

COMM' HANDI : For a Different Communication

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Abstract

COMM' HANDI project results from the collaboration between Toulon University (I3M – IUT (University Institute of Technology) and the ADAPEI (Association for helping disabled children). It concerns the creation of communications interfaces personalized for polyhandicapped children and teenagers.

Key words

Polyhandicap, Communication, Sensory disorder, Symbolization, Adapted Specific Material

1. Introduction

In communication, three facts must be considered as important parameters: will to communicate, being able to communicate and knowing how to communicate [1]. For the multi-handicapped person, the dependence is particularly efficient when the speech ability is absent under its articulated form. However, the multi-handicapped people can communicate in their different own way and we shall then list their capacities of communicating with other people.

Observing behavior is an effectient way to establish a communication assesment which must be completed by the preliminary consideration of the sensory disorders (confusions) and by family and interdisciplinary observations. For example, the analysis of movements, look, singing exercises.... can allow to define specific equipments in order to ease the expression of needs, choices, feelings...

The main difficulty in the elaboration of a personalized for communication lies in the

development of specifically designed equipments adapted to capacities and difficulties of a young polyhandicapped person. That is why a partnership was set up since 2014 between the University of Toulon (I3M laboratory and IUT Institute) and ADAPEI Association (University providing the technical skills in realizing the projects). This collaboration results in several projects of communication interfaces realized with students of IUT Electrical Engineering Department. This common work won an "Espoir de l'innovation" award during the last "Var Terre d'Innovation" contest organized by Var Departemental Council (equivalent of county)

First, "polyhandicap" term will be defined and the relation of communication of/with the multi-handicapped child will be specified. Some ideas will be detailed, in particular on how taking into account, exploiting and of developping the existing means of communication, and how to lead these people towards the discovery of their symbolization possibilities. Then, tools set up in an establishment for children and multi-handicapped teenagers will be more particularly described in their two important functions : identification and contact facilitation. Clinical cases will be presented afterwards to understand better the individual work that needs to be performed so as to improve the relation of communication with the multi-handicapped child. Finally, emergent working hypotheses will be discussed.

2. Polyhandicap

Polyhandicap is "a serious multi-expression handicap, associating severe or deep driving and mental deficiencies, causing an extreme limitation of autonomy, perception possibilities, expression and relation". This definition includes numerous clinical expressions, according to the prevailing of either the motor or mental disability. Polyhandicap can be even worsen by other deficiencies or disorders. It requires specialized techniques in medical follow-up, learning relation and communication means, development of the intellectual and sensorimotor learning capacities that contributes to the exercice of an optimal autonomy [2].

Specialists generally agree on polyhandicap causes : 20% accidental, 20% viral, 20% genetics, 40% still being unexplained. The functional effects of the various deficiencies change as the child is growing up. The initial handicap can worsen with secondary handicaps. For example, the behavior disorders (stereotypies, auto-aggressiveness, psychotic fold) can take an important place and make difficult to draw the line between polyhandicap and very regressive overdrawn psychoses.

The intellectual deficiency of the polyhandicapped person results in difficulties to understand

his spatio-temporal location as well as memorization troubles, reasoning confusions, misunderstanding of relations between situations, and most of the time, the absence of articulated language. The possibilities of expressing feelings are however preserved as well as the contact with the environment. To obtain autonomy, medical care has to include the development of the skills and not be based on the missing capacities of the person.

Concerning motor disorders, they are practically constant. Epilepsy affects 40 to 50 % of multi-handicapped people and 20-25% have difficulties to balance epilepsy. Sensory disorders are a part of multi-handicapped persons invalidating problems. They get worse as the person is getting older. Essentially, these disorders are audition problems – that are difficult to evaluate, since the subject understanding is necessary for this – that could even go to total deafness and vision disorders (40%). Both visual and hearing sensory deficiencies are rare but they cause particular problems for rehabilitation and communication.

Handicap law voted in France in February 11th, 2015 [3] recommends the integration of all handicapped to the school ; it supposes that they can learn. Thus, every polyhandicapped person must be able to benefit from an access to a cognitive education [4].

Polyhandicapped people generally express in a nonverbal language of their own that their entourage has to discover and understand. Therefore, the starting point is the acquisition of a communication mean (verbal or nonverbal), to express “yes/no”, needs and make choices. Then, the development of personalized communication means each can be considered.

Communication is the action of establishing a relation with others to transmit information: the transmitter formulates and passes on an information; the receiver receives and decodes it. In this aim, a set of verbal and nonverbal means to exchange ideas, knowledge, information, feelings... has to be used. It is not a conscious educational practice since it exists before the appearance of the articulated language, which is supported by this set. There are several invariants which enable a better identification and understanding the multi-handicapped person communication [5]:

- It is a multimodal and most of the time nonverbal communication,
- It is specific in shape and nature,
- It does not relate to any communication standard; the interactions are thus not conventional
- It requires an analytical precise evaluation and raises the problem of behavior interpretation.

Communication in the case of polyhandicap can be passive, purely emotional, deliberate or active. We have to assume that every human being is able to communicate, to progress and to learn how to differentiate the receptive and expressive conducts. It is then a question of considering every human being capable of communication while accepting: the idea to adapt to the specificity

of the multi-handicapped person, the prospect of small progressions and regressions, the important and sometimes necessary moments of latency before the person reacts.

The general motricity of a multi-handicapped child is disrupted. Therefore, it is important to inhibit the motor pathology to ease the action. The position where the child is installed is therefore an essential element to interact (BOBATH concept [6]). The discovery of the environment is the basis of the language construction whatever it is (articulated speech, body movements, specific communications code). So, sollicitating several means of communication will help to improve it. The more available means a child has to express (gestural, verbal, visual), the more he will have the possibility of doing it. In daily life, the child evolves in a "bath of language".

The polyhandicapped child also needs for this "bath of language" but it has to be more complete than for non-handicapped child so as to structure the language, whatever the difficulties faced. Therefore, a multimodal "bath of language" which associates gesture, word and image (photo, pictogram, ideogram) gives several possibilities to the multi-handicapped child to understand what surrounds him and to be understood by other people. The used syntax should not be complex but it has to convey correctly an information by several possible channels [7].

The behavior observation remains the most effective way to establish a summary of the communication capacities. Thus, the collection of information from the educational and medical teams enables to refine it. Before that, it is essential to take into account the sensory disorders for a correct observation.

The setting of an assessment grid about the personal and internal communication in the medical institution seems the the most effective way to collect the data corresponding to its project and to the goals designed for the personalized project of every child. The assessment grid must be specific to develop a coherent personalized project. The communication summary concerns [8]:

- The auditive and visual sensory capacities. They are tested through a musical listening, a manipulation of sound toys, the use of soap bubbles, the visual pursuit of a colored object ...
- The reception capacities and understanding : Does the child look at his/her interlocutor? Can he/she fulfill a request ? Does he/she stop a stereotypical behavior if we ask him/her?
- The global expressive attempts. They also concern the attention time of the child.
- Designation
- Symbolic gestures (spontaneous or by imitation). We have to know if the child uses them and/or if he is sensitive to their use (like signed bed songs).
- Vocal possibilities

- Verbal possibilities.

It is also necessary to plan an observation time with the children having autistic disorders with stereotypies, so as to understand their moments of appearances and if they have a particular meaning a particular relation with the situation. Thus, therapists would be able to know if these stereotypies have communication intention or not. Finally, the communication assessment grid is sometimes reassessed for the impact analysis of the proposed alternate communication method.

After this detailed assessment has been done, the communication skills can be developed. It is with this aim that several communication interfaces have been designed by our laboratory.

3. Examples of interfaces

3.1. Speech synthesis

This project was designed for a 14-year-old multi-handicapped teenager. He is very spastic and in a wheelchair. He has verbal capacities (he articulates some words) and vocal capacities but this requires big efforts to him (difficult articulation, salivation, important latency). His cortical blindness does not allow him to learn a successful visual designation code. Furthermore, the learning of a tactile discrimination was not considered since he showed little interest for this exercise.

He suffers from hyperacusis which makes him feel discomfort to wear an audio headset (he turns his head to remove it). Taking all these things into account, the choice has been done to make the teenager learn how to use a contactor connected to a vocal box with head movements, so as to play various sounds or sentences. The teenager can thus communicate by movements of his head, that he is able to control thanks to the team of therapists. The contactor must be placed behind the head and it is necessary to explain him that he has to raise his head for a correct use (Fig. 1)



Fig. 1. Speech synthesis commanded by movements of head.

It is based on a sound board that enables to record several messages. Several function modes are planned (Fig. 2).

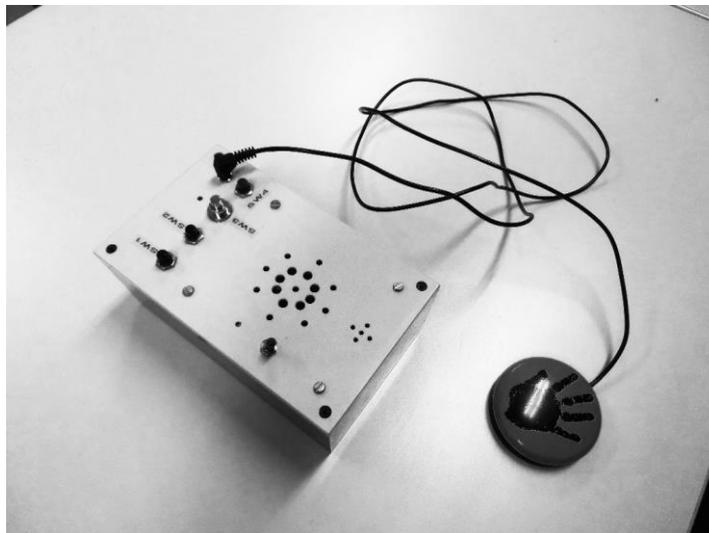


Fig. 2. Speech synthesis and contactor.

For example, a first click on the contactor activates 4 consecutive “wishes” messages : “go to the toilets”, “rest”, “watch TV”, “to eat/to drink”. A second click validates one of the four messages. Various sets of messages are possible to activate depending of the situation, in terms of needs,

wishes, feelings.

3.2. Improvement of the ergonomics of a speech synthesis.

The GoTalk speech synthesis enables some multi-handicapped children to communicate by pressing on a keyboard touch, each one being associated with a photo, an image or a pictogram. However, pressing precisely with the fingertip in the middle of the touch can be difficult. This is why a therapist had an idea to add a transparent plastic touch with 3 supporting points so as to be able to validate the choice wherever the fingertip is on the key. The child has thus less efforts to do to put his finger on a precise place, and the communication is eased.

Keys can be very easily removed when the purpose of a rehabilitation work can consist in a search for improvement of the positioning control of the arm, the hand, or a finger...

3.3. Rotating tray commanded by arm movement

This project was developed for a multi-handicapped teenager who possesses an athetotic movement perceived as negative since source of embarrassment in daily life. Work is centered around a work on constraint and instruction. The goal is to use this problematic movement so as to turn it into something positive. He is a very agitated young man who has great difficulties to "settle". His ability of listening to other people is weak. He systematically throws the objects which are presented to him. It is difficult to identify an intention of communication with its singing exercises.

A work on objects palpation without seeing them improved its differentiation between objects that can be thrown and those who can not. It enabled to give positive value to the athetotic movement. Thus, the work on objects palpation during individual session enabled him to make its athetotic movement positive since he is now able of controlling it.

A specially designed rotating tray enables the teenager to make a choice of images using only the movement of his arm, that he can control since his athetotic gesture is perceived positively. When the arm is moving near a proximity sensor, the tray turns and a new pictogram among those placed on it appears inside a small window. The therapist that knows well the child prepare the 4 images to place on the tray so that a choice can be done depending on his needs or pains (drinking, eating, watching TV, toothache...)

3.4. Designator wire

This equipment enables a girl suffering from polyhandicap to make choices between several images representing needs (meal, activities...) with the fingertips. It is useful when pointing out is not possible, either too constraining or non acquired (Fig. 3). Images are simply hanged on a wire with small pliers. Images and pictograms are chosen by the therapists depending on his observation of the child to help him express her wishes, needs, feelings...



Fig. 3. Designator wire

3.5. Ergonomic contactor support.

Choosing or expressing a need using a contactor put on a table can be hard for some children since they can not place their hand horizontally. The contactor inclination must be then adapted to the child capacities. In this aim, slopped supports has been conceived for 5 children aged from 6 to 10. On these supports, contactors are stuck skidproof strips so that they don't move when children will press on them (Fig. 4) Hand gestures implying a designation action are therefore made easier.

4. Discussion on each interface

Speech synthesis limit lies in the presence of repetitive movements on the contactor that can be observed when the request or the training takes too much time. It is then hard to answer if it is caused by nervousity, impatience, or if using contactor for too long created a stereotyped movement. In this learning phase, we can think that using a new material creates excitation. In fact, the teenager or child wants to show everybody that he can use the contactor.



Fig. 4. Slopped contactor support

Nevertheless, even if its use is bad, he understood the casual link. Is it due to nervousity or impatience? Is it about a stereotypical movement engendered by the long-time use of the contactor? At this phase of learning, we can think of "the excitement" of the new material as an important reason. Indeed, this teenager is waiting to show to all that he can use his contactor. However, the young man who uses it seems to have understood the casual link between using the contactor and an emitted sound. Furthermore, he also showed he was able to use the contactor with his wrist.

The ergonomics improvement of a speech synthesis by adding keys adapted to fingertips touch, turns out to be very positive for polyhandicapped children with imprecise hand control. Indeed, these touches facilitate the use of a GoTalk keyboard and enable these children to understand more quickly the casual link between action and sound. Thanks to their simple use, the multidisciplinary team can quickly progress in making a child learning how to use a speech synthesis.

The rotating tray commanded by arm movement enables to express various requests. The limit of this project lies in the latency between request and answer (rotating time) which raises problem to establish effective communication. The young man seems to wait the confirmation that its request is maintained by the system.

The designator wire turns out to be very effecient and enables a first learning of the designation function. It also enables the team to evaluate the child's symbolization capacity. This equipment can also be used for learning how to point out.

The use of sloped supports for contactors turns out to be particularly effective for the children

in wheelchair who have a visual limitations of horizontal plan. For other children with good motor skills, these supports enable an easier use of contactors. However, the limit of this tool lies in the fact that supports are not fixed to the table and can be thrown on the ground (willingly or not).

4. Perspectives

4.1. Designation by ITC

The initial idea is to enable young multi-handicapped persons to indicate photos then pictograms using a computer so as "to communicate" with other people. When designating with hands is too difficult (causes: spasticité, shivers or lack of gesture control) , designation using eyes can be a good solution. We thought of using a laser pointer mounted on glasses. However, the available tools are not adapted to polyhandicap, because of material constraints (glasses move because of the wheelchair headrest and backseat. Solutions are still being investigated.

A specifically designed software able to record a laser movement, could enable polyhandicapped children to communicate, by choosing various items on a computer screen. The items would be much more diverse than with only paper pictograms.

4.2. Designation with joystick

Some young multi-handicapped people are learning how the use of an electric wheelchair. Most of these wheelchairs required the use of a joystick. It seems interesting to develop a specific communication software which would enable these people to use a software tool with this interface.

4.3. Ergonomics improvement of an talking communication book

The ergonomics improvement of talking book keys is a work possibility to facilitate its use. The current keys are small and ask for a dexterity few children suffering from polyhandicap possess.

4.4. IT adaptation to "eye tracking"

A software and hardware adaptation to communicate with eye or mouth movement could able him to express himself. The use of a device filming the eyes of the handicapped child could be an interesting tool to develop the skills of communication of this young man.

4.5. Strip for ergonomic support of contactor

Knowing the limits listed previously, it is intended to develop a belt for maintaining communication supports on the table to enable the use for the biggest number possible of children.

4.6. Serious Games

We also work on conceiving serious games adapted to polyhandicapped and/or autistic children. Serious games are software including an amusing aspect that enables to deliver a message (educational, marketing, etc.) and/or to estimate the user by the interactions whom he will have with the game. Applications of serious games exist in various fields [9], particularly health and handicap [10] [11].

The first game we are currently developing - in the continuity of our acquired experience - makes children walk in a forest where they will find objects to be collected. The psychiatrist accompanying the children can get relevant information from their chosen items, i.e. knowing their preferences, according to the nature and the characteristics of the selected items. The psychiatrist could use them to improve the communication with the children.

5. Conclusion

Our work aims at showing that whatever communication method is chosen, it is essential to adapt the existing material or to create it so that the polyhandicapped child can appropriate and uses it easily. Multidisciplinary work is essential to the sustainability of communication method. The multidisciplinary will shed light on the chosen method and the possible evolution of its use. We were able to show that polyhandicap requires techniques specialized in the learning of relation and communication means. It also requires to be creative and imaginative.

The starting point of each development work must be made of the expression of needs and choice. The material could be made after evaluating competences and communication capacities. It is also necessary to take into account the specific answer time of polyhandicapped children to a request.

Finally, partnerships with various professionals must be done so as to improve communication techniques. Competencies of each member of the team are indeed sometimes unknown, and requires to be solicited for the whole project benefit.

6. References

- [1] <http://comm-ci-comm-ca.over-blog.com>
- [2] Annexes XXIV Ter au décret n°89-798 du 27 octobre 1989 relatives aux conditions de prise en charge des enfants ou adolescents polyhandicapés par les établissements et services d'éducation spéciale.
- [3] Loi n°2005-102 du 11 février 2005 pour l'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées.
- [4] E. Zucman, *Auprès de la personne handicapée - Une éthique de la liberté partagée*, 2007 ; Eds Vuibert, France.
- [5] D. Crunelle, *Le polyhandicap. Aider la personne polyhandicapée à se construire et à mieux vieillir (DVD)*, 2009 ; Ortho Edition, France.
- [6] B. Bobath, K. Bobath, *Développement de la motricité des enfants I.M.C*, 1986 ; Eds Masson, France.
- [7] E. Cataix-Negre, *Communiquer autrement. -Accompagner les personnes avec des troubles de la parole ou du langage : les communications alternatives*, 2011 ;Solal Editeurs, France.
- [8] K. Bartalucci, *L'incidence du polyhandicap sur la communication*, Actes du XXVIe Congrès Scientifique International de la Fédération Nationale des Orthophonistes, October 2014 ; Nantes , France.
- [9] J. Alvarez, D. Djaoudi, *Introduction aux Serious Games*, 2012 ; Eds Questions Théoriques, Valenciennes, France.
- [10] N. Hocine, A. Gouaïch., S. Cerri et al., *Adaptation in serious games for upper-limb rehabilitation: an approach to improve training outcomes*, 2015 ; *User Modeling and User-Adapted Interaction*, Vol. 25, issue 1, pp. 65-98, Eds. Springer Netherlands, Pays-Bas.
- [11] M. K. Holden, *Virtual Environments for Motor Rehabilitation: Review*, 2005 ;*Cyberpsychology and Behavior*, Vol. 8, no. 3, pp. 187-211 Eds. Mary Ann Liebert, USA.
- [12] P. Abellard, A. Abellard, *Virtual reality and serious games for rehabilitation*, June 2015; *International Conference on Virtual Rehabilitation*, Valencia.