

## Enhancing the Lives of People with CP and other Developmental Disorders: San Francisco 2001 Annual Conference Colloquium Report

—By Kathryn Goldman Schuyler, Ph.D, GCFP

The Colloquium on “Enhancing the Lives of People with CP and Other Developmental Disorders” offered an opportunity for members of the *Feldenkrais*® community to dialogue with those who make such services available. The primary guests of the *Feldenkrais* community were Bill Pelter, Assistant Executive Director of the Cerebral Palsy Center for the Bay Area (CPC) and Lisa Kleinbub, Manager of Health and Behavioral Services for the Regional Center of the East Bay. The CP Center’s Wellness Coordinator, Maureen Berndt, expressed her enthusiasm for having *Feldenkrais Method*® work as part of her program. Also participating were staff and participants from the CPC, in addition to *Feldenkrais* practitioners and students from around the world.

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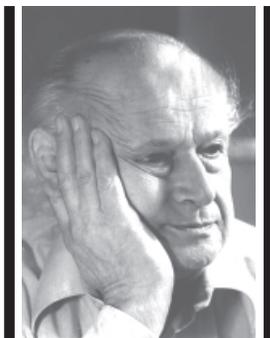
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Most FGNA Annual Conference sessions involve movement; their primary focus is on learning through doing. In contrast, the colloquia are devoted to enhancing individual and collective practice through dialogue about fundamental issues. As professionals whose training emphasizes sensing and kinesthetic learning, we do not often focus directly on improving our ability to talk together as a means of extending the impact of our work in the world. **The design of this colloquium was to initiate face-to-face conversations between *Feldenkrais* practitioners and the staff of such behavioral science-based service centers in order to see how we might foster more connection in the future, thereby enabling more people to benefit from *Feldenkrais Method* work.**

The Cerebral Palsy Center for the Bay Area (CPC) was formed in 1939 by parents of children with developmental disabilities when they were told by the state that there was no place for their children to go to learn. It was the first special education program for people with severe disabilities. Subsequently, the California State Board of Education took over the work with children, and the center refocused on educational programs for adults. It currently serves approximately 75 adults, over half of whom have little or no functional speech. It has a nationally-recognized computer learning center, a workshop that does large-scale mailings where participants work and earn money, and a city program that enables participants to experience daily activities in downtown Oakland. **The center works from a person-centered or holistic model that focuses on the client as a whole person.** Its approach is to ask participants: “What can we, as an enterprise, provide in terms of support so you can achieve the things you’d like to in your life?”

The Regional Center system is unique to California, but there are analogous programs nationwide. The Regional Center of the East Bay (RCEB) is a private, nonprofit corporation under contract with the California Department of Developmental Services. RCEB provides intake, assessment, and case management services to over 11,000 individuals and their families in Alameda and Contra Costa counties (see <http://www.rceb.org>). There are 21 autonomous regional centers across the state of California, serving 171,430 clients (see <http://www.arcanet.org>). RCEB funds therapies after generic resources such as Medi-Cal have been used to their maximum. According to Ms. Kleinbub, the RCEB has recently begun to look into wellness, women’s health and the overuse of medicines. Ms. Kleinbub is interested in partnering with organizations to apply for wellness grants from the state, because this allows her department to try new things and do research on their effectiveness.

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“In order to incorporate the *Feldenkrais Method* into our services,” stated Ms. Kleinbub, “we would have to consider its effectiveness as demonstrated by outcomes.”

Alejandra Menendez, a participant in the program at the CPC, and Mandi Palfreyman, a staff member of the CPC, shared their experiences with the *Feldenkrais Method* as people with CP who have felt its value in their lives. Participants from the *Feldenkrais* community included very experienced practitioners like Carla Oswald Reed and Maralee Platt from the Amherst training, (who have worked for over a decade with people with CP and other neurological disorders), as well as recent graduates like Moshe Zyskind (who came over from England for the conference and to participate in this session) and current trainees like Kristi Drullard, who were eager to talk with more experienced colleagues. Many of the *Feldenkrais* practitioners who participated have no other opportunities to interact face-to-face with colleagues who are working with issues such as CP and autism.

### **An Opportunity for Dialogue**

The intent of the morning session was to give each group a chance to articulate and share their dreams, needs, and constraints in order to understand one another better and to find where our visions for the future are in synch. The goal: to help one another realize those ineffable “unavowed dreams.” All participants described what they hope to bring into being via their work. For example, Marianne Kagan wants to expand her work with the parents of affected children. Carla Reed dreams of catalyzing the creation of a model day program for differently-abled infants and/or children centered on *Feldenkrais Method* work. Bill Pelter and Maureen Berndt shared with us what they have already created in terms of a wellness program at the CPC, along with their dreams for expanding it.

Lisa Kleinbub, of RCEB, mentioned that she didn’t know a lot about the *Feldenkrais Method*. She went on to state that “I’ve heard a lot about how it contributes to the improvement of function as an educational modality and am interested in seeing how it might help our clients” – the thousands of people served by the regional center. Maralee Platt stated that she was “thrilled to see the *Feldenkrais Method* moving into institutions” and to see the interest being expressed in expanding its presence.

It is hard to share in writing the excitement expressed by the group at having the opportunity to dialogue and expand learning in this area. The warmth and commitment of all present was huge. As Paul Boyce said, “There is something about working with people with such disorders that seem to have such potential—it really is nourishing to do so.” Jennifer Lee commented: **“I feel I’m working with the heart of Moshe’s work in doing this work at the CP Center.”** However, many felt what Charlotte Chavez said: “I am very excited about doing this workshop—I am getting a little discouraged with the progress that I’m making.”

Progress is often gradual in our work. Sometimes it is difficult to distinguish between small, significant learnings and lack of momentum. A session like this and preparing for it helped us all to see the worth of our contributions, as well as the way we and our students seem to be in a mutually nourishing process of learning. Decades ago Gurdjieff coined the phrase “reciprocal maintenance” to describe a process in which each part of a healthy system supports the ongoing development of the other. The colloquium helped us all to sense how often this is true in our practice, particularly in working with “differently abled” adults and children.

As we spoke together, both guests and practitioners realized that we shared a focus on the whole person and an orientation towards asking people: “What do you want to achieve and accomplish?” and making this the context for all services and learning.

As Bill Pelter commented, “Everyone in this room is a pioneer. What you’re pioneering is the notion that there is something that can be done for the people whom you serve. What you’re up against is a world that may not understand that this is possible. **We’ve had to learn that ‘No’ and ‘You can’t do that’ are only starting points, not the end.”**

Shifting from discussion of dreams to a focus on constraints, we discovered that those present experienced a variety of types of problems in making their dreams realities. Among the things identified were:

- Implementing a vision or dream takes considerable time, energy, patience, and work.
- The Regional Centers have a “day rate” for reimbursement of activities, and the *Feldenkrais Method* is only one

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element among many for them. Not all regional centers are familiar with our work, nor do they all support it.

- To work with organizations, whether the CPC, regional centers, or any others, one needs to step into the systems and culture of the organization. One needs to be able to recognize the nature and expectations and then work comfortably within that culture. Many practitioners have little experience in these areas.
- Planning and communicating with institutions is a skill required to develop new programs with existing institutions. Some practitioners work well in such contexts, where others do not.

### **A Study of the Impact of Feldenkrais Method Work**

In developing the colloquium, the CPC and I completed a study of the impact of the work done to date at the center. A staff member with no personal experience of the *Feldenkrais Method* asked a series of six questions to those who had received sessions for three or more months. The questions were designed to apply “appreciative inquiry” methods in order to discover what people valued in their experience of *Feldenkrais Method* lessons. The interviews were conducted privately, so each participant could think about and fully express his or her views. On the average, the participants had received an average of three individual sessions per month for four to twelve months.

The report uses quotes from the participants at the center in order to describe their experience of the work in their own words. As practitioners, we know what we say the work ought to do. It is different to hear what people with severe limitations say it has actually done for them. **It is evident that it enhanced core feelings of efficacy and power, giving people a feeling deep within themselves that they could do more of what they want in life.**

Over and over, the participants said that the lessons reduced their pain, made them more aware of themselves, helped them to relax and get work done more effectively, and made them feel stronger. Maureen Berndt emphasized the importance of pain reduction for the center’s population. “So many people there are in pain much of the time. How can they focus on working at the computer if their whole body is screaming in pain?” From my work there, I can also see that the reverse is important: when people want very much to work on the computer, they are more motivated to do enough *Feldenkrais Method* work so they can, in fact, do what they want.

Among the things participants reported frequently were experiences like the following:

- “She (Kathryn) touches my body and (then) I have more control of my body.”
- “I know when I’m becoming spastic. The *Feldenkrais Method* work has given me the ability to relax my muscles so I can have the freedom to move again.”
- “I’ve learned about the importance of breathing for freedom of movement. When my body is tense or working too hard, I can take deep cleansing breaths in order to free up tense muscles and make movement happen.”
- “I am more aware of changes in my body as I go through various activities such as standing, walking, sitting. If changes need to be made, I am able to make adjustments within myself to make movement easier.”
- “I don’t talk too fast—I slowed down my speech. I don’t stutter any more.”
- And it is powerful to hear that someone commented: “I’m not as aware that I have a disability as before.”

After hearing the results of the study, Lisa Kleinbub commented, “I see people getting expensive medical treatments but they do not tend to receive other sorts of modalities. We might be able to help with this and expand what can be provided. Research on outcomes will be a real road to getting that to happen. Even if medical approaches are used, there are benefits to having other approaches involved—they’re very complementary.”

### **Videotapes Used to Share the Learning and Impact of Colloquium**

I had prepared tapes of sessions at the CPC, so we could bring the reality of the learning into the room without having to embarrass any of the participants by having them feel “watched.” *Feldenkrais* Educational Director and Trainer Ruthy Alon joined us for this segment of the colloquium, as we watched and discussed videotapes in order to consider what leads to effective work with people with severe disabilities of different types.

Since I had previously taken a year off to assist in videotaping sessions with children with developmental disorders, I was very aware of the importance of developing a visual record when I first launched this program. It is often difficult to get tapes made, but I would encourage all practitioners to do so, particularly if they are beginning something that might be

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useful with regard to research and development in our community. We cannot anticipate which students will learn, which will do little—and which will have their whole life changed by the experience. **Because I had tapes made near the start of the work at the CPC, colloquium participants could view the early sessions juxtaposed with recent ones and see the extent of the learning. It can be startling when such change is made visible.**

We viewed selections from tapes to show the transformation in behavior of one woman at the center. She has been transformed by the work we have done together—but I had no way of guessing that this would happen when we began. When we began, I wondered whether there was any value in working with her at all. She would lie on the table mumbling to herself, seemingly out of touch with me, “reality,” and her body. She would talk incessantly with invisible friends while I touched her. She did not seem like an obvious candidate for successful *Feldenkrais Method* work. And yet—of all the people I have worked with, I have had more fun working (and playing) with her—and her very personality and life have been transformed.

Bill Pelter described this change process from his perspective, “She lived cognitively in a very private and internal world. She had an uncertain gait and walked with one hand on a wall. One day, someone passed me and said in a normal tone ‘Good morning, Bill.’ It was the first time I heard her say anything at a volume near the way we normally speak—and she spoke for the first time in a complete sentence. Before, she spoke in fragments, separate words and little pieces of words.”

“As a result of doing the work with Kathryn, she’s able to carry on a full conversation. She’s more in the world now. She initiates. Before, she was like a planet that would orbit by from time to time rather than being here with us. **I can only attribute it to the *Feldenkrais Method* work, because it’s the only thing that’s different in her life.**”

### **Next Steps**

In order to build on the colloquium and not promise more than we can actually deliver, a number of actions are planned. The participants decided to remain in touch by email and to become the hub of a support network for one another. Any *Feldenkrais* practitioners who would like to connect with this group can be put on the list by sending an email to: <info@coherent.org>

In addition, those present wanted to learn more about qualitative outcome research. As many of us are aware, it has been difficult to document the uniquely powerful contributions that the *Feldenkrais Method* brings to people’s lives using traditional quantitative research methods. Aside from the difficulty of obtaining funding for longitudinal studies, it has been challenging to ascertain what to measure. Qualitative research, on the other hand, may be able to support the documentation of changes in the quality of people’s lives. **A workshop is being developed for the *Feldenkrais* community to learn about the range of appropriate qualitative research methods.** It will help us form a group which is interested in improving our skillfulness in writing case studies and interviewing both our students and those who experience the changes in them. We may design a research study collectively. It will be held at Alliant International University’s Alameda Campus on May 18, 2002, from 10 AM to 3 PM. Cost will be a small donation of \$50. It will be taught by Dr. Mary Frambrough, who is an expert in qualitative research methods and a dynamic and engaging teacher, who has agreed to work with us in this project. Those interested in participating should contact me at: <kgschuyler@alliant.edu>

It is the deep hope of all participants that the colloquium has planted seeds which will lead to valid research studies and foster increased use of *Feldenkrais Method* work with people with CP and autism. ■■■

(Author’s Note: I want to formally thank Bob and Sharon Thomas for donating their time and equipment and making it possible for us to have high-quality, edited tapes to view at the colloquium. Their generosity and help in recording the learning gave us the means for a rich learning experience.)

**“I also know that if a person is having troubles with his movements, I can probably improve the movements and thereby improve his health and well-being.”**

—Moshe Feldenkrais—