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International Aphasia Treatment

The Japan-U.S. Connection

by Roberta J. Elman

As speech-language pathologists, we enter the profession with hopes that our clinical skills will improve the quality of life for clients with communication disorders and, perhaps, that we will have an impact on one another. The importance of sharing ideas with fellow professionals should not be underestimated. Like a pebble that is thrown into a still pond, ripples may reach much farther than we realize. The growth of programs for individuals with aphasia in Japan is an example of those "ripples."

Takashi Endo, an SLP in Japan, has pioneered international trips for people with aphasia. Inspired by the book Living After a Stroke (Law & Paterson, 1980), Endo organized 60 people—individuals with aphasia, their family members, and several SLPs—to travel from Japan to London in 1992 to share a day of activities, talking, and singing. Since that time, and assisted by a professional tour company, Endo has escorted Japanese groups to international Friendship Days in eight other cities: New York, Stockholm, Sydney, Seoul, Toronto, Brussels, Honolulu, and Cusco, Peru.

Speech-language pathologists Takashi Endo (left), Roberta Elman, and Asuka Tanaka meet one another at the U.S.-Japan Aphasia Friendship Day in California in 2007.
In 2006 I received an e-mail from him asking if members of the Aphasia Center of California (ACC) in Oakland would be willing to meet with a group of people with aphasia from Japan in 2007 for a U.S.-Japan Aphasia Friendship Day.

**Making the Connection**

When Friendship Day arrived—after complicated logistics with translators had been worked out—15 banquet tables were set up; at each table were an American with aphasia, a Japanese person with aphasia, and a student translator, as well as a sprinkling of ACC staff members, volunteers, and American or Japanese family members.

For those arriving late, it was difficult to determine who actually had aphasia—all of us were using pads and pens, photographs, and gestures to describe our life stories. We were figuring out how to bridge the dual language barriers of English/Japanese and aphasia. Through songs, physical activities, and personal stories, true connections were made and have endured to this day.

Endo surprised me when, during his introduction, he held up a book I'd written on group treatment and stated that it prompted him to start the first aphasia day program in Japan, which led to additional programs and services. Realizing that people in Japan with aphasia benefited from the sharing of our work, I wanted to investigate how professionals in the U.S. could benefit from clinical ideas in Japan—and soon had the opportunity.

In May 2008 I arrived at Narita airport outside Tokyo at Endo's invitation to speak at a regional conference in Saitama for people with aphasia, family members, and providers. I was the only presenter at the conference who did not speak Japanese. My presentation slides and handouts were translated into Japanese, and I had full-time translators—four women who had either studied English or speech-language pathology in the United States.

Now it was time for me to be inspired! On the first day of my visit, I visited Endo's aphasia day program, Habataki ("Flying High"), to see how our ideas were being interpreted and implemented, and the unique aphasia programs that had been created in Japan. SLPs in the United States and other English-speaking countries have had few opportunities to learn about the Japanese approach, however, because of language and cultural barriers.

The cultural barriers are, at times, somewhat subtle. I believe some communication problems are caused by cultural differences in what is considered polite. In Japan, it is considered impolite to ask too many questions. At a regional conference last year, I was the first presenter ever to invite questions following my presentation; Endo explained to the more than 600 attendees that asking questions was standard procedure at U.S. conferences. In addition, most people in Japan are more reluctant than residents of other non-English-speaking countries to communicate in English, a language they do not know well.

**Programs in Japan**

The Japanese approach to working with people with aphasia includes six facets: peer circles, conferences, conversation classes, sheltered workshops, supported conversation, and day centers.
• **Aphasia peer circles.** In addition to traditional rehabilitative services for people with aphasia, a spontaneous volunteer program of aphasia "peer circles" began to develop in Japan as people with aphasia and their family members sought out one another and set up meetings at their homes or in other locations. In 1984, a stroke survivor living with aphasia founded the Japanese Aphasia Peer Circle Association (JAPC), which set out to hold a national conference of aphasia peer circle members and encourage the creation of additional circles. Approximately 230 active aphasia peer circles meet regularly throughout Japan, with an estimated membership of about 8,000.

• **Conferences.** This year the JAPC’s 27th national conference will be held in Fukui. Regional conferences of aphasia peer circles—such as the 2008 Saitama conference I attended—draw hundreds of people. The conference included presentations by health care professionals, people with aphasia, and others whose lives have been affected by aphasia; performances by local entertainers; and participatory activities. These conferences are similar to the Speaking Out! conference organized by the National Aphasia Association in the United States.

• "**Aphasia Live.**" In 1983, a Public Health Act for the Elderly was enacted in Japan. This national legislation caps inpatient rehabilitation to three months for people with conditions such as stroke (Endo, 1996). After the three months, public health nurses are responsible for establishing rehabilitation plans for people with chronic health conditions who return home. In 1985 Endo advocated successfully with public health nurses in Saitama for funding for community-based speech-language pathology services for people with aphasia. Funding was approved for aphasia conversation classes, called "Aphasia Live," facilitated by an SLP and assisted by community volunteers. "Aphasia Live" groups were created across the country, and by 2000, there were approximately 100 such groups meeting nationwide (Endo, 1996).

• **Sheltered workshops.** Japanese parents of children with developmental disabilities successfully advocated for the establishment of sheltered workshops. In 1983 a sheltered workshop was established in a suburb of Tokyo for people in their 20s and 30s living with aphasia. Of the estimated 6,000 Japanese workshops for people with cognitive and physical challenges, six are for younger people living with acquired aphasia. These workshops receive funding from the local government as well as from individual contributors. Different products are created at each workshop—they range from speech-language treatment materials to calendars, crafts, toys, and games—and participants receive a nominal wage for each day that they attend.

• **Supported conversation.** Following a 1999 visit to the Aphasia Institute in Toronto, SLP Yoko Tamura and her colleagues developed training programs for communication partners of people with aphasia. In 2005, she founded a nonprofit organization to sustain the program. Training programs are provided in Tokyo, and are also being created in other major cities.

• **Aphasia day centers.** In 2000, Japan enacted the Act of Long Term Care Insurance for the Elderly, which provides funding for people with chronic disabilities age 40 and older to attend day programs. These programs could be administered by either nonprofit or for-profit organizations. Endo received government funding to start the aphasia day centers, each serving 10 people with aphasia each weekday. One center, for example, occupies a three-room apartment in a Tokyo suburb and has four paid staff members—a social worker, a care worker, and two SLPs—in addition to speech-language pathology student interns and other volunteers. Six aphasia day centers are in operation.
International Collaboration

Aphasia intervention in Japan has been influenced by programs developed in other parts of the world. In addition, unique programs have been created in Japan that merit attention from SLPs worldwide. It is important to note that Japanese programs receive funding through government programs, even though these programs were not originally developed to provide services for people with aphasia (Endo, 1996; Npo Waon, 2004).

Government funding for programs such as "Aphasia Live," aphasia day centers, and sheltered workshops demonstrate the impact on service delivery and communicative access for people with aphasia when systems-level change is made (Simmons-Mackie, Kagan, Christie, Huijbregts, McEwen, & Willems, 2007).

I asked Endo if he would have written to me about the impact of our work on his decision to open an aphasia day center, if we hadn't been able to meet in person during his 2007 visit to the ACC. He told me that he would have been too embarrassed to write such a letter. It made me realize how important it is to keep dropping those pebbles—you may never know how wide their ripples flow.

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References


