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"How Well Do I Know You?":

Intersubjective Perspectives in Music Therapy When Working with Persons with Profound Intellectual and Multiple Disability

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Received: 6 June 2019 Accepted: 8 March 2020 Published: 1 July 2020

Editor: Daphne Joan Rickson Reviewer: Juyoung Lee

Abstract

The limited possibilities of understanding the inner reality of people with profound intellectual and multiple disabilities (PIMD) pose strong barriers for the development of a therapeutic relationship. Based on reflection on practice this contribution describes how music can be used for the realisation of continuous, attuned and harmoniously intertwined interactions that enable to gain deeper understanding of the person with PIMD and identify his/her positive personality traits. These reflections may be grounded in the theoretical framework of intersubjective communication. The author describes the role of music in both short-term and long-term interactions and discusses the benefits of music therapy for people with PIMD as well as for the interdisciplinary team support.

Keywords: *multiple disabilities, interaction, relationship, understanding*

Introduction

I'd worked with a girl called Lucy for two years. She was diagnosed with autism and was admitted to a preschool facility for children with special educational needs (SEN). Despite the fact that in the early stages of therapy positive changes in her behaviour and our interactions were observed, in the long-term progress began to wane. Lucy had been happy when I played for her but was less able to sustain or increase her activity during the interaction. I'd often ask myself and colleagues whether there was any benefit of this therapy for her. Parents as well as the facility's directors had always insisted on continuing. It was true that no other intervention at that time showed greater effect. Lucy had, moreover, seemed very happy during music therapy sessions. The therapy had ended when she went on to elementary school. I hadn't seen her for a while after that.

Two years later I'd been finishing my dissertation. One day I went to one of the schools in which I had been collecting data for the research, to perform a short musical program for several classes as a way of showing gratitude for their cooperation. About half-way through this program the door had opened and Lucy, who was just finishing second grade,

Publisher: GAMUT - Grieg Academy Music Therapy Research Centre (NORCE & University of Bergen)

DOI: https://doi.org/10.15845/voices.v20i2.2843

> came in. Her facial expression was one of happy surprise. She sat very close in front of me, stared into my eyes, and laughed. She seemed to emerge from her autistic world in a way I had never experienced before. A few minutes later she seemed to close up, sat further away from me again, and reacted in her usual pleased but somewhat distant way. This short encounter, however, was enough to show me how important music therapy had been in her life.

Stories such as this one had been rather rare in my music therapy practice with people with profound intellectual and multiple disabilities (PIMD). However, their importance lies in the fact that they helped me get a glimpse of the person who is often hidden from the outside world by an almost impenetrable communication barrier. Severe limitations in mental and physical functions create a state in which it is extremely difficult to understand a person with PIMD. This complicates the course of the music therapy process and from the very first moments of establishing contact with this group of people poses a challenge (Lee, 2014). The music therapist often finds themself in a vacuum-like space trying to capture any kind of signal that could point them in the right direction. However, working with music provides the therapist with a unique means through which it is possible to partially overcome some of above mentioned problems.

Background on music therapy practice of the author

First, I would like to introduce my music therapy practice. As a music therapist I have been engaged mostly in close interaction with people with PIMD. Many of those were diagnosed with cerebral palsy and experienced a combination of profound and severe disabilities in the areas of cognition, mobility, communication, and perception. Besides my private practice I worked as a music therapist and a special teacher in a school for children with special educational needs in the Czech Republic. There, pupils with PIMD were taught according to an educational program that was mainly aimed at practicing basic skills of every-day life, independence, communication, and health-related goals. Education based on this program usually took place in a special class and teachers had a big open space available for work. I would spend several hours a day engaged in direct work with my pupils. In addition to group and individual music therapy, I have had the chance to experiment with creating a therapeutic environment that enabled a complex application of various interventions. The integration of these interventions into a natural educational and life context proved to be very beneficial for pupils with PIMD. We also tried to get these pupils involved in community-oriented arts therapy programs aiming to reduce the impacts of social exclusion. Music therapy played an integrative role, which was facilitated through a complex process aiming to understand the thoughts, emotions and motivations of my pupils, using music as a bridge in communication. One of the greatest advantages of this job was that I could observe persons with PIMD in many different situations within educational / therapeutic contexts as well as in their ordinary lives.

Summary of music therapy approaches in people with PIMD

A short summary of music therapy literature and research evidence about people with PIMD will be offered in this section. Traditionally, the developmental and neurobehavioral perspective is being accented in many publications dealing with music therapy with this population. The developmental perspective is emphasized in application of Greenspan´s model in music therapy with people with PIMD by Barbara Wheeler & Sylvia Stultz (2008) in AQR (The Assessment of the Quality of Relationship) scales based on theories of Daniel Stern (Schumacher, Calvet, & Reimer, 2019) or Betz Held Strengths Inventory based on theory of Jean Piaget (Betz & Held, 2013). There is considerable behavioural research about contingent music (Standley, 1996) and music therapy with people with PIMD may be integrated into neuro-rehabilitation. An example of this is music therapy with sensory stimulation (Meadows, 1997), techniques of

neurologic music therapy (Thaut & Hoemberg, 2016) or somatic listening, such as vibroacoustic therapy (Kantor et al. 2019; Katusic, Alimovic, & Mejaski-Bosnjak, 2013).

Another traditional perspective found in music therapy literature is connected with musical engagement of people with PIMD. Paul Nordoff and Clive Robbins (2007) offerred guidelines for participation in vocal and instrumental activities. Orff music therapy and some other music therapy approaches honour the well-known methods of music education (Voigt, 1999). There are protocols for participation in musical movement activities (Meadows, 1997), and participation in instrumental and vocal music therapy activities may be supported by different adaptive strategies (Wheeler, 2013), including musical technologies (Akazawa, Okuno, & Kawai, 2014).

Important areas of current research in people with PIMD are communication and interaction (for a summary of music therapy literature in this area see McFerran, Lee, Steele, & Bialocerkowski, 2009). This area is closely connected to most important core domains of quality of life, e.g. interpersonal relations, social inclusion or emotional well-being (Petry & Maes, 2009). Several authors found that the communication in persons with PIMD may be developed through song-choices procedures (Elefant, 2010; Lee & McFerran, 2012; Thompson & McFerran, 2015) and other studies focused on the effects and conditions that support communication development (Gilboa & Roginsky, 2010; Holck, 2004; McFerran & Shoemark, H., 2013; McFerran & Stephenson, 2010). Anne Steen Møller (in Wheeler, 2013) proposed a theory of five interactive stages in music therapy with people with PIMD that can serve as a manual for assessment of interaction level and for further planning of intervention. In most developmental models of music therapy, e.g. creative music therapy, Orff music therapy or an approach of Karin Schumacher, there is a strong focus on building attunement, sensitive responsiveness, co-regulation, emotional bonds, and many other components typical for good interpersonal relationship. These qualities are essential for positive interaction process found in studies of persons with PIMD and their caregivers (Hostyns & Maes, 2009).

Theory of inter-subjectivity in music therapy with people with PIMD

Close observations of mutual interactions between therapists and people with PIMD may give us more information about their inner world. This is possible to explain by the theory of intersubjective communication that was described as the ability to fit the subjective control to the subjectivity of others (Trevarthen, 1979). During the first months of development, infants are able to communicate with innate skill, and this innate intersubjectivity leads before the end of the first year to the learning of culturally conditioned meanings(Trevarten & Aitken, 2001). These protoconversations are realised through vocal, movement, or tactile means and reflect closely the intersubjective communication of people with PIMD. Because there is a close connection between early non-verbal communications and musical process based on the theory of communicative musicality (; Malloch, 1999; Malloch& Trevarthen, 2009), the theory of intersubjectivity can be used as a fitting theoretical framework for the music therapy in people with PIMD.

Some authors suppose that music therapists´ subjective feelings could be considered as a reflection of clients´ feeling states in an intersubjective perspective (Wheeler, 1999) or as Anthi Agrotou (1998, p 49) wrote “the therapist's emotional response to the patient [countertransference] enables him/her to voice the patient's affective state through his/her own music.” These outcomes of intersubjective communication analysed from the part of therapist may be helpful for understanding the experience of people with PIMD, because it is not possible to obtain their reflection directly (Lee, 2014, p. 48). It is sure, that music therapists´ reflection of intersubjective communication may be very useful for understanding the people with PIMD, although it should be accompanied with a necessary level of a critical attitude. The reason is a strong risk of bias in interpretation of non-verbal signals in some people with PIMD. I remember several persons with severe cerebral palsy who were not able to express their negative feelings unless they started to cry sorely. This gap in their non-verbal communication

was filled by signals that were usually interpreted as a smile or as feelings of pleasure. Since in ordinary clinical situation we miss other possibilities how to verify our interpretations, there is a good reason for carefulness. However, in music therapy practice there is no option how to get closer to the personality of people with PIMD.

The nature of intersubjective communication with people with PIMD had always intrigued me, just as it did a number of my colleagues. I found it important to focus on this positive aspect of their being rather than on their disabilities. I had asked myself whether it was possible, at least partially, to understand the hidden inner psychodynamic processes that must inevitably impact the interaction with these persons in music therapy and whether we could capture a glimpse of their world that is so hard for us to perceive, as outsiders. The purpose of this paper, therefore, is to share my understanding of the unique significance that music can have in a developing relationship with people with PIMD. The following sections explore the specifics of musical interaction at any given moment as well as the development of relationship over longer periods of time.

Verbal and musical interactions at any given moment

As human beings we have an inherent need to search for meaningful interactions. Psychotherapist Albert Pesso described these interactions as 'shapes' and 'counter-shapes' (Pesso, Pesso-Boyden & Vrtbovská, 2009). When analysing verbal interactions with people with PIMD it is evident that the core problem is their inability to offer responses that are meaningful to their communicative partner. Interaction is almost exclusively one-sided (coming from the therapist towards the person with severe multiple disabilities) with minimal reciprocity. Since such interactions are usually perceived as uncomfortable for the communication partners and since the therapists, even under these circumstances, have an intrinsic need to establish a fluent interactive stream they unconsciously start using various compensatory strategies (Figure 1). These strategies have repeatedly been observed during analyses of video recordings of interactions between the helping professionals and persons with PIMD (Kantor, 2013).

During verbal communication the compensatory mechanisms involve mainly making comments for the person with PIMD, also called *parallel talking* (Lechta, 1990). Following remarks made by a teacher towards a girl with PIMD may serve as an example:

> Hello Jana, I'm happy to see you! How was your weekend? (Pause) Well, I see you look happy, I'm sure it was good, right? (Here, the communication partner fills in the empty gaps in the communication by making comments which enable a fluent continuation of the interaction. There is a pause, a smile and waiting for response). I went to…" (Kantor, 2013)

The quality of an interaction that uses this strategy is determined by the person's ability to empathetically understand the person with PIMD, their knowledge of the context of a given situation, and their ability to deal with their own feelings about perceived communicational failures. It is difficult to maintain such interactions over an extended period of time due to eventual lack of content.

Musical interaction, on the other hand,has specific and undeniable benefits. In musical interaction there can be high levels of synchronisation between the therapist and the person with PIMD which fosters the continuous reciprocal interaction over a longer period of time. Instead of concrete semantic themes that can hardly generate a prolonged communication, musical communication can be based on emotional content. Music assists in maintaining an interaction that uses various interaction patterns (Schumacher, Calvet, & Reimer, 2019). The silence that may occur when the music therapist gives space to the person with PIMD must not necessarily be perceived as uncomfortable since it weaves into the pattern of a developing musical form. Moreover, therapists may also react not only to non-verbal communication, e.g. the breathing rhythm (Pavlicevic, 2007), but may also reflect their own feelings and incorporate them into their improvisations as ideas for further course of the interaction (Figure 2). This tech-

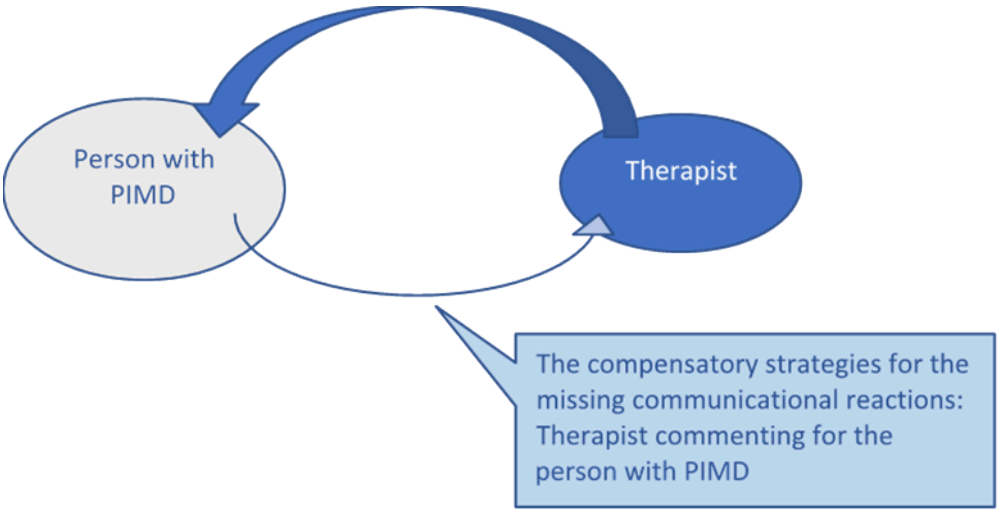

Figure 1

Scheme of verbal interaction based on compensatory mechanisms (Author, 2014).

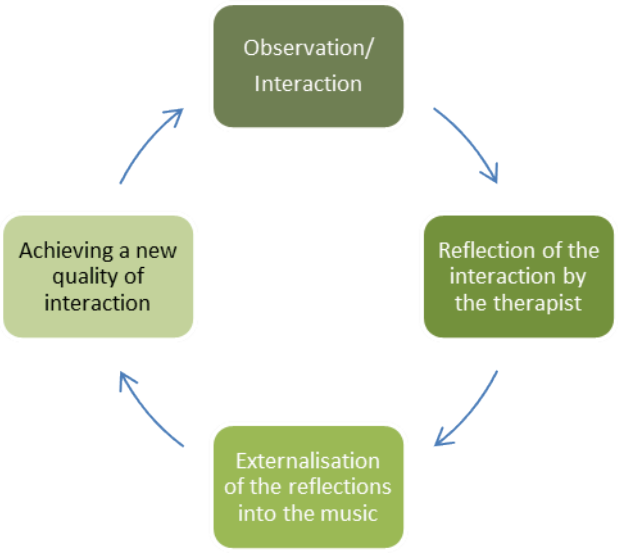

Figure 2

Incorporation of the therapist's insights into the musical situation.

nique that fosters the feeling of reciprocity and continuation has been mentioned in different forms in the music therapy literature.

Empathic improvisation, for example,

> involves a therapeutic method that was applied by Juliette Alvin where, typically at the beginning of a session, she would play an improvisation on her cello that empathically complemented the client's way of being. Specifically, it meant taking into account the client's body posture, facial expression, attitude on that particular day, previous knowledge of the client's personality and characteristics, and then playing something to the client that formed a musical interpretation of their way of being at that moment. (Wigram, 2004, p. 89)

This process is circular, and its quality is influenced by the ability to observe, to achieve synchronisation, to correct time reactions, etc.

The process of incorporation of the music therapist's insights into the music and its use in the interaction situation may be illustrated with the following example. I had once worked with a girl called Dana both as a special educator and a music therapist. She had a severe form of cerebral palsy manifested by diparesis, intellectual disability, anarthria, epilepsy, and other health problems. The girl had been the youngest in the

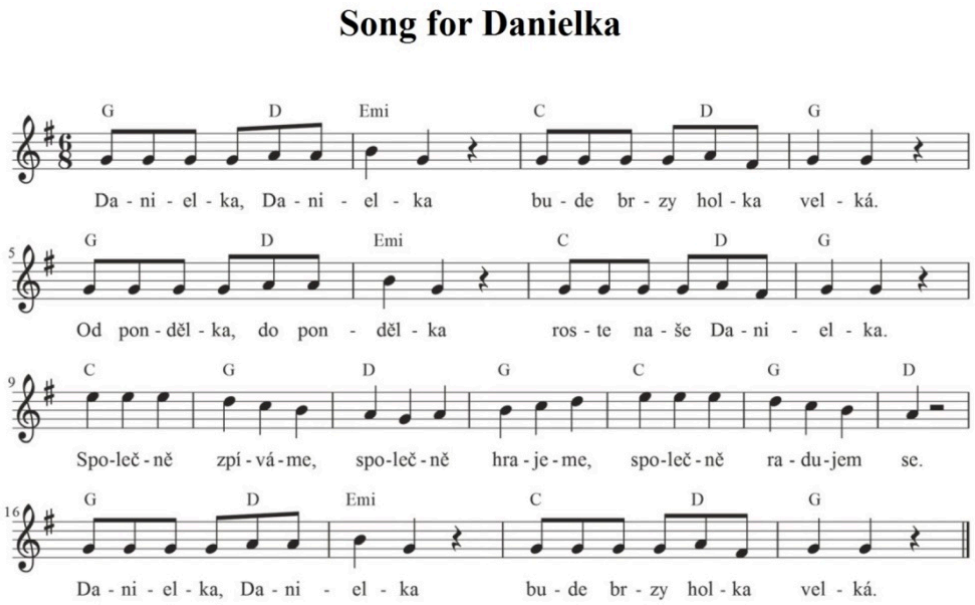

Figure 3

Song for Danielka (Kantor, Ludíková, & Drlíčková, 2016).

class and had seemed petite and fragile next to other pupils. As I had realised this is how I perceived her, I had composed a short song about it (Figure 3). The translation of the song is as follows: *Danielka, Danielka, soon will be a big girl. From week to week our Danielka grows. We sing together, we play together, we rejoice together."*

Dana had shown interest in the song. Despite the fact that most of the time she had been shut in her own world, her sounds and gestures had become lively upon hearing the song, and she had pointed towards herself. I had asked whether I should play the song again, and, non-verbally, she had tried to express a "yes." I had repeated the song a few times and then had led a monologue about the idea of what it would be like for her to grow up. Dana had liked the song that was closely connected to her, very much. The original self-reflection on an insight had been incorporated into music and brought into the relationship with Dana in order to empower her. This had opened up a new theme of growth and empowerment that fired up our interaction and made it develop to a new dimension on a musical as well as non-musical level. Without music, it would not be possible to achieve this kind of interaction with such a high level of intersubjective connection.

The themes of musical interactions

Although there is limited research in music therapy literature systematically exploring therapists' self-reflections on interactions with people with PIMD (e.g. Lee, 2014; Lee & McFerran, 2012), the nature of such interactions is obvious in some case studies (Nordoff & Robbins, 2007; Wigram, 1991, etc.). Most musical interactions with people with PIMD revolve around care, getting attention, praise, showing respect, musical overcoming of strong emotions and experimenting with musical stimuli and reactions to them, as attested in interviews with music therapists (Kantor, Ludíková, & Drlíčková, 2016). This analysis of music therapists´ self-reflections suggested they intuitively perceived that an important goal of their intervention was to meet the psycho-social needs of these clients. That is, they wanted to address needs that are closely linked with interaction, belonging, understanding, respect, and appreciation. (Ayinde, 2013). On a similar note, Juyoung Lee (2014, p. 70) described the claims of her research participants: "Their roles are not only to provide joyful experience but also to explore and maximize the clients´ potential developments and to support their psychosocial needs."

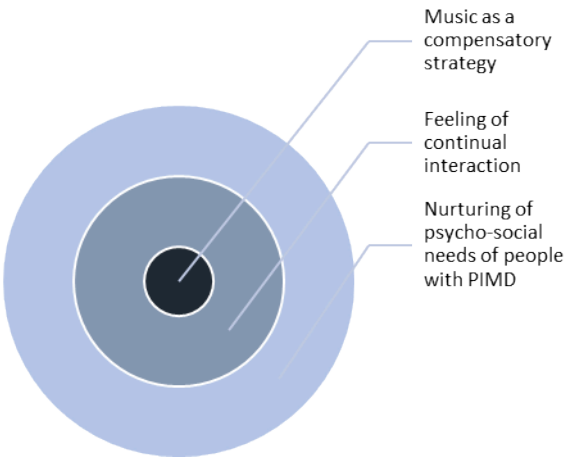

Figure 4

Musical interaction is the key to saturating the deprived psycho-social needs in people with PIMD.

This is a very important benefit of music therapy, as the research in people with PIMD informs us that the main issue concerning the interaction in everyday life is not defined by its quantity, but by a low level of bio-behaviour states of people with PIMD (Munde, Vlaskamp, Ruikssenaars, & Nakken, 2009) and by the quality of interaction that is not satisfying for the communication partners (Axelsson, Granlund & Wilder, 2013; Axelsson & Wilder, 2013).

Long-term development of relationships with people with PIMD

Some authors described the development of long-term relationships between music therapists and people with PIMD in terms of regular and consistent engagements, showing responsiveness and building familiar interaction routines (Lee, 2014; Drlíčková, 2015), in expressing needs for human intimacy, creative exploration, autonomy, and in creating attachment bonds (Agrotou, 1998), in two-side acceptance and increasing understanding for a client (Kantor, Ludíková, & Drlíčková, 2016), etc.

A few years ago, a research method had been developed for this purpose - video microanalysis guided by interpretative phenomenological analysis – that produced "a thick, rich, and unique description of a meaningful moment, which occurred between a music therapist and a client who has profound intellectual and multiple disabilities" (Lee & McFerran, 2014, p. 367). There is a need for further research in this area that will explain the hidden process of intersubjective communication between the client and the therapist in different stages of their relationship development. As shown in the introductory case there is a certain evolution happening under the surface of observable reactions and relationship is being strengthened on the part of the therapist as well as the person with PIMD. Unfortunately, it is very challenging to describe this evolution without clear communication and behavioural reactions from the client.

Another idea is that thanks to the establishment of a long-term relationship, professionals are able to gain a deeper understanding of the person with PIMD and to name their positive personality traits (Kantor, 2013). The theory of intersubjective communication offers a framework for explanation of how this understanding is gained (which the professionals usually are not able to explain). Research evidence (Kantor, 2013) shows that positive traits of people with PIMD are most often related to gratitude, strength, sensitivity, spontaneity, sincerity, authenticity, openness, curiosity, sense of accomplishment, enthusiasm in group activities, assertiveness, friendship, students having strong personalities ("students are themselves"), joyousness, sense of humour, emotional harmony, being content with little, having ever-good intentions, and the desire to learn and to gain independence.

This finding is significant in relation to the criticism that the process of evaluation and documentation sometimes receives, due to the fact that more often than not the

portfolios of these persons are lists of deficits and negative statements (Betts, 2012). The pollution of therapeutic, pedagogic, and social professions by the medical paradigm had in the past led to seeing these persons through the distorted focus on their disabilities. In the 1960s it was still possible to encounter research that tried to prove that it is not possible for a family with a child with PIMD to have a happy life (Trapp & Farber, 1962). The studies were sometimes aimed at collecting evidence to segregate the persons into institutional care. Another impact of such studies, however, lay in the great stigmatisation of severe and profound functional disability. In the Central European setting the situation lasted much longer. It was not until the 1990s that a gradual normalisation of the living environment of this group of people had begun, had led to their participation in education, and to a progressive application of standards for the achievement of an adequate quality of social care.

A music therapist working with a person with PIMD needs to have knowledge of the course of the development of the society's attitudes towards this group of people in order to understand the social context of intervention. Their important goal is to bring information into the teamwork that are related to the personality, potential, competencies, abilities, and other positive characteristics of people with PIMD. Based on authentic statements of music therapists it maybe said that music therapy experiences enable people with PIMD to be seen as people with unique personalities and concrete traits, rather than characterised by their disabilities. Of course, music is mainly a means in this process, although essential. The music itself must be supported by the personal and therapeutic maturity of the therapists.

Conclusion

That the continuous, attuned and mutually fitting musical interactions can support a long-term relationship development may be one of the arguments for the important role of music therapists in interdisciplinary teams, especially in schools and social care services. Music therapists may be a key person to bring unique set of information about the person with PIMD due to a deep intersubjective experience. This concerns especially information about positive personality traits and competencies that are important for social inclusion of these persons and perceiving them as valuable human beings.

Furthermore, my aim in this article is to increase the hopes of therapists working with this population. The stories of people with PIMD often miss a happy ending and results of therapy may be transitory or hard to observe although the intervention is long-term. As music therapists working with this group of people, we need, therefore, to acquire an unflinching faith in the potential of musical interaction and the reciprocity of human relationship. We need a strong belief that repeated musical interactions are not lost behind the mask of disability and they do support the well-being of our clients. Without these, music therapy cannot contribute to so longed-for inclusion trends that are, in the case of many people with PIMD, still more a fiction than reality.

About the author

Dr. Jiří Kantor is a music therapists and special teacher with more than 10 years experience with persons with PIMD and their families. Nowadays, he is responsible for MA in music therapy at Faculty of Education, Palacký University in Olomouc and co-responsible for the activities of mentee centre from Palacký University affiliated to JBI Centre of Excellence at Masaryk University in Brno. His research activities focus mainly on vibroacoustic treatment, arts therapies in schools, music therapy and special needs.

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