

MULTI-SENSORY EXPRESSION AS A WAY OF COMMUNICATION FOR PEOPLE WITH PROFOUND AND MULTIPLE LEARNING DISABILITIES

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Abstract

The article presents the results of a research study conducted with people with profound and multiple learning disabilities (PMLD) in relation to the specifics of their communication. The study was conducted in the years 2016-2017 in Slovakia. Respondents in a research sample had a combination of intellectual, physical and sensory impairment. The research was carried out by a mixed-methods approach consisting of a qualitative and a quantitative phase in an Snoezelen therapy environment, in specially designed rooms with a typical colour scheme – a white room, a dark room, and a playroom. The first phase of the research was focused on the analysis of the use of the multisensory environment for a group of people with PMLD receiving residential care in the social services facilities. The article describes the second phase of the research aimed at the qualitative exploration of the communication aspects of people with PMLD and the possibilities of their support. Extraction of effective communication factors was accomplished through qualitative methodology from observations of people with PMLD interacting with professionals in multi-sensory rooms. The presented results are focused on the area of communication competences in the prepared environment using alternative and augmentative forms of communication. Communication has proved to be one of the main problems affecting the integrity and autonomy of a person with PMLD. It is closely related to the overall quality of life and the creation of social relationships and links to the social network. The findings are important for accurate and effective use of Snoezelen therapy environment in practice. The paper is a partial outcome of the project VEGA 1/0598/17 Evaluation of The Effective Factors of Multisensory Approaches in Therapeutic Education.

Keywords: expression, people with severe combined disabilities, Snoezelen therapy, communication

1 PEOPLE WITH PROFOUND AND MULTIPLE LEARNING DISABILITIES IN THE CONTEXT OF ASPECTS OF A MULTI-SENSORY ENVIRONMENT

A person with profound and multiple learning disabilities (PMLD) has many limitations in life. Restrictions requiring healthcare or compensatory aids also include limitations in everyday life, social status, family and social relationships. Expression in a common communication form is in many cases more or less impossible. It is for this reason that it is appropriate to look for a different way of communicating, maintaining and

establishing contacts and functioning in everyday routine activities. A multi-sensory environment is a means of self-expression even if it is not in the usual way.

A person with PMLD also has a problematic place in our society at the present time, preferring an inclusive approach. As these individuals may exhibit some specific and particular communication difficulties that further affect other personality components, perceptions of identity, family, and institution of which support is provided, their incorporation and acceptance is a challenging task for the society. Given the difficult consequences of this combined disability, searching for communication options remains a relevant topic. The multi-sensory environment, by its incites, calls for communication, but it is also a secure environment in which communication can evolve.

Fowler (2007, p. 22) claims that "multisensory rooms are a good space to support sensory activities in people with multiple disabilities". Multi-sensory environment takes into account their individual needs, possibilities and abilities (Ponechalová, Lištiaková, 2010). It is also suitable for receiving stimulation through basic touch therapy – basal stimulation (Friedlová, 2015).

In general, in Slovak conditions it is applied in specialized rooms, also called rooms Snoezelen therapy. They are appropriately arranged with various stimulation equipment and their installation in facilities providing care to disabled people is rather costly. In these types of facilities, there are currently three types of rooms that are listed by Fowler (2008):

- White,
- Dark blue,
- Colorful – playroom.

The white room is designed mainly for relaxation, it is a space for stimulating in a pleasant environment. A dark room is particularly suitable for stimulating vision if one of the impairments is also visual. The dark blue room is equipped with the same instruments as white, the difference being total darkness in blue color, the use of UV lamps and objects from UV active material, which provides a stronger stimulus. According to Pagliano (2001), the multi-sensory environment is particularly well suited for assessment, giving the diagnostician the opportunity to monitor the child in an environment that the stimulus itself offers.

According to Fowler (2007), it is deliberately designed to make its components stimulating to all senses. The components of multi-sensory rooms include (Stražilová, Lucká, 2011, quoted by Kováčová, 2011):

- A musical waterbed with speakers placed under the water mattress, spreading vibrations throughout the body, stimulating active spontaneous movement, relaxation of the muscle spasticity, encouraging positive emotions, making a smile on the face. The music flowing into the mattress is chosen based on personal choice;
- A leaf chair to stimulate vestibular perception, concentrate on fluctuating movement, and to realize the position of the body itself;
- Aromatherapy - an electric device producing a scent of smell, acting on gut feeling, choosing fragrance is chosen according to the intention of therapeutic intervention, activating, or soothing;
- Bubbler - produces bubbles falling on the entire body surface;
- A water tube - a visual stimulus designed to monitor rising bubbles and changing colors, also has a controller that a person with multiple disabilities can use to control colors and bubbles over and above limits;
- Mirror sphere - visual stimulus, serves for visual-motor coordination;
- Color-changing optical fibers - serve for visual stimulation, active observation of the moving light stimulus, hand dragging, color exploration.

A colorful multi-sensory room or playroom encourages movement, it is full of colors and it supports fantasy. The colorful room is also most similar to a room typical for facilitating therapy of sensory processing (Lessner Lištiaková, 2017).

In the play room, an expert has the opportunity to prepare obstacle lanes with different focus:

- Static obstacles in space,
- Balancing obstacles, bulk boards, benches, designed to maintain balance,
- Changing the body position in the space through a swing, balancing plate,

- Scooter board intended for movement in the room in the room or in the seat. Structure in a multi-sensory environment creates space for the client's own language, although it may not always be typical of the environment (Fábry Lucká, 2017).

The concept of expression can be characterized as revealing, an expression of a particular impulse. Expression is actually a result of an emotional or affective relationship with emotional coloring. Expression is the basis of each of the therapeutic techniques that Slavík (2009) considers an indispensable part of specialized intervention. It is the capacity of a person who is motivated to express themselves. The projection can be achieved through movement, drawing, melody, and the like. Expression may not be just a finished "product". Expressivity can be considered even when one responds emotionally - both positively and negatively. Expression is the message of our physical and psychological "I" (self), and in an environment in which expression is induced by provoking individual sensory perceptions.

Expression is possible even if there is no verbal communication. Movement expression is the expression of a person through body action, not necessarily an active movement in the sense of exercise; in a person with limited momentum, often a physical expression is only a minimal movement act. Expressive communication is thus possible even if it is not at first glance in the usual form.

A multi-sensory, prepared environment is also suitable for verbalizing psychomotor-oriented activities. It offers security, creativity and shared experiences for a group form of work. In specific cases, it is possible to use it in an individual form, such as:

- Body stimulation through body change (swing, water bed, weighing boards),
- Physical stimulation through visual stimuli (as well as visual-motor support), for example, when using optical fibers or a bubble cylinder,
- Physical stimulation through vibrational stimuli (waterbed, vibrational aids) (Fábry Lucká, 2017).

In the years 2016-2017, a research was conducted in Slovakia on the use of aspects of multi-sensory environment in facilities providing some form of service to people with PMLD. In the following paragraphs we will present a research proposal and partial results focused on the area of communication support in this environment.

1.1 Research Study

The research was focused on the qualitative study of the impacts of multiple disadvantages on the communication area and the related building of new relationships and links. The aim was to explore direct relationships with the application of specific intervention strategies in the context of multi-sensory aspects.

The survey sample consisted of five respondents with PMLD who were involved in the intervention in the structured multi-sensory environment. There were three women and two men with communication problems in which communication was conducted in an alternative way, through gestures, nonverbal or neuro-vegetative expressions.

The research was conducted from January 2016 to January 2017, as a pilot study for continuing the project on aspects of specific interventions in therapeutic pedagogy, followed by the creation of categories on the basis of which we analyzed and interpreted the data obtained in the context of communication.

The method of research data processing was a case study, for which data was collected through direct observation in the intervention process in a multi-sensory environment during individual meetings. Reichel (2009, p. 29) argues that "the subject of the study is trying to describe the case study in detail, yet in a complex way, in its complexity and integrity". Gillham (2005) considers the case study to be the greatest advantage of being specifically focused on the individual, when describing the real situation of the individual "here" and "now".

Based on observations and data we have identified significant variables in communication, namely the use of compensation strategies in communication.

On the basis of the information we obtained, we identified the specifics of the communication process in terms of providing intervention in the institutional environment, in the context of:

- Relationships,
- Support from the institution,
- Support from the family environment.

In these areas we identified up to 250 variables. Subsequently, we divided them into areas, three subcategories and categories which are clearly presented in Table 1.

Autonomy	Strategy in client communication	Communication strategies – other people
Uniqueness in communication	Reluctance to communicate	Ignorance of the communication system
Custom dictionary	Communication partner preference	Fear of communication
Own nonverbal expression	The need for an interpreter	Predicting communication
Receiving communication from the surroundings	Rejection of communication	Insufficient time to answer
Support for natural expression	Inability to choose a communications partner	Absence of communication – time factor
Inability to express oneself to the environment		Incorrect interpretation of communication
Dominance versus submissiveness		Fluctuation of employees of the facility where they are provided services

Tab 1- Communication aspects

The problem area is the perception of **autonomy and uniqueness**, both verbal and non-verbal. It is often disrespected because the speech is marked by the current situation and the client's condition. The client is forced to express themselves immediately and to the point. Support for communication through various communication strategies is an area where support from both professionals and the family environment is needed. Accepting a client's offer for communication is a support of his / her personality competencies, or through giving the client a feeling of freedom of choice. Providing the ability to communicate – to be dominant, is often a new option for the client, because they are mostly only a passive recipient due to communication constraints, waiting for someone to contact them. Promoting natural expression of the client is another meaningful unit for recognizing and localizing difficulties, as communication is often specific rather than usual (Research Demonstration 1).

Research demonstration 1: M. communicates with the environment mainly through the component of non-baldness - eyelid. Her eyes closed with disagreement, her eyes open when she is happy. Moving the eyes to the sides means that communication needs to be continued and she is looking for answers. From the start it is a difficult process, but for a person who repeatedly communicates with her it is possible to understand. Without knowing her autonomous nonverbalism, her physical "I" it would not be possible for her to communicate with her surroundings. She has a spastic form of cerebral palsy, communication is not easy for her. Therefore, she communicates best when she has the opportunity to relax, feel comfortable and safe. This feeling is supported by the stay in a multi-sensory ready environment, in a specialized white room. As a favorite place she chooses a music waterbed. She is gradually releasing her body and communicates through her non-verbal means about important topics such as her stay at home, her mother's health, or the importance of having coffee after that meeting.

The field of communication strategies includes a **lack of communication opportunities**. The clients are often so busy with the program and device mode during their stay at the institution that they do not have the time and the power to create space for communication. In communication, a relatively common mis-interpretation of interaction was identified for various reasons, whether it is the diversity of clients' communication to each other or the unwillingness to understand another form of speech. Reluctance to communicate is particularly evident when there is insufficient support from the surroundings – whether family or institution. Improper interpretation of communication is a common problem, especially if it is associated with a lack of experience with the type and specifics of communication. Another important unit is the need for

an intermediary or a guide in communication. However, this can also lead to a lack of privacy. An intermediary should be a person the client knows and trusts (Demo from Research 2).

Research Demonstration 2: B. communicates through a communication table with real photographs. This device still keeps her connected, as it often links to the topics that interest her. The subject of her dialogues, however, is usually a person of reference, a favorite drink or activity. In the multi-sensory environment, she works with an expert who understands her vocabulary. The role also plays a long period of cooperation. In a white room, B. is relaxed and without a communication device immediately points to a swing in the shape of a falling leaf. With some help, she moves. As soon as the specialist sits her down, she relaxes and begins to use voice and speech. This is the space for her to communicate through the sounds and respond to communication even verbalized "yes" and "no".

The identified issues in the area of communication strategies on the part of the environment include **unwillingness to communicate by staff, especially in relation to education**. There is also a barrier to communication of the client in terms of the aspect of high turnover of employees. Employees, despite the effort, sometimes fail to learn how to communicate with clients, and leave the facility to another job. Employees appear to possess a problematic lack of patience in communicating with the client, and thus not providing enough time to express a communication intention, which presents another area of misinterpretation of client communication. The last issue of this category is non-communication by the team due to a full or non-compatible timetable. Thus, the client can only feel like "goods" shifting from an employee to an employee without their personal commitment and free will (Research Demonstration 3).

Research demonstration 3: P. communicates verbally, but due to the spastic form of cerebra palsy, his speech is difficult to understand. P. communicates especially with women who meet his ideal of beauty. As he is not mobile,- he uses a mechanical wheelchair. An employee is there to support the interaction and participation in the environment.

The employee communicates with him - "How are you? What's new? And what do you want to do inside? What do you need that room for? She does not give a chance to the client to respond, she just leads a monologue. When P. takes a breath to respond, he is immediately interrupted. The employee is not interested in the answers and does not wait for the reactions of the client.

1.2 Conclusion

The aim of the qualitatively oriented research study was to identify and analyze communication variables in people with multiple disabilities in the process of assessment and intervention. We were interested in what specifics in communication strategies can be identified in the clients themselves, their close family environment and the environment of the institution where the intervention is implemented in a multi-sensory environment.

Specifically, we defined the communication competencies of people with multiple disabilities in three categories – client / individual with multiple disabilities in the context of relationships, client in the context of institutional support, and client in the context of family support. We considered the research problem based on more than 250 meaningful units.

In the context of the client, we identified abilities in the area of communication competencies - removal of specific / non-specific reasons for rejecting communication, providing the optimal space for communication, active use of alternative ways of communication. On the basis of the identified categories, we have also defined limits in the following areas - inadequate communication skills, problems communicating and developing communication for specific or non-specific reasons, minimum space for communication, problems with using alternative ways of communication, selective communication on the part of the client.

In the context of the family, we identified the client's possibilities – change of communication strategies in the family, correction of parents' attitudes to the phenomenon of disability. Limits can be identified in the following categories – parents' communication strategies towards the client and the client's communication strategies towards parents.

On the basis of the above variables, we have also identified communication strategies on the part of both the experts and the client (client's autonomy in communication – expert understanding, the possibility to express themselves in the form of their own expression). Limits can be identified in the following categories: client communication strategy towards other clients of the institution (misunderstanding of another client on the basis of different alternative means of communication) and communication strategy by the institution's experts (misunderstanding of communication, ignorance of the alternative and augmentative communication system used by the client).

The multi-sensory environment appears to be an appropriate structured environment for the assessment and intervention process. In this environment, the clients have the opportunity to express themselves through their own means of expression and to create their own communication system. Based on observations, we also found in this environment that, in particular, the environment of a white specialized room leads to a relaxation that facilitates communication on both sides - both the professional and the client.

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