

Aspects of deafblindness in Japan

By Jacques Souriau

Introduction

In the extraordinary world of deafblindness, one can feel at home in any place on this planet. Cultures differ, but when it comes to deafblindness, the challenges are the same.

In June 2016, I was offered the opportunity to experience the universality of deafblindness in a country where the culture is quite unique: Japan. It is a fact that international collaboration and professional publications are greatly influenced by European and American (private or public) organizations using English as the main language of communication. As a result, too little is known of countries (and there are many) which do not participate as intensively in this network. Therefore, when I got an invitation to take part in a project that would give me the possibility to have a direct contact with deafblind people, family members and professionals in Japan - a country known to me for its sophisticated culture and advanced technology, I said "yes" without hesitation.

This invitation came to me from two colleagues: Mrs Megue Nakazawa and Professor Masayuki Sato. Mrs. Megue Nakazawa, once a senior researcher at the National Institute of Special Education in Japan¹, she now occupies the position of Principal at the Yokohama Christian School for the Visually Impaired (Kunmoo-Gakuin)². Her professional activities led her to develop a strong interest in blindness and deafblindness. I had the pleasure to meet her on the occasion of a long study visit in Norway and France during the 1990's as well as during various Dbl conferences. At the Yokohama Christian School for the Visually Impaired (where there are also six deaf individuals, she is one of the successors of Mrs. Sadako Imamura, once a familiar figure at past Dbl conferences. As the principal of a school for multi-disabled blind students, Megue Nakazawa is interested in improving the competencies of her staff members as communication partners for the deafblind children, especially with regards to sustaining the children's engagement maintaining contacts and also exploring further

¹ <http://www.nise.go.jp/>

² Kunmoo-gakuin 181 Takenomaru Naka-ku, Yokohama-shi Kanagawa, 232 JAPAN

the dynamics of tactile communication. Her hope is also that these newly developed communicative competencies would be equally useful and relevant for the other students of the school who are not deafblind.

Professor Masayuki Sato is in charge of the Research and Support Centre on Higher Education for the Hearing and Visually Impaired at the famous Tsukuba University of Technology³. In this context, he has contact with a few students with acquired deafblindness and leads a project aiming at making available an E-learning system that would work for them. This research is supported by a Scientific Research Grant from the Japan Society for the Promotion of Science⁴.

Thanks to this grant, I was able to collaborate with Megue and Masayuki to meet people with congenital and acquired deafblindness and organize working sessions with various professionals and researchers.

Consulting and Being Practitioners Again

The first part of the project was focused towards the congenital deafblind children among the 30 multi-disabled blind children are enrolled in the Yokohama Christian School for the Visually Impaired (KUNMOO-GAKUIN). The plan was for me to first observe the activities of those deafblind children then lecture to the staff at the end of the day. However, if one wants to understand the communication profile and developmental potential of each individual child, simple observation is not enough. It is difficult to provide relevant advice without the kind of information obtained from direct contact. Therefore, I made a personal encounter with each of the children, with each communication interaction filmed to provide the staff members and families with material for video analysis. Through these sustained personal interactions, I could feel and explore directly each child's favorite contact modality, allowing them to expand their own initiatives. As well I was able to identify their present competencies and potential for further improvement.

In other situations, my lack of mastering Japanese sign language considerably limited the richness of our exchanges. To resolve this, we organized small online coaching sessions where I was giving guidelines to a professional while he was interacting with a child. This method requiring mutual trust and active collaboration proved to be quite successful. For example, together with a teacher (following a request from the parents), we managed to help a child to use tactile (instead of visual) signing for communicating while using her residual vision to access events around her. This resulted in her

³ www.tsukuba-tech.ac.jp/english/

⁴ <https://www.jsps.go.jp/english/>

changing her physical approach for accessing information and communication. With another child, the teacher had set-up a challenge for her to understand and differentiate the signs (and the concepts) for 'bread' and 'rice' in the context of an activity where she could touch and eat these two kinds of food. The success of such a project depends a lot on the competency of the teacher not to interrupt the tactile contact and to react to the child's initiatives in a structured and playful way. During that session, the child did not initially produce these two signs; but later in the day, she was seen producing them for herself, in a thinking moment, proving that something had built up in her mind during the exchange with her teacher, equipping her with a new tool for thinking and, hopefully, for communicating.

Another anecdote worth reporting was meeting a 19 - year old male student at the school who was quadriplegic. My wife, Mimi, who accompanied me on the trip to Japan (and who worked through her professional life with congenital deafblind children), was observing my interaction with this young man. She believed that she could work with him using the bodily approach based on the Feldenkrais method^{5,6}.

This method is a form of physiotherapy based upon observing the bodily initiatives of the individual and reacting to their responses through focusing on communication and at the same time enhancing the quality and consciousness of the individual's emerging bodily actions. He clearly engaged in this relationship with pleasure, concentrating for such a long time, that the tiredness of my wife and our time schedule made it necessary to put an end to the session. Staff members (including the financial manager of the school) observed this interaction and expressed interest in exploring this approach further. This procedure appeared to be in line with their own practice and offered further possibilities for the young man's development. The following day, the staff member in charge of him tried the same method through my wife's coaching. Its relevance to this young man became evident, but of course its success will depend on proper training and practice.

During the three days spent in the Yokohama Christian School for the Visually Impaired, it seems that some changes happened thanks to the mutual engagements between the staff members, the students and us, the visitors. A climate of trust developed, based on very practical shared experiences that were commented upon during the evening lectures. The staff members discovered the importance of video analysis for understanding the dynamics of interactions and co-constructing a frame of references allowing a better adjustment to each individual developmental profile. At the same time, some mothers spent time in the school to observe our activities with their children. It

⁵ Feldenkrais M. (1985) "The potent self" traduction française (1990) "La puissance du moi." Editions Robert Laffont, S.A. (p.21).

⁶ Learning and Communicating through Movement: Dbl Review 57, July 2016

was an occasion for them to have access to our methods of observation and to make links with their lives at home. Hence, the sessions with the children took actually the form of a 'quadrilogue' involving the child, the mother, the teachers and the visitors. And a fifth element must be added to the picture: these exchanges would not have been possible without the permanent availability of Megue Nakazawa, the principal, who took care of the Japanese-English translation.

This dynamic learning atmosphere around the children had also important witnesses: a team from the TBS TV Network, led by Mr. Toshiyuki Kawakita, was filming us all the time with a purpose worth mentioning. Mr. Kawakita is following how some important social problems are being dealt with through state, private or even individual initiatives. Deafblindness happens to be one of the issues that he has followed up since a decade ago. Mr. Kawakita is perfectly acquainted with the questions related to congenital deafblindness and knows very well about the Yokohama Christian School for the Visually Impaired.

A visit to Tsukuba University of Technology

After three busy days in the context of congenital deafblindness, we travelled to the Research and Support Centre on Higher Education for the Hearing and Visually Impaired in the Tsukuba University of Technology (about one hour from the center of Tokyo) where Pr. Masayuki Sato took over the lead of the second part of my program.

Tsukuba University of Technology offers special university programs (including full boarding) for students with sensory impairment. I had the opportunity to visit several University programs including a design course for deaf students, an acupuncture training program for blind students and met a team in charge of sport activities for the blind. During these visits, I was quite impressed by the level of accessibility equipment available for mobility and accessing information. It was pleasing to observe that Japan provides supports for students with sensory impairments.

However, this level of accessibility is not sufficient for deafblind students. Pr. Sato wishes to enroll a brilliant young deafblind man into the graduate program of Tsukuba University. He managed to get a grant from the Japan Society for the Promotion of Science to design an E-learning system providing the deafblind student with a distant access to lectures and discussions through an automatic braille captioning system. There are definitely many challenges to make this initiative work for this young man to allow him to participate in and understand the lectures, which are much more than just text! But the professor is confident that the collaboration between the university team and the deafblind student will produce solutions for designing the project in an advanced and feasible way.

Two fascinating interviews in Tokyo

After a couple of days at the Tsukuba University of Technology, we went back to Tokyo where two important interviews had been arranged for me with two people who are deafblind people: Miyuki Ara and Atsushi Mori.

Miyuki is a young lady who has acquired deafblindness. To communicate, she uses Finger Braille⁷, a method that was created in Japan in 1981. With Finger Braille, the interpreter sits next to the deafblind person and taps characters in braille, onto the uppermost digit of the middle three fingers of each hand like the keys of a braille writer. It follows the traditional system in Japanese braille of hiragana and katakana characters⁸. This method requires a good knowledge of braille; it is quite fast and it is also possible to symbolize emotional aspects. With two interpreters, one for English-Japanese translation and the other for finger braille, we managed to have a long and fluent conversation. It took place at the Meiji Gakuin University⁹ where she is studying. Most of our conversation was focused on the education of congenitally deafblind children, a situation that was obviously intriguing to her. We addressed typical but central questions like how these children understand the world; how they build up concepts and how language can be introduced. Miyuki recently published a book based on her own experiences; but our conversation proved that she is also interested in accessing other types of deafblind experiences.

Atsushi Mori is a fascinating young man. He was born totally deafblind but the aetiology is unknown. I had the occasion to meet Atsushi before during the Dbl World Conference in Perth (2007). He was much younger but was already fluent in sign language along with good reading skills. I remembered that we managed to have a conversation using tactile signing in spite of the differences between French and Japanese sign languages, but, of course, an interpreter was necessary for a more precise and extensive exchange.

This time, I met Atsushi in the Japan Lutheran College in Tokyo¹⁰, along with Pr. Sato and Megue Nakazawa. Atsushi is now 24 years old and he uses sign language (not finger braille) for conversations. I did not know what to expect from this new encounter, but I quickly realized that Atsushi was perfectly prepared. He told me that he was working on a thesis that would allow him to join the Tsukuba University of Technology

⁷ fingerbraille.com; <https://www.youtube.com/watch?v=eTC-ZmILCu4>

⁸ <https://coscom.co.jp/hiragana-katakana/index.html>

⁹ www.meijigakuin.ac.jp/en

¹⁰ www.luther.ac.jp/english

where Pr Sato is working to make the program accessible to him. He wanted to know my opinion about the feasibility and relevance of the topic he had chosen: *The difficulty understanding 'Fantasy' for a congenital deafblind person and the process by which he came to recognize, understand and appreciate Fantasy?* The reason for him to choose such a problem is extremely interesting. His first idea had been to write a thesis on his own experience with deafblindness, which is a wide and quite common topic among deafblind people who managed to write about their own disability. But an event made a new and more precise idea spring in his mind. One morning, he told his mother that he had just met the girl next door. His mother was quite surprised because she knew that the girl next door was not at home. She said that this event must have happened while he was dreaming. This statement was a shock for Atsuchi, because it made him aware that he had treated something imaginary that happened only in a dream as if it were real. He realized that he did not know really what fantasy is. This event was the last part of his progressive elucidation of the differences between reality, fiction and fantasy.

Arsushi was able to read textbooks and stories in his later elementary school years and he could understand fiction, because fiction is based on reality and logical cause-effects connections; but he had trouble with a world of fantasy where a fish can speak or fly. And then he realized that the world of his own dreams (and other people's dreams) was full of unrealistic and illogical events. This discovery puzzled him and triggered his interest in sharing this experience with other people and making it the topic of an academic research. One could venture in trying a hypothetical explanation for this difficulty differentiating reality from fantasy in the following manner: Sighted-hearing people are reminded all the time that there is something real around them because they have to negotiate with it when they move and communicate. But when you are deafblind, you spend a big part of your life with your own thoughts or within a perimeter of accessibility which is limited to the tactile channel and reduced by the lack of easy mobility; therefore, the world inside and the world outside can be easily mixed up. This is a possible explanation but it has to be explored further.

I told Atsuchi that his thesis could be an exceptional contribution to the knowledge of how congenitally deafblind people think and construe reality. There are very few people on the planet that were born totally deafblind and that are, at the same time, able to fully understand and express themselves in the language of the culture they live in. They are the only ones that live in the country of the 'congenitally deafblind' and can report directly to the citizens of the country of 'sighted-hearing' people about what happens where they live.

This happens also in the world of autism where people with Asperger Syndrome¹¹ have both the personal and permanent experience of autism and can, at the same time,

¹¹ www.webmd.com › Brain & Nervous System › Autism

inform other people about the way they understand the world, the challenges they meet and the solutions they build up. In this way, they help to understand better what is the life experience of other people with autism who do not have the possibility to express and promote the form of their relations to life. Atsuchi could therefore be a precious messenger from the 'world of congenital deafblindness' and inform us about things that other congenital deafblind people cannot express directly and clearly, leaving families and professionals with the tough task to find ways to access it (for instance through video-analysis based on relevant and sophisticated semiotic frameworks). Atsuchi shared also with us another interesting problem that sheds light on how language competencies and knowledge of the world connect in the life of congenitally deafblind people. Atsuchi is perfectly fluent in sign language and reads braille, but he suffers from the gap he experiences between his full-fledged linguistic competencies and his limited accumulated knowledge of the world he lives in. This is probably the reason why he became an expert in the public transportation system of Tokyo. His precise daily and direct experience with it gives him a sound ground for building up a secure overview of the whole system. In many other domains of life, his language works on quicksand for lack of direct bodily experience. This is a typical problem in the context of congenital deafblindness where teachers and family members must make a point to secure enough practical bodily experience for language to develop on a sound basis. In the case of Atsuchi, what is exceptional is that he developed language (as a system) much faster than the life experience it should be connected to. In many ways, Atsuchi is what ethnologists call an informant¹², a native who can bring direct and relevant information about the culture which is studied. Having the privilege to have a long conversation with him was a wonderful conclusion for this fascinating trip in the world of deafblindness in Japan.

Concluding the visit

These eleven days were very busy, but some free days gave us the opportunity to get more than a decent share of the Japanese culture under the careful guidance of Megue Nakazawa and Masayuki Sato, including a wonderful tea ceremony, public baths, wonderful sushi's, temples etc. Everywhere we enjoyed a very warm and active experience of collaboration with the professionals and the families, and hopefully learned a lot from each other.

¹² www.anthrobase.com/Dic/eng/def/informant.htm

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