this was because collective as well as individual effort was required.

A solution to the management of alcoholism was seen to lie in a community of peers who would create an association of mutual aid in which those involved would simultaneously help others and themselves. A key element of the solution was embracing the identity of alcoholic. Saying "I am John Doe and I am an alcoholic" was seen to be the first step in breaking a self-defeating cycle and requiring a positive self conception and positive relationships with others. The success of the Alcoholics Anonymous model was replicated in the emergence of parallel organizations dealing with the problems of chronic drug abusers, compulsive gamblers, mentally ill and physically disabled persons and homosexuals (Sagarin, 1969, 1971; Oka and Borkman, 2003).

A second turning point in the challenge of the dominance of clinical professionals and the emergence of the self-help/mutual aid/advocacy movements for deviant persons was the notion of "minority group" and the emergence of a minorities civil rights movement that challenged stigmatizing definitions of race, ethnicity, sexual orientation and other putatively objective conditions and the limitations on opportunities and freedoms placed by these definitions. A key element of this movement was the development of slogans that announced pride in identities (race, sexual orientation) that were heretofore defined as undesirable.

By saying, individually and collectively "I am Black or Gay and I am proud" one announces that one is a member of community that gives positive meaning to one's life and is the basis for a host of positive relationships. The minority group notion and the related focus on rights and freedoms, based both in natural justice and state-made constitutions and charters or bills of rights, came to be used by a variety of organizations including those representing persons considered to have various disorders or disabilities (Fine and Asch, 1988; Hahn, 1994; Gordon and Rosenblum, 2001; Donoghue, 2003).

A third turning point was the rise of consumers' rights organizations representing persons who were the recipients of various kinds of professional services. Such organizations demanded the right to have a say in the kinds of services offered to them and provided critiques of both professional treatment and the state's failure to provide adequate services. Organizations of psychiatric consumers/survivors pioneered this approach but it soon came to taken up by organizations representing persons with a broad range of disabilities and disorders. Governments, aware that self/mutual aid/advocacy groups might reduce the costs of state-financed social and health care services, provided incentives, including tax-exempt status and tax-deductible donations for the emerging groups and other resources (Gartner and Riessman, 1977; Hill, 1984; Romeder, 1982; Lavoie, Borman and Gidron, 1994).

An interesting analysis of this shift from professional expert models to self-help/mutual aid/advocacy models was provided by the social constructionist and pioneer of labeling theory, John Kitsuse. Building on Lemert's notion of primary and secondary deviance, which Lemert in turn had borrowed from the speech pathologists Bluemel (1932) and Van Riper (1937, 1939), Kitsuse (1980:9) introduced the notion of tertiary deviance to describe "the deviant's confrontation, assessment and rejection of the negative identity imbedded [sic] in secondary deviation, and the transformation of that identity into a positive self-conception." Just as the notion of secondary deviance addressed the issue of how stigmatized identities came to be attached to conceptions of disorder and normative violation, the notion of tertiary deviance showed notions of undesirable difference could be transformed from stigmas to conceptions of alternative but nonetheless acceptable or even desirable modes of being.

There is now a considerable body of literature on minority rights and consumer-based challenges of clinical models of disorder and disability and the emergence of self-help/mutual aid/advocacy organizations. With the exception of Borkman's important but little publicized research by Borkman (1971a, 1971b, 19731974, 1975, 1976a, 1976b, 1999; Borkman and Zapplola, 1972) however, there has been little attention given to the extent to which this shift has taken place with regard to the issue of stuttering.

The literature suggests there have been important differences in the way this shift has taken place with regard to phenomena such as mental disorder, sexual orientation and various types of physical disability (Powell, 1990a; Riessman and Carroll, 1995). Different organizations representing deviants have developed different relationships with the professional institutions that make them the object of intervention and thereby earn a living and build careers and reputations. This relationship (Sagarin, 1971; Lavoie, Borkman and Gidron, 1994; Hahn, 1994; Pill, 1995; Pill and St. Louis, 1995; Gordon and Rosenblum, 2001; Donoghue, 2003) has been complex and diverse. It ranges from radical hostility (some organizations representing gays and lesbians and psychiatric survivors) to working relationships built on various degrees of mutual cooperation and understanding (some of the organizations representing persons with chronic physical or mental illness or disability).

In the following section, we present an exploratory case study of the rise of self-help/mutual aid/advocacy organizations working with persons who stutter. While the movement that has taken place is an international one our focus will primarily be on developments in the United States and Canada.

The Rise of the Self-Help/Mutual Aid Advocacy Movement for Persons who Stutter

A self-help/mutual aid/advocacy movement was slower to develop for stutterers than for other categories of persons defined as deviant. In his classic 1951 text, *Social Pathology*, the godfather of labeling theory, Edwin Lemert, declared that self-help/mutual aid/advocacy groups for stutterers did not exist. He argued that the few efforts to form such groups were unsuccessful because of the fundamental concern of stutterers to avoid situations where they might be compelled to speak. Lemert went on to explain that:

> …there is not any indication of social organizations among stutterers. As far is known, stutterers outside of clinics do not seek out one another's company nor do they form groups among themselves. In fact, the effort of one speech correctionist, known to the author, to organize a community group of stutterers failed conspicuously. It is not surprising that stutterers have no special group life when it is remembered that communication is the medium of culture and the requisite for social organization. The social situation is the nemesis of the stutterer, hence he tends to avoid it whenever he can, unless he can enter into it as a nonverbal participant (Lemert, 1951:151-153).

Two decades later, Lemert reiterated that "stutterers - unlike the blind, the deaf, the physically handicapped, narcotics addicts, criminals, and other deviants - do not form a group of their own nor do they develop a subculture. Furthermore, they neither organize nor support therapy groups comparable to Alcoholics Anonymous" (1970: 181-182). The view of most of the professional community was "that stutterers were not good prospects for self-help organizations. Fearful of speech and reluctant participants in situations, stutterers (so it was thought) would be unwilling to join groups devoted to exploring a disability that profoundly shamed them" (Jezer, 1997:233-234).

Lemert's initial statement that stutterers avoided banding together, while not absolutely true, did reflect to a considerable degree the reality of the 1950's where the few groups that emerged struggled to survive. By 1970 when Lemert reiterated his claim, however, a viable self-help/mutual aid/advocacy movement for people who stuttered had clearly emerged. In research in the early 1970's, Borkman identified the existence of 18 groups - both active and disbanded - in North America, South America, Europe and New Zealand. Using the response of the majority of the members of each group as the group response, she surveyed sixteen groups to find out their major characteristics and the factors related to their survival or demise. Of the ten surviving groups, six had survived five years or more. The oldest and largest of the six (a group in Sweden) was founded in 1952 and had 400 members at the time of the survey (Borkman, 1974).

Borkman's profile of active and disbanded groups showed that active groups tended more than disbanded groups to be larger in size, to have a formal structure (constitutions, elected officers, dues, newsletters), to have an affiliation with a speech clinic, to place a high value on educating the public about stuttering, and to have 10% or more of their membership consisting of speech therapists. Active groups were less likely than disbanded groups to state that fluency was an important group goal (Borkman, 1971a, 1971b, 1973, 1974, 1975, 1976a, 1976b; Borkman and Zappola, 1972).

In the sections that follow, our aim is to compare different generations of self-help/mutual aid/advocacy groups for stutterers, to identify their conceptions of stuttering, persons who stutter and desirable adaptations to stuttering, to examine their relationships to professional experts working with stuttering, to assess their relative emphasis on self-help, mutual aid and advocacy, and in recent years to examine the role of global communications technology such as the Internet.

The Council of Adult Stutterers

The Council of Adult Stutterers, founded in 1966 by non-stuttering Catholic University of America speech therapist Eugene Walle and two of his stuttering clients, can be considered a first generation self-help/mutual aid/advocacy group for stutterers. Walle was influenced primarily by the non-avoidance approach of therapists who stuttered such as Johnson, Van Riper and Sheehan. He took seriously the advice of Joseph Sheehan who had cautioned against members meeting socially on the basis that members of a clinic-based group he had founded in the 1950's had retreated into a self-commiserating network that did not take the opportunities to work on their deep-seated patterns of avoidance and their reluctance to accept themselves as stutterers (Borkman, 1999:97). What began as a small self-help group in the Washington D.C. area became, over the next few decades before its virtual demise in the 1980's, a national organization with several member groups across the United States

The Council's mandate was to simultaneously practice non-avoidance principles and to educate stutterers and the general public about stuttering. An important notion was to accept oneself as a stutterer and make that identity known to others. Being a stutterer was viewed as a core aspect of self that one could not realistically expect to change. One had the choice however of one would stutter and how one would identify oneself. By stuttering openly without attempts to hide or avoid, many of the secondary problems of stuttering would diminish and there might, but only as a by-product, even be increased fluency. If anything, fluency for a person who stuttered was viewed as a negative that might lead him to the futile pursuit of something he could never hope to sustain.

Membership in the Council was based on being affiliated with a member group. As well as regular meetings where members met in a speaking circle format to discuss their efforts to stutter openly without avoidance, groups affiliated with the Council encouraged members to give public lectures to service groups and even produced a series of films and television programs. The Council published a journal, *The Journal of the Council of Adult Stutterers*, which promulgated communication practices based on a non-avoidance philosophy as the preferred form of adaptation to stuttering and dismissed any efforts that involved trying to speak fluently as a form of quackery (Emerick, 1972). An important feature of the journal was the telling of inspirational stories of individuals, such as those below, who did not let stuttering stand in the way of them leading successful lives. For example:

> Mary Licari's…offering was brief and moving, somehow evolving from an almost mute stutterer to the eloquent, self-accepting person she has become. Mary told us that despite her stuttering she has been a den mother for the Cub Scouts, Girl Scout leader, she has published articles, she worked her way through college, and helped to put two bills through Congress and has a letter hanging from her wall from President Eisenhower as proof (*Journal of the Council for Adult Stutterers*, 1970:3).

And:

> Frank began with many hard blocks such as characterize all of us in particularly [sic] crisis situations ; within half an hour though, he had established sufficient rapport with the audience of speech and hearing therapists that the hard blocks altogether vanished leaving only the 'true stuttering' we wished we had all the time (*Journal of the Council for Adult Stutterers*, 1973:8).

Statements expressing the non-avoidance ideology abound on the pages of the journal, and the open avowal of stuttering and the use of voluntary stuttering are continually stressed.

By the 1980's, the original Washington group began to disintegrate although the Council retained a focus on advocacy at the national level (Borkman, 1999). Several factors were at play in its demise. First, the non-avoidance philosophy of stuttering management (always a difficult one to accept and incorporate into everyday life) had lost its dominance in speech pathology as its foremost proponents Johnson, Sheehan and Van Riper retired or died.

Second, was the emergence of a new generation of fluency shaping approaches to therapy, most notably the Hollins Precision Fluency Shaping Program operating out of Roanoke, Virginia. Several members of the original Washington D.C. group took the Hollins Program and split off to form a separate group dedicated to maintaining the skills they had learned (Borkman, 1999). Although maintenance of fluency after therapy continued to be a crucial issue, the gains in fluency gained in the program were sufficient to convince many stutterers that controlled fluency was not the impossible dream that Sheehan and Van Riper considered it to be.

Third, two new stuttering organizations emerged: Speak Easy, a federation of groups in the eastern United States and the National Stuttering Project (NSP), an organization with individual as opposed to group memberships, on the west coast. The emphasis on individual memberships rather than a federation of groups proved more viable and the NSP, following the success of several national conferences, soon became the dominant self-help/mutual aid/advocacy group for stutterers in the United States. By the end of the 1980s, with it becoming increasingly clear that the National Council of Adult Stutterers was going to continue to decline and that the NSP was on the rise, the NSP became the single national stuttering organization in the United States.

The National Stuttering Project/National Stuttering Association

The National Stuttering Project (NSP), which emerged in the 1970's, can be considered a second generation self-help/mutual aid/advocacy organization that initially took a more radical approach than the two east coast-based organizations, the National Council of Adult Stutterers and Speak Easy. Neither of the NSP's co-founders, Bob Goldman and Michael Sugarman, were speech therapists and neither was closely aligned to a particular school of stuttering therapy in the way the National Council reflected the non-avoidance approach.

As a student of sociology at the University of California, Santa Barbara, Sugarman was very much influenced by the ideas of labeling theory, particularly the notion that the responses of professional experts to deviance could have deleterious effects. Goldman who had experienced severe bullying and teasing because of his stuttering, sought to both challenge negative stereotypes and develop positive self-images. One of his early campaigns which succeeded in getting the NSP national media attention was a campaign against the mocking of stuttering he claimed was portrayed by the popular cartoon character, Porky Pig. As a car salesman, Goldman was also notorious for handing out business cards to potential customers identifying himself as "B-b-bob Goldman, the Stuttering Toyota Salesman". In 1979, Sugarman gave a presentation entitled "The Advocacy Movement in Stuttering and the Failure of the Profession" to the annual meetings of the American Speech and Hearing association (ASHA). According to Sugarman, it was the first presentation made to that organization from the perspective of consumers of speech therapy services (Caggiano, 1999).

Unlike the National Council, the NSP did not align itself with a specific therapeutic ideology, whether non-avoidance or one of the contemporary controlled fluency approaches. Its approach to stuttering therapy was to welcome the open expression of ideas about the etiology and treatment of stuttering but to endorse no particular therapy or therapists. The NSP did not favour the essentialist notion of "stutterer" preferring to speak instead about stuttering or disfluency or persons who stuttered. On whether stuttering might be "cured", there was openness to the possibility that this might occur through any one or a combination of methods.

One of the major figures in NSP's development, John Harrison, a San Francisco consultant, told of how he successfully overcame stuttering through over a decade of work using a variety of psycho-spiritual methods. The message was to accept and love oneself, to take on new challenges and to achieve personal growth through individual and collective efforts. The NSP was clearly strongly influenced by the "touchy-feely" emphasis of the personal growth and recovery movements associated with California culture (Harrison, n.d).

The NSP took as its motto, "You Are Not Alone" to encourage persons who stuttered to work together in local support groups which would be chapters of the national organization. According to Sugarman, the NSP was "empowered by individuals in local groups" (Caggiano, 1999:1). The aim of the support groups was to assist individuals to express themselves more comfortably or effectively (whether they stuttered or not) and to grow through acts of service to help others. Chapters working with this philosophy spread across the United States rapidly eclipsing in number groups working under the umbrella of the National Council of Stutterers or Speak Easy.

At the national level, NSP led by its charismatic new Executive director, John Ahlbach, made its mark through annual conventions, several newsletters, the setting up of special committees to advocate on behalf of persons who stuttered, the development of a dialogue with other self-help/mutual aid/advocacy groups for persons who stuttered and with associations of speech therapy professionals, public awareness and education initiatives, and special programs for youth. Reflecting the reality that the organization had become a well–established organization, as opposed to a temporary "project", the NSP formally changed its title from the National Stuttering Project to the National Stuttering Association (National Stuttering Association, 2003).

Since the late 1970's, conventions have been held annually in major cities in different regions of the United States. Each convention is a mixture of presentations by keynote speakers (ranging from distinguished therapists to well-known athletes and media figures who stutter, self-help workshops, social events, and "open mike" sessions where members of the audience are encouraged to speak, no matter how badly they stutter, in a supportive atmosphere. Each convention includes a celebratory dinner, fund-raising auction, and dance and an emotionally charged closing ceremony where members hold hands and sway to the music of an inspirational song. While some critics might view this as an orgy of west -coast emotionalism, the annual convention has had the powerful effect of inspiring people to change their lives. For many individuals across the United States and Canada, the annual convention is the highlight of the year that leaves them with a positive glow that lasts for weeks.

The newsletter, *Letting Go*, is sent to all members of NSP. The newsletter provides information on events sponsored by local chapters, accounts by persons who stutter, occasional comments on approaches to therapy written by professionals and persons who stutter, and letters from readers. In recent years, Letting Go has included a special section entitled Our Voice, written by and for teenagers who stutter. *Stutter Buddies* is a quarterly newsletter written by and for children age seven to 12 who stutter. *Care* is a quarterly newsletter directed at the parents of children who stutter.

The NSP advocacy committee has focused on public education about stuttering and encouraging people who stutter to challenge negative stereotypes about stuttering and to stand up for their rights in the face of discrimination in the workplace and the marketplace. William Parry (1998, 2003), a lawyer and chair of NSP advocacy committee, has lobbied to have stuttering given judicial recognition as a disability under the *Americans with Disabilities Act* of 1990. Individual members of NSP have responded to cases of poor treatment by fast food restaurants by contacting managers and administrators and asking them to include an Awareness of Courtesy Toward Stutterers plan in their employee training programs (Stutelberg, 1996). A great deal of media coverage of NSP was provided by challenges of stereotypes of persons who stutter in popular cultural portrayals. Campaigns against the cartoon character Porky Pig, first by Bob Goldman and later by Ira Zimmerman, and a campaign against the portrayal of stuttering in the film "A Fish Named Wanda" were particularly significant.

As part of it s public and professional outreach, the NSP has participated in training programs for speech pathologists, created brochures, pamphlets, posters and audiovisual materials, held workshops for children and parents, and organized activities with professional associations. The NSP played a key role in establishing an International Year of the Child Who Stutters in 1996 and in organizing workshops for consumers and professionals at the International Fluency Association's world congresses on fluency disorders (Caggiano, 1999, National Stuttering Association, 2003).

As the NSA looks to the future it faces a financial crisis in part engendered by its success in meeting many of its goals of self-help/mutual aid/advocacy. It costs a lot of money to operate a national organization with such broad objectives and diverse initiatives. NSA's biggest challenge now is to the raise the money it needs to survive with its objectives and initiatives intact.

The Canadian Association of People who Stutter (CAPS)

The first Canadian organization to claim that it represented a national organization for persons who stuttered in Canada was *Speak Easy* founded by Michael Hughes and centred in St. John, New Brunswick. Speak Easy was loosely modeled after but not formally affiliated with the organization of that name operating out of New Jersey. With the aid of a grant from the Canadian government, Hughes became an essentially one-man operation publishing a newsletter and holding regular "national" meetings always in St. John. With the rise of the NSP across the United States, there was some thought of further expansion into Canada, but an apparent gentleman's agreement between Hughes, Speak Easy U.S.A., and the NSP executive resulted in a situation where Canadians could be affiliated as individuals with the NSP, but no NSP chapters would be set up in Canada (Ahlbach, personal communication, 1990).

Like Speak Easy in the United States which was relegated to serving persons who stuttered in the North East United States, Speak Easy Canada primarily drew its members east of Quebec. In Quebec, an organization called ABC (Association des Begues du Canada) was founded by Laurent Bouchard in Montreal to serve French-speaking stutterers primarily in Quebec. With neither Speak Easy nor ABC having the capacity or vision to meet the needs of persons who stuttered across Canada, several leaders in the incipient Canadian self-help/mutual aid advocacy movement in conjunction with several prominent speech therapy professionals met in Edmonton in 1989. One of their accomplishments was the planning of a national conference for persons who stutter in Banff Alberta in 1991. Here, the beginnings of a new Canadian national organization known as CAPS (Canadian Association of People Who Stutter) were sketched out with Jaan Pill, Jim Rowlett, Lyn Kelly, Larry Stone, Michael Niven, Peter Wyant, and Allen

Chapman and Einer Boberg playing key roles. Pill became CAPS' first national coordinator (Pill, 1991).

While the organizers of CAPS were unable to work with Michael Hughes for a variety of reasons and indeed disavowed his type of approach, they were influenced by and had good relationships from the outset with the NSP in the United States. CAPS, nonetheless, developed its own approach to self-help/mutual aid/advocacy for persons who stutter. Unlike the eclectic NSP (with its stance of non-identification with particularly types of therapeutic philosophy), CAPS, particularly at the outset, was more strongly influenced by contemporary comprehensive approaches to controlled fluency, maintenance, and relapse prevention as developed and practised by Einer Boberg and Deborah Kully in Edmonton, Robert Kroll in Toronto, and Marie Poulos, Will Webster and Ann Meltzer in Ottawa.

Of central importance to the Canadian approach was the recognition that controlled fluency approaches, while initially effective in managing stuttering in clinical settings and in the short run, required intensive follow-up maintenance and booster programs to be effective in the long run. The approach that emerged was that professionally assisted self-help/ mutual aid groups that focused on practising and polishing fluency skills in a supportive setting could help stutterers make the transition from the clinic to the wider community. Eventually, as persons who stuttered improved their communication skills and gained confidence, the objectives of public education and advocacy increasingly came to be added into the mix.

The relationship between professional speech pathologists and persons who stutter has been a central issue for CAPS from the outset. Pill, one of the key figures in the Canadian self-help/mutual aid /advocacy movement, and co-founder of CAPS noted that, while the professional treatment he had received had been beneficial in achieving fluent speech, he was motivated to form a self-help group to help himself and others like him to become more comfortable and confident speaking in all kinds of settings, including public forums. He writes that: "I wanted to speak with other people who stutter… because, having received treatment enabling me to make fluent presentations to large groups, I wanted some help in feeling more comfortable about my new level of fluency" (personal communication, July 27, 2003).

For Pill, this objective meant learning from professional speech pathologists but not becoming over-reliant on them. In handwritten notes from a meeting prior to the official launch of CAPS in 1991, Pill recorded that the aim of CAPS is to "work closely, in a cooperative relationship with professionals, but we are independent of them. We have to maintain a clear distinction between…[them and ourselves]…" (Pill, notes, 1991).

Nonetheless, the reliance on therapeutic expertise was initially considerable. At its inception, the leaders of the association were primarily individuals who had received a specific type of therapy: controlled fluency. Indeed, at its inaugural meeting in 1991 considerable discussion on the relationship between self-help group and speech professionals focused on whether self-help groups should even be open to stutterers who had never received formal therapy. Almost inevitably, formal therapy meant the type of controlled fluency programs run in Edmonton by Einer Boberg and Deborah Kully, in Ottawa by Marie Poulos and her successors, and in Toronto by Robert Kroll.

The Association's second conference in 1993 was dedicated to the much-loved Marie Poulos, who had died in an automobile accident in the fall of 1991. Like Einer Boberg in Edmonton, Ms. Poulos was one of a group of influential controlled fluency therapists who stressed the importance of self-help/mutual aid/advocacy groups in helping individuals to maintain fluency learned in the clinic and improve overall communication skillls. CAPs leaders encouraged local groups to use a speech maintenance manual produced by Ms. Poulos and her colleague, Will Webster, a psychologist at Carleton University.

When the CAPS constitution was approved in 1995, it codified that the organization was "committed to working closely with speech professionals and treatment centres, but are independent of them." CAPS took a page from the NSP and formally adopted a non-partisan stance toward professional therapy making it clear that controlled fluency was not necesssarily a goal that individual stutterers should pursue. Here, the leaders of CAPS seemed to move closer to the position put forward in the *Draft Bill of Rights and Responsibilities for Persons Who Stutter* at the 17th NSA convention in Chicago and the third IFA World Congress in Nyborg, Denmark. The Draft Bill called for the right "to choose to participate in therapy… appropriate for one's unique needs, concerns and characteristics" or "to choose not to do so" (Draft Bill of Rights and Responsibilities for Persons Who Stutter, n.d.).

While the emphasis on cooperation between CAPS and the professional speech therapists and clinics influential in its founding has continued over the years, there are some restrictions placed on CAPS membership. Non-stuttering speech-language professionals can only be non-voting members of CAPS and as such do not enjoy the electoral and voting rights and privileges outlined in the CAPS constitution. Consequently, while clinicians and others who do not stutter can join and participate in CAPS in a variety of ways they are not eligible for election to the CAPS Board of Directors.

Therapists and students studying to be therapists frequently attend conferences and have even been on conference planning committees. Also, a column in the association's newsletter is set aside for professionals. At the 2003 conference, the program for children who stutter was developed and largely by speech therapists, rather than by people who stutter. Typically, at the CAPS conference a significant number of attendees are clinicians, and it is not uncommon for professional experts to be keynote speakers or to give workshops at a conference.

In CAPS's 7th national conference in Toronto in August 2003, the independent yet respectful relationship it has developed with professional therapy is clear. The theme of the conference is "Moving Forward with Confidence". The keynote speakers, Rubin "Hurricane" Carter, Richard Inomata, and Deborah Kully reflect its tripartite emphasis on individual perseverance in the face of enduring adversity (Carter), personal growth and community development through self-help/mutual aid/advocacy (Inomata), and the value of the professional expertise of knowledgeable and skilled clinicians and researchers (Kully). Workshops address such topics as what's new in therapy, self-esteem issues, parent information and support, and workplace issues.

Like the NSA, the major challenge of CAPS is likely to be maintaining its viability in the face of the high financial cost of success. As well, the fact that its scope of activities in Quebec and Atlantic Canada is limited is also an issue.

Analysis

The self-help groups that are currently viable are those that are not based on a particular program or clinical approach to the disability, rather those that seek to work with clinicians of all stripes, without taking a position on the effectiveness of a particular therapy. Those groups that have not been able to deal with the transition from a charismatic or authoritarian leader to bureaucratic leadership, or those that continue to be based solely on one therapy have seen less growth, if not decline. The successful groups have used the concept of local groups linked to a central office, while those groups that have died or failed to grow, as would be expected, have remained more centralized.

Both CAPS and NSA have incorporated expertise from professionals into their activities, such as conferences and publications. Indeed, the NSA has worked closely with clinicians on some matters, such as offering training that is credited by the ASHA. The professional community has also used the self-help groups as a means to acquire subjects for experiments and studies. Indeed, the recent scientific studies conducted by the professional community find that self-help groups are an important part of the recovery process for many persons who stutter (Reardon and Reeves, 2002; Yaruss, et al., 2002, Pill and St. Louis, 1995). Of course, a challenge for the groups in the future will be maintain their relationship with the professional community while simultaneously maintaining their distinctive goals of self-help, mutual aid, and advocacy.

The relatively close relationship that has arisen between the self-help groups and the professionals is explained by at least three factors.

First, the lack of success that professionals have had in developing a permanent cure for stuttering, and the continuing problem of maintenance of fluency, leaves open a space for self-help organizations.

Second, the fact that a significant number of influential professionals are themselves people who stutter and share common experiences and concerns with other stutterers has helped make clear to professionals who do not stutter that self-help, mutual aid, and advocacy are important for success beyond the clinic (Pill, 1998).

Third, the leaders of the self-help movement must have a degree of control over their stuttering in order to perform effectively in managing the organization, and interacting with the stakeholders, the media and others. As Pill's story indicates, for many the requisite degree of mastery was at least partly a result of professional therapy. Not surprisingly, as "successful" graduates, these individuals are unlikely to take a radically negative view of the professional community akin to the anti-psychiatric views of psychiatric survivors.

The complementary, rather than a competitive approach being pursued by most stuttering self-help/mutual aid/advocacy organizations (certainly the largest ones) and many in the professional/clinical community is based on different spheres of competence and knowledge that each has, and can provide to the individual who stutters (Powell, 1990b). If both communities are careful to operate within their respective fields of expertise, then we predict a continuation of the cooperation existing to date. However, the increasing sophistication and growth of the self-help groups, and their involvement in research-related activities points to areas in which friction may develop.

Technological advances, particularly the Internet (which people who stutter generally have embraced, as a less stressful means of communication than the telephone) provide the larger groups increased means to reach potential members, as well as influence key groups. Unlike other disabled populations, the Internet (with its emphasis on written and graphical communication rather verbal) has generated vibrant on-line self help/mutual aid/advocacy communities. These allow persons who stutter to seek support from others, without resorting to the difficulties that many stutterers experience in placing telephone calls. As a result, it well may well be that stuttering self-help groups will continue to prosper as they reach out to persons that are geographically isolated, or are not yet willing to "come out." However, the increasing sophistication of Web-based telecommunications and the emerging capacities for audio and video transmission, may deter some persons who stutter from speaking to each other rather than communicating via the Web.

Today, the primary challenge facing self-help/mutual aid/organizations for persons who stutter is not their relationship with professional experts. As organizations such as the NSP/NSA and CAPS have expanded their mandates, and some of their founding visionaries moved on to other roles, they face many difficult challenges. Perhaps the greatest of these are finding the financial resources and corporate leadership skills required to survive in a tough fiscal environment.

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