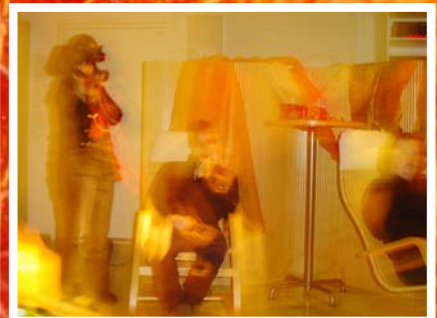


**Multisensory Environments in social care:  
Participation and empowerment in sociocultural multisensorywork**

Doctoral academic thesis  
James Cook University  
Australia



**Marja Sirkkola**

Multisensory Environments in social care:  
Participation and empowerment in sociocultural multisensory work

Thesis submitted by  
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In August, 2009

**for the degree of Doctor of Education**  
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Participation and empowerment in sociocultural multisensory work

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*Experience occurs continuously, because the interaction of live creatures and envioning conditions is involved in the very process of living.*

(Dewey, 1934, p. 35)

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Finally, I have to ask; ‘Am I happy with this work?’, and the answer is ‘Of course not completely’, but I’m happy that the learning process still continues and that there are interesting plans and opportunities for the future. This ‘EdD-trip’ has been such an interesting experience.

*The best moments usually occur when a person’s body or mind is stretched to its limits in a voluntary effort to accomplish something difficult and worthwhile ... optimal experience is something that we make happen. (Csikszentmihalyi, 2002, p. 3)*

I dedicate my work to ‘Lynn and David’

## **Abstract**

This Doctor of Education Portfolio Thesis reports on a set of four applied and authentic research activities directly related to my workplace. I coordinate courses at HAMK, a Finnish University of Applied Sciences that prepares students and staff in the use of Multisensory Environments (MSEs) in social care. MSEs are dedicated spaces where multisensory stimulation is controlled to match the perceived needs and interests of people with disabilities. MSEs are used internationally for sensory stimulation, pre-cognitive communication, social interaction, leisure and relaxation, therapy and education. Furthermore, MSEs have become a popular tool for many social care providers in increasing social wellness of people who are vulnerable to being marginalised.

Although MSEs are thought to hold considerable potential in the facilitation of empowerment and participation, very little research documenting evidence based practice is available to inform practitioners. This research, therefore, seeks to investigate MSE use in Finnish social care with people with moderate to profound and multiple disabilities. The research focus is the promotion of client participation and empowerment, with the added goal of using research findings to inform the development of university and other course materials for the preparation of students and staff.

I began my research with a qualitative pilot study to collect information on the current nature of MSEs in Finland. A semi-structured questionnaire was given to 23 MSE practitioners. Even though the results of this study were not translated into English, they strongly influenced the formulation of my research questions. This was because the results made it clear that the way the MSE was used in Finland was different to the way it was used elsewhere. MSE practitioners tend to be guided by a particular form of social pedagogy called sociocultural animation. They also challenge the notion of the MSE being a dedicated space, choosing to continue MSE type activities into everyday environments. I therefore, introduced a new term ‘sociocultural multisensory work’ to describe this Finnish style MSE experience.

The three research questions at the core of this work are as follows:

1. In what ways can participatory action research (PAR) be applied with people with moderate or profound and multiple disabilities in the context of the MSE?
2. What is the nature of sociocultural multisensory work?
3. What are the implications for staff education in regard to develop MSEs and sociocultural multisensory work?

The first study relates to the first question. It consists of a survey of the MSE research literature to identify whether or not any methods currently exist where client participation and empowerment is employed. There is also a focus on the possibility of using participatory action research for MSE research. The analysis of 42 studies employed Kemmis and McTaggart's (2000) five aspects of practice to sort and critically analyse the literature. The study revealed that even though the participation of people with vision impairment and multiple disabilities has not been explicitly employed in research, MSE practitioners did express interest in developing more effective communication strategies to promote participation. Key strategies identified included multidisciplinary teamwork, staff education that explicitly teaches participatory research knowledge and the application of an ongoing reflexive-dialectical perspective on practice. The literature review also revealed that there were precedents for using PAR in MSE research. The precedents were both at the individual and social levels. The research was both qualitative and quantitative. However, the participation of the clients was at a rudimentary level with the focus more on adhering to the epistemological demands of the paradigms.

The second study also relates to the first research question. It reports on an innovative, four-month multimedia music and dance project, conducted in a Finnish MSE at a vocational special school in a city in southern Finland. This

project involved 12 adolescents with moderate to severe learning disabilities in a participatory action research activity that culminated in a community concert. The course adopted a sociocultural approach to develop students' use of multimedia. Participants were purposefully given only minimal assistance in learning how to use the multi-media equipment (computers, digital and video cameras, lighting system). They composed their own digital music on computers. They then prepared an accompanying dance performance. Synchronised lights and pop music effects greatly enhanced the overall multisensory experience. Throughout the whole project regular opportunities were provided for collective student reflection using multimedia. The results helped to demonstrate that it was possible to organise an activity in the MSE where practice could be viewed "as socially-, historically- and discursively constituted by human agency and social action" (Kemmis & McTaggart, 2000, p. 587).

The third study relates to research questions two and three. In this study focus group interviews were used to investigate the ways that 12 experienced Finnish practitioners working in three MSEs with adults with profound and multiple disabilities (PMD) apply sociocultural animation. A synthesis of the interviews underlines the essential roles of clients' free choices in sensory activities and the need for high-level communication between interdisciplinary MSE team members. Results indicated that although much of what the

practitioners do is consistent with non-Finnish ideas, much is also distinctly Finnish.

The main finding of the three research projects has been to better describe the emerging concept of sociocultural multisensory work. An outcome of this research has been the development of the idea of happiness capital, which has helped to produce a useful teaching and planning tool. 'Happiness capital' is derived from the theories of 'social capital' and 'cultural capital' (Bourdieu, 1984; 1990; Coleman, 1988; Putman, 1993;1996). Prior to the introduction of the concept of 'happiness capital' little acknowledgement was given to the importance of happiness as a precursor for participation at either the individual or group level. Linking happiness capital to Bronfenbrenner's (1979) ecological systems theory, with its five nested developmental contexts provides a much more sophisticated and systematic way to consider well-being in the MSE.

In addition to the primary analysis of each research project, I also subjected the three research projects and the portfolio to a secondary analysis using bricolage. This became my fourth study. A concern from the primary analysis of the results was that valuable nuances of the information were being lost through reductionism. Bricolage is a complex, multimethodological, and a multilogical form of inquiry used especially in social, cultural, political,

psychological and educational domains (Kincheloe, 2005, p. 323), and provides another way of sifting information in order to better understand the dominant forms of power. Research bricolage allows us to reconsider how these dominant forms of power impact on all acts of knowledge production and it helps to spotlight the dangers of abstracting phenomena from their sociocultural and temporal contexts.

The goal of this study was to investigate MSE use in Finnish social care with people with moderate to profound and multiple disabilities and in the process use the findings to inform future development of university and other course materials. The significance of the findings is discussed.

Keywords: empowerment, Multisensory Environment (MSE), participatory action research (PAR), people with moderate or profound and multiple disability (PMD), research bricolage, staff education, sociocultural multisensory work, social pedagogy

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## **Abbreviations**

AAMSE = American Association of Multi Sensory Environments

ADHD = Attention deficit hyperactivity disorder

ADL = Activities of daily living

APA = American Psychological Association

AS = Asperger's syndrome

ASD = Autism spectrum disorder

BJLD = British Journal of Learning Disabilities

CBPR = Community based participatory research

DfA = Design for all

EBP = Evidence based practice

ECTS = European credit transfer system (1 ECTS = 27,5 hours)

ENOA = European Network of Animation

FDUV = Förbundet de Utvecklingsstördas Väl (Swedish), Association for the care of persons with intellectual disability

HAMK = Hämeen Ammattikorkeakoulu (Finnish), University of Applied Sciences

HRD = Human research development

IASSID = International Association for the Scientific Study of Intellectual Disabilities

ICT = Information and communication technologies

ID = Intellectual disability

IMRF = International Multisensory Research Forum

INFED = Informal Education Homepage

IPE = interdisciplinary professional education

IPL = interdisciplinary professional learning

ISNA = International Snoezelen Association

ITACCA = International Federation of Arts Councils and Culture Agencies

JARID = Journal of Applied Research in Intellectual Disabilities

JCU = James Cook University

JPPID = Journal of Policy and Practice in Intellectual Disabilities

JSPEVI = Journal of the South Pacific Educators in Vision Impairment

LD = Learning disability / Learning difficulty

MSE = Multisensory Environment

MSW = Multisensory Work

PA-chair = Physio-acoustic chair

PAR = Participatory action research

PCP = Person centered planning

PIMD = Profound intellectual and multiple disability

PMD = Profound and multiple disability

PMLD = Profound and multiple learning difficulty

POET= Point of Entry Text

QoL = Quality of Life

RDC = Research and Development Center

RCVE = Research Centre for Vocational Education and Training, (University of Tampere)

SI = Sensory integration

SIB = Self-injurious behaviour

SIRG = Special interest group

SJDR = Scandinavian Journal of Disability Research

SPD = Sensory processing disorder

TEACCH = Treatment and Education of Autistic and related Communication handicapped CHildren

VI/MD = vision impairment and multiple disabilities

WHO = World Health Organisation

WWS = World Wide Snoezelen

ZPD = Zone of proximal development

## **1 Chapter**

### **Introduction to ‘Multisensory Environments in social care’**

As an exchange student in Brown Deer High School (Milwaukee, Wisconsin, USA, 1974-5) I had the good fortune to meet a wise psychology teacher named Mrs Williams. Part of Mrs Williams developmental psychology course involved voluntary work, therefore on several Saturday mornings her students supported children with disabilities in a swimming pool and in playground activities. At that time I understood very little about disabilities and was quite worried about my own abilities as a facilitator. Lynn, a tiny little five year old girl, was my first experience of working with an individual with disabilities and she became a valuable guide in teaching me about facilitation. I was amazed and almost terrified at how fragile she was in the swimming pool. I realised how much courage and trust she must have had on me helping her keep her head above the water. I can still remember her blue lips and her shivering after swimming. Maybe we stayed too long in the water or maybe the water was too cold, but she never complained.

I think I learnt a lot by doing physical activities at the playground and in the swimming pool with Lynn. She may have learned something as well; at least that is what I wrote later in my psychology assignment. This first practical learning experience with Lynn was essential for my introduction to understanding of the complexity of the matters concerning people with disabilities. I wanted to learn more about disabilities.

## **1.1 Professional background and focus of the research**

After my high school graduation in Finland I choose a career focusing on disabilities. My first academic studies were at Justus Liebig University, Giessen, West Germany (1977-82), and I became a special teacher focusing on PMD and Art. I also had an option to take some courses in the department of physical education. Fortunately, one of my teachers was Professor Krista Mertens, who had just finished her thesis (Bachman & Mertens, 1977<sup>1</sup>). I was interested in a chapter from this thesis concerning sensory work and this topic and interest continued when we some thirty years later met again at a snoezelen experts' meeting in Stockholm and Örebro, Sweden. Krista Mertens as the president of the International Snoezelen Association (ISNA) organized meetings and invited me to join the experts' group. We have been involved in international research and other projects involving co-operation ever since (Mertens, 2006; 2008).

After graduating from Justus Liebig University in Germany I worked as an art therapist in Hattelmala Hospital in Finland. In 1995, a Finnish Multisensory Environment (MSE) called 'Perception Center Pilvipeili' was built and developed as an action research project. This MSE was planned and built together with students and a small team of teachers of the Hämeenlinna Institute of Social Services (where I had my first permanent teacher position for seven years). For

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<sup>1</sup> References are on pages 190-233



me it was a valuable opportunity to observe practical situations involving various visitors and the student's working with people with disabilities in a white room, activity room, music room, and black light and nature corners. We had little theoretical background for snoezelen environments and relied mostly on our own experiences. From this background I completed my Finnish vocational education licentiate thesis about the development of collective meanings of Pilvipeili's small multisensory team on the ideology and work in a Finnish snoezelen environment (Sirkkola, 1998).

Currently I am a principal lecturer at HAMK (University of Applied Sciences, Finland), teaching at the Degree Program in Social Services. After reading two MSE-books by Paul Pagliano (1999, 2001) I contacted him with the request to be my research supervisor with me studying in Finland and communicating with him by e-mail. My primary research interest is in the empowerment and participation of individuals with disabilities. I also want to develop new tools for the active use of MSEs and find the development of qualitative research methods essential. Furthermore, I want to develop the MSE-curriculum and my work at HAMK.

## **1.2 Multisensory Environment and people with moderate to profound and multiple disabilities**

Pagliano (1998) defines a MSE as a dedicated space or room

... where stimulation can be controlled, manipulated, intensified, reduced, presented in isolation or combination, packaged for active or passive interaction, and temporally matched to fit the perceived motivation, interests, leisure, relaxation, therapeutic and/or educational needs of the user. It can take a variety of physical, psychological and sociological forms. (p. 107)

Pagliano suggests that this environment is user-centric in so far as it is designed to fit individual needs. For many individuals with profound and multiple disabilities (PMD), the

...relationship between self and the external environment is tenuous. ... [The individual's] sense windows to the outside world can be so narrow, rigid, inflexible, unstable or fragile that extensive and ongoing environmental engineering is necessary to increase the likelihood of learning and development occurring. (Pagliano, 2001, p. 8)

This raises the questions: How to create a user-centric MSE? How to research this complexity? Medical model research method tends to focus on identifying

characteristics that would help with diagnosis and treatment, but what would be the best model for social care? In research using an ecological model, the research methods chosen need to recognise that the exceptional individual exists within a complex interaction with environmental forces. One particular strategy that fits the ecological model is participatory action research (PAR).

How can people with moderate to profound and multiple disabilities authentically participate in the research process? How can they objectify their own experiences? Keeping these goals in mind, suitable approaches can be identified using action research spiral of 'plan, act and observe, reflect, revise plan, act and observe' (Kemmis & McTaggart, 1988/97, p. 11).

My research projects include the development of creative actions to promote participation and to create new tools. Accessible multimedia and theatre techniques motivate the participants to create something unique of their own with joy and feelings of success as a group. A Finnish approach of sociocultural animation is applied (Freire, 2001; Hämäläinen<sup>2</sup> & Kurki, 1997) with the aim to increase social capital (Putnam, 1993; Bourdieu, 1984; 1990; Lochner, Kawachi & Kennedy, 1999). My intention is to develop this approach to fit the needs of people with profound and multiple disabilities.

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<sup>2</sup> In this thesis the Finnish letter ä/Ä is placed under the letter a/A in references

What kind of research and literature is available? 'Physical surroundings centered'-style of reporting about MSEs started with the seminal work of Hulsegge and Verheul (1986 Dutch, 1987 English) in their book "Snoezelen: Another World". Verheul was not particularly interested in formal research. Cavet and Hogg (1989, p. 10) quote him: "It is not necessary to write it down, let it happen". However, at the 2002 establishment of the International Snoezelen Association (ISNA) Verheul, together with Mertens from the Humboldt University in Berlin, Germany, strongly advocated the importance of research into the pedagogical and therapeutical uses of the Snoezelen (Verheul & Mertens, 2002).

MSE research measures the mental effects of the MSE (Cuvo, May & Post, 2001; Baker *et al.*, 2003; Kaplan *et al.*, 2006), physical changes in participants with disabilities (Hutchinson & Kewin, 1994; Shapiro, 1995; Shapiro, Parush, Green & Roth, 1997; Pinkney, 1998; 2000), or chronic pain (Schofield, 1994, 2003; Schofield & Davis, 2000). The use of MSEs with elderly who are confused (Pinkney & Barker, 1994; Baillon *et al.*, 2005; van Weert *et al.* 2005; van Weert *et al.*, 2006) is today's most common research topic. Pagliano (1999; 2003) paid attention to social changes and noticed also the value of computer technology, but very little research has been conducted into socio-emotional learning in the MSEs.

The artificial nature of MSEs has been criticised (Whittaker & Kenworthy, 1997) because of the extensive use of plastic furnishings and technical equipment, such

as fibre optic sprays and effect wheels. The aesthetic value of the environment should therefore get more attention than it currently has been receiving (Berleant, 1992, 1997; Raskin, 1995). The environment has a connection to the meaning of aesthetic experience. A number of researchers are currently arguing for greater attention to be given to the aesthetic and restorative value of the MSE (Kaplan & Kaplan, 1989; Kokkola & Kotilainen 1997; Korpela, 1997; Pagliano, 1999; Rappe, Lindén & Koivunen, 2003, Shusterman, 2001). This does not mean that more MS equipment is needed. Rather it means using evaluation to identify what equipment is relevant and potentially beneficial, starting with simple things favouring the ideas of all the participants, and ignoring the commercial readymade MSEs.

Research literature often describes the passive use of MSEs (Vlaskamp, deGeeter, Huijsmans & Smit, 2003). Instead of passive relaxation, I want to investigate creative actions, 'learning by doing' (Blatner, 1997; Dewey, 1999), and socio-emotional learning including communication (Goleman, 1996; 1998; Isokorpi, 2003) with the help of reflective learning focusing on self-efficacy and self-advocacy (Bandura, 1994; Kolb, 1984; Pennell, 2001) plus self-regulation (Wehmeyer & Schalock, 2001).

Finally, I would like to study the use of professional learning of interdisciplinary multisensory teams (Beairsto, Klein & Ruohotie, 2003). The main ideas are that

emotional competences can be learned, and that participation in MSEs enables people with disabilities to actively construct more meaning in their lives.

### **1.3 Applied participatory action research**

A key element of participatory action research (PAR) is empowering the person with a disability as a research participant. According to its prime originator, William Foote Whyte (1998; 1991), the goal of PAR is to increase the relevance of research by placing individuals being studied at the centre of the decision-making process and ultimately to empower people (Tewey, 1997). They participate in the design and conduct of all phases (e.g., design, execution and dissemination) of the research that affects themselves (Brown, 2001). Seymour-Rolls and Hughes (1995, p. 1) define “PAR as a method of research where creating a positive social change is the predominant driving force”. Additionally, Danley and Ellison (1999) note, that the concept of action is important.

The goal of PAR is to improve a situation and to make concrete changes. Proponents of emancipatory approach criticize, that PAR is more oriented toward problem solving in particular situations, than in social transformation (Seelman, 2001). Selener (1997) described PAR as a process by which members of a group or community identify a problem, collect and analyse information, and act upon the problem in order to find a solution. The idea of including people with moderate to profound, and multiple disabilities in the research process goes to the

very heart of PAR (Freire, 1973; 2001) and is an enormous challenge, especially when these individuals have little or no identifiable means of communication.

#### **1.4 Research bricolage**

Conducting and writing on contemporary multidisciplinary research, including a variety of theories and philosophies of everyday life will not be an easy task. On the contrary, an obvious need for multi-methods becomes evident when researching the complex realities of MSEs as a slow seven year research process. Research bricolage described by Kincheloe and Berry (2004) offers an opportunity to use multiple data collection and convincing models of analysis. Attention of the research is directed toward processes, relationships, and inter-connections among phenomena (Kincheloe, 2005, p. 323).

Bricolage in relation to multimethod and multilogical interdisciplinary research is a relatively new method, emerging in the mid-1990s (Kincheloe & Berry, 2004). Year 2000 (p. 1061), Denzin and Lincoln introduced possibilities of *bricolage*, defining it in their 'Handbook of Qualitative research' and explaining the connection to Claude Lévi-Strauss (1966, p. 19), who first used the term *bricoleur* in his book 'The Savage Mind' to describe any spontaneous act to extend the 'imager's mind' .

Kincheloe (2005) has used the term bricolage in educational research to signify the use of multiperspective research methods. Research bricolage means understanding complexity and power of realities, it has an ability to develop multiple research approaches and theoretical constructs, and it offers a path to new form of rigour in research. Richer, thicker and more rigorous empirical knowledge makes us aware of what it both can and cannot claim. Bricoleurs are aware of their own assumptions about knowledge production and the nature of knowledge (Kincheloe & Berry, 2004, pp. 32-34). In Kincheloe's conception of the research bricolage, diverse theoretical traditions are employed in a broader context to lay the foundation for a transformative mode of multimethodological inquiry. Using these multiple frameworks and methodologies researchers are empowered to produce more rigorous and praxiological insights into socio-political and educational phenomena. Ereaut and Imms (2002) describe the term 'bricolage' as diversity, pragmatism and creativity in method and interpretation of qualitative research.

The researcher-as-methodological-*bricoleur* should have a working familiarity with a variety of methods of collecting and analysing empirical materials. This familiarity should include understanding the history of each method and technique as well as hands-on experience with each to fully appreciate the limitations and strengths of the various methods and, at the same time, see clearly how each, as a set of practices, creates its own subject matter (Denzin & Lincoln, 2000, p. 642).



Kincheloe and Berry suggest that 'learning the bricolage is a lifelong process' (2004, p. 32). Both researcher positionality and phenomena in the world are highly valued in bricolage. The researcher should be capable of dealing with the complications of socio-educational experience and ever changing, emergent models of learning, thus - the life long learning process is needed.

Bricolage catalyses the construction of new multilogical and emancipatory forms of epistemology and ontology, that have the potential to bring new insights to the 'MSEs in social care'- topic. My reasons for using bricolage are; to research interdisciplinary local developments, to use multiple data collecting and analysing methods to collect a rich data from everyday interdisciplinary practices of MSEs and sociocultural work done in MSEs. I want to use contemporary perspectives of social, cultural, psychological, and educational research to promote understanding and communication and to create developmental projects that allow for a better informal, and more rigorous mode of interdisciplinary work.

### **1.5 Goals and research questions**

The goal of this study is to investigate MSE use in Finnish social care with people with moderate to profound, and multiple disabilities and in the process use the findings to inform future development of university course materials and curriculum development.

My three research questions are:

1. In what ways can participatory action research (PAR) be applied with people with moderate to profound and multiple disabilities in the context of the MSE?
2. What is the nature of sociocultural multisensory work?
3. What are the implications for staff education in regard to develop MSEs and sociocultural multisensory work?

### **1.6 Protocol of the doctor of education research projects and portfolio activities**

Preliminary work of the portfolio thesis consists of arranging the projects to ensure that they are feasible; writing the first literature review, collecting data from literature, and planning the MusaSaurusII-project.

Confirmation seminar and research approvals:

- Doctor of Education confirmation seminar (May 6, 2004),
- Permission from James Cook Ethics Committee (October 15, 2004, Appendix 1),
- Ethics Approval from the vocational special school in Finland (April 22, 2004),

- Research permission from three social care administrators of three cities in Southern Finland before the focus group interviews are conducted (January, 2006),
- Individuals' consent forms and permission for video recording to be organized before the beginning of the research project

The Portfolio Thesis will consist of several activities including: one pilot study, four research projects and numerous other portfolio activities (Appendix 2, p. 224).

The pilot study and four research projects will be arranged in following five ways:

1) The first research project is a literature review of MSE-research published in English and with a particular focus on people with PMDs, research methods, recommendations and needs for future research. The research method is literature analysis of MSE disability research (N=23, published 1991-2006) and MSE dementia research (N=19, published 1993–2006) with the overall focus on participation. The aim is to identify which research methods are considered most suitable for use in MSEs with a focus on the possibility of using PAR for MSE research. The review is followed by a literature analysis to identify whether or not any methods currently exist where client participation and empowerment is employed. The analysis employs Kemmis and McTaggart's (2000) five aspects of

practice to sort and critically analyse the literature. The first journal article is based on this literature project (Chapter 2, p. 18).

2) A semi-structured questionnaire is used as a pilot research project to investigate MSEs in Finland with the aim of identifying the present situation and staff's ideas for future educational needs. Answers will be collected at two meetings of 'The Finnish Multisensory Net group' (2004; 2005) or through the internet. This method and data will be used to involve Finnish experts in my research, by investigating their opinions on how to continue as a staff educator and what kind of developmental work and research is needed. The results were used in a presentation at ISNA's 2005 World Symposium in Berlin (Sirkkola, 2005d) and for staff education purposes. The pilot study is an investigation into the background and current use of MSEs in Finnish social care with the aim of expanding the repertoire of current approaches through research and development of those in use through the design of new approaches.

3) The second research project is the MusaSaurusII-project (a multisensory environmental creative activity project involving adolescents with learning difficulties) at a vocational special school in Hämeenlinna, Finland. I want to investigate ways to improve the quality and range of activities that can be performed in a MSE using PAR and such visual methods as digital multimedia. This project is an investigation using applied PAR to research and develop new, activity enhancing tools for MSEs.

Participants of MusaSaurusII-project are:

- 12 vocational special school students, who want to participate in music-activities in MSEs during their leisure time, and learn new multimedia skills.
- Two social service students who plan to work in the area of social care, and want to improve their skills in sociocultural animation with the 12 vocational students.
- Three leaders from the vocational special school, who wish to improve the MSEs and the choice of free time activities available at the school.
- A multimedia assistant, Tuomas Ala-Opas, co-editor of articles, books and pdf-publications.

One article will be based on this research project (Chapter 3, p. 57)

4) The third research project includes focus group interviews of staff members of three MSEs in Finland. Staff members take care of adults with PMDs. They plan, build or develop their already existing MSEs and evaluate their work with these focus group interviews. Focus is on participation and empowerment of clients and staff members. Focus group interviews (1-1½ h) will be arranged in three small staff member groups. Data will consist of videoed focus group interviews and their thematic analysis. One article will be based on these data (Chapter 4, p. 86)

5) Finally, the fourth research activity is to build up a bricolage of the complex data. This is a secondary analysis of all data, aimed at preventing reductionism

and increased the rigour of the results. One article will be based on all previous data and introduce the theoretical results (Chapter 5, p. 124).

### **1.7 Ethical Considerations**

Ethics approval from the James Cook University Ethics Committee will be obtained before any data are collected. A high standard of ethics will be followed in all parts of the research.

The James Cook University Ethics Committee's final permission starts the main research work. Permissions from Finland will be obtained according to the research procedure.

Permission for the production of a DVD-video of the MusaSaurusII-project and the Music videos has will be signed by the director of Perttula and all the participants. The DVD-video will be used as teaching material and as an aid to apply for money for the next projects. No one will be especially pointed out in the film, the group activities will be in the main role.

### **1.8 Conclusion**

There are hardly any texts about MSEs specifically written for social care. Pagliano's (1999, 2001) books focus on education. Research tends to focus on

school settings (Houghton, Douglas, Brigg, Langsford, Powell, West, Chapman & Kellner, 1998) or research, done in the area of medical rehabilitation (Kenyon & Chia, 1998; Chan, Fung, Tong & Thompson, 2005). There is a need to focus on social care and critically evaluate the research methods, especially qualitative strategies.

For the development of the Finnish MSEs in social care, it is necessary to describe the current situation before conducting further research (pilot study). At the same time it is important to build international connections and conduct mutual research projects. Furthermore, the improvement of applied and interdisciplinary research, which is culturally sensitive and socially transformative, is needed. This means investigating the Finnish way of using MSEs in social care and implementing the emerging results into new tools, theory and staff education materials.

Although information and communication technologies (ICT) are popular and advanced in Finland, the amount of research in the area of emotions and accessible multimedia is still very limited. I am interested in investigating whether the use of digital multimedia can motivate participants to active reflection. I believe that a combination of PAR, creative actions and MSEs offers people with disabilities opportunities for participation.

References of this chapter are on pages 190-223.

## **Chapter 2**

**Marja Sirkkola and Paul Pagliano**

**Increasing the level of participation of individuals with vision impairment and multiple disabilities: An analysis of the Multisensory Environment research literature**

Journal of South Pacific Education in Vision Impairment (JSPEVI)

(sent 12 of August 2008, revised 20 of August 2008, published January, 2009, 4(1), 15-24)

### **Abstract**

The aim of this literature survey is to identify methods to promote greater levels of participation of individuals with vision impairment and multiple disabilities in Multisensory Environment research. The analysis of 42 studies reveals that participation of individuals with vision impairment and multiple disabilities is not yet explicitly employed in MSE research. However, MSE staff members express interest in developing more effective communication strategies and recognise the need to engage in critical self-reflection to encourage increased levels of participation. Key strategies to endorse participation identified were trans-disciplinary teamwork, where the person with a vision impairment and multiple



disabilities is included as a team member, staff education that focuses on participatory research know-how, and the application of an ongoing reflexive-dialectical perspective on practice.

## **Introduction**

Throughout the world Multisensory Environments (MSE) have become popular places for individuals with vision impairment and multiple disabilities (VI/MD). MSEs are dedicated spaces "where stimulation is controlled ... to fit the perceived motivation [and] interests ... of the user" (Pagliano, 1998, p. 107). The controlled multisensory aspect may make these environments more suitable for individuals with VI/MD than for other clients with minor disabilities because it allows the MSE practitioner to take the user's sensory abilities into account.

The MSE practitioner learns how to control stimulation to fit the unique sensory communication requisites of a particular user by consulting with that client and including him or her in the decision-making process. Participation is therefore an important feature of the MSE. Identifying ways to promote this multisensory pre-cognitive dialogue can be challenging. This is because users often have profound communication disorders. To be able to support increased levels of participation the MSE practitioner must therefore employ a sophisticated repertoire of specialised techniques.

## **Purpose statement**

Evidence based practice (EBP) is a problem-based approach through which learning stems from one's information needs, particularly those of the practitioner (Sackett, Rosenberg, Gray, Haynes & Richardson, 1996). EBP, therefore, offers opportunities to improve the way MSEs are used with clients. Due to a lack of high quality research, most surveys of the research literature become 'bogged down', focusing more on the need for increased levels of scientific rigour (Cuvo, May & Post, 2001) rather than examining the research for information that might inform practice (Biesta, 2007).

One of the difficulties facing MSE researchers is the MSE *per se* is not a therapy, nor is it an educational approach, it is a medium of communication where multisensory stimulation is used to converse at a concrete or pre-cognitive level through controlled sensory stimulation. This medium is particularly valuable for individuals who find communication at a more abstract cognitive level (i.e., through speech and language) too confusing (Pagliano, 2008a). Once the individual is able to communicate with the world outside their own body using multisensory stimulation, this achievement opens up the possibility for the MSE to be used in particular ways, for example, for leisure, relaxation, therapy and education.

The aim of this research literature survey, therefore, is to identify methods used to promote greater levels of participation of individuals with VI/MD in MSEs. This survey will focus on the way the MSE practitioner includes the client in practice. As Frankish (2008) writes: "If we want more evidence-based practice, we need more practice-based evidence" (p. 1).

## **Participation**

In their chapter on participatory action research (PAR), Kemmis and McTaggart's (2000) caution "To the extent that social research ignores the participant view, or imposes itself (in process or its findings) on participants, it is likely to be regarded as illegitimate, fostering alienation or hostility, and thus provoking resistance" (p. 590-591). This warning is acutely relevant for research involving individuals with VI/MD particularly those with disorders of communication because of the tendency for others to speak for them. The idea of having someone speak for you, fails to acknowledge the possibility that the individual concerned may need to communicate at a more concrete pre-cognitive multisensory level.

In a study by Kitchin (2000), which sought the opinions of 35 people with disabilities on disability research, "the respondents articulated a need for inclusive, action-based research strategies, where disabled people are involved as consultants and partners not just as research subjects" (p. 25). Increasingly it seems people with disabilities themselves are strongly supporting the idea of

participatory research, with many now publicly echoing the participation principle of "nothing about us without us" (Ball, 2005, p. 81).

With this challenge in mind the authors conducted a survey of snoezelen® and MSE literature to identify possible research strategies that would fit the requirement of the research being participatory. When choosing research studies it was decided to be as eclectic as possible, deliberately embracing studies from a diverse range of methodologies and client groups.

### **Participatory research**

Participatory research is defined as "systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting change" (Frankish, 2008, p. 1). Three key aspects of participatory research are people, power and praxis (Finn, 1994). Participatory research focuses on the needs and experiences of those people who are involved in the research. These needs and experiences are considered within a context of power, so participatory research is an examination of how theory and practice are combined in action.

"Participatory Research seeks to de-elitise and de-mystify research thereby making it an intellectual tool which people can use for life improvement" (Tilakaratna, 1990, p. 3). This is in contrast to elitist research where the

"fundamental underlying assumption is that people are incapable of doing research - it is a monopoly of the elite who know scientific methodologies" (p. 1).

Brown (2001) elucidates:

Children with disabilities and persons with mental retardation historically have been viewed as not being able to articulate their concerns. Researchers must now be sensitive to mechanisms whereby people can participate meaningfully in research ways not previously thought possible. While family members are important participants, if persons with disabilities can participate meaningfully, researchers may want to consider that a first choice. (p.162)

As Tilakaratna (1990) asserts, professionals who adopt a participatory research methodology must be "highly sensitised ... willing to dialogue ... on more or less equal terms" (p. 3). Participatory research involving individuals with VI/MD, especially when disorders of communication are involved, is therefore a particularly challenging pursuit where more concrete pre-cognitive multisensory forms of communication are used.

## **Vision impairment and multiple disabilities (VI/MD)**

The term vision impairment and multiple disabilities (VI/MD) describes a set of conditions where the individual has a vision impairment and more than two other disabilities (McLinden, Douglas, McCall & Arter, 2002, p. 91). These may include intellectual, physical and sensory disabilities but most often involve disorders of communication. These individuals may find it challenging to maintain their awareness of environmental events. Their ways of communication are therefore likely to be highly idiosyncratic and strongly influenced by context. This is particularly the case for individuals with vision impairment. In addition to their disabilities these individuals frequently have medical complications such as seizure disorders that further exacerbate active participation (Vlaskamp, deGeeter, Huijsmans & Smit, 2003).

According to Kitchin (2000, p. 25) the concept of those with disabilities becoming partners in research brings with it the danger of omission of those with the most severe combinations of disabilities. These individuals may be outside research efforts because they are perceived as too difficult to include, especially when vision impairment and disorders of communication are involved. Any form of participatory research with individuals with VI/MD therefore is highly ambitious but none the less worthwhile.

In participatory research, working together is a central component. However, as Walmsley (2004, p. 66) observes “Remarkably little has been written about what supporters (or non-disabled researchers) do when supporting people with learning difficulties in a number of contexts including participatory research”. The authors’ stratagem therefore was to try to identify a set of incremental steps employed in the research literature that demonstrate some movement towards the practice of more inclusive research.

Two contexts, which seem to have some potential to involve the individual with VI/MD in the research process are snoezelen® and MSEs. The authors, therefore, decided to survey this literature to assess how such participatory research might be happening in these environments and in what arrangements. The authors were guided by Kemmis and McTaggart’s (2000, p. 595) recommendation that: “The criterion of success is not whether participants have followed the steps faithfully, but whether they have a strong and authentic sense of development and evolution in their practices, and the situations in which they practice”.

### **Snoezelen® and Multisensory Environments (MSEs)**

The word snoezelen®, created by combining two Dutch words for ‘sniff’ and ‘doze’, is a term introduced by Hulsege and Verheul in 1974 (Verheul, 2003). Working at De Hartenberg in the Netherlands, they used snoezelen® to describe their purpose built environments for people with disabilities. The emphasis was

on facilitation of interpersonal relationships through multisensory stimulation (Hutchinson & Haggard, 1994). As Hulsegge and Verheul (1987, p. 11) explain:

One could give many descriptions of what precisely 'snoezelen' is, but through word and image it is only partly possible to give an exact representation of what happens. Ultimately, personal experience alone can provide an overall picture.

The radical feature of snoezelen® was its emphasis on client led leisure choices and the accompanying notion that it be nondirective, lacking specific educational or therapeutic aims predetermined by those facilitating access to the multisensory experiences (Hogg, Cavet, Lambe & Smeddle, 2001). Personal experience has been closely aligned to leisure and leisure it is argued possesses its own potential for self-development and self-realization (Hogg *et al.*, 2001). According to Hulsegge and Verheul (1986/7) Snoezelen® clients were to choose what they wanted to do. They were invited to participate and be active in ways that were personally suitable and relevant. Furthermore in the original concept, a session's duration depended more on the clientele's responses than external limits imposed by the carer (Lai, 2003). As a leisure approach then, snoezelen® provided a welcome option to the care environment culture of the time (Burns, Cox & Plant, 2000).



In response to the word 'snoezelen®' becoming a registered trademark, a new term 'Multisensory Environment' (MSE) was coined (Pagliano, 1999). The original snoezelen® concept was reinterpreted in more complex terms as an open-minded or multifunctional space (Pagliano, 1998). Pagliano (1998, p. 107) defined that the MSE "can take a variety of physical, psychological and sociological forms" including a "dark room" (Pagliano, 2001, p. 25) for individuals with vision impairment. For Pagliano (2001) "The MSE is designed from the ... [individual] out" (p. 63). Such a blueprint works at many levels from the physical to the emotional. As such the MSE becomes an incubator to support the very beginnings of exploration of the environment with the individual as participant action researcher (Pagliano, 2006).

For the remainder of this paper the term MSE is used as an umbrella term to include both the MSE progenitor the snoezelen® and the MSE itself. This is because both the snoezelen® and the MSE provide a similar array of lights, sounds, aromas, vibrations, movements and tactual stimuli within an enclosed and controlled space. They both promote safe opportunities for individuals to participate in their own research. The clients' own needs, or sensory diets delineate what the snoezelen® or MSE are and how they are experienced (Messbauer, 2005).

## **Inclusive research goes beyond the either or**

For Pagliano (2006):

A common criticism of Multisensory Environments (MSEs) relates to the lack of available research to validate their use. This criticism often highlights the point that most published research is of fairly poor quality, qualitative in nature or employs a case study methodology with little or no opportunity for generalisation. (p. 23)

He further proposes: "such criticism does not seem to demonstrate an adequate understanding of the enormous complexities and fine nuances associated with this emerging area" (p.23), and in particular the idea that the MSE is a purpose built environment specifically designed to involve the client in research, for the individual to gain insight into how to increase and develop levels of engagement with the outside world.

A key concern regarding this quest to increase the legitimacy of social research by involving people with VI/MD in the research is the interface between subjectivity and objectivity.

Yet I know, as Elliot Eisner discusses, that it will be difficult to wean scholars and the ... public from a view that measuring, comparison, and outcomes are all that matter. ... We've opened a space to ... stimulate more discussion of working the spaces between subjectivity and objectivity ... (Ellis & Bochner, 2000 p. 761)

Inclusive research goes beyond the either or.

MSE literature is diverse in its scope. This is because MSEs are for both children (Shapiro, Parush, Green & Roth, 1997) and adults with disabilities (Vlaskamp *et al.*, 2003), for individuals with dementia, of which 70% have a vision impairment (Staal, Pinkney & Roane, 2003), for people with mental health problems (van Diepen, Baillon, Redman, Rooke, Spencer & Prettyman, 2002), and those in palliative care (Schofield, 2003), for leisure, relaxation, interaction, development, learning and intervention (Messbauer, 2005). MSE research similarly involves disciplines as varied as education, nursing, psychology, psychiatry, occupational therapy, physiotherapy, speech language pathology and allied therapies (art, aroma, music).

### **Method of analysis**

The authors wished to find a way to sort the MSE literature to ascertain what, if any, research could be described as being participatory, even if only in rudimentary ways. They searched for an all-encompassing approach, a model that would allow examination to occur across a broad range of research methodologies and types. It was, therefore, decided to use Kemmis and McTaggart's (2000, pp. 575-578) five aspects of practice as a basic framework for organising the literature. The five aspects of practice are:

1. *"Practice as individual behavior, to be studied objectively"*
2. *"Practice as group behavior or ritual, to be studied objectively"*
3. *"Practice as individual action, to be studied from the perspective of the subjective"*
4. *"Practice as social action or tradition, to be understood from the perspective of the subjective"*
5. *"Practice as reflexive, to be studied dialectically"*

The fifth aspect recognises that the study of practice is a political process because the process of examination involves change.

This view of practice challenges the dichotomies or dualisms that separate the first four views from one another; the dualisms of the individual versus the subjective. It attempts to see each of these dimensions not in terms of polar opposites, but in terms of the mutuality and relationship between these different aspects of things. (p. 578)

The goal of aspect five is to regard MSE practice as a reflexive process involving an ongoing procedure of directing one's thinking about the practice back upon itself. As Lather (1991) explains, a reflexive process "focuses on our too easy use of taken-for-granted forms" and its use "might lead us towards a science capable of continually demystifying the realities it serves to create" (Lather, 1991, p. 15). Studying practice dialectically involves the process in which two apparently opposed ideas, namely subjective and objective plus individual and group become

combined into a unified whole. MSE practitioners, therefore, employ an epistemological perspective, which Kemmis and McTaggart (2000) describe as "never either, always both" (p. 575). For the MSE the fifth aspect attempts to understand practice from all four perspectives. They all provide vital information to inform practice.

## **Results**

The results are reported in two parts. Part one consists of an overall analysis of the studies and their allocation to the five aspects according to methodology, discussion and recommendations for future research. Part two provides a more in-depth analysis of studies located under aspect five.

### **Overall analysis**

Of the 42 MSE studies analysed, 23 focused on disabilities and 19 on dementia or other health issues. The disability studies covered a range of difficulties but mostly centred on multiple disabilities. The dementia studies were included because of similar challenges regarding difficulties with communication, their relative high quality and their relevance regarding research methodology. Inclusion of these studies was further justified from the perspective of the high incidence of vision impairment and the increased risk of people with disabilities such as Down syndrome developing early onset dementia (Straetmans, van

Schrojenstein Lantman-de Valk, Schellevis & Dinant, 2007).

For the first aspect "*Practice as individual behavior, to be studied objectively*" research reporting on "practices seen 'primarily from the outside'" was identified (Kemmis & McTaggart, 2000, p. 575), using "quantitative, correlational-experimental methods" (p. 581). Research practice is "seen in terms of performances, events and effects" (p. 576). For example, the Houghton *et al.* (1998) empirical evaluation to examine the effects of MSE use on 17 individual children with severe disability fits this characteristic. Their study used ANOVA to reveal a statistically significant increase in a number of particular skills exhibited by the participants from pre- to post use of MSE. Further disability studies that fit under the first aspect include Thompson and Martin (1994); Ashby *et al.* (1995); Shapiro *et al.* (1997); Slevin and McClelland (1999); Vlaskamp *et al.* (2003); Matson *et al.* (2004); Chan *et al.* (2005) and Kaplan *et al.* (2006) (see Table 2:1, p. 36).

The second aspect "*Practice as group behavior or ritual, to be studied objectively*" similarly "views practice "from the outside" but sees it in terms of the social group" rather than the individual (Kemmis & McTaggart, 2000, p. 576). A study by Moffat *et al.* (1993) was located under both the first and second aspects. The study, which followed a multiple baseline research design, investigated the effects of snoezelen® on people with dementia, with several hypotheses written in terms of the group of 12 patients. For example, hypothesis one was "Patients and

staff enjoy snoezelen sessions" (p. 23). Other dementia studies matching both the first and second categories were Moffat *et al.* (1993); Pinkney (1997); Hope (1998); Baker *et al.* (2001); van Diepen *et al.* (2002); Baker *et al.* (2003); Baillon *et al.* (2004; 2005) and van Weert *et al.* (2005; 2006) (see Table 2:1, p. 36).

For the third aspect "*Practice as individual action, to be studied from the perspective of the subjective*", the authors identified research that reported on "attempts to understand practice 'from the inside'" (Kemmis & McTaggart, 2000, p. 576), using "qualitative methods (including autobiographical, idiographic, and phenomenological methods)" (p. 577). One study that fits this aspect was by Bakker (2003) who describes her experiences with her father who has Alzheimer's disease. In the paper she "evaluates the relevance of good environment, including interesting sights, smells, sounds, tastes, and tactile sensations, in increasing functional abilities and comfort of older people with dementia" (p. 46). Further studies that match include Hutchinson and Haggart (1991); De Bunsen (1994); Hope (1997); Kenyon and Chia (1998); Martin *et al.* (1998); Pulsford *et al.* (2000); Andersson and Johansson (2003); Kwok *et al.* (2003) and McCormack (2003) (see Table 2:1, p. 36).

The fourth aspect "*Practice as social action or tradition, to be understood from the perspective of the subjective*" similarly "attempts to understand practice 'from the inside'" (Kemmis & McTaggart, 2000, p. 577) and likewise uses qualitative methods. The difference however is on understanding practice "as part of a social

structure that contributes to forming the way in which action (practice) is understood by people in the situation" (p. 577). A fascinating example is by Pulsford *et al.* (2000) which was previously included under aspect three. It appears under aspect four as well as aspect three because of the authors' focus on a group activity. As the authors state "Most researchers prefer MSEs as a setting for individual patients to experience either sensory stimulation or relaxation. Woodlands therapy (WT) builds on this approach. In WT, the multi-sensory environment becomes an adjunct to small-group recreational activity" (p. 651). Notwithstanding there being no disability research, several other dementia studies correspond to aspect four: Zinn (2000); Bakker (2003); Staal *et al.* (2003); Cox *et al.* (2004); Hope and Waterman (2004); Hope *et al.* (2004), van Weert *et al.* (2004) and van Weert *et al.* (2006) (see Table 2:1).

The fifth aspect "*Practice as reflexive, to be studied dialectically*" (Kemmis & McTaggart, 2000, p. 578) provides a broader classification that transcends "each of these two dichotomies individual-social and objective-subjective by seeing both in dialectical terms for a taxonomy of different approaches to the study of practice" (p. 575). Aspect five most closely fits participatory research. The authors were not able to identify any research that could be described as participatory. It was only possible to distinguish research that contained rudiments of participatory research, a process described in the following section.



## **Rudimentary aspects of participatory research**

Sorting literature into the first four aspects was reasonably straightforward. Sorting literature into aspect five was more difficult. As stated previously the first sort did not identify any MSE literature that explicitly matched aspect five. It was therefore decided to conduct a new search for what was called rudimentary aspects of participatory research. This involved scanning the literature on participatory and participatory action research, to compile a list of possible elements that could be described as participatory (Kemmis & McTaggart, 2000).

Those identified included a focus on:

- Clients' preferences or individual needs
- Family members' participation or interaction
- Staff training, participation or interaction
- Values of participatory research in developing environments and methodology (evaluation, reflection, development or need for change)

Once the list had been compiled the MSE literature was re-examined to see if these elements were present. Identifying these elements was more complicated than the original sorting into the first four categories because all details of each

study including the discussion, recommendations and conclusion needed to be carefully considered.

Following the new less stringent allocation process using the four elements 25 of the 42 studies were located under aspect five (see Table 2:1), 13 disability and 12 dementia. The best examples identified were in the dementia area by van Weert *et al.* (2004) and van Weert *et al.* (2006). The studies reported on how the research "effected a change from task-oriented care to resident-oriented care" (van Weert, Kerkstra, van Dulmen, Bensing, Peter & Ribbe, 2004, p. 397) or "showed ... [an] increase in 'Positive Person Work' and decrease in 'Malignant Social Psychology'" (van Weert, Janssen, van Dulmen, Spreeuwenberg, Bensing & Ribbe, 2006, p. 656). Furthermore both studies involved attempts at staff training. The other studies that contained some elements of participation, particularly with regards to future plans, can be found in Table 2:1.

**Table 2:1. Sorting 42 MSE disability, dementia and other health issues research into Kemmis & McTaggart's (2000) five aspects of practice**

Focus: Perspective:	Individual	Social	Both
Objective, Quantitative	(1) 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14,	(2) 2, 6, 7, 11, 13, 14, 17, 21 [8]	2, 6, 7, 11,14, 17, 21 [7]

	16, 17, 19, 20, 21, 22, 23 [21]		
	24, 26, 27, 30, 31, 32, 35, 36, 39, 40, 41, 42 [12/33]	24, 26, 27, 30, 31, 32, 35, 40, 41 [9/17]	24, 26, 27, 30, 31, 32, 35, 40, 41, [9/16]
Subjective, Qualitative	(3) 1, 3, 10, 11, 15, 16, 18 [7]	(4) [0]	[0]
	25, 28, 33, 39, 42 [5/12]	28, 29, 33, 34, 36, 37, 38 [7/7]	28, 33 [2/2]
Both	1, 3, 10, 11, 16 [5]	[0]	(5) Participation 1, 3, 4, 6, 10, 13, 15, 16, 18, 19, 20, 22, 23 [13]
	39, 42 [2/7]	[0/0]	24, 25, 27, 28, 29, 33, 34,36, 37, 38, 39, 42 [12/25]
<p><b>(1-5) Five aspects of practice (Kemmis &amp; McTaggart 2000, pp. 575-9)</b></p> <p><b>[x/x] Total number of studies: 1st disability (top), 2nd dementia, 3rd both</b></p> <p><b>Listed chronologically with categorisation given after year of publication.</b></p>			

### **MSE disability research**

- 1) Hutchinson & Haggard (1991); 1, 3, 5
- 2) Long & Haig (1992); 1, 2
- 3) De Bunsen (1994): 1, 2, 5
- 4) Thompson & Martin (1994); 1, 5
- 5) Ashby, Lindsay, Pitcaithly, Broxholme & Geelen (1995); 1
- 6) Withers & Ensum (1995); 1, 2, 5
- 7) Lindsay, Pitcaithly, Geelen, Buntin, Broxholme & Ashby (1997); 1, 2
- 8) Shapiro, Parush, Green & Roth (1997); 1
- 9) Houghton, Douglas, Brigg, Langsford, Powell, West, Chapman & Kellner (1998); 1
- 10) Kenyon & Chia (1998); 1, 3, 5
- 11) Martin, Gaffan & Williams (1998); 1, 2, 3
- 12) Slevin & McClelland (1999); 1
- 13) Cuvo, May. & Post (2001); 1, 2, 5
- 14) Lindsay, Black, Broxholme, Pitcaithly & Hornsby (2001); 1, 2
- 15) Andersson & Johansson (2003); 3, 5
- 16) Kwok, To & Sung (2003); 1, 3, 5
- 17) Leng, Woodward, Stokes, Swan, Wareing & Baker (2003); 1, 2
- 18) McCormack (2003); 3, 5
- 19) Vlaskamp, Geeter, Huijsmans & Smit (2003); 1, 5
- 20) Matson, Bamberg & Smalls (2004); 1, 5
- 21) Singh, Lancioni, Winton, Molina, Sage, Brown & Groeneweg (2004); 1, 2

22) Chan, Fung, Tong & Thompson (2005); 1, 5

23) Kalpan, Clopton, Kaplan, Messbauer & McPherson (2006); 1, 5

**MSE dementia or other health issues research:**

24) Moffat, Parker, Pinkney, Garside & Freeman (1993); 1, 2, 5

25) Hope (1997); 3, 5

26) Pinkney (1997); 1, 2

27) Hope (1998); 1, 2, 5

28) Pulsford, Rushforth & Connor (2000); 3, 4, 5

29) Zinn (2000); 4, 5

30) Baker, Bell, Baker, Gibson, Holloway, Pearce, Dowling, Thomas,  
Assey & Wareing (2001); 1, 2

31) vanDiepen, Baillon, Redman, Rooke, Spencer & Prettyman (2002); 1, 2

32) Baker, Holloway, Holtkamp, Larsson, Hartman, Pearce, Scherman,  
Johansson, Thomas, Wareing & Owens (2003); 1, 2

33) Bakker (2003); 3, 4, 5

34) Staal, Pinkney & Roane (2003); 4, 5

35) Baillon, vanDiepen, Prettyman, Redman, Rooke & Campbell  
(2004); 1, 2

36) Cox, Burns & Savage (2004); 1, 4, 5

37) Hope & Waterman (2004); 4, 5

38) Hope, Easby & Waterman (2004); 4, 5

39) vanWeert, Kerkstra, van Dulmen, Bensing, Peter & Ribbe (2004); 4, 5

40) Baillon, van Diepen, Prettyman, Rooke, Redman & Campell (2005); 1, 2  
41) van Weert, van Dulmen, Spreeuwenberg, Ribbe & Bensing (2005); 1, 2  
42) van Weert, Janssen, van Dulmen, Spreeuwenberg, Bensing & Ribbe (2006); 1, 3, 5  
**For full details see references, pp. 47-55**

Details outlining why each of the 25 studies were allocated to aspect five are given in Table 2:2.

**Table 2:2. MSE research located under aspect 5 further sorted according to four rudimentary elements of participatory research**

**Research focus on:**

**Clients' preferences or individual needs:**

- Identify **preferences**, future cooperation with snoezelen staff and other staff (4)†
- Research on participants' **favourite activity** (13)†
- Future plans for developmental work, **evaluation of individual needs** and staff's working habits (15)†
- Effectiveness of the **activity the participants had already chosen**, discussion of individual needs in MSEs (19)†
- Implications of findings, future assessment and treatment discussed in a developmental way, enjoyment as goal, looking for the **most reinforcing equipment** (20)†
- Future plans and questions (patient-led, **preferences**, sensitive and

planned application) (27)†

- Developing new assessment of **stimulus preferences** in MSE (34)†
- Conduct a **stimulus preference** screening, prepare an "individual snoezel care plan" (p. 659) (42)†

**Family members' participation or interaction:**

- Task "goals were selected by either the **family** or the residence" staff (p. 446) (23)†
- Relative's mood and stress scales, plans to study **carer-patient interaction** more deeply in the future (24)†
- Free choice to participate, attention to **family-client relation** (29)†
- Improving and maximizing well-being in multisensory environments, **caregivers and visitors**
- **Opinions are valued**, solving a problem in a participatory way (36)†
- Individual "lifestyle history interview with **family members**" (p. 659) (42)†

**Staff training, participation or interaction:**

- Ideas of developmental work, **staff training** (10)†
- Staff members participation in reflecting their work, developing a new tradition (37)†
- Collaborative group development, democratic action research, **staff has an active role in the research changing culture of care** (38)†
- Changing care from task oriented to resident-oriented by staff training and implementing a new intervention (39)†
- **Staff "trained** in snoezelen showed a statistically significant increase in the

total number of verbal utterances ... duration of resident gaze ... affective touch ... and smiling" (p. 665) (42)†

**Values of participatory research in developing environments and methodology (evaluation, reflection, development or need for change):**

- Multiple methods, dialectic way of planning developmental work in future (1, 3)†
- Need to develop a new treatment method, **need for change** (6)†
- Multiple methodology, intentions to develop the environments and the method (16)†
- Developmental idea to bring a treatment method to Canada (18)†
- Evaluative and developmental attitude, **values that fit PAR** (22)†
- Author engaged in the **evaluation process**, staff 's monthly improving meeting, change in the culture of care environment (25)†
- Ethnographic analysis, comparison to well-being, person-centred principles in communication (28)†
- Suggestions for a better multisensory environment (33)†
- " ... suggested a reflexive and sensitive approach was considered something that a positive user of the room should possess" (p. 54) (37)†
- Aim to "effect a change from task-oriented care to person centred care according to" Kitwood's Dialectical Framework (p. 657) "participant observation" (p. 666) (42)†

† For key to numbers see Table 2:1.



## **Discussion**

According to Whyte (1991) the goal of participatory action research (PAR) is to increase the relevance of research, by placing individuals or groups being studied at the centre of the decision-making process, in order to empower them (Tewey, 1997). Those involved participate in the conduct of all phases including design, execution and dissemination of research that affects them (Brown, 2001). PAR "has emerged from a significant shift of perspective in social and educational research to research which aims to avoid privileging the perspectives of professional researchers in favour of the perspectives of the ordinary participants in social settings" (Kemmis & McTaggart, 2000, p. 566).

In this research literature survey the authors were not able to identify any MSE related PAR studies, nor could they find any participatory studies. They, therefore, decided to delve deeper into research types by subdividing participatory research into four rudimentary elements. This strategy located 25 studies.

From Table 2:1 it can be seen that the majority of the 42 MSE studies focused on the individual (aspect 1 objective 33, and aspect 3 subjective 12, shared 7, which gives a total of 38 or 90% of the studies) and on the objective (aspect 1 individual 33, and aspect 2 group 17, shared 16, total 34 or 81%). Of the 23 disability studies the majority similarly focused on the individual (aspect 1 objective 21, and aspect 3 subjective 7, shared 5, total 22 or 96%) and on the objective (aspect 1 individual

21, aspect 2 group 8, shared 7, total 22 or 96%). Greater balance was found in the 19-dementia studies with the focus on the individual (aspect 1 objective 12, and aspect 3 subjective 5, shared 2, total 15 or 79%), and on the objective (aspect 1 individual 12, and aspect 2 group 9, shared 9, total 12 or 63%). Least overall attention was given to aspect 4 the subjective-social, with no disability studies and only seven (37%) dementia studies or 17% of the overall total.

Table 2:2 lists four elements of participatory research and describes why each of the 25 studies (13 disability and 12 dementia were included, see Table 1 Aspect 5). Decisions regarding the categorisation were informed by research title, stated aims, research methodology and future plans, some of which merely hinted at a desire to increase levels of participation of clients, family members or staff in forthcoming research. Still the results do indicate that at least four elements of participatory research are currently in practical use in MSE research.

### **Conclusion and recommendations for future research and practice**

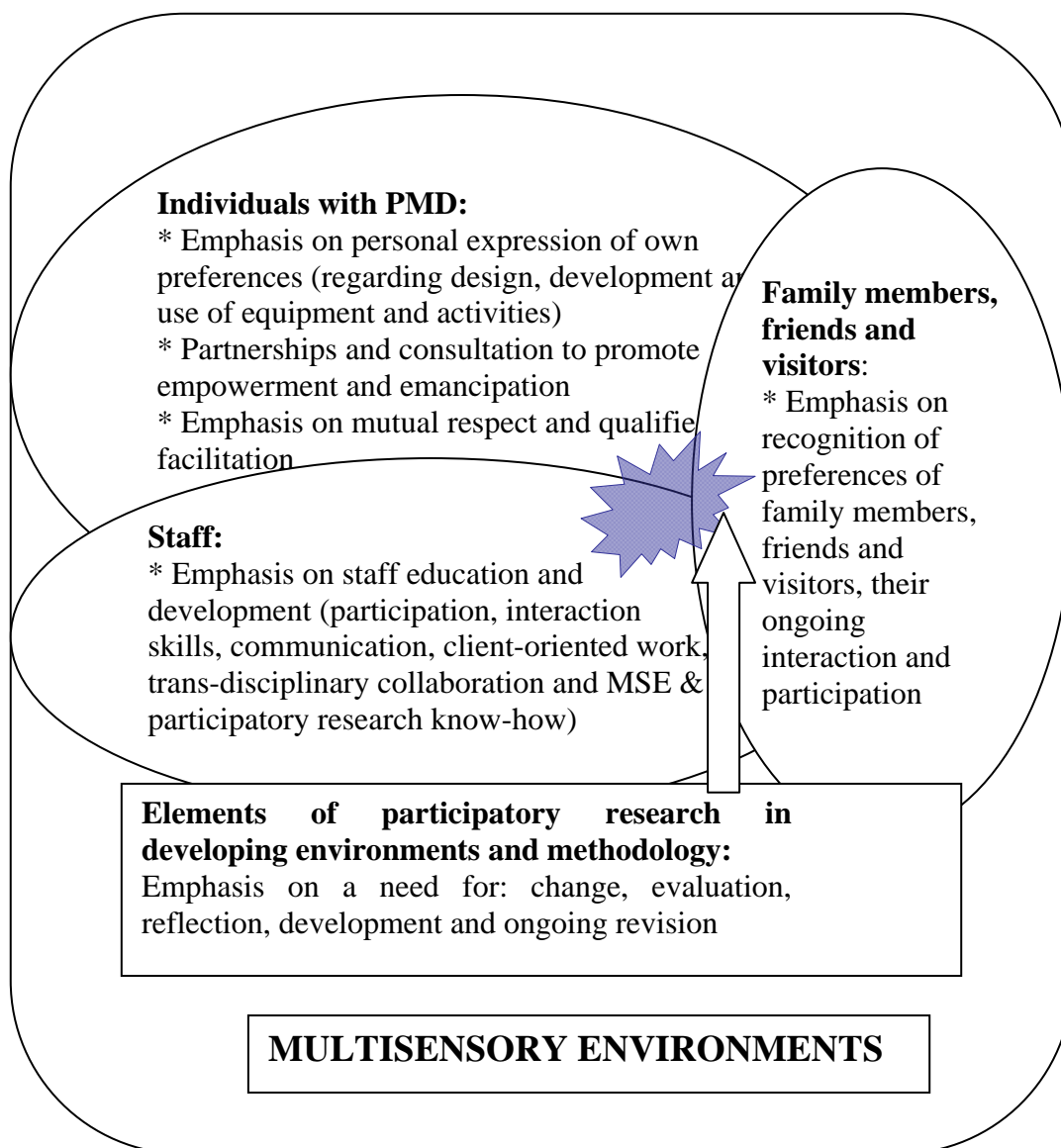
Even though the idea of participatory research for people with VI/MD, particularly those with extreme disorders of communication, might at first seem preposterous, given the extreme vulnerability of this group, it is even more important that the issue continue to be explored both in research and in practice. As Kemmis and McTaggart (2000) argue:

... participatory research ... emerged more or less deliberately as ... [a form] of resistance to conventional research practices that were perceived by particular kinds of participants as acts of colonization—that is, as a means of normalizing or domesticating people to research and policy agendas imposed on a local group or community from central agencies often far removed from local concerns and interests. (p. 572)

In this paper the authors surveyed the MSE literature and identified a number of studies that reveal that some characteristics of participatory research are being employed. Figure 1 serves as a summary of the analysis of current MSE research literature and in the process demonstrates that it is possible to use a range of elements of participatory research in the MSE involving people with VI/MD and/or dementia. Key strategies to endorse participation identified were trans-disciplinary teamwork where the person with VI/MD is included as a team member, staff education that focuses on participatory research know-how and the application of an ongoing reflexive-dialectical perspective on practice.

According to Kemmis and McTaggart (2000), practice should be researched in reflexive-dialectical ways and this may mean the need for more deliberate and well-coordinated participatory research involving individuals with VI/MD to be undertaken in co-operation with international research teams. The authors hope the proposed model (see Figure 2:1, p. 46) will facilitate this process.

This research survey helps to demonstrate that it is not only possible to conduct research into MSE practice where individuals with VI/MD are included as research participants, it also suggests strategies to help make it happen. The MSE provides an exciting opportunity to connect with individuals with VI/MD using more concrete, pre-cognitive forms of communication that enable these individuals to express their likes and interests.



**Figure 2:1. Participatory elements used in MSEs with individuals with PMDs to promote more social and historically constituted, critical and dialectical research**

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## **Chapter 3**

**Marja Sirkkola and Tuomas Ala-Opas**

***MusaSaurus II: a multisensory environment creative activity project  
involving adolescents with learning disabilities***

British Journal of Learning Disabilities (BJLD)

(revised manuscript sent June 26, 2009)

### **Accessible Summary**

- Twelve adolescent vocational school students with learning disabilities used music, dance, computers and digital cameras during a Finnish research project called *MusaSaurus II*,
- A community concert was successfully organized for friends, family members and other students,
- Participation in creative activities increased interaction and empowerment

## Summary

This paper reports on *MusaSaurus II*, an innovative, four-month multimedia music and dance project, conducted at a vocational special school in southern Finland. Twelve adolescents with moderate to severe learning disabilities participated in the optional evening course, which culminated in a community concert. The course was an applied participatory action research which adopted a sociocultural approach to develop students' use of empowering digital multimedia. 'Learning by doing' methods was used and hence only minimal assistance was given in learning how to use computers, digital and video cameras, and special lighting. They composed their own digital music on computers and prepared an accompanying dance performance. A major focus was on exploring the way the media itself helped facilitate participation. Particular attention is given to describing the ways digital media were used, which roles were taken and the ways group reflection was possible by re-visiting the videos and pictures. Ordinary residential school environments with special equipment served as temporary Multisensory Environments, where synchronised lights and pop music effects greatly enhanced the overall multisensory experience. Throughout the whole project regular opportunities were provided for collective student reflection. Participants believed that *MusaSaurus II* was successful in offering roles (taking pictures, being a model, helping others in multimedia techniques and



reflecting the activities), facilitating and promoting creative involvement and supporting and expanding social skill and communication development.

### **From Multisensory Environments to sociocultural multisensory work**

Pagliano (1998, p. 107) defines a Multisensory Environment (MSE) as *a dedicated space ... where stimulation can be controlled, manipulated, intensified, reduced, presented in isolation or combination, packaged for active or passive interaction, and temporally matched to fit the perceived motivation, interests, leisure, relaxation, therapeutic and/or educational needs of the user. It can take a variety of physical, psychological and sociological forms.*

Sociocultural multisensory work is based on Pagliano's definition of MSE, but it additionally emphasizes participation, expressive qualities of creative group activities and the use of empowering digital media for reflection. Ordinary everyday living environments are preferred to specially built MSEs. Sociocultural multisensory work can be defined as an application of the MSE to social care. Sociocultural multisensory work has half of its roots in social pedagogy (Freire, 2001) and aims at preventing marginalisation of vulnerable people by empowering them through meaningful activities. A tool called sociocultural animation combined with multisensory environments and creative actions is used for facilitation of group activities (Ala-Opas & Sirkkola, 2006; Sirkkola, Veikkola

& Ala-Opas, 2008). Sociocultural animation means sensitivity in social interactions, spontaneity, freedom of choice and action. Participants are seen as active, creative and able to change their environments. It is essential for people to be connected to other human beings and culture through participating in empowering activities (Hämäläinen & Kurki, 1997; Hämäläinen, 1998).

An underlying principle with regard to social care in Finland is the idea that all people, including those with severe disabilities, have an inalienable right to participate fully in society. One way for this to happen is through creative endeavours, particularly of a sociocultural nature. Social participation is thought to be important as it empowers people and improves their quality of life. Using creativity to encourage and enhance social participation is an approach that is particularly valuable, because it enriches the individual experience. The challenge with this approach though arises when people have severe disabilities that limit their sense abilities, self-expression and social skills.

Creative activities in MSEs are aimed at offering participants an opportunity to belong to a group, to have freedom to express oneself and one's feelings within that group, and yet experience acceptance of being a unique person. These experiences are believed to support a more balanced and interesting life for adolescents with learning difficulties within their communities.

## **Development of the *Saurus* Projects**

The authors prepare social care staff to work with people with disabilities in Multisensory Environments (MSEs). Since 2001, together with their university students they have been researching the use of creative activities in a Multisensory Environment (MSE) as a means of promoting participation of individuals with learning disabilities. Participatory Action Research (PAR) has been applied to local projects where creating a positive social change is ‘the predominant driving force’ (Seymour-Rolls & Hughes, 1998, p. 1). In PAR the goal is for all participants to take part in the design, conduct and dissemination of the PAR-projects to the best of their abilities (Kemmis & McTaggart, 2000; Brown 2001). In applied PAR projects, researchers are viewed ‘less as experts, professionals, and principal investigators, and more as consultants, facilitators, and coaches’ (White *et al.*, 2004, p. 10).

The authors, together with their six university students, conducted two applied PAR projects prior to the current study. The participants chose the name *Saurus* because they had a fascination with dinosaurs. The first project, *DigiSaurus*, (*digi* for digital) used pedagogical drama as a technique to encourage three 14 to 16 year old boys with Asperger syndrome to explore their creative potential. These three participants learned how to perform their own small sketches. These became miniature pantomimes involving gesture and body language choreographed to express particular emotions. The sketches were videoed by the advisors and then

extensively reviewed and discussed with the participants to examine what had happened.

*MusaSaurus I*, the next project at a vocational special school, involved a group of students with moderate to severe learning disabilities (moderate to extreme difficulties with reading, writing and communication). Musa, a Finnish slang word for music, was chosen by the participants. They imagined themselves as pop idols and formed a band to lip-sync and mime the songs. These performances were used to prepare a concert, which was then presented in front of a huge, live audience.

*MusaSaurus II*, stage two of the project at the same vocational special school, combined music, dance, drama activities and multimedia in ordinary MSEs. Participants were five adolescent females and seven males between 16 to 20 years all with moderate to severe learning disabilities. It was a functional group in which 10 of the participants could read and only two participants needed some help in writing their names. In addition to learning disabilities, the participants had severe difficulties in social skills and various difficulties in communication. Three males had a diagnosed Asperger syndrome and two females had Down syndrome, only one man had a severe intellectual disability. All participants, but one, were able to walk and dance without support. For two participants idiosyncratic verbal interaction was possible, and therefore music, dance and

digital pictures added a particularly welcome option for self-expression and nonverbal communication.

The 12 participants already knew each other and had chosen this activity as their evening program. They experimented with using digital media and create their own music using computers. They then worked together to prepare a disco dance performance to accompany their music and finally prepared a video of the show.

The contents of the 10 sessions were planned in a cooperative way. Formal ethics approvals from the local ethics committee and the first author's university were obtained. All participants and the director of the vocational school signed a consent form in the name of the legal guardians.

All three projects were designed to enable participants to engage in multisensory sociocultural creative activities. A crucial feature of these projects was the way digital photography and video recording were used to facilitate participation, promote social interaction and make student reflection possible. This tool was given the name 'empowering digital media'. The performances were video recorded by the participants who were then able to view what they had done. The students' confidence to communicate their ideas increased and they demonstrated considerable pride and enjoyment at their work.

## **Empowering digital media**

New technologies are emerging rapidly in today's world. Digital media is in everyday use all over the world. It is easy to use and it offers immediate concrete feedback. For students with learning disabilities (especially those who are visual learners), videos, simulations, virtual environments, pictures and other multimedia may be effective teaching tools (Parsons, 2006; Parsons *et al.*, 2006). Some research using videos has already been conducted in disability research. For example, Mick *et al.* (2008) collected ethnographic notes and video recordings of what actually was going on in the everyday lives of people with learning disabilities. Videos have been used to teach social skills (Parsons, 2006), model skills like making simple meals like sandwiches (Rehfeldt *et al.*, 2003) or to recognize emotions and facial expressions (Ekman & Friesen, 1969).

Digital media has been used as an assessment and treatment tool in therapy. Digital media provides people with opportunities to engage in meaningful, purposeful tasks that are related to real-life interests and activities (Weiss *et al.*, 2003). However, little research (if any) has been done to investigate the ways adolescents with severe learning disabilities use digital media for communication and self-expression in creative activities within MSEs.

Empowering digital media differs from photo therapeutic techniques (Weiser, 2001) and empowering photography (Savolainen, 2005) because the process of picture taking is more important than the photographic skills and quality of the final products. *MusaSaurus II* used digital media as a tool to collect research data, but also to gather material for reflection and to empower participants to interact with each other. Social interaction and reflecting on the creative productions are the main focus. However, the purpose of the pictures in all three methods is to empower participants and to enrich their lives.

Empowerment is a synonym for internal feeling of power (Siitonen, 1999), and it refers also to a constant process of enabling individuals and groups to take part in collective action (Daly & Cobb, 1994). Empowering digital media has two dimensions: intrapersonal - and interpersonal;

Intrapersonal empowerment focuses on the capability of the participant to pursue appropriate and complementary social and achievement goals through the establishment of an agenda. This is possible when someone has a belief in his or her ability to be empowered. Intrapersonal empowerment exists when the person perceives that he or she has the capabilities to act, and can be seen as a positive force. Social skills, interpersonal and group skills are linked to intrapersonal empowerment (Siitonen, 1999).

Interpersonal empowerment occurs when individuals or groups work with each other to meet their needs. This can be considered as a positive force of power, because it is about equal power relationships rather than domination. Interpersonal empowerment is the pursuit of goals by participants who are not in conflict with peers or advisors (Sullivan, 2002).

Empowering digital media aims to facilitate an accepting atmosphere where participants can take risks. Succeeding brings self confidence which supports self-appreciation. This increases self-esteem, which leads to intrapersonal empowerment. Sensitive facilitation includes welcoming, encouraging and listening to the participants' voices.

Multisensory experiences can be tailored to match the unique sense abilities and self-expression capabilities of the individual as a way of providing more personally meaningful social opportunities. The process of designing such experiences generally occurs in a purpose built MSE because it affords the ongoing control of a much larger repertoire of stimuli; however, this project did not occur in such an environment. Rather it occurred in a casual gathering area for the residential students and then transferred to a concert hall.



## **Activities and atmosphere**

A warm, inviting atmosphere was created in a common living room through the use of lit candles, tea and biscuits, comfortable chairs and beanbags. At the beginning of each of the ten sessions a cooperative planning took place. This is where participants made decisions about the evening's optional activities (composing music with computers, dancing rehearsals, taking digital media, planning marketing, lighting, cafeteria, and clothing for the concert). Participants also arranged a competition to decide on the name and printed their own T-shirts for the show. After each session's creative activities and the group reflection a small multisensory exercise was conducted using colourful lights, aromatherapy candles, music, story telling, stretching and relaxation.

## **Collecting and analysing data of *MusaSaurus II***

All participants played an active role in data collection. Together with the authors they video-taped all the sessions. The authors applied 'learning by doing' methods advising the participants only if they had technical problems with the cameras. In the beginning, participants were shown how to use the equipment, but some of them ended up teaching each others and the authors the finer points of the camera and video use. Additional data were collected using participatory observation and two theme interviews. These were very intensive and required all participants to join in.

During the project, reflective discussions were always held before and after each session with all participants and several times together with the advisors from the vocational special school. Participatory observation was documented into a project diary after each session. Two university students and three local advisors were responsible for the organization of the project and the two authors joined the activities offering technical assistance. The authors participated fully in all activities being simultaneously sociocultural animators and positive role models.

A project diary and the 10 two-hour videos were analysed. This involved multiple viewings and the recording of new data. Information from one personal diary was combined with video analysis, and the two researchers held reflective discussions to gain consensus of what occurred. The authors wanted to avoid unnecessary translations from Finnish to English so instead of quotations from participants, we looked for small events which represented qualitative experiences. Special interest in the analysis was, however, on the roles offered by the empowering digital media

## **Results**

Results are first discussed in general and thereafter three small cases are offered to illustrate personal diversity of the participants. Theoretical results are then organized under three topics: ‘roles offered by empowering digital media’, ‘reflection on creative activities’ and ‘facilitating participation to creative activities in ordinary MSEs’.

A major aim was to gather information to describe and better understand how participants used digital media. The participants started by testing the technical abilities of the cameras through zooming in on the environment and onto particular objects, and then zooming quickly onto faces, but always very quickly (as if they were afraid to document the facial expressions). The idea of interviewing each other while filming seemed to be influenced by popular TV programs like Finnish Idol. The participants often asked stock Idol questions like: “How do you feel now?” Most often the answer was “Great, I feel great!”

After the sessions and the final concert, it was estimated that 10 out of 12 students had had substantial use of the digital cameras. Only two girls refused to use the digital cameras. All five girls, even those two not interested in taking pictures seemed to enjoy being photographed. Sometimes ‘being a model’ empowered also the quiet and shy participants sufficiently for them to answer questions, that is if someone was there to film and interview simultaneously. All five girls and

two of the seven boys who had other active roles in creating and performing in MSE's, but did not actually take pictures or shoot videos, seemed to enjoy re-visiting the videos and arranging the prints of digital pictures onto the walls of the Concert Hall.

### ***MusaSaurus II – three cases***

The following cases, all males, were chosen because they help to illustrate the types of achievements made during the four-month project. These three males clearly made the greatest progress in developing their technical and social skills.

#### Case 1

Matti who is 19 years old was particularly enthusiastic at being involved in using multimedia. He had severe difficulties in verbal communication and sometimes was too loud and hasty. However, he could participate and concentrate on the activities when observing the events through the camera lens. The camera lens provided him with a tool to observe and record the activities. It also seemed to provide him with a way to temper his own boisterous behaviour. He was very active in producing music. Also he was the only one who brought his own instrument (a digital piano) to the final concert and improvised an extra solo for his performance. His use of digital media developed enormously during the four-months. Also he had substantial verbal contact with both students and advisors telling them what to do in front of the camera. This active involvement seemed to

greatly help him in his social skills. It provided him with someone to talk to and something to talk about. Beneficial for his interaction was the fact, that the other participants were not so much annoyed with his behavior when he was filming.

Matti was happy when his digital pictures were re-visited right after they were taken, and he remembered exactly which pictures he had taken. He found the whole experience affirming. This feeling became evident later, when some of the pictures were colour printed and placed on the wall of the Concert Hall. He also took pictures of himself and posed himself together with his favourite advisor. He obviously enjoyed the acceptance and physical closeness he gained while taking the peer-pictures. Matti clearly liked being an active part of this community.

## Case 2

In many ways 17 year old Jukka displayed almost the opposite personality to Matti. His main problem was his shyness; he hardly ever said anything aloud or asked for attention. He was always polite and quite self-assured in what he did or what he did not like to. Jukka's communication and social skills needed support due to his inability to initiate contact with other participants. Like Matti, he could be interactive when filming and interviewing others. From the second session onwards, he was constantly involved in taking pictures or filming and was talkative when interviewing the other students while filming. When collectively re-visiting the videos he had filmed, he sat in front of the group and clearly enjoyed the attention he gained through his clever film products.

When we talked about the options of creative actions, Jukka always chose to film and at the end wanted to be the one who documented the whole concert process on film. This was an important personal decision since he did not want to dance or make music. He was determined to practise the use of the camera.

One of the most memorable moments for everyone was, when Jukka used the video camera and projected live videos of the audience and concert onto a big screen during the final event. He was skilful and his skills were admired within the group and his community. Empowering digital media offered Jukka a new role to interact with others and to show and enjoy his technical talent.

### Case 3

Pentti, a 19 year old male participant was taking part in a *MusaSaurus* project for the second time. This year he insisted on re-visiting the previous year's concert-video and commented on the happenings with great enthusiasm. His moderate learning disability seemed to be the reason for the special school placement, but on the other hand he was one of the most skilful participants, due to his social, technical and musical skills. The previous year he had helped to open the camera cases and arrange the cords, the stands, and the multisensory equipment like the colourful lights. After the sessions Pentti always helped to collect the equipment, shut the camera cases and carry them to the author's car. Since he had used digital cameras already at the previous year's *MusaSaurus*, he stated that he wanted to

create music. He played an important role during the concert, arranging lights and mixing the music. He enjoyed these new activities more than taking digital pictures or videos. However, since he was so technically adept, he also enjoyed helping others in finer techniques of picture taking and filming. Pentti was clearly empowered by his skills in teaching multimedia to his peers and by his freedom to arrange the MSE through powerful light and sound equipment.

### **Roles offered by empowering digital media**

Empowering digital media offered three roles on several levels. These three roles were 1) being a picture taker or 2) being a model for the pictures and/or 3) helping others in multimedia techniques.

The role of picture taker was either passive or active in interaction. The passive picture taker did not communicate or interact and simply took pictures of the physical environment. On the next level, the active picture taker interviewed, guided, and arranged situations for picture taking. The picture taker could advise the others in how to perform and act in the creative situations or during the practising. The art of picture taking developed through levels from passive picture taking of the physical environment to active interviews of participants and eventually documenting the creative activities. The last level was digital picture taking which evolved into documenting the final music and dance performance in

an interactive way. This included short real time interviews and recording the creative activities in the ordinary MSEs and during the final concert.

The other role in empowering digital media is the role of being a model for picture taking. Since all activities were documented, being a model could mean, for example, being a creative actor, dancer, assistant for lights and sound or any other activity. Similarly this role can be passive or active in interaction. In the passive role the participant did not necessarily want to be in the picture and could make a choice to move away from the cameras. The next step in passive role towards activity is when participants allowed picture taking and continued performing without comments in front of the cameras.

The active side of the model's role empowered the participant to co-operate with the picture taker. Jointly, the picture taker and participant could reach the next level of active role. At this level active participants arranged new creative and interactive situations which empowered the other participants to join, and thus quite intensive social interaction occurred.

The third role, helping others in multimedia techniques, was possible for those who had participated in similar projects and could already use multimedia. This role was always active and rewarding. Interaction could also happen without words. It seemed that these small but intense moments enhanced physical closeness and authentic emotions. Also those, who had just learned the basics of



using a digital camera were willing to show the next person, for example, how to zoom or use the flash.

Picture taking, performing as a model and even helping others created exciting situations for social interaction. Those students, who never talked to each others, interacted through the camera and seemed to enjoy this new possibility of social communication. The temporary MSEs with massive colourful lamps, band decorations and such real equipment as microphones and amplifiers highly animated participants to take active roles as ‘performing artists’.

### **Reflection on creative activities**

Personal reflection of creative actions took place with digital pictures and videos, as participants did this as a solitary activity or with the group, and focusing on the performance as a group or as an individual. Participants made personal choices in deciding to whom they showed their pictures or videos and what they did with them. Deleting some technically unsuccessful digital pictures occurred often, but deleting of videos did not happen at all.

Empowering digital media does not emphasise the importance of critical reflection of the person’s skills. Instead, it provides an opportunity to observe and underline the individual’s performance as part of the group activities and creative performances. This experience of togetherness and being a creative part of the

performing group seemed to empower the individuals and may strengthen their self-esteem. Digital pictures, videos and verbal appraisals of the group multiply this experience. The boys' capacities to reflect especially improved during the process from simple re-visiting the pictures to critical comments and ideas how to improve the performance. In this small experiment, the girls' development was not so easy to observe, since they were more interactive than the boys throughout the project. They seemed to enjoy more being models than taking pictures even if they mastered the digital techniques.

Collective reflection differs from personal reflection since it focuses on the group's performance and common success instead of personal skills. Collective reflection offered participants and the advisors an opportunity to give positive feedback to each other and an opportunity to plan the next events collectively. Successful creative group actions aim to offer feelings of sensation and an experience of being together "The Stars of the Show". Collective reflection emphasizes that every single person's input is important, unique and irreplaceable for the group.

Moments of sharing the feelings and experiences of the activities were important for the whole *MusaSaurus II* group, which included participants, local advisors, university students and us as participating team members. Spontaneous peer and group picture taking sessions activated physical closeness and immediate re-

visiting of the digital pictures were often intense moments with lot of laughter and positive empowering emotions.

### **Facilitating participation to creative activities in ordinary MSEs**

The general atmosphere and the environment during the project aimed at being motivating. Everyone was facilitated to feel free to choose which roles they wanted to have and where and with whom they wanted to do their activities. The sociocultural approach allows individuals the choice to not fully participate in all activities and there were times when some decided they would rather stay on the couch observing the performances of others than be actively involved themselves.

All creative activities are of course different and need local planning. Based on our project experiences we propose the following seven options for facilitating empowerment and participation in creative activities in ordinary MSEs. They are:

1. Arranging accessible and age appropriate creative group activities in MSEs to provide meaningful opportunities for participants to take part in, to document and to re-visit or reflect on,
2. Planning all activities together with the participants in a manner, where systematic collective reflecting on the activities is possible (in the beginning of sessions, during sessions and after each session to make a more specific plan for the next time)

3. Providing 'easy to use' multimedia and MSE equipment (music - and lighting equipment, computers and software for making music, and clothing for performances)
4. Accepting resistance, non-involvement and different levels of participation in activities by offering options and providing enough time for participants to choose
5. Arranging opportunities for relaxation in MSEs either before, in-between and / or after the activities
6. Using sociocultural animation especially for immediate re-visiting of digital pictures, for verbal and nonverbal positive feedback during the actions, and for collective reflections
7. Believing in 'learning by doing' methods and trusting in the participants' creative abilities, instead of teaching too much and telling how to do things 'correctly'

### **Concerns**

The limitations of this project are as follows: The *MusaSaurus II* – project was a small PAR project applied to the local needs of 12 vocational special school students with moderate to severe learning difficulties. Such creative activities as dancing and making digital music were included in the project as creative activities but the research focused on the use of empowering digital media. For sociocultural research projects it is not important to know precisely which

limitations the individual participants have. Instead, it is vital to find and use potential creativity, talent, and practical abilities of the group and to arrange possibilities for empowerment for the whole group. For this reason generalisation of the results to other projects in other cultures may be difficult.

## **Conclusion**

Projects such as *MusaSaurus II* can facilitate creative activities, collective reflections, and create empowering intrapersonal and interpersonal situations. They offer the possibility of exploring new roles, such as belonging to and being involved in creative interactions in a group. Individual and group experiences are important for all students, but especially essential in strengthening self-esteem of students with severe learning difficulties.

The main focus was to find out how the participants use digital media and which roles they take during the project. The results of the three cases indicate how empowering digital media increases participants' communication and positive interactions. Empowering digital media is an excellent tool for adolescents to participate in age appropriate activities, to interact with each other and to learn how to reflect collectively. Through *MusaSaurus II*, advisors and peers animated each other in their creative performances.

Creative multisensory environments and the staff attention enriched all participants; the resultant concert was a product of more than the individual performances. Exciting ordinary MSEs with inspiring atmospheres can have a role in stimulating all participants to take novel and popular roles. For best results it is essential that participants can choose their favourite activities.

The authentic experiences of the project participants and the experiences of the 200 people joining the concert are written into the students' thesis papers and in this article. We believe that it is worthwhile to research the possibilities of empowering digital media and creative activities in ordinary MSES more closely and to expand such an approach to younger students, adults and elderly people with moderate to severe learning disabilities. The cultural aspects of the use of digital media need further research with particular investigation to focus on the needs of adolescent females.



**Picture 3:1** MusaSaurusII-project, photo by Sirkkola & Ala-Opas (2004)

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## **Chapter 4**

**Marja Sirkkola and Paul Pagliano**

**Empowerment in three Finnish Multisensory Environments: Experiences of 12 interdisciplinary staff members working as service providers for adults with profound and multiple disabilities**

(Submitted to *Scandinavian Journal of Disability Research*, April 16, 2009, and reviewed October 2009)

### **Abstract**

This research used focus group interviews to investigate the ways that 12 experienced Finnish practitioners working in three Multisensory Environments with adults with profound multiple disabilities (PMD) apply sociocultural animation, a form of Finnish social pedagogy that emphasises human dignity. A second research focus, therefore, was to examine the ways staff practices might be influenced by the specifically Finnish sociocultural context. A synthesis of the interviews underlines the essential roles of clients' free choices in sensory activities and the need for high-level communication between interdisciplinary MSE team members. Results indicate that although much of what the practitioners do is consistent with non-Finnish ideas, much is also distinctly Finnish.

## **Introduction**

Morris (1997, p.54) believes it is not possible to have "care *and* empowerment" because it is "the practice of caring which has led to the perception of ... people [with a disability] as powerless". She explains:

Empowerment means choice and control; it means that someone has the power to exert choice and therefore maximise control in their lives ... . Care ... has come to mean not caring about someone but caring for in the sense of taking responsibility for. People who are said to need caring for are assumed to be unable to exert choice and control. (p.54)

Morris, therefore, rejects the idea of care as a practice where responsibility is taken for an individual. The provision of "adequate support" (Morris, 1997, p. 55) to enable the individual to exercise choice and control, she argues, is a human rights issue to be promoted whenever and wherever possible.

A deep concern for the incompatibility between caring and empowerment is what led Hulsegge and Verheul (1987) to develop Snoezelen in the Netherlands in the 1970s.

## **Snoezelen**

The original Snoezelen consisted of a series of sensory rooms for relaxation and leisure. When Hulsegge and Verheul (1986) first developed Snoezelen their emphasis was on the client having free choice and control. Even when the person had severe difficulties in communication, facilitators were encouraged to carefully observe the individual so adequate support could be provided to enable that person to exercise genuine free choice and control. The appropriation of the term Snoezelen® by the commercial company ROMPA as a trade mark for their products prompted the emergence of a new term Multisensory Environment (MSE).

## **Multisensory Environment (MSE)**

The purpose behind both Snoezelen and MSEs is to improve the quality of life of people with disabling conditions, particularly those who have experienced some form of sensory deprivation. Snoezelen and MSEs have been constructed in many countries throughout the world and they are becoming increasingly popular. This is despite the scant scientific evidence regarding their efficacy (Vlaskamp, deGeeter, Huijsmans & Smit, 2003; Kaplan, Clopton, Kaplan, Messbauer & McPherson, 2006; Singh, Lancioni, Winton, Molina, Sage, Brown & Groeneweg, 2004).

One reason for their popularity is the idea that the MSE is a form of media through which a person can communicate choice and control rather than a particular type of therapy (Sirkkola & Pagliano, 2009). According to Pagliano (1998) a MSE is a space:

... where stimulation can be controlled, manipulated, intensified, reduced, presented in isolation or combination, packaged for active or passive interaction, and temporarily matched to fit the perceived motivation, interests, leisure, relaxation, therapeutic and/or educational needs of the user.(p.107)

Pagliano (2008) went on to describe the MSE as a form of media for communication at a concrete or pre-cognitive level. Controlled multisensory stimulation becomes "an individualised behaviour scaffold" where successful use is dependent upon staff being sensitive to "ongoing internal changes in the individual" (Pagliano, 2007, pp. 4-5). This, therefore, requires "frequent monitoring, systematic evaluation and both short and long term adjustments of the external environment coupled with the use of highly specialized pedagogy" (Pagliano 2007, pp. 4-5).

## **The Finnish experience**

Sirkkola (2005) has estimated there to be at least 200 MSEs in Finland across the domains of special education, health and social care. In Finland many MSE practitioners have had professional MSE education offered as part of the Social Services Degree Programme at HAMK, University of Applied Sciences (HAMK, 2008).

Pagliano's ideas on the MSE have been largely adopted, although local adaptations have also been introduced. This is because his ideas are considered to be congruent with the Finnish cultural aspirations of egalitarianism, participation and empowerment together with an affinity for the natural environment: forests, lakes, summer cottages and saunas and its sentiment of melancholy (Lewis, 2005). One popular Finnish adaptation to the MSE is the social pedagogical approach called 'sociocultural animation'.

## **Sociocultural Animation**

Sociocultural animation is used in special schools and social care units that have chosen social pedagogy as their main framework for action. Social pedagogy first emerged in Brazil (Freire, 1973; 2001), but was later adopted in other countries, often in modified ways to suit local conditions. In Finland, Hämäläinen and Kurki



(1997) combined Freire's ideology with ideas taken from German and Spanish social pedagogy and reinterpreted them to fit important Finnish social values like egalitarianism and cultural democracy (Koivunen & Marsio, 2008). The result is Finnish sociocultural animation, an approach to working with people who are vulnerable, that focuses on preventing marginalization through participation and empowerment. This approach therefore fits neatly with the idea of the MSE as a form of sensory media for communication of choice and control.

The aim of empowerment is to increase the social strength of individuals and their communities. Siitonen (1999) describes empowerment as an internal feeling of power, which enables the empowered person to develop confidence in his or her own capacities and thereby find joy and pleasure in day to day activities. Ryan and Deci (2001) argue that empowerment links to self-determination and emerges through essential elements, such as autonomy, self-regulation, initiation, self-realization and responding to events (Wehmeyer & Schalock, 2001). According to Ryan and Deci (2001), if people have a good feeling about their own self-determination they are curious, vital, and self-motivated.

Empowerment gained through participation in community activities is such a highly regarded value in Finnish society (Siitonen, 1999) that any focus on promoting client empowerment will also be extended to strengthen staff empowerment. Empowerment therefore is not viewed in isolation. It is thought to apply simultaneously to both client and practitioner.

Sociocultural animation involves staff working to better understand each client, by being more aware of their particular chronological and sociocultural context (Vygotsky, 1978; Bronfenbrenner, 1979; Bronfenbrenner, McCelland, Wethington, Moen & Ceci, 1996). It further involves staff dealing forthrightly with any human dignity difficulties by involving both clients and staff in activities that promote mutual feelings of togetherness and belongingness (Hämäläinen, 1999; 2003).

The concepts behind sociocultural animation resonate with the principles of normalisation (Nirje, 1985) and social role valorization (Wolfensberger, 1985) in that they each emphasise the importance of ensuring that people not only live in, but also become active members of their respective communities. The adaptation of sociocultural animation has therefore necessitated an expansion of Pagliano's idea of the MSE to take it out of the confines of a particular room and move it into the individual's everyday life space. Sirkkola (2008) calls this adaptation 'sociocultural multisensory work'.

### **Sociocultural Multisensory Work**

Sociocultural multisensory work goes beyond the unfettered offer of multisensory activities within MSE prototypes (Pagliano, 1999), to promote meaningful everyday life events. The Finnish MSE experience therefore incorporates elements such as sauna and bathing facilities, kitchens and ordinary everyday

living areas with open fireplaces. Everyday activities like baking, gardening and the pursuit of creative endeavours such as music, visual art and handicrafts are all linked to the sociocultural animation process.

Combining the theoretical and practical elements of sociocultural animation, with MSE theory and practice is both novel and challenging. This is because individuals with profound and multiple disabilities have exigent disorders of communication that make conventional participation and empowerment especially problematic. Since MSE practitioners come from a diverse range of different disciplines, communication between staff needs to be interdisciplinary, where members use a shared conceptual framework and draw together disciplinary-specific theories, concepts and approaches to address a common problem (Rosenfield, 1992; Frattali, 1993).

### **Research aim**

The aim of this research was to use focus group interviews with 12 experienced Finnish practitioners (social workers, nurses or therapists) working in three communal day centres with adults with profound multiple disabilities (PMD) to investigate how they collectively apply sociocultural animation in the MSE. A second research focus is to examine how their practices are specifically influenced by the Finnish sociocultural context.

## **Focus group interviews**

According to Eskola and Suoranta (1998), the interview is one of the most common research methods for gathering qualitative information in education and sociology in Finland. A group interview is essentially a qualitative data gathering technique that finds the interviewer directing the interaction and inquiry. Depending on the purpose of the interview this process can be either structured or unstructured (Denzin & Lincoln, 2000). Some authors make a distinction between group interview and focus group interview: group interview can be applied to collect and create information of specialized professional areas broadly, whereas focus groups typically emphasize a specific theme or topic in depth (Bryman, 2001).

The focus group data collecting method is relatively time consuming, but easy to modify to match the researcher's purposes. In Finland, the focus group interview is often used for gathering evidence-based knowledge of evolving practices. In this research, the focus group interviews are used for four important reasons:

1) social interaction in the group produces freer and more complex responses than in other types of interviews, 2) the researcher can probe for clarification and solicit greater detail during the interview, and 3) responses have high face validity due to the clarity of the context and detail of the discussion (Cohen, Manion &

Morrison, 2000; Bryman, 2001; ISUE–Focus Group, 2007). A fourth local reason relates to diversity of language and culture and the need to translate ideas from Finnish and/or Swedish to English and back. This is because even if the focus group was held in Finnish and/or Swedish (the languages used in the MSEs under investigation) the research report is being prepared in English.

Due to the complexities of language and culture it was felt that the best research method would be to use the one with which participants would be the most familiar and which was relatively easy to conduct across the three languages and cultures. It was more important to collect data about how members of the multisensory team discussed the focus areas (participation and empowerment) than what their opinions as individuals were (Bryman, 2001, p. 336). Furthermore the opportunity to form collective meanings was considered to be particularly important and relevant for interdisciplinary team members.

### **The three worksites**

All three worksites have both indoor and outdoor MSEs and use ordinary living areas for everyday multisensory activities. The largest work site is located in the middle of a small forest and has a new sensory garden with outdoor equipment, such as a wheelchair swing and a carousel. The other two sites have access to gardens and arrange various outdoor activities, including sensory walks,

celebrations and picnics for multisensory purposes. All sites have specific plans to develop their outdoor MSEs in the future.

Indoor areas include multisensory rooms, sensory walls and corners or small tents with multisensory mobiles and related equipment. The main room for all settings is the '*White Room*' (Pagliano, 1999, pp. 43-44), which is used at least weekly. Considerable emphasis is placed on ensuring that the MSEs and their equipment are as natural as possible; this means, for example, that no plastic trees or flowers or kitsch-style decorations are used. Instead, recently developed Finnish high tech equivalent is included, such as the physio-acoustic chair (Kärkkäinen & Mitsui, 2006; Lehtikoinen, 1994). A computer attached to a physioacoustic chair creates low frequency sounds (below 60 Hz) through six amplifiers. These sound vibrations resonate to relax muscles and other body tissue. In other words, the body starts to vibrate with the low frequency sound. At all three work sites physio-acoustic chairs are used for clients' multisensory relaxation and wellness, but at one of the sites they are offered also for the staff members' wellbeing aiming to prevent stress and treat high blood pressure (Sirkkola & Nieminen, 2007).

### **The focus group interviewees**

During the year 2006, 12 experienced MSE practitioners were interviewed in three groups comprising (three, four and five members respectively). They had

various professional backgrounds: five social instructors (Bachelor's degree from a university of applied sciences), six practical nurses (Occupational degree from a vocational institute) and one music therapist. The interviewees had an average of six years experience working with individuals with PMD. Finally, 11/12 of the participants had undertaken staff education courses at HAMK.

### **The research process**

The three focus group interviews were held at the staff members' work settings. They were conducted in Finnish and Swedish as required and held during working hours. Throughout the study a high ethical standard was maintained: permission forms were signed by all interviewees and their administrative heads and approval obtained from the ethics committee at each work site.

The focus group topics were sent via e-mail to the three work sites a week before the interview took place. All three interviews lasted from 80 to 95 minutes and were video recorded. Each interview began with a 'warm up' consisting of discussions about each team member's job description, prior professional studies or special interests relating to MSE use.

The Finnish author conducted the interviews and facilitated the group interaction. She kept the discussion on track by asking two open-ended questions formulated

to stimulate discussion and to motivate the group into providing innovative and practice-based answers.

*The two open ended questions were:*

- 1) In what way is sociocultural animation used to strengthen client and staff empowerment at Finnish MSEs?
- 2) In what ways are creative activities and everyday experiences used in Finnish MSEs?

The interviewer assisted the group discussions by inviting interviewees to precisely define all relevant terms and themes and to share stories from their daily work in the MSEs to illustrate practices. If the explanations were not sufficiently clear, additional examples were requested.

### **The process of data collection and analysis**

The process of data collection and analysis followed eight distinct steps applied from Cohen, Manion and Morrison's (2000) advice in the following way:

1. At the completion of each interview, the researcher took time to prepare her own personal field notes in which she identified the main ideas raised during the interview and recorded her own thoughts.



2. The researcher then viewed the video and reflected on its contents adding further comments and observations to her field notes. This review and reflection process occurred on the same day as the original focus group interview.
3. On the day after the interview the researcher reviewed the video again and added further commentary to her field notes and started to prepare a transcript of the most relevant parts of the discussions.
4. Once steps one to three had been completed for all three focus group interviews the researcher collated her notes from the interview transcripts and organised them by main ideas. The most informative ideas were then translated from Finnish / Swedish into an English script.
5. Next the English script was forwarded to interviewees by email with an invitation for them to comment on its accuracy, to provide clarification if necessary, to rewrite parts or even to add new ideas. Even though all interviewees were proficient in English, they were given the option to reply in Finnish, Swedish or English.
6. Although feedback provided by the interviewees confirmed the accuracy of the researcher's interpretations, a number of respondents did provide additional information and examples.
7. Revised transcripts were then analysed and further characterization applied to form six categories of the main ideas, collective meanings and key issues of the focus group topics.

## **Results**

Results are organised under six categories. Direct translations of interviewees' narratives are stated in italics. Points not in italics were synthesised from multiple statements made during the focus group interviews.

### ***1) Enabling free choices of activities***

An ideal MSE for adults with PMD is easy to change to suit particular purposes, the most important of these being relaxation and choice; something that begins with the client deciding whether he or she wishes to enter the room or start an activity. This continues by providing opportunities for individual clients to practice free choice by either selecting a particular activity or choosing to do *'nothing but be together'* in the room. Time is available *'to do nothing'* if that is the client's preference.

The opportunity for relaxation was thought to be important for both clients and staff. Both require demand free moments, especially in work environments where the strident vocalisations of restless individuals and the pressure of daily routines can cause serious sensory stress to both clients and staff. In line with the need for a calming and relaxing ambience, staff cautioned against offering too many boisterous activities or exaggerated forms of stimulation: *'Sometimes just closing*

*sliding doors and working in smaller groups can help to reduce unwanted and stressful noise sensations.'*

Empowering participation in creative activities means, that it is not the adviser who tells the client what to do, instead the adviser offers options. Listening sensitively is crucial.

*Many clients are able to express that they don't like something. They turn away or vocalize something or, for example, simply spit the food away if they dislike it. If someone is afraid of a new experience they can try it or leave it or do something else.*

Mime and gesture, but also breathing, pulse, sweat, stiffness, or anxiety, help staff understand what is occurring without verbal indications.

*You can also tell the difference if someone does not like, for example, the music or massage; client cannot verbalize a dislike, and may also show no signs, but may be very relieved, when taken away from the situation. Sometimes clients can be too dependent on acceptance and just be polite; or they may simply be unable to show their hesitation. They do not show their dislikes immediately, but show their happiness afterwards, when the unwanted situation is over.*

Sometimes the ability to listen sensitively and accurately may be reached only after several years of work with the client.

## ***2) Connections to learning and pleasure***

Learning and getting used to new environments may take time:

*... eventually you get empowered. If a client does not take part at the beginning of activities in a MSE it may take even half a year or more until that person wants to come in or try something. However, finally it may even turn out to be his most favourite activity like hand massage, relaxation on a physio-acoustic chair or sleeping under a ball blanket*

(weighted blanket with plastic balls inside, used for deep touch pressure and relaxation).

Empowerment means learning new social competencies, for example, being in a group:

*... one young man has improved his social abilities in our MSE. Two years ago he could not stand classical music and only wanted to listen to rock. Today he has learned to accept other kinds of music and he knows that if he*

*waits long enough, his turn will come and he then has a possibility to choose his favourite music.*

Altering the MSE by moving some pieces of furniture or equipment may lead to positive surprises, but they are also essential for the clients to experience novelty. However, changes of environment engender extreme anxiety causing the client to leave the room or refuse to participate. Therefore, staff members must know their clients' habits and personalities well. On the other hand clients need to trust their caregivers, since mutual reliance is a prerequisite for enjoyment. Promises like *'nothing dangerous will happen'* or *'if you dislike something you can stop the activity'* may be sufficient.

*Maybe some kind of a trade, an extra cup of coffee or some similar offers, have to be done when negotiating about trying new things. Also the promise to stop, for example, the massage or music, if the activity is not liked, may help.*

Even though minor surprises and changes in MSEs are beneficial for learning, it is essential to have a steady plan. Repetition of routines helps the clients to understand and remember what is going on. Enough time to react to the offers and for choosing one's favourite activity animates learning.

*The morning sessions, where everyone has their own role to do something special, are created to animate the clients towards active participation. There are routines like singing songs, asking and answering 'who is here?' and roles of telling about the weather or today's activities.*

Pleasure and reward were felt when *'something goes smoothly with the clients'* or when the clients were happy and pleased. *'Empowerment is a feeling, when you have had success with some new thing in a MSE, and you get excited about that. It is joy of success when you have offered a moment of good feeling to another person.'*

### ***3) Ergonomics, practical ideas and backup from administrators***

When hoists and furniture in a MSE are functioning well and are ergonomic, then both the clients and staff members are able to enjoy *'physical empowerment'*. This enables them to concentrate on the other positive aspects of being in the MSE.

Empowerment also translates into increased opportunities for members to build and develop MSE's equipment and physical surroundings according to the team's ideas. If someone gets an idea for improvement, most often there is a desire to try the idea immediately. Administrators should back up the MSE team appropriately, because it can be very disempowering to wait for months for financial support or for technical assistance. Some innovations may even be economical: A narrative

concerning staff's creative interventions focused on a visit to an ice skating hall. One person's wheel chair was impossible to lift into the ice ring and therefore the staff used an old orange, plastic chair with twisted legs instead. This client, who was very restless and repeatedly swinging her upper body, now sat still and enjoyed the fast ride on the plastic chair smiling and concentrating on this novel experience. It is of note though that the same chair, when used as an ice-sledge, did not appeal to the other clients at all. Many empowering multisensory experiences are client centred and therefore provide unique sensations that somehow tap into individual needs.

Every individual have their own pace and own variations for how, when and for how long time to use multisensory equipment and arrangements, as illustrated in following example:

*One person, normally sitting in a wheel chair, can also roll and crawl on the floor. It took her almost two years to figure out and communicate that she enjoys rolling into a multisensory tent. She makes noises with the mobiles and scratches the walls. One of the advisers then scratches the tent's walls from outside and this make the person giggle.*

#### *4) Success in creative and sensory activities*

Wheelchair dancing and sensory theatre were mentioned as examples of activities performed by advisers together with their clients. Examples of activities where clients could more fully participate, were other creative art and music events using technical aids like Sound Beam (device which uses sensor technology to translate body movement into digitally generated sound or image), microphones and special music instruments specifically designed to promote client participation.

*During a sensory theatre performance and during its practice period a woman resident experienced moments of empowerment, when she was performing a poem and used a microphone. Her voice was originally quiet and shy, but was then transformed by the microphone. She gained great enjoyment from experiencing her loud and clear voice through the microphone.*

Everyday activities like baking and cooking inspire a person's sensory attention. Empowerment can be seen as gaining satisfaction from success in these daily activities. Also handicraft activities such as ceramics, making candles, finger painting during art sessions, kneading dough, and beauty treatments like sugar massage or a cucumber mask were named as examples of empowering sensory activities for clients. Similarly, common early childhood games based on rhythm,



surprise, 'hide and seek' and repetition of gestures and voices were used to enhance creativity and communication with clients. Sometimes the lack of lifts or other technical aids made it difficult to arrange activities involving physical movement. Simple activities involving movement were jumping and bouncing on a trampoline together with a helper. Singing and rhythmical clapping were easy to carry out with adults with severe physical disabilities. Activities such as playing in the ball pool, lying in a waterbed or hammock were also used.

Even though horseback riding and swimming often demand extra personnel and special environments, these activities were used as part of personal multisensory programs. Clients may benefit from these demanding special sport activities in several ways, as their sensory and movement systems are activated. Additionally, the rare feelings of independence and excitement may animate empowerment. This happens, for example, when a person is safely floating in a warm pool or riding on a horse experiencing the rhythmical movements, sounds, smells and warmth of the horse. *'Clients feel happier and appreciate themselves more; they have a chance to improve their self-esteem'*.

##### ***5) Multisensory signs, reminiscence and multimedia***

Multisensory signs are nonverbal or verbal signals that inform the individual about the next activity. They facilitate understanding in the individual with sensory problems regarding what is going to happen. Multisensory signs may

have same sensory elements as the new activity, for example, a sniff of a particular spice introduces a baking session.

Another tool to increase sensory awareness is digital media. Large colourful digital pictures projected to the wall or ceiling provide an inspiring tool that can capture special personal multisensory moments. It is particularly valuable for sighted clients to revisit an enjoyable activity afterwards through a visual reminiscence moment. Voices, sounds and movement, like walking and swinging, are easier to capture on video than in still pictures. Staff started to think, how videos could be used with a client who was blind:

*A blind person was horse back riding for the first time and was advised to pay attention as to how the horse turns to that side where she balances and looks, and how the horse then starts walking in to that direction. It was very empowering for her to notice that she herself was the leader of that big animal.*

On many occasions staff put in a tremendous amount of preparation in order to be able to offer a special sensory activity, for example, a sensory walk in a forest. *'Then the activity is over in a few minutes!'* To prevent frustration of this type revisiting the activity on video or looking through still pictures of the activities might be experienced as pleasurable and empowering. Both clients and staff could

benefit from these virtual experiences and could enjoy the success of previous happenings.

All three places used every day massage and music selected by the clients themselves. Staff members offered several options and waited for a sign as to which CD or aromatic oil for massage was preferred, as indicated by a smile, gesture or any verbal signs of acceptance. Sometimes these responses appear very slowly and the staff member waits patiently, not hurrying or even deciding on behalf of the client. In music groups each song has a simple picture as a symbol so that sighted participants can choose their favourite songs by looking.

A music therapist told a story about one tiny person and her personal signs; He was able to hold her in his arms and swing, or dance with her according to the music. When he stopped moving, the person had to give a sign; for example, some verbal sound or movement, if she wanted this interaction to continue. Some days she wanted this 'dancing' to continue for a longer time and some days she could stand it just for a couple of minutes. This narrative raised questions concerning the first time, when some kind of a sign is invented or noticed. *'When and how did this sign start? How are these sensitive nonverbal signs noticed and memorized?'*

## ***6) Empowerment through communication***

*'It is important, that staff members know each other well and have a good relationship with each other.'* Even if people use different work methods and theoretical frameworks, they feel free to ask another team member about their opinions and even criticize each other without hesitation or umbrage.

Since most people with PMD are not able to talk, it is very important that the staff members communicate a lot with each other and with their clients. They want to find out what their clients' intentions and meanings are, what their likes and dislikes are, and how the other staff members interpret the clients' personal signs. Finding solutions to these problems as a team, empowers the staff members but is simultaneously also a part of the client empowerment. *'It is essential to find out what the clients' free choices for multisensory activities are.'*

In difficult situations the morals and ethics of what to do next are to be discussed with all staff members and a suitable action plan needs to be developed. For example, if a person starts to engage in self-injurious behaviour when in the MSE, the activity should be stopped and the client gently removed from the space. Sometimes advisers need to be strict without any further conversations. This may happen, for example, if the clients get too confused, irritated or loud. Clear instructions what to do and for how long may be needed. This is interpreted as

understanding of the needs of the client, not as neglecting their wishes and choices.

## **Discussion**

The discussion is divided into three parts: 1) Use of sociocultural animation in Finnish MSEs, 2) Congruence of staff comments with Pagliano's MSE description, and 3) The pertinence and value of the focus group interview as a research method into client and staff empowerment in MSEs.

### ***Use of sociocultural animation in Finnish MSEs***

According to the focus group interviews, clients were '*dealt with human dignity*' (Hämäläinen, 1999) while they visited MSEs or during the everyday multisensory situations. The sociocultural animation helped to create reciprocity of empowerment, which is the basis for '*experiences of togetherness*'. Other forms of sociocultural animation were identified in the attitudes towards the clients, for example, not just motivating the client, but sensitively listening to what the client's own choices were and in the appreciating attitude towards colleagues' knowledge of the clients. Therefore also continuous dialogues among staff members were highly valued and critical comments appreciated in order to develop multisensory practices. During the focus group discussions many questions were raised and collective answers were negotiated. Knowledge about

each client was more precise if team-members shared their experiences and understandings, but emerging questions showed that there are still many unanswered practical questions.

The assumption that sociocultural animation's important element, client empowerment, links to self-determination (Wehmeyer & Schalock, 2001), gained some credence in the practitioners' examples on how they work and how their clients respond in various situations of everyday life. According to their experiences: sociocultural animation 1) increases clients autonomy, whether it be active or passive, 2) allows clients to self-regulate by choosing for how long activities last, how many sensory inputs are taken at one time and with what kind of volume or speed these inputs are arranged, 3) facilitates client initiation and response to events, and 4) facilitates self-realisation.

Besides activities in MSEs, everyday situations and creative activities were used at all three work sites to increase the amount of multisensory experiences. Creative multisensory activities were most often practiced in ordinary living environments. This may sometimes not be the optimal solution, for example, for adults with visual impairments, who might benefit more from activities under black light with fluorescent materials. An everyday living environment and being together in a group seemed to be more common than individualized therapy sessions in Finnish MSEs. Besides sociocultural aims, there might be economical and practical reasons for this, since most of the day activities in Finland are

arranged as group initiatives and only some forms of music, speech or physiotherapy are provided for one client at a time. It is obvious that more focus group discussions and specific research about this matter are needed.

### ***Perceived congruence of staff comments with Pagliano's MSE description***

The 12 interviewed staff members underlined that empowering work in the MSE is a demanding '*process which needs highly specialized pedagogy*' (Pagliano 2007, p. 5). In this case social pedagogy is used and as Pagliano explains, '*it can take a variety of physical, psychological and sociological forms*' (Pagliano 1998, p. 107).

No single person alone can work with this challenging task with each client being so different. Therefore the value of interdisciplinary teamwork, where staff members develop a shared local conceptual framework, cannot be overestimated.

The observation that '*Successful use of the Multisensory Environment must be sensitive to ongoing internal changes in the individual*' (Pagliano, 2007, p. 5) was discussed during the focus groups. Staff members underlined the importance of recognizing unique learning processes demanding individual scaffolds and freedom of choice. It was particularly interesting to note how Pagliano's (2007, p. 5) description of the '*Multisensory Environment as a process ... [becoming] an individualized behaviour scaffold*' was repeated in interviewees' own words:

gaining more self confidence, looking happier, giggling and as clients' successful participation in activities leading to feelings of empowerment.

It was felt that when working together as a team, staff members of the three Finnish MSEs were competent to arrange activities to '*fit the unstable sense abilities*' (Pagliano, 2007, p. 5) due to their previous staff education in MSEs and due to their long experience of using this medium creatively. These MSEs are well equipped with spaces and utensils, allowing the presentation of '*simulation in isolation or in combination, intensified or reduced and shaped for passive or active interaction*' (Pagliano, 2007, p. 4).

Additionally these MSEs offer opportunities for natural out-door experiences and group activities, and expand on the idea of the MSE being a "*dedicated space*" (Pagliano, 2001, p. 8). This dedication allows also national and sociocultural differences accepting, for example, the idea of a Finnish sauna being a MSE.

Staff members believe that Pagliano's descriptions of MSEs were useful when they were combined with Finnish social pedagogy. However, one important difference was observed; Finnish social pedagogy and its tool sociocultural animation underlines the meaning of communities (people living or working together), and values empowering togetherness in addition to individual's learning, therapy and leisure processes.



*The pertinence and value of the focus group interview as a research method into client and staff empowerment in MSEs*

Focus group interview was chosen, because it was thought to be a suitable way to gather authentic, detailed information about a particular topic. It was particularly valuable for the reason that the 12 staff members were familiar with this interview technique and it enabled them to comfortably and confidently share their understanding of how Finnish social pedagogy theory and praxis could come together for clients with PMD in the MSE. Familiarity was necessary because this report required communication across three different languages and cultural contexts.

Collecting data by videoed focus group interviews and using them to identify practical knowledge was an interesting, but a slow process. Videos enabled appreciation of nonverbal responses, for example, where participants nodded, smiled or made some other gestures for approval or denial to someone else's suggestion. Analyzing data involved a careful advancing of translations from Finnish and Swedish to English using ongoing iterations. This occurred because the interviewees could read and then comment on the English text before the final version became ready for publishing. The process enabled us to uncover important cultural assumptions previously taken for granted, the most significant of these being the idea that sociocultural animation is indeed possible with adults with

PMD even those with the type of exigent disorders of communication that make empowerment especially problematic.

A third positive feature of the focus group interview was that it gave the Finnish researcher a chance to join the three discussions in real time and elicit explicit examples from everyday practice that would clearly demonstrate how theory could be put into practice. This required the interviewer to be ever vigilant not to personally over estimate the possibilities of sociocultural animation while subtly keeping the dialogue squarely focused on everyday practice.

Finally there were two aspects concerning the quality of the method that need to be considered, namely data collection and analysis. There is the danger that the 12 staff members possibly wanted to please the interviewer during the focus group dialogues because she was personally familiar to them. This phenomenon is always a challenge in interviews particularly when interviewees are trying to be polite. In order to minimise this problem the interviewer tried to focus the dialogue onto how to overcome difficulties staff might experience when working with their clients in the MSE. The second aspect concerning the quality of the research is the authenticity of the translated results. This was an enormous challenge, but it was greatly helped by the Finnish researcher who is personally fluent in all three languages describing the interview process in considerable detail, iterating the translated texts among participants and retranslating ongoing discussions.

The concept of rigor in qualitative research is construed as confidence in the findings representing the meanings presented by the participants (Creswell, 1998). Since the participants of the focus group interviews all were content with the description of the results, it is believed this method served the research aims.

## **Conclusions**

The goal of this research was to describe the ways that the Finnish social pedagogical approach 'sociocultural animation' is used within a practical context in the MSE. Special focus was on client and staff empowerment, creative activities and everyday multisensory experiences. Four interlinking conclusions can be drawn:

- 1) Finnish social pedagogy integrates well into MSE practices. Evidence for this can be found in the productive use of sociocultural animation in everyday practices when empowering adult clients with PMD. The influence of social pedagogy can be observed in staff members' interest in developing their own professional abilities for the benefit of their clients' wellbeing in MSEs.
- 2) Sociocultural animation combined with knowledge of use of MSEs is a meaningful blend. It is applicable especially in social care and special education, where clients actively participate in the MSE in groups where the emphasis is on social interaction and empowerment rather than simply engage in individualized therapy sessions.

3) Sociocultural animation was described as a flexible and practical approach, which can benefit both MSE's accent on individual's needs and social pedagogy's emphasis on empowering togetherness. Social pedagogy's and MSE's aims are to increase self-determination, togetherness, emotional balance, communication and appreciation of other people.

4) Empowerment, as a result of sociocultural animation in MSEs, is seen as a developing process of obtaining basic opportunities (self-determination and self-support) for people with PMD. This is achieved by communication with staff members, use of creative multimedia and MSEs, that offer sensory experiences, joy and pleasure for both clients and staff members.

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## **Chapter 5**

### **Bricolage of ‘MSEs in social care’**

#### **Introduction**

Bricolage is a complex, multimethodological, and a multilogical form of inquiry used especially in social, cultural, political, psychological and educational domains (Kincheloe, 2005, p. 323). In this article I apply bricolage as a secondary analysis method to be able to provide a more personal view of my portfolio thesis’ project results than those potential results presented in co-edited scientific journal articles and peer reviewed conference presentations. I use Berry’s (2004) advice to use a bricolage map and discuss my secondary results under four ‘combined’ topics. However, this article begins with a brief description of those of my professional and cultural backgrounds which may have affected my studies in general. This bricolage explores and clarifies those epistemological and ontological decisions I made during my research process. Cultural differences in language, practical work in MSEs and academic expectations between my studying place in Australia and working environment in Finland were so different that some further analysis was needed. I realised that my international audience at world conferences and readers of scientific articles valued not only the research results, but that some cultural information was also beneficial for them. To

increase rigor of my investigations I used multiple research methods and made several international portfolio activities together with my colleagues and co-writers (Appendix 2, p. 225). With this article I aim to introduce who I am, what I think and what I have achieved during my thesis work.

### **Personal background and professional positions**

My first connections to Multisensory Environments (MSE) were through books (Hulsegge & Verheul, 1986; Pagliano, 1999), through excursions to European snoezelen/MSEs, and through connections to the International Snoezelen Association (ISNA). In my workplace I experienced challenging tasks to develop theoretical and practical contents of Finnish MSEs within social care. For these purposes I also had to build an international research network. My part time studies could be integrated to my work which included: curriculum development, teaching, project work and research co-operation with MSE-professionals.

In this article ‘my story’ begins from the first Finnish Snoezelen-Network meeting, which was held in Helsinki in 2001. The popularity of the topic ‘snoezelen’ was so great, that the organizers had to limit the amount of people who could join in. Every participant was eagerly telling about their snoezelen-rooms, how many of them there were and which equipment they had. Hardly anyone talked about the background theories of the work or what actually happened with clients in those environments and for what reasons.

This network procedure was repeated annually and since I was at that time working as a principal lecturer of HAMK (University of Applied Sciences, Finland), I began thinking about the possibilities of staff education to increase practitioners' critical awareness and pragmatic knowledge of snoezelen.

On reflection of those past experiences the questions I would now ask are: What were the orders of reality in snoezelen/MSEs? What were the ontological, epistemological and ethical paradigms in use? Without knowing it then, I had found the seed for my future research questions.

My interest in snoezelen and other multisensory methods developed at HAMK where I first worked as a senior lecturer at the Vocational Teacher Education College and later as a principal lecturer of the Degree Program in Social Services. I organized multisensory relaxation and social interaction environments for students and staff to have their own multisensory experience. Students' developmental projects took place at HAMK's MSEs, but the authentic MSEs at co-operators locations (with real clients) were, however, the actual learning environments for 'learning by doing'.

HAMK offered basic courses on snoezelen for its own students but also at the Open University of Häme, so that actually, staff education on snoezelen started in 2000. Eventually, after reading and applying the ideas of two books by Dr Paul

Pagliano (1999; 2001) I started to use the term MSE with the term snoezelen. The snoezelen/MSE-method was and still is a big topic, a ‘hot potato’, in Finland. In order to be able to teach these topics at university level, it became necessary for me to learn more. Therefore I applied for studies at James Cook University, School of Education in Townsville, Australia with Paul Pagliano as my ‘overseas’ supervisor.

My international academic background, my current position at HAMK, and our team’s shared interest on sociocultural work plus my reliance in socio-constructivism (Vygotsky, 1978) literally forced me to search for multiple realities of ‘MSEs in social care’. Social pedagogy emphasises authentic traditions of each cultural group or minority and helps people to keep their personal traditions. For example, immigrants with their families, various age groups and people with spiritual or religious backgrounds have their own kind of culture. For staff members at MSEs it is, therefore, important to be aware of various cultural traditions.

Due to my cultural background with four active languages (Finnish, Swedish, German and English) in everyday use, I became a cultural bricoleur before even knowing that the word. *Bricoleur* is French and the word’s original meaning is ‘the construction or creation of a resourceful use of whatever materials are to hand’. However, interpretive bricoleurs are more than simply ‘jacks-of-all-trades’; they are interventors in the best sense of the word (Denzin & Lincoln, 2000, p.

1061). Bricolage employs a range of interpretative strategies that emerge from a detailed awareness of the field of hermeneutics and ability to use the hermeneutic circle (Berry, 2004, p .125). In this context I will discuss my own perspectives, backgrounds, and positions in the web of reality. This way the complexity and multidimensionality of the interpretive process is comprehended by the bricolage.

According to my EdD-research plan I first needed to know ‘What was going on in the Finnish MSEs?’ and ‘What kind of research had already been completed?’ I was especially interested if and how people with disabilities were involved in research, and ‘How could client participation be increased?’ Perhaps my educational background from Germany and living six years close to the School of Frankfurt’s hegemony in critical hermeneutics combined with the social pedagogy by Freire (2001) affected me unconsciously: I wanted to be critical and find authentic answers from real life. Therefore, I decided to use multiple research methods with participatory observation and investigate the use of applied Participatory Action Research. I had to find a flexible research design for my complex portfolio thesis and a suitable strategy for my ever-changing research field. In ‘personal epistemological crises’ I have always relied on good seminal books and this time I found two works: the ‘Handbook of disability research’ (Albrecht, Seelman & Bury, 2001) and the ‘Handbook of Qualitative Research’ (Lincoln & Denzin, 2000).

Lincoln and Denzin (2000) paraphrase Thomas Berry, who had explained that:

... we are between stories. The Old Story will no longer do, and we know that it is inadequate. But the New Story is not yet in place. And so we look for the pieces of the Story, the way of telling it, and the elements that will make it whole, but it hasn't come to us yet. So we are now the ultimate bricoleurs, trying to cobble together a story that we are beginning to suspect will never enjoy the unity, the smoothness, the wholeness that the Old Story had. As we assemble different pieces of the Story, our bricolage begins to take not one, but many shapes.(p.1060)

Additionally, Denzin and Lincoln (2000, p.1060) explain that we are in a new age where multivoiced texts, cultural criticism, and post-experimental works will become more common, as will more reflexive forms of fieldwork, analysis and intertextual representation. I think that they, almost a decade ago, predicted the future of qualitative research accurately. At least I decided to use interpretive research bricolage as my overall research strategy and eventually as a method for a secondary analysis of my diverse results. I wanted to increase rigour ('true reality') for my EdD Portfolio Thesis' potential results. This time the book by Kincheloe and Berry (2004) *'Rigour and complexity in Educational Research'* finally convinced me to start learning how to use this novel method.

Methodological bricolage became personally important since my results derive from a collection of various data: one literature analysis, three research projects, four peer reviewed scientific articles, and 27 national and international portfolio activities (see Appendix 2, p. 225). Complex data of this nature are almost impossible to introduce briefly in any typically conventional way. On the other hand summarising and essentialisation are not appreciated in bricolage and, therefore, some special tools (introduced later in this chapter) are used (Kincheloe & Berry, 2004). According to Kincheloe and Berry (2004, p. 1) the French term *bricolage* is used in educational research to “signify the use of a variety of research tools and ways of seeing”. The particular emphasis here is the idea that bricolage provides "a new conception of rigour in research that is culturally sensitive and socially transformative". Much other research is "reductionist and ultimately misleading" (back cover of the book) because it does not provide sufficient opportunity for the research to explain the chronological, sociocultural context. I want to be ‘culturally sensitive’ by being critical and reflective in my ‘socially transformative’ research and in my everyday work at HAMK. Bricolage could neatly serve my purposes.

Furthermore, to make the research process even more complex and exciting, my six year research project follows an emergent design described by Cavallo (2000). Therefore, my research plan became apparent only through ongoing interaction with clients (people with disabilities), practitioners, researchers, MSE-specialists and university students, and by sensitively listening to their needs and wishes. My



guiding research questions emerged into their final form during this process, which culminated in an important time in Finnish MSE development and international multisensory research and disability networks (ISNA<sup>3</sup>, IMRF<sup>4</sup>, and IASSID<sup>5</sup>).

### **What happened before the secondary bricolage?**

At first, I focused on participatory multisensory approaches involving people with profound, and multiple disabilities, but as my own understanding grew, I also started to investigate interdisciplinary team members' participation and empowerment, as well as their staff education. I offered basic courses on snoezelen/MSE, and according to the national system, planned and conducted also so called 'Professional Specialization Studies' on MSE/Multisensory work. This was my challenge to develop the curriculum to an international level (Sirkkola, Veikkola & Ala-Opas, 2008b). Towards the end of the research process it became apparent, while working together with my co-researcher Tuomas Ala-Opas, that we needed to start defining the emerging concept of sociocultural multisensory work in greater detail (Sirkkola, Ala-Opas & Pagliano, 2009).

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<sup>3</sup> ISNA= International Snoezelen Association

<sup>4</sup> IASSID = International Association for the Scientific Study of Intellectual Disabilities

<sup>5</sup> IMRF= International Multisensory Research Forum

My three final research questions are:

1. In what ways can Participatory Action Research be applied with people with moderate or profound and multiple disabilities in the context of the MSE?
2. What is the nature of sociocultural multisensory work?
3. What are the implications for staff education in regard to develop MSEs and sociocultural multisensory work?

The first research question started my theoretical bricolage and was followed by investigations on a novel combination of social pedagogy with MSEs, which is called sociocultural multisensory work. These first two research questions led me to a more practical question concerning the emerging results' implications for staff education. The first question and its potential answers are presented and discussed in my articles (Chapters 2, 3, and 4), furthermore the results were the evidence presented in my conference paper (Sirkkola, 2008b). The second question's data were collected from two participatory research projects (MusaSaurus II - project and a focus group interview) and the results are discussed in Chapters 3 and 4. However, this Bricolage-chapter's aim is not to discuss the research questions one by one or to summarize the overall results, but to increase the all over rigour of the thesis 'MSEs in social care'. Researcher's personal history, professional background and positions are introduced (Chapter 1 and Chapter 5). These narratives highlight personal assumptions, cultural traditions, epistemology, ontology and values of sociocultural multisensory work

and their possible power relations' effects to the topics of the work. In the secondary bricolage the potential theoretical and practical results are revisited and discussed from multiple new angles with an additional aim to find new important topics for future investigations. However, the third original research question concerning the implications of previous results to staff education of MSE and sociocultural multisensory work, gets most of the attention and critical reflection, since no other article has yet been written on this topic.

### **Lack of knowledge on Multisensory Environments in social care**

Awareness of the existence of snoezelen/MSEs had arrived in Finland during the late 1980s and early 1990s. However, the results of my pilot project, in which data were collected with a semi-structured interview questionnaire (N=23) showed that practitioners and educators were not substantially aware of the aims and possibilities of these approaches. Practitioners used several background theories and methods (e.g., Sensory Integration, Basic Stimulation, Humanistic approach by Rosemarie Parse) in combination with snoezelen/MSE and they wanted to learn more about applied research methodologies (Sirkkola, 2005c).

To my knowledge, there were/are no books or texts in Finnish about MSEs, and nothing specifically written for social care. Pagliano's (1999; 2001) books, written in English, focused mostly on education. The rest of the English research also tended to focus on school settings (Houghton *et al.*, 1998) or they focused on the

area of medical rehabilitation and therapeutic effects (e.g., Long & Haig; 1992; Ashby, Lindsay, Pitcaithly, Broxholme & Geelen, 1995; Shapiro, 1995; Shapiro, Parush, Green & Roth, 1997; Lai, 2003). To be able to find the essence of ‘MSEs in social care’ there was a need to focus on social matters. My plan was not only to use, but also to develop qualitative research methods and tools for ‘easy to apply and access’ data collecting methods.

Through research literature and critical-reflective discourses at international conferences, I realised that there is a growing global popularity of the topics of participation and empowerment among the social sciences and education. However, relatively little had been written about these topics in connection with profound, and multiple disabilities and even less (if anything?) about sociocultural aspects within MSEs (Sirkkola & Pagliano, 2009). The combination of social pedagogy and multisensory methods seemed to need a theoretical frame, supportive evidence and new accessible and motivating tools for sociocultural animation.

My colleague Tuomas Ala-Opas (my co-researcher, master of theology, rock musician, multimedia enthusiast and a member of our multisensory team) and I were interested in investigating how the use of accessible multimedia could motivate and facilitate participants to engage in active individual or group reflections. Our proposal (based on own previous projects) was that the combination of applied PAR and the use of creative actions within the MSE

would offer increased opportunities for active involvement to all participants. One of the research projects called *MusaSaurusII*-project focused on the use of visual methods with multimedia. We developed a tool called ‘empowering digital media’, which can also be used as an accessible participatory data collecting method (see Chapter 3; Sirkkola & Ala-Opas, 2009).

Later when our colleague Päivi Veikkola (body psychotherapist and psychologist) joined our multisensory team at HAMK we added the important aspect of body-awareness to our research topics and started offering international summer courses on ‘Space Experience and Body Expressions’ (Sirkkola & Veikkola, 2007; 2008). To avoid one-sided reductionism, we invited our workshop participants in Germany and Canada to produce international data on empowerment and participation in the context of MSEs (ISNA’s Workshops 2006; 2007). This topic continues as a workshop ‘Cultural Aspects of MSEs’ at ISNA’s Symposium in Denmark, November 2009.

### **Beginning of the research process**

To start fulfilling the Finnish practitioners’ need and requirements to learn more about theories and working methods suitable for MSEs in social care, I decided to start searching for local definitions of an ontology, epistemology and pragmatic paradigms concerning snoezelen/MSE. I thought that the best way to organize this was together with the most advanced Finnish practitioners who already used

social pedagogy in MSEs, with their clients and my students and colleagues from HAMK. To create authentic possibilities for critical-reflective interactions I conducted four research projects, and wrote articles that all dealt with topics of participation and empowerment in MSEs (Chapters 2, 3, and 4).

My research process was complex and did not follow a 'safe linear logic'; instead it used a 'fuzzy logic' and was in this perspective similar to my everyday professional work at HAMK. The research focuses on applied studies with pragmatic multisensory topics and was immediately accepted among my colleagues at HAMK. This 'approval' provided me sufficient collegial support during the research years. Almost all projects and many of the portfolio activities were time wise emerging on top of each other. At the same time as I started to investigate the developments of the Finnish MSEs and listened to the needs of clients and their caregivers, it became important to build international connections and start conducting mutual research projects with members of ISNA. Simultaneously the need for arranging international courses in English and long-lasting staff education for MSE practitioners became evident. I think that instead of bricolage I could have used ethnography and grounded theory as well: I was working in the middle of MSEs and their development. However, I choose bricolage, since it suited the interdisciplinary, complex and ever-changing research field and offered the possibility to use multiple and applied methods plus it finally led to critical evaluation and reflection of various potential results as their secondary analysis.

My professional history and current needs to develop MSEs in social care, led me to become a methodological and interpretive bricoleur, being a cultural and linguistic bricoleur even before starting my thesis process. Collecting a rich data with multiple methods was my goal, but what exactly is bricolage?

### **‘Point of Entry Text’ and the tools used in my bricolage process**

*The teacher bricoleur views research methods actively rather than passively, meaning that the researchers actively construct their methods from the tool available rather than passively receiving ‘correct, universally applicable’ methodologies. (Kincheloe, 2003, p. 249)*

Research bricolage uses a variety of tools (Kincheloe & Berry, 2004). Four tools have been applied to my research and their use is introduced next:

1. The first tool is called ‘Point of Entry Text’ (POET), and it serves as an introduction to the research topic. Most often a text, for example, a small story, a note book or official paper, is used as a POET. However, also pictures or even old drawings can be offered as a POET. I used a simple diagram to introduce the focus of my complex research area. My theoretical frame (drawn as overlapping circles) and my first research question are used for this purpose in Figure 5:1, p. 139. My theoretical frame consists of three areas: 1) Multisensory environments

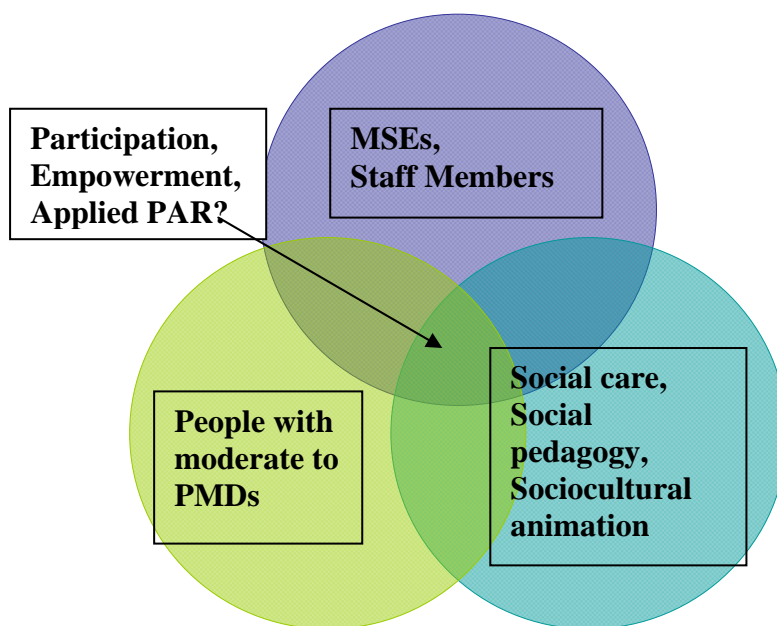
(MSEs) including the members of staff and the physical environments, 2) social care influenced by social pedagogy, and sociocultural animation, and 3) people with moderate to profound and multiple disabilities (PMDs). The focus of my research, locates in the overlapping area of the three circles (participation, empowerment and applied PAR) with the first research question: 'In what ways can PAR be applied with people with moderate or profound and multiple disabilities in the context of the MSE?

These specific decisions concerning the 'POET' are explainable due to my primary theory, which generates from social pedagogy's sociocultural animation (Freire 2001; Hämäläinen & Kurki, 1997) combined with theories of participation (Hall, 1981), empowerment (Siitonen, 1999) and applied Participatory Action Research (PAR) (e.g., Kemmis & McTaggart, 1997; Tewey, 1997). Figure 5:1 (see following page) introduces my POET with the first final research question above the figure.



**The first final research questions:**

- 1. In what ways can PAR be applied with people with moderate or profound and multiple disabilities in the context of the MSE?**



**Figure 5:1. Point of entry text (POET) of ‘MSEs in social care’** is a diagram consisting of MSEs (including staff members and the physical multisensory environments), social care and social pedagogy (including sociocultural animation) and people with moderate to profound and multiple disabilities (PMDs). The focus of this thesis is on participation, empowerment and applied Participatory Action Research (PAR), which can shortly be described as ‘investigating together with people with disabilities’. The first final research question is placed on top of the figure (the two other research questions are presented on p. 12).

2. Another tool of bricolage is the '**Layers of transparency**' meaning the different levels, episodes and history of the research and its activities. In this thesis I use narrative style, e.g. the introductions of the Chapter 1 and this Chapter 5, to illustrate the way that the past decisions and actions along my career have influenced un/consciously my later research bricolage. The style of writing in 'I' form is most often the case in bricoleurs' texts. My four co-written articles demonstrate other types of scientific writing which are more formal (Chapters 2, 3, and 4) and so provide layers of transparency, particularly when the same issue is revisited from different perspectives.

My articles and other presentations reveal something of the recent history of snoezelen/MSE development. Some expressions, research topics and research methods start cumulating (e.g., interdisciplinarity and evidence based practices) and give information about the latest interests in the MSE-field. Denzin and Lincoln (2000, p. 1058) explain "...we care less about our 'objectivity' as scientists than we do about providing our readers with some powerful propositional, tacit, intuitive, emotional, historical, poetic, and emphatic experience of the 'Other' via the texts we write."

**3. Feedback looping** is a tool for reflexivity. Berry (2004, pp. 128-146) suggests re-visiting the POET regularly to reflect upon the research process. Throughout the studies I reflected on my process in my learning diary and conducted critical-

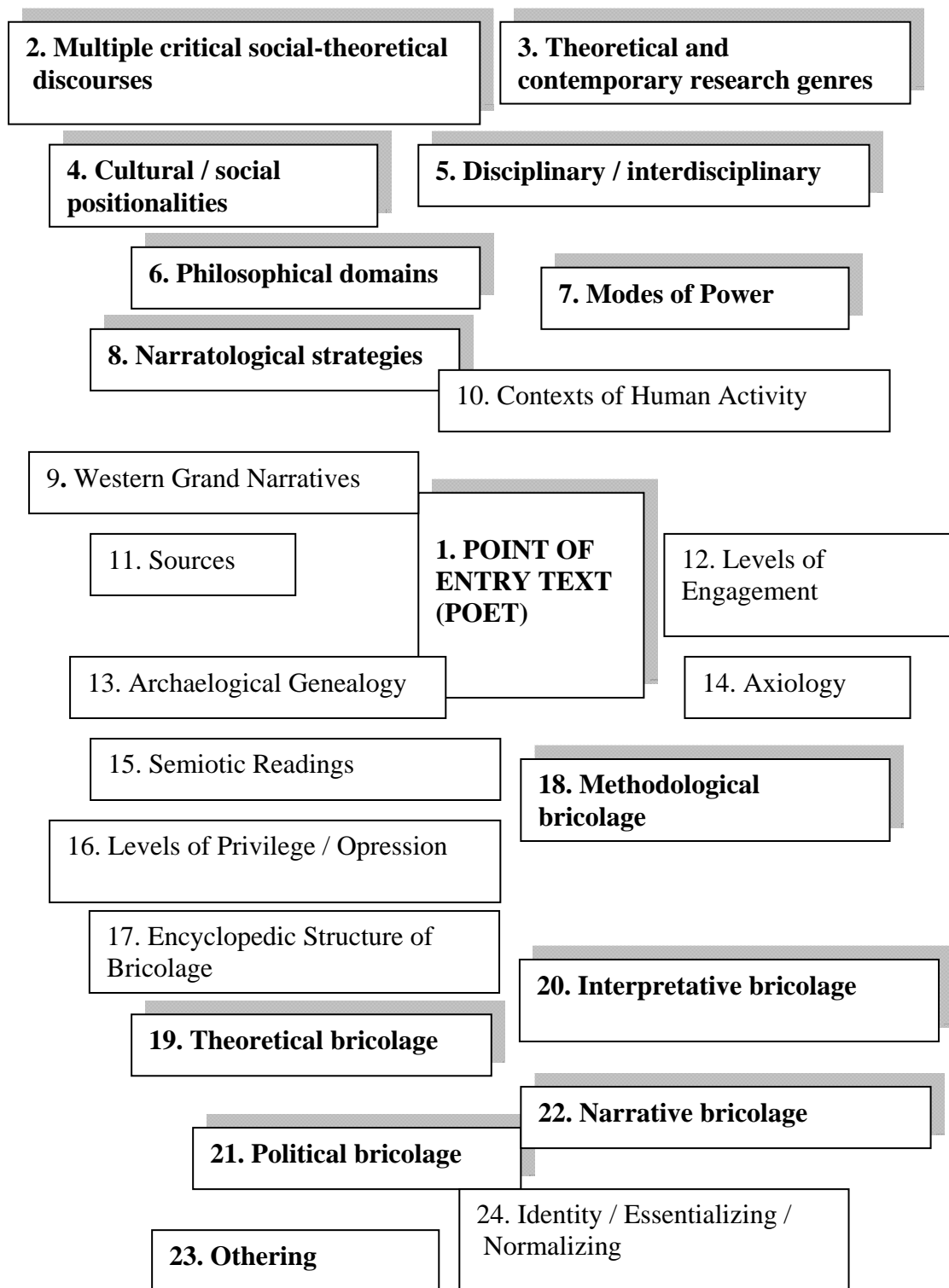
reflective discourses with my co-researchers and other snoezelen/MSE/disability experts.

**4. A bricolage map** is the main tool in my research (Figure 5:2, p. 143). It is first used when planning a research, but also throughout the research process for reflecting. Kincheloe and Berry (2004) call this reflecting as ‘threading through the bricolage map’. The map starts with the POET and offers possibilities to ‘thread through’ relevant areas from 2-24 different, non-linear, complex and sometimes overlapping points. Basically, the map helps to recognise own ambitions, discoveries and breakthroughs by the levels of engagement at a certain point of the research. According to Berry (2004) one can visit the areas once or not at all, or as many times as needed. I use this map to make my research more rigorous through considering each point and by discussing and critically reflecting on the most important points. Chapter 5, therefore, offers a rich and thick research narrative with the help of a secondary bricolage of the previous research. On the other hand, it would be difficult to evaluate this portfolio thesis’ potential results with more typical (old fashioned) measures of such qualitative studies as trustworthiness, truth values, applicability, consistency and neutrality (Lincoln & Cuba, 1985, p. 290).

Berry (2004) underlines that it is important to notice, that those areas of the bricolage map, which are not included in one’s own research, could also hide valuable meanings and opportunities that must be useful for the specific research

area. Critical bricoleurs should at least be aware of those areas, which are left outside considerations. A novice bricoleur like me ‘is able only to skim their [the areas’] surface meanings’ as Berry (2004, p. 114) notes. However, I intend to discuss some details of my research projects and portfolio activities in different ways and examine other levels than was possible in the journal articles.

The Figure 5:2, A frame for a bricolage map suggested by Berry (2004, pp. 108-127), is illustrated on the next page. The figure forms my bricolage frame for ‘MSEs in social care’.



**Figure 5:2.** A frame for a bricolage map suggested by Berry (2004, pp. 108-127). Points shadowed and printed in bold letters are the most meaningful in my research and are therefore discussed in more details under four combined topics.

I used some of the 24 bricolage map topics more than others and explain how I considered, evaluated or used the chosen area's topics in my secondary analysis process. Even the use of a bricolage map does not necessarily prevent the reduction of knowledge and values. To avoid essentializing, bricoleurs use cross-examination, meaning critiquing the knowledge of a text / world/ experience and so also critique what they have produced as knowledge. Additionally I explain why I did not use all points and discuss their possible meaning and values for future MSE research. The bricolage map (Figure 5:2, p. 143) is applied to fit my research and helps me present and discuss my secondary results under the following four 'combined' topics:

- I) Multiple critical social-theoretical discourses and philosophical domains
- II) Disciplinary and interdisciplinary knowledge in multisensory work
- III) Interpretative bricolage as narratives
- IV) Political bricolage and modes of power

### **Multiple critical social-theoretical discourses and philosophical domains**

*The purpose of research conducted within the critical paradigm is not just to describe or understand social phenomena, but also to change them.*

(Grogan & Simmons, 2007, p. 37)

The main aim of bricolage is 'the promise to support basic democracy (Kincheloe & Berry, 2004, p. 137). The main theoretical result of this thesis; the emerging

concept 'Levels of Happiness Capital' (Sirkkola, Ala-Opas & Pagliano, 2009) introduces possibilities for active citizenship and aims towards the cultural democracy of all people at various levels (individual, community and society). Figure 5:3 below presents the levels of happiness capital in sociocultural multisensory work.

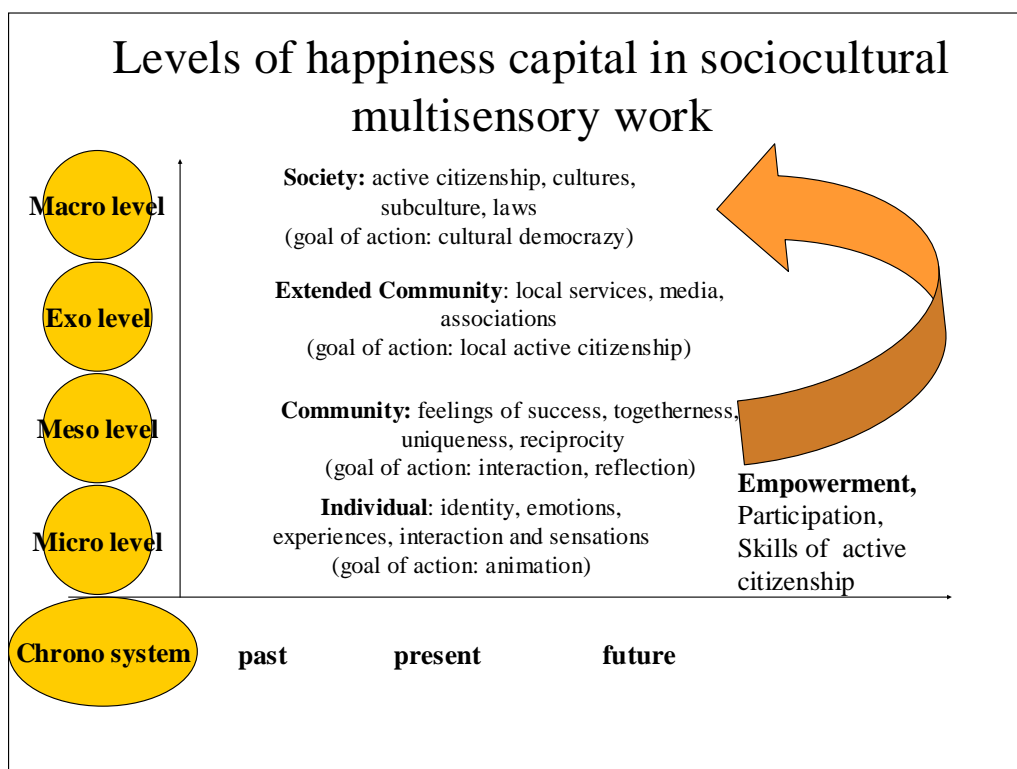


Figure 5:3. Levels of happiness capital in sociocultural multisensory work, based on: Vygotsky (1978), Bronfenbrenner (1979), Bourdieu (1984), Sirkkola, Veikkola & Pagliano (2007), and Sirkkola, Veikkola & Ala-Opas (2008).

In preparation of this concept we used critical discourses: the main paradigm is Finnish social pedagogy, which tries to integrate all individuals into the society. It deals with processes of human growth that tie people to the systems, institutions and communities that are important to their well-being and life-management (Hämäläinen, 2003). Finnish social pedagogy has three main elements: 1) activities 2) community, and 3) experiences (Hämäläinen, 1999). It animates people to pedagogical self-help, to strengthen their feeling of togetherness in community (people who live or work together), and it tries to prevent problems with pedagogical interventions. .

Furthermore, we combined the Ecological system theory of Bronfenbrenner (1979) with the aims of social pedagogy and MSE. Ecological systems theory describes the patterns of environmental events as interaction between the developing person at Micro- (family, peers, classroom etc.), Meso- (two Microsystems in interaction), Exo- (external environments which indirectly influence development; parental workplace, parks, libraries) and Macro- (larger sociocultural context, national economy, political culture, subculture, global events) levels and as a Chronosystem (evolution of the external systems over time). Each system contains roles, norms and rules that can powerfully shape development in sociocultural multisensory work.



The media of snoezelen (Hulsegge & Verheul, 1986/1987) / MSE (Pagliano, 1999; 2001) are not introduced here, since they are already described in the Chapters 2, 3, and 4. However, it may be worth mentioning, that the aim of my four research projects was not only to prove these media's efficacy or to be critical of them, but also to apply 'the best parts of each tool' (Kincheloe, 2004, p. 144) and make a bricolage of multisensory methods suitable for Finnish practitioners. Sociocultural multisensory work became possible by applying old methods and adding novel tools to them, for example, sociocultural animation and empowering digital media (Chapters 3 and 4).

Furthermore, to increase multiplicity of discourses and add a flavour of hope, joy and happiness to the novel concept, we borrowed the word *capital* for our use. Putnam (1993), Coleman (1988) and Bourdieu (1984) offered theories of social and cultural *capital*, that gave us the idea and critical support in constructing our concept. The term *capital* officially refers to a set of usable recourses and power relations, and *capitalism* may refer even to cheap labour (children, women, people with disabilities etc.). In our case, in Happiness Capital, positive emotions are arranged without money; smile, giggle, tickle and hugs are valuable, but in MSEs they can be created with no extra currency (Sirkkola, Veikkola & Ala-Opas, 2008).

Since my main focus group were people with moderate to profound, and multiple disabilities, it seemed necessary to consider developmental psychology and

theories of socio-constructivism (Vygotsky, 1978). The theory of ‘Zone of proximal development’ and socio-constructivist ideas were therefore applied in practical sociocultural animation situations. These experiences were then applied in constructing the concept of sociocultural multisensory work and the tool of empowering digital media.

Since my research focuses on ‘Finnish social pedagogy in action’, I am interested in all pragmatic solutions related to the use of these theories in practice (Dewey, 1933; Kolb, 1984; and Lewin, 1946) to increase participation and empowerment in MSEs.

In addition I applied several philosophical domains ‘...produces ideas about how and why the world is or should be, such as; how we come to know/be/act, what is knowledge (epistemology), being (ontology), axiology (the disputational contours of morality and value)...’ (Berry, 2004, p. 117).

I apply the following philosophical domains in my studies and teaching: Heidegger’s hermeneutic phenomenology (1996) and Husserl’s reflective phenomenology (1995), pragmatism as described above, and humanistic ideas of egalitarianism (Finnish constitution, 1999) and democracy combined with social pedagogy. My epistemological ideas for knowledge-building include the ideas of multiple, free, complex, developing, ever changing realities and creating interdisciplinary knowledge as a group process. I, therefore, base my ontology on

the following ideas: everyone being unique and creative and needing togetherness in a supportive and accessible community. Due to my personal background my axiology is based on western civilization's moral and values, democracy, and egalitarianism. Finally, the values of sociocultural multisensory work are: social justice (equality, inclusivity, access, self-determination and democratic participation) which lead to empowerment, bringing possibilities of accessible creative activities and experiences to increase happiness capital.

The emerging concept of sociocultural multisensory work derives from multisensory methods, but more importantly, it is based on the above mentioned philosophical domains. We (teachers, practitioners, students and clients) try to evaluate and develop empowering tools for the use of sociocultural animation with the support of these philosophical domains. Sociocultural multisensory work's applied philosophy is, that all MSEs, tools used in MSEs, methods of interaction, and arranged cultural experiences are individually accessible (in MSEs) and adapted to all people (in everyday life at community and society levels). Therefore, it is crucial that the clients co-research their local environments.

Philosophical domains help considering ontological questions on 'being – not doing'- axis and 'What is multisensory perception? Is it being or doing?' (Heidegger, 1996). This type of question is already included in the multisensory

work curriculum development, but definitely needs more attention in the future (Sirkkola, Veikkola & Ala-Opas, 2008b).

Limitations of my research concerning the chosen theories are the following: social pedagogy and its tool sociocultural animation were chosen to present Finnish theories, even if there were some other background theories in use. This was because social pedagogy is the chosen theory at HAMK and the influence and effect of the method in MSEs was of interest to me. Furthermore, the focus of my work is on the concept of sociocultural multisensory work within social care and only thereafter, attention is given to interdisciplinary research and interdisciplinary team work. The core of the whole thesis is based on HAMK's teaching environment and its possibilities to offer staff education. How should the results be used in other universities? What happens if only part (or no-one) of the multisensory team wants to use social pedagogy and sociocultural animation?

### **Disciplinary and interdisciplinary knowledge in multisensory work**

Noticing the importance of well-functioning interdisciplinary team work is another important result of my research and influences especially the curriculum planning of basic studies and staff education of sociocultural multisensory work. Due to prejudice, jealousy and possible fear of the unknown, interdisciplinary work is also one of the most difficult areas of development in many ways. 'One has to know one's self, before understanding the others' (an old Finnish proverb)

includes the wisdom of critical self reflection. Besides interdisciplinarity group reflection subjective reflection is essential for well functioning multisensory work. I practiced self reflection during my studying process and wrote the following in my reflective diary (30.09.2007):

*Paul [Pagliano] was talking [in Jyväskylä, Finland] about neuroplasticity and the two pleasure systems in the brain. He thinks there is a pedagogy of hope and proposes that the brain is always developing and changing according to the demands placed on the individual by their environment, the sensory input they receive and their level of interaction. Every individual with autism or PMDs must find their own 'brain pathways', not only the highways. This means an evolution of human beings, not only the personal history of an individual. Finding own pathways might result in the discovery of other sensory pathways or other combinations of sensory input. The whole idea of MSEs is very complex and these ideas are not easy to apply in the real world. There is a profound need for interdisciplinary teams and staff education. The importance of neuroplasticity starts to makes sense ... .*

I started my EdD- process to make sure that I know what 'MSEs in social care' means within one discipline, but interdisciplinary teamwork quickly became one of my main research focuses and influences the organization of staff education at HAMK. The importance of interdisciplinary communication was underlined many

times during critical discourses as the most important feature of successful team work. The focus group interviews, literature analysis and many critical-reflective discourses at conferences repeated the same tune 'communication between staff members is important'. Therefore, the two Professional Specialization Studies and all basic studies in Multisensory Work at HAMK were purposefully arranged as multidisciplinary courses, since they offered the possibility of communication for various disciplines but also possibilities to mix novice and expert practitioners to learn together and later develop as an interdisciplinary team.

### **Interpretative bricolage as narratives**

My cultural and social positionalities as a bricoleur can be listed as follows: female, white, middle aged, non-disabled, western, upper middle class, married with an academic husband, three adult children, principal lecturer at the Degree Program in Social Care at HAMK (University of Applied Sciences) with professional background as an art therapist, special teacher and vocational teacher educator with special interest in MSEs, social pedagogy and international perspectives. My cultural background offers me the opportunity to speak fluently Finnish, Swedish, German and English (which is typical for most Finns). My first academic degree in Germany was a way to learn German language and culture. My interest in languages caused me to study the Spanish, Estonian and Russian languages. The second academic degrees, Masters in Special Education, Licentiate in Vocational Education and Teachers diploma are from Finland and

the EdD will be from Australia. I live in a small town with enough cultural events, own house and a summer cottage with Finnish saunas.

I wrote a relatively long introduction to the first and this chapter on purpose. I wanted to explain my professional interests and historical backgrounds to give a change for readers to critically evaluate my background theories influence on thesis results. These may hide cultural and personal assumptions even if my intention is to provide neutral and rigorous results.

My co-writers, co-researchers and colleagues are all white, well educated, non-disabled professionals. Most are educators at university level and interested in MSEs, social pedagogy and international perspectives. One is from Australia, the rest are Finns, or from the UK, Germany or the USA. All travel a lot and have multiprofessional experiences and qualifications.

Most staff members working in Finnish MSE are Finnish and possess a vocational education. Today some immigrants and refugees who have studied Finnish or Swedish and work in social care, have other racial and cultural backgrounds (many of them are from African and Asian countries, but also from Estonia and Russia). Some of the clients with disabilities belong to these cultural groups. Therefore, it is essential to include cultural know-how to staff education.

At the international associations' conferences I met several specialists and practitioners from all over the world. Most of them have been white Europeans

with only a few exceptions. During my life, I have had only one black African teacher, my drumming teacher. Of course I have met and become friends with several people from other countries, but have only minimal professional experience of different races. Therefore, I am happy that we started to arrange annual international Summer Schools at HAMK and got a possibility to invite Snoezelen teachers from other countries. We arranged a course 'Space experience and body expressions' (Sirkkola & Veikkola, 2007; 2008) twice as part of the Professional Specialisation Studies we have arranged an excursion to visit Swedish MSEs.

Various cultural experiences are important in vocational education and staff education, since they prepare the staff members to attend international conferences (Sirkkola, Veikkola & Ala-Opas, 2008a). The cultural aspects and local developments, case studies and technical interventions and preparing presentations for conferences are important modules in curriculum planning at all staff education levels.

Since bricoleurs are aware of what is missing from their own work, I now consider what Grand Western narratives I might have used: It might have been possible for me to have included such discourses as: capitalism (not only happiness and cultural capital), socialism, Christianity, Neo-Marxism, or patriarchy and heterosexuality to my writing, but I leave this possibility for others. Democracy and liberal humanism (ruling assumptions, values and meanings of



the modern epoch; a commitment to ‘*man*, whose essence is *freedom*’, where the human being seeks a political system, which guarantees freedom of choice) are the ideological Western Grand Narratives, that probably influenced my writing and were assumptions behind the texts describing good life and happiness in multisensory work. Social Pedagogy (Freire,1973) may not yet be a Grand Narrative, but it influenced my choices and guided my research process enormously

Three years ago I started to write the thesis report in a traditional way, using passive past tense-style trying to be objective and strictly academic. Then the idea of bricolage was introduced to me. This method changed the whole system of my writing and thinking about qualitative research methodology. My thesis writing became more personal as the academic style could be changed to various types of narratives. It is a pity though, that I cannot write in my own language, Finnish. Writing in English reduces my ability to use creative and interesting expressions. I have to rely on my Basic English vocabulary and those expressions I have learned during my annual conference visits abroad. In preparation of my texts I had to use editorial support and proof-readers. This was interesting, helpful and I learned a lot, but sometimes these procedures may have changed my texts to be more ‘average’ and I am afraid, not very critical nor surprising.

Another concern about the narrative style is that I had to use many translations. In two of my projects I used videos for data collection (*MusaSaurusII*-project and

focus group interviews) and I wrote scripts of the most important discussions in Finnish. It was often impossible to translate participants' narratives and idiosyncratic expressions to English. This is the price one has to pay, when using several languages and paddling between cultures. In addition, you often experience feelings of disempowerment and otherness, and being a stranger. In my case, such cultural traditions as Finnish sauna, ice dipping and vodka helped in most desperate situations, but most of the times I (also) reflected on my learning diary.

The questions I posed myself in the diary are like these: Am I doing the right things? Should I add something or leave something out? Am I able to answer my research questions with the data I am collecting? How can I add the experiences gathered to my results in the way they emerge? Have I taken care of all aspects I have planned to do? Should I add or leave something away? Am I critical enough?

These were typical questions noted in my reflective learning diary, that I first wrote in Finnish and then, without planning, started to write in English (30.09.2007). Writing in English started after the ISNA conference in Montreal, where we presented a keynote (Pagliano & Sirkkola, 2007) and some further lectures at Jyväskylä and Vaasa Universities. I translated Pagliano's lectures from English to Finnish or Swedish and then the emerging questions from the audience back to English.

I wrote about theoretical and practical matters in my reflective learning diary. As an example of this, I translated some thoughts about Musa Saurus II-project first written in Finnish (17.01.05) to English (24.04.09):

*Tutkimuksellisia ajatuksia projektista; Ennen kuin kehitysvammaisia nuoria voi osallistaa, ohjaajat on osallistettava tutkijoiksi. On niin helppoa puhua PAR:sta, mutta toiminta onkin jo paljon vaikeampaa! Miten tämän voisi muuttaa?... Reflektoinnissa muutamat ohjaajista ovat jo tajunneet kuinka vaikeaa sosiokulttuurinen animointi on todellisuudessa.... Oppivan organisaation teorit ovat tässä varmaankin taustalla. Tutkijat ovat keskellä muuttuvaa ongelmakenttää koko ajan...*

*Ideas about the research project; before you are able to include the adolescents with disabilities you have to engage the advisors to participate in being co-researchers. It is so easy to talk about PAR, but much more difficult to act accordingly! How could I change this? ... In reflection, at least some advisors have already understood how difficult sociocultural animation is in practice. Theories of 'a learning organization' are close what we do. Researchers are in the middle of ever changing fields of problematic...*

The Finnish text demonstrates, not only the contents of my diary, but also the difficulty of multilingual research where many things have to be translated to

English. Later, when my British, American and Australian proof readers helped me with my English texts, I learned that there are also several traditions of sophisticated English. Some further restrictions to my writing occurred due the advice from journal editors and from James Cook University. These regulations have a connection to power relations, addressing the question: 'Whose advice is valid?'

### **Political bricolage and modes of power**

Young (2000) identifies five faces of everyday life's oppressive power as: exploitation, marginalization, powerlessness, cultural imperialism and violence. All these powers are still present in civilized western countries, especially when the focus is on disabilities and social care. These oppressive powers are easy to demonstrate by opening any local or international program from TV or radio or reading headlines of a newspaper. I want to reflect the way these power relations function in MSEs.

I had at least five different groups of people connected to my research whom I could observe and whom to ask about the matter of power relations: people with PMDs, their carers (interdisciplinary teams), my own students and colleagues at HAMK and the international experts (specialists) group snoezelen/MSEs.

People with profound and multiple disabilities form a minority (about 0.13 % of Finnish population) and are a marginalized group needing everyday help from others. They most often have limits in communication and additional limitations in senses. My main contact to people with disabilities comes from MusaSaurus projects and from a four week working placement in the UK. I was fortunate to work in the UK for four weeks and be part of and closely observe everyday life of a boarding school for adolescent students with profound, and multiple disabilities. Many of the students had severe vision impairments and I saw the way the specialists worked with them in the MSEs. They called their working method 'developing choices', which gets very close to the ideas of Finnish sociocultural animation at personal level. I was lucky to participate in the early phase of interdisciplinary team work and to observe the use of videoed data of a special student's week's main interactions with the members of interdisciplinary multisensory team. My result about good communication and free atmosphere being core values of well functioning teams, was evident from the British practice.

Often when I meet people with disabilities, my focus is on the student, advisor of the activity or on the physical environment and technical equipment. Staff members were working at health and social care sector (majority of them being females with low incomes) and often described as 'hardworking and stressed group of professionals' fighting against organizational disempowerment. In many cases they were or became HAMK's students.

Teacher - student relationships at any level of education involve power and hierarchy combinations, which may create problems of power. The tensions between professionals (social and health care) are recognisable and produced due to the scare of either medicalisation or socialization depending whose point of view it is. This power related situation actually made my colleagues and I start to define what sociocultural multisensory work means within social care, but I am pleased that organizational arrangement towards interdisciplinarity is made at HAMK. The creation of the Research and Development Centre for Wellbeing, which is a multidisciplinary combination of crafts and recreation, social services and health care, offers a possibility to share curriculum especially at the Professional Specialisation Studies and basic course-levels.

Interdisciplinary teams work (sometimes) well, but need 'time and space to grow'; willingness to co-operate and to work with each other as a team is essential. It can happen if there is good will and sensitive understanding of other disciplines' aims and goals. I underline the importance of a curriculum, which is planned to mix adult and younger students of various disciplines. It is much easier to work later in interdisciplinary teams, if there has been an early experience of interdisciplinary working gained at the basic studies level.

I co-operated with international experts and specialists, a group of people with a high standard of prestige and knowledge. Between the nationalities and research groups where there may exist hierarchies and power relations. This becomes more

evident when considering whose point of view is the most authentic, correct or most reliable. Conferences are great venues for open discussions and forums to present personal points of view. My experience is that (similarly as in team work with interdisciplinary staff members) there should be more time at conferences for reflecting groups and small discussions providing opportunities for critical opinions (which are not necessarily negative).

As an example of power issues within snoezelen/MSE; The value and existence of local and applied views versus global and original concepts is an important question. On the other hand, originality demands definitions of one's own methods and critical exclusion of 'strange applications'. Commercial companies sometimes want also to 'own' theories and apply for trademarks (e.g. Snoezelen®, Basale Stimulation®, and Ayres Sensory Integration®). MSE was created to offer a trademark-free scientific multisensory field for objective research.

My results are based upon local projects' results, may be difficult to universalize due to the cultural and political differences between countries. Knowing these differences, I tried to create rigour in my scientific articles by telling precisely what, where, why and how the results were gathered. I created practical knowledge together with the practitioners and colleagues from those data we managed to collect locally. Our aim was to develop MSEs' everyday practices and ordinary living areas according to the clients' needs and wishes.

My portfolio activities culminated in arranging the 16 international students of the Professional Specialization Studies in Multisensory Work (2008) to focus on creating local definitions of own work and descriptions of developmental projects and later travel to Germany, to introduce those to global audience at ISNA's conference in Neuwied. The point of participation to conferences is that local – global – dimensions offer possibilities to learn from others and maybe even consider new perspectives to own snoezelen/MSE/multisensory work.

### **Othering**

How to end a bricolage chapter without summarizing or essentializing the results?

I think the topic of 'Othering' is a good way to end up thesis;

*How does the bricoleur ensure that the worlds inhabited by human beings are reported in a manner that keeps intact the dignity, freedom, and agency of the Other(ness)? Bricolage realizes that all studies are about othering even when autobiographical or naming positionality. (Berry, 2004, p. 126)*

Within social care and especially when talking about people with profound, and multiple disabilities the question of *Othering* is present all the time. Perhaps care givers, family members and friends are the closest interpreters of these people, but unfortunately I had to focus out this important group from my work. As a participatory researcher, I tried to get as close as possible to the original personal



meanings, but sometimes there are really no ways of confirming the authenticity of preferred opinions or creative ideas. Trust in a relationship and humour should be discussed more in future research.

I started this portfolio thesis with a short story about a tiny girl, Lynn, in the USA. It concerned her trust for me and my facilitation experience in the swimming pool with her. Now I want to end this work with a small narrative from UK. It was a small nonverbal moment, a hilarious interaction with David, a youngster with profound, and multiple disabilities and many respiratory health problems:

I was assessing David in a drama class, but he was half asleep most of the time. At the end of the class we were supposed to quietly read children's books and I read a story about an African village. I tried to pronounce the difficult African names and David just kept on dozing. I got to a page where a boy gets a drum and starts playing it: ZUMBA-ZUMBA-ZUMBA...David awoken and stared at me with awe. I repeated quite silently zumba-zumba-zumba. He smiled and looked me in the eyes. I said once more 'yes, he got a drum ...ZUMBA-ZUMBA-ZUMBA...' and we both giggled loudly. The drama teacher wisely joined our episode and hissed: 'Shhhhhhhh...you should be quiet while reading!' David and I gazed each other and without even saying a word we just continued our reciprocal hysteric laughing. We could not stop...

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## **Chapter 6**

### **An overview of the portfolio thesis process**

#### **Definition of terminology**

The Multisensory Environment (MSE) is a complex yet flexible medium where targeted sensory stimulation (visual, aural, tactile, kinaesthetic, olfactory and/or gustatory) is presented to the user. Pagliano (1998, p. 107) defined the MSE in the following way:

The ...MSE is a dedicated space or room for relaxation and/or work, where stimulation can be controlled, manipulated, intensified, reduced, presented in isolation or combination, packaged for active or passive interaction, and temporally matched to fit the perceived motivation, interests, leisure, relaxation, therapeutic and/or educational needs of the user. It can take a variety of physical, psychological and sociological forms.

All participants in my research who were users of the MSE had some form of disability. There are several ways to define disability. My preferred social model defines disability as "a limit or loss of opportunities to take part in community life because of physical or social barriers" (Altman, 2001, p. 103). This social model contends that everyone is equal and demonstrates that it is society, which causes

barriers preventing people with disabilities from participating in the activities of local community. It is society that restricts their opportunities to be a part of that community. Therefore the social model focuses on changes required in society to help break down those barriers including addressing attitudes, social support, information, and physical structures.

Social care is the practical expression of this definition of disability. In Finland, social care provides support services to enhance and promote the participation and empowerment of people who are vulnerable to being marginalised. At my institution, HAMK (University for Applied Sciences) in Finland, we have set up a Research and Development Centre for Wellbeing, a multidisciplinary combination of crafts and recreation, social services and health care. The MSE is a part of the service delivery. Fundamental to social care at HAMK is social pedagogy and therefore this is the main theory driving my doctorate.

In Australia, the United Kingdom and the United States of America, social pedagogy is a relatively unfamiliar term. This is very different in a number of non-English speaking European countries where social pedagogy has a high profile (Germany, France, Spain, Sweden, Denmark and Norway). In Finland, social pedagogy plays an important role in services that relate to social care or education. Hämäläinen (2005, p. 1) explains that:

In theory and practice it [social pedagogy] deals with processes and problems of human development and education in terms of citizenship, social identity, life capacity, participation, and inclusion. It covers all the areas of social education having a foothold in all the fields and forms of early, youth and adult education.

Hämäläinen and Kurki (1997) are two authorities on Finnish social pedagogy. The main practical method is called 'sociocultural animation', a tool that can be understood as '... working with people and groups so that they participate in and manage the communities in which they live' (Smith, 1999, p. 1). Kurki (2008) has written about sociocultural animation in care for elderly explaining how important personal perspectives are without forgetting the importance of togetherness. In addition, ENOA (2006, p. 1) defines animation:

...as a tool of empowerment. It is based on the following idea: through active participation people undertake responsibility for and take control over their own life. This can lead to mobilization of own strength, which will make gain of more self-control and self-confidence possible. In this way there can be activation of resources (skills, decisions) and of participation in social life.

In other words sociocultural animation is connected with participation and empowerment. These themes of participation and empowerment are crucial to my doctorate.

### **My professional practice in relationship to the MSE**

I have been an academic at HAMK for more than a decade. I am currently principal lecturer in the Degree Program in Social Services. I teach and advise a variety of students from a range of disciplines and practitioners from diverse occupations. I have a long-standing interest in MSEs. I completed a Degree in Special Education, from Justus Liebig University, West Germany in 1982, and my Finnish licentiate thesis was in the area of using action research in the MSE (Sirkkola, 1998). Over the years I have worked in and visited many MSEs throughout Europe.

At HAMK, we have MSEs for practical experiences, for special projects and for research. I coordinate courses that prepare staff in the use of MSEs in social care. I have taught multisensory approaches and social pedagogy for many years.

### **Why the research was undertaken**

The goal of this study was to investigate and develop MSE use in Finnish social care with people with moderate to profound, and multiple disabilities and in the

process use the results to inform future development of university course materials.

When the Research and Development Centre for Wellbeing was in the process of being established, the ramifications of social pedagogy in this special social context needed to be explored. My colleagues and myself felt compelled to start defining our own discipline and associated core competencies. Meditating on the theoretical underpinning of practical multisensory approaches was my challenging task.

Many of the people we work with in the MSE have profound and multiple disabilities (PMD). We had used the terms 'participation' and 'empowerment' in relation to power and marginalisation for many years at HAMK, but were there extra dimensions to these terms in a MSE context? How could the MSE be usefully researched? Was applied participant action research (PAR) an appropriate approach?

I included all these questions in my confirmation seminar research plan, presented in 2004. I wrote a literature review on my topics. This review was expanded later to become journal article I, a critical analysis of the MSE literature, which was published in the *Journal of the South Pacific Educators in Vision Impairment*, 4, 1, pp.15-24 (Sirkkola & Pagliano, 2009a).

As my research journey progressed, my research questions became more refined. My concerns also addressed staff issues. I published papers (in Finnish and English) on ‘sociocultural multisensory work’, a term that refers to the application of social pedagogy when using MSEs. The three final research questions became:

1. In What ways can participatory action research (PAR) be applied with people with moderate to profound and multiple disabilities in the context of the MSE?
2. What is the nature of sociocultural multisensory work?
3. What are the implications for staff education in regard to develop MSEs and sociocultural multisensory work?

I believed this study would address issues relevant to both users and staff, germane to service delivery, within a compassionate and socially just social pedagogy context.

### **The structure of my dissertation**

To find answers to these questions, I conducted, in addition to the already mentioned critical literature analysis, three other research projects involving people with disabilities or staff members working in MSEs. My four research projects all used different research methods and were designed to spotlight different aspects of the MSE in social care.

The first project was a critical literature analysis of MSE disability research (N=23, published 1991-2006) and MSE dementia research (N=19, published 1993–2006) with an overall focus on participation and the possibility of using PAR for my MSE research. (Dementia was included because it is a rapidly growing part of social care and because the area of dementia is increasingly overlapping with that of disability. The research methodologies used were also relevant.)

The second project was a pilot study that employed a qualitative methodology. A semi-structured questionnaire was conducted with MSE practitioners in order to investigate the nature of MSEs in Finland. Questionnaires were collected at two meetings of ‘The Finnish Multisensory Network’ (2004; 2005). There were 23 respondents and the questions encompassed the following areas: foundation year of the MSE, multisensory rooms and equipment in use, background theories in practical use, visions and needs for future work, possible threads and opportunities of running the MSE, plus lot of free space for additional comments and questions or small narratives to explain the use and gathered evidence of good practices in MSEs. The aims were to describe the present operation of MSEs in Finland and to collect ideas from Finnish MSE specialists for ongoing staff education for my research. The results were not translated into English, but were used for a presentation at the ISNA 2005 World Symposium in Berlin (Sirkkola, 2005d) and for HAMK’s staff education purposes. The results of the questionnaire helped to refine my third research question in relation to staff education.

The third project was 'MusaSaurusII-project' (a MSE creative activity project involving adolescents with moderate to severe learning disabilities) at a vocational special school in Hämeenlinna. It involved the application of participatory action research (applied PAR), the use of digital media to record the creative activity and the use of that media to develop and promote visual group reflection. The revised journal article II (Chapter 3, Sirkkola & Ala-Opas, 2009) is based on this project.

The fourth project was an investigation using focus group interviews of 12 staff members at three MSEs in Finland. These experienced practitioners were taking care of people with PMDs in institutions located in Southern Finland. They commented on the planning, building and development of their MSEs. The focus was on participation and empowerment of clients and staff members. Data consisted of videoed focus group interviews (3 x 1½h) followed by a thematic analysis. The submitted journal article III (Chapter 5, Sirkkola & Pagliano, 2009b) is based on this research project.

In addition to the above research projects I also presented a poster entitled: *What is sociocultural multisensory work?* at the IASSID (International Association for the Scientific Study of Intellectual Disabilities) 2008 Congress in Cape Town, South Africa (Sirkkola, 2008). A journal article on this topic will be presented at the Come to Your Senses – Conference, October, 2009, in Toronto, (Sirkkola, Ala-Opas & Pagliano, 2009). I consider this poster presentation and conference presentation as the culmination of my research work and therefore it was included



in my pre-completion seminar. It explores the concept of levels of happiness capital in sociocultural multisensory work. 'Happiness capital' (see Chapter 5, Figure 5:3, p. 145) is derived from theories of 'social capital' and 'cultural capital' (Bourdieu, 1984; Coleman, 1988; Putman, 1993). It facilitates the possibilities of creating positive emotions, and to increase state of well-being and feelings of togetherness by using creative activities in MSEs at individual, community and society's levels (Bronfenbrenner, 1979).

### **Results and analysis of the four research projects**

The first study consisted of a survey of the MSE research literature to identify whether any methods currently exist where client participation and empowerment is employed. The analysis of 42 studies employed Kemmis and McTaggart's (2000) five aspects of practice to sort and critically analyse the literature. The second study was a small semi-structured interview (N=23) which was analysed statistically and by themes. The third study used applied participatory action research and participatory observation and multimedia as data collecting methods. These visual data were analysed thematically. The fourth study used focus group interviews to investigate the ways 12 experienced Finnish practitioners working in three MSEs with adults with moderate to profound, and multiple disabilities apply sociocultural animation. These data formed a synthesis of the interviews' discussions.

## **Portfolio**

As well as conducting these research projects, I also assembled a research portfolio of related information and activities. I presented 11 times at international symposia, conferences or congresses, and worked four weeks at a British Special School for adolescents with PMDs. I believe that the most important professional activity for me was to develop the curriculum for 'Professional specialisation studies in multisensory work'. This one-year study was first organised in Finnish with 15 students (2004-2005) and then in English for 16 international students (2008). We have an interdisciplinary multisensory team at HAMK. My colleagues, Tuomas Ala-Opas and Päivi Veikkola, were my co-teachers, co-presenters and co-editors in many of my presentations and publications. My supervisor, Associate Professor Paul Pagliano, was my main international co-operator and we presented one keynote lecture and a workshop (ISNA 2007, Montreal; Pagliano & Sirkkola, 2007), which was published in both English and French plus we wrote three further journal articles together. I kept a professional diary of MSE reflections throughout the study period as well as field notes.

In addition to the primary analysis of each research project, I also subjected the four research projects and the portfolio to a secondary analysis using bricolage.

## **Bricolage**

A concern from the primary analysis of the results was that valuable nuances of the information were being lost through reductionism. Bricolage provides another way of sifting information to knowledge.

According to Kincheloe and Berry (2004, back cover of the book) the term bricolage is used in educational research “to signify the use of a variety of research tools and ways of seeing”. The particular emphasis here is the idea that bricolage provides "a new conception of rigour in research that is culturally sensitive and socially transformative". Much other research is "reductionist and ultimately misleading" (back cover) because it does not provide sufficient opportunity for the research to explain the chronological, sociocultural context.

Bricolage was important because my research journey spanned several different languages, cultures and multiple research methods, not to mention the added challenge of working with research participants who themselves had disorders of communication. As Kincheloe (2004) explained "Bricoleurs account for the influence of 'being in the world' both for themselves, other researchers, and the phenomena they set out to study" (p. xi).

I reviewed my research projects and portfolio and arranged all practical and theoretical results under themes that directly related to my three research

questions. Instead of ‘tinkering’ (Kincheloe, 2004, p.3), my learning and research processes were more like weaving and strengthening a net. Potential answers and new questions were emerging with an accelerating speed. During these past six months, when I was analysing the data I had to struggle to keep my mind and actions focused on my final research questions, and to be extremely patient. I had to be able to build up my skills of doing bricolage, knowing that critical bricoleurs do not value essentializing and summarizing and are astutely aware of the power relations and of all that is left out due to the narrowing of the focus to the research questions.

### **Bricolage addressing the three research questions**

I now offer a brief theoretical and practical reflection on my three research questions using bricolage.

#### **1. In what ways can participatory action research be applied with people with moderate to profound and multiple disabilities in the context of the Multisensory Environment?**

During the first literature analysis I not only identified a lack of peer reviewed research that related to MSEs, PAR and people with PMDs. I also discovered that staff members were interested in developing their abilities in participatory activities and methodological knowledge. ‘The rudimentary elements of

participation research' are described in journal article I. These results imply that there is a need to continue participatory projects and to develop methodological applications to help inform practice. This research is significant because in the past the idea of including people with PMDs in the research process, especially those with severe disorders of communication was regarded as being not possible, or too difficult or worse still, not worth the effort (an implication of a process of intellectual devaluation and discrimination).

In my journal articles I describe the core of PAR as a process of finding the most empowering creative activities for each individual and group of clients. This type of sensitive scaffolding of the participant's self-determination is an example of sociocultural animation. Empowerment refers to a constant process of enabling individuals and groups to take part in collective action.

The MusaSaurusII-project convinced me that the adolescent participants enjoy involvement with digital multimedia in MSEs enriched with colourful theatre lamps, microphones and amplifiers (used in their chosen ways). Each participant had a preferred role, be that performer, video maker, taking still pictures or arranging light and sound checking. I observed the ways that pleasure was expressed by increasing levels of communication and through nonverbal emotional expressions. Revisiting the videos of previous activities with the participants created strong feelings of togetherness and group success. This project implied that multimedia in the MSE has the potential to create and

promote social happiness, arrange possibilities for visual group reflection (an exciting breakthrough that demonstrates that it is possible to find ways to include people with PMD in an action research spiral) and provide feelings of togetherness.

My personal observations provided more evidence of possibilities regarding how to use applied PAR and create and promote social happiness in MSEs. Wellness technologies other than multimedia, such as interactive sound rooms and light games, offered novel options for creative activities for those participants who have difficulties in expressing themselves through language or difficulties in their sensomotoric systems (Sirkkola, Veikkola & Ala-Opas, 2008b).

Discussions during the focus group interviews concerned the daily events of client and staff empowerment. This research project showed me the connection between empowering participation and reflective discussions. Both appeared to increase communication and feelings of togetherness in a community. Furthermore, reflective discussions between staff members and in interdisciplinary team meetings seemed to increase both staff and client empowerment (Sirkkola & Pagliano, 2009b). 'Intrapersonal empowerment' (Siitonen, 1999) is possible when someone has a belief in his or her ability to be empowered. This belief exists when persons perceive that they have capabilities to act, and can be seen as a positive force. 'Interpersonal empowerment' occurs when individuals or groups work with each other to meet their needs. Internal empowerment can be

considered as a positive force of power, because it is about equal power relationships rather than domination.

My own experiences of reflective discussions took place with ‘MusaSaurusII’-participants, HAMK students and my co-researcher Tuomas Ala-Opas. We discovered that the best time for these group reflections was right after the project-session. This helped us to include all participants in the reflection and to tie the practical events back to the theory of sociocultural animation (Sirkkola & Ala-Opas, 2009) so the process directly relates to praxis.

## **2. What is the nature of sociocultural multisensory work?**

I consider the emerging concept of sociocultural multisensory work as my main result. Its theoretical tool is the 'level of happiness capital'. This tool supports practitioners in planning more options for their clients with PMDs to visit interesting local environments. For example, attending outdoor jazz concerts, building snow castles and sculptures in the city park or joining cultural ceremonies like celebrating the beginning of summer season (first of May) or wondering the burning of big fires at the midnight summer festival, may offer exiting multisensory experiences, but especially feelings of togetherness in joyful multisensory communal events. This tool is used for teaching, understanding, planning and researching sociocultural multisensory work. The complex everyday

practices in the MSE can be described at four levels (micro, meso, extended meso and macro) within the perspective of time.

I am convinced that sociocultural multisensory work requires active citizenship in the development of local and national social politics. Empowering participation is an internationally interesting topic, already familiar at the individual level, but less addressed at the community and at the broader social levels. In Finland, and in many other countries, there is a lack of accessible communal MSEs, indicating the need for better ‘design for all’ (DfA) planning.

### **3. What are the implications for staff education for developing MSEs and sociocultural multisensory work?**

Staff education seemed to be the key for solving all challenges in the development of applied PAR in MSEs: how to apply research methodologies, new practical tools and technologies. The most important result for me was to recognise the need and importance for an ongoing, long-term staff education for interdisciplinary MSE and sociocultural multisensory work teams.

I noticed that not only practical tools associated with sociocultural animation and group reflection, but also professional, linguistic tools are needed. Defining terminology in interdisciplinary groups helped to widen the perspectives of various professionals to include people with PMDs. The idea of an



interdisciplinary team is not only to share the visions, the aims and the goals, but also to act accordingly (Sirkkola, Ala-Opas & Pagliano, 2009).

I learned that professional group reflection leads to collective knowledge production, for example, regarding the best practices on how to involve people with disabilities in an applied PAR process. Advising students in their projects and supervising their thesis writing helped me to build up a multilayered insight into the possibilities and challenges of MSE and sociocultural multisensory work.

The main theoretical result was the construction of a new international curriculum, Professional Specialisation Studies in Multisensory Work. Its practical result was arranging the studies as a one-year part time study, first time in Finnish (2004–2005) and then for the first time in English in 2008, at HAMK.

### **Conclusion and significance of this study**

Local developmental work and applied PAR on sociocultural multisensory work continues to be an ongoing process in Finland.

Results of ‘MSEs in social care’ dissertation:

- Introduces theoretical and practical opportunities in the ways to involve people with disabilities in developing their multisensory

environments and everyday practices together with staff members

(e.g., empowering multimedia and group reflection)

- Helps future planning and running of MSEs at micro, meso and macro levels with the help of a new tool ‘levels of happiness capital’
- Informs practitioners various options how to develop their MSE and inspires them to use evidence based research knowledge in their everyday practices
- Indicates that bricolage is an interesting research tool to extract an extra layer of descriptive richness from the multiple data.

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ETHICS REVIEW COMMITTEE Human Ethics Sub-Committee APPROVAL FOR RESEARCH OR TEACHING INVOLVING HUMAN SUBJECTS				
<b>PRINCIPAL INVESTIGATOR</b>		Marja Sirkkola		
<b>CO- INVESTIGATOR</b>		Tuomas Ala-Opas, Häme Polytechnic, Finland		
<b>CO- INVESTIGATOR</b>		Dr Paul Pagliano, Professor Nola Alloway		
<b>SCHOOL</b>		Education		
<b>PROJECT TITLE</b>		Multisensory environments in social care		
<b>APPROVAL DATE</b>	15 Oct 2004	<b>EXPIRY DATE</b>	25 Aug 2006	<b>CATEGORY</b> 1
This project has been allocated Ethics Approval Number with the following conditions:				<b>1891</b>
<ol style="list-style-type: none"> <li>All subsequent records and correspondence relating to this project must refer to this number.</li> <li>That there is <b>NO</b> departure from the approved protocols unless prior approval has been sought from the Human Ethics Sub-Committee.</li> <li>The Principal Investigator <b>must advise</b> the responsible Ethics Monitor appointed by the Ethics Review Committee: <ul style="list-style-type: none"> <li>periodically of the progress of the project;</li> <li>when the project is completed, suspended or prematurely terminated for any reason;</li> <li>if serious or adverse effects on participants occur; and if any</li> <li>unforeseen events occur that might affect continued ethical acceptability of the project.</li> </ul> </li> <li>In compliance with the National Health and Medical Research Council (NHMRC) "National Statement on Ethical Conduct in Research Involving Humans" (1999), it is <b>MANDATORY</b> that you provide an annual report on the progress and conduct of your project. This report must detail compliance with approvals granted and any unexpected events or serious adverse effects that may have occurred during the study.</li> </ol>				
<b>NAME OF RESPONSIBLE MONITOR</b>		Vick, Dr Malcolm		
<b>EMAIL ADDRESS:</b>		malcolm.vick@jcu.edu.au		
<b>ASSESSED AT MEETING</b>		<b>Date:</b> 25 Aug 2004		
<b>APPROVED</b>		<b>Date:</b> 15 Oct 2004		
[forwarded by email without signature]				
Tina Langford Ethics Administrator Research Office Tina.Langford@jcu.edu.au		Date: 18 October 2004		

**Portfolio activities of ‘MSEs in social care’**

The portfolio activities consist of; 1) writing scientific articles and, 2) editing a book and a pdf-publication, 3) attending and presenting at international specialist’s meetings and conferences plus a working placement in UK, and 4) attending and presenting at Finnish seminars and meetings 5) arranging and developing staff education for Finnish and international staff members.

1) Co-edited scientific journal articles:

Sirkkola, M., & Pagliano, P. (2009a). Increasing the level of participation of individuals with vision impairment and multiple disabilities: An analysis of the Multisensory Environment literature, *Journal of the South Pacific Educators in Vision Impairment (JSPEVI)*, 4,(1), 15–24.

Sirkkola, M., & Ala-Opas, T. (2009), (manuscript submitted and revised, April 2009, *British Journal of Learning Disabilities*), *MusaSaurus II: A multisensory environment creative activity project involving adolescents with learning difficulties.*

Sirkkola, M., & Pagliano, P. (2009b), (manuscript submitted March 2009 and reviewed October 2009, *Scandinavian Journal of Disability Research*). Empowerment in three Finnish Multisensory Environments: Experiences of 12 interdisciplinary staff members working as service providers for adults with profound and multiple disabilities.

Sirkkola, M., Ala-Opas, T., & Pagliano, P. (2009). Multisensory Environments: Challenges and possibilities of sociocultural multisensory work for people with profound and multiple disabilities, paper at *Come to Your Senses – Conference*, Toronto, October 21.-25,2009.

2) Co-edited MSE publications:

Ala-Opas, T., & Sirkkola, M. (Eds.), (2006). *Sosiokulttuurinen multisensorinen työ – kokemuksia vammaistyöstä*. [Sociocultural multisensory work – Experiences from work with people with disabilities]. Hämeen Ammattikorkeakoulu, University of Applied Sciences. HAMKin julkaisuja 7/2005. Finland, Saarijärvi: Saarijärven Offset Oy.

Sirkkola, M., Veikkola, P., & Ala-Opas, T. (Eds.), (2008). *Multisensory work: Interdisciplinary approach to multisensory work. Local definitions, specialisations studies and developmental projects*. Article collection written together with international students of Professional specialisation studies in multisensory work. HAMK, University of Applied Sciences. Pdf-publications 7/2008.

Sirkkola, M., & Ala-Opas, T. (2008). Introduction to multisensory work. In M. Sirkkola, P. Veikkola, & T. Ala-Opas (Eds.), *Multisensory work: Interdisciplinary approach to multisensory work* (pp. 8-11). HAMK, University of Applied Sciences. Pdf-publications 7/2008.

Sirkkola, M., Veikkola, P., & Ala-Opas, T. (2008). Professional Specialisation Studies in Multisensory Work.. In M. Sirkkola, P. Veikkola, & T. Ala-Opas (Eds.), *Multisensory work: Interdisciplinary approach to multisensory work* (pp. 12-14). HAMK, University of Applied Sciences. Pdf-publications 7/2008.

**3) International portfolio activities:**

- i. Attended *the 5<sup>th</sup> Annual Meeting of the International Multisensory Research Forum (IMRF)*, Barcelona, Spain, June 2–5, 2004
- ii. Attended *the MSE Conference*, Lancaster, England, June 8–10, 2004
- iii. 3) Attended the 12<sup>th</sup> Congress of International Association for the Scientific Study of Intellectual Disability, (IASSID), Montpellier, France, June 14–19, 2004
- iv. Attended the International Association's (ISNA's) meeting for experts in Stockholm and Örebro, Sweden, August 30–September 3, 2004.
- v. Presented three papers (Sirkkola, 2005a; 2005b; 2005c) and a workshop (Sirkkola & Ala-Opas, 2005) at the 3<sup>rd</sup> Symposium of International Association (ISNA), *The world discovers snoezelen*, Berlin, Germany, September 29–October 1, 2005.
- vi. Attended the World Wide 1<sup>st</sup> Conference, Heel, Netherlands, October 3-4, 2005.

- vii. Presented a workshop (Sirkkola & Veikkola, 2006) and wrote an article (Sirkkola, 2006) to ISNA's 4<sup>th</sup> Symposium *Snoezelen: Support concepts and projects*, Mitterteich, Germany, September 28–October 2, 2006
- viii. Worked at Meldreth Manor School in Cambridge, UK, October 3–31, 2006
- ix. Attended IMRF's 3 day conference *Making sense of art: Making art of senses* at Oxford University, October 27-29, 2006
- x. Presented a poster (Sirkkola & Nieminen, 2007) at *IMRF's 8<sup>th</sup> Annual Meeting*, University of Sydney, July 5-7, 2007
- xi. Presented a key note lecture (Pagliano & Sirkkola, 2007) and a workshop (Sirkkola, Veikkola, & Pagliano, 2007) at ISNA's 5<sup>th</sup> Symposium *Discovering a new world*, Montreal, October 20-21, 2007
- xii. Presented a poster (Sirkkola, 2008) at IASSID's 13<sup>th</sup> Congress, *People with intellectual disabilities: Citizens in the world*, Cape Town, South Africa, August, 25-30, 2008
- xiii. Presented a workshop (Sirkkola, Veikkola, & Ala-Opas, 2008) together with 16 international MSW-students, and wrote a paper (Sirkkola & Ala-Opas, 2008) to ISNA's 6th Symposium, *Snoezelen: Insights into national and international practical work*, Neuwied, Germany, October, 2-5, 2008,



**4) National portfolio activities:**

- i. Lectured at HYVe-conference (Wellness technology conference), Summer University of Hämeenlinna, Finland, *Multisensoriset ympäristöt ja uudet innovaatiot* (Multisensory Environments and new innovations), (Sirkkola, 2004), October 5–6, 2004.
- ii. Attended the meeting, collected data and presented at the *Finnish Multisensory Network group*(Seinäjoki, 2004; Paimio, 2005)
- iii. Lectured at a seminar of FDUV, Association for Autism and Asperger's Syndrome, Jaatinen & A Change for the child, *Multiprofessional Multisensory Work* (unpublished PowerPoint presentation in Finnish), November 10, 2006.
- iv. Lectured at the Universities of Applied Sciences' Seminar for pre school education, *Multisensorinen työ varhaiskasvatuksessa* [Multisensory work at pre school education], (Sirkkola, 2007a), (PowerPoint presentation sent to audience), Tampere, Finland, February 26, 2007.
- v. Presented a key note lecture *Vaikeimmin vammaisen henkilön osallistaminen ja voimaannuttaminen multisensorisen työn avulla* [Facilitating participation and empowerment of people with PMDs in MSEs], (Sirkkola, 2007b), at the Finnish Association on Intellectual and Developmental Disabilities *Menossa mukana-* seminar, Lahti, Finland, November 15, 2007.

- vi. Lectured for staff members of Helsinki City Adult Services for Social Department, *Osallisuus, voimaantuminen ja onnellisuuden pääoma* [Participation, empowerment and happiness capital], (Sirkkola, 2007c), (PowerPoint presentation sent to audience), Kirkkonummi, Finland, November 3, 2007.
- vii. Presented a key note lecture *Monimuotoinen multisensorinen toiminta* [Multiple multisensory activities], (Sirkkola, 2007d, at Sesam-seminar in Helsinki, November 29-30, 2007. Retrieved May 20, 2008, from <http://groups.yahoo.com/Jaatistietoisku/message/1312>
- viii. Lectured at University of Åbo, in Vasa (Sirkkola, 2008), *Studia generalia, Happiness Capital*.
- ix. Lectured at University of Jyväskylä's symposium for special teachers, *Osallistava multisensorinen oppimisympäristö* [Multisensory Environment facilitating participation], (Sirkkola, 2008), Jyväskylä, Finland, August 4-5, 2008.
- x. Presented *Kokemuksia multisensorisen työn opettamisesta* [Experiences of teaching multisensory work] at the Finnish Multisensory Network meeting in Helsinki, February 2, 2009.
- xi. Final portfolio activity; wrote an essay, and described the relationship between the thesis and the work portfolio as *An overview of the portfolio thesis process* (Chapter 6)

**5) Curriculum development and teaching at *Professional specialisation studies in multisensory work* and at HAMK's International Summer Schools:**

- i. Sirkkola, M., & Ala-Opas, T. (Autumn 2004 - Spring 2005). First interdisciplinary *Professional specialisation studies in multisensory work*, 30 ECTS (15 Finnish students)
- ii. Sirkkola, M., & Veikkola, P. (May 2007 and May 2008) HAMK's International Summer School; *Space experience and body expressions*, 1½ ECTS (16 and 39 Finnish and international students),
- iii. Sirkkola, M., Veikkola, P., & Ala-Opas, T. (2008). First international interdisciplinary *Professional specialisation studies in multisensory work*, 30 ECTS (16 international students)

## Increasing the Level of Participation of Individuals with Vision Impairment and Multiple Disabilities: An Analysis of the Multisensory Environment Literature

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### ABSTRACT

The aim of this survey of the literature is to identify methods to promote greater levels of participation of individuals with vision impairment and multiple disabilities in Multisensory Environment research. The analysis of 42 studies reveals participation of individuals with vision impairment and multiple disabilities is not yet explicitly employed in MSE research. However, MSE staff members do express interest in developing more effective communication strategies and recognise the need to engage in critical self-reflection to encourage increased levels of participation. Key strategies to endorse participation identified were trans-disciplinary teamwork where the person with vision impairment and multiple disabilities is included as a team member, staff education that focuses on participatory research knowledge and the application of an ongoing reflexive-dialectical perspective on practice.

**Keywords:** vision impairment and multiple disabilities (VIMD), multisensory environment (MSE), snowden8, participatory research, participatory action research (PAR), trans-disciplinary teamwork.

Throughout the world Multisensory Environments (MSE) have become popular places for individuals with vision impairment and multiple disabilities (VIMD). MSEs are dedicated spaces "where stimulation is controlled ... to fit the perceived motivation [and] interests ... of the user" (Pagliano, 1998, p. 107). The controlled multisensory aspect may make these environments more suitable for individuals with VIMD because it allows the MSE practitioner to take the user's sense abilities into account.

The MSE practitioner learns how to control stimulation to fit the unique sensory communication requisites of a particular user by consulting with that client and including him or her in the decision-making process. Participation is therefore an important feature of the MSE. Identifying ways to promote this multisensory pre-cognitive dialogue can be challenging. This is because users often have profound disorders of communication. To be able to support increased levels of participation the MSE practitioner therefore must employ a sophisticated repertoire of specialised techniques.

### Purpose Statement

Evidence based practice (EBP) is a problem-based approach where learning stems from one's information needs, particularly those of the practitioner (Sackett, Rosenberg, Gray, Haynes & Richardson, 1996). EBP therefore offers opportunities to improve the way MSEs are used with clients. Due to a lack of high quality research though, most surveys of the research literature become bogged down, focusing more on the need for increased levels of scientific rigour (Cuvo,

May & Post, 2001) rather than examining the research for information that might inform practice (Biesta, 2007).

One of the difficulties facing MSE researchers is the MSE *per se* is not a therapy, nor is it an educational approach, it is a medium of communication where multisensory stimulation is used to converse at a concrete or pre-cognitive level. This is particularly valuable for individuals who find communication at a more abstract cognitive level (i.e., through speech and language) too confusing (Pagliano, 2008). Once the individual is able to communicate with the world outside their own body using multisensory stimulation this opens up the possibility for the MSE to be used in particular ways such as for leisure, relaxation, therapy and education.

The aim of this survey of the research literature therefore is to identify methods used to promote greater levels of participation of individuals with VIMD in MSEs. This survey will focus on the way the MSE practitioner includes the client in practice. As Frankish (2008) argues: "If we want more evidence-based practice, we need more practice-based evidence" (p. 1).

### Participation

In their chapter on participatory action research (PAR), Kemmis and McTaggart's (2000) caution "To the extent that social research ignores the participant view, or imposes itself (in process or its findings) on participants, it is likely to be regarded as illegitimate, fostering alienation or hostility, and thus provoking resistance" (p. 590-591). This warning is acutely relevant for research involving individuals with

VI/MD particularly those with disorders of communication because of the tendency for others to speak for them. The idea of having someone speak for you, fails to acknowledge the possibility that the individual concerned may need to communicate at a more concrete pre-cognitive multisensory level.

In a study by Kitchin (2000), that sought the opinions of 35 people with disabilities on disability research, "the respondents articulated a need for inclusive, action-based research strategies, where disabled people are involved as consultants and partners not just as research subjects" (p. 25). Increasingly it seems people with disabilities themselves are strongly supporting the idea of participatory research, with many now publicly echoing the participation principle of "nothing about us without us" (Ball, 2005, p. 81).

With this challenge in mind the authors conducted a survey of snoezelen® and MSE literature to identify possible research strategies that would fit the requirement of the research being participatory. When choosing research studies it was decided to be as eclectic as possible, deliberately embracing studies from a diverse range of methodologies and client groups.

### Participatory Research

Participatory research is defined as "systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting change" (Frankish, 2008, p. 1). Three key aspects of participatory research are people, power and praxis (Finn, 1994). Participatory research focuses on the needs and experiences of those people who are involved in the research. These needs and experiences are considered within a context of power, so participatory research is an examination of how theory and practice are combined in action.

"Participatory Research seeks to de-elitise and de-mystify research, thereby making it an intellectual tool that people can use for life improvement." (Tilakaratna, 1990, p. 3). This is in contrast to elitist research where the "fundamental underlying assumption is that people are incapable of doing research - it is a monopoly of the elite who know scientific methodologies" (p. 1). Brown (2001, p. 162) elucidates:

Children with disabilities and persons with mental retardation historically have been viewed as not being able to articulate their concerns. Researchers must now be sensitive to mechanisms whereby people can participate meaningfully in research ways not previously thought possible. While family members are important participants, if persons with disabilities can participate meaningfully, researchers may want to consider that a first choice.

As Tilakaratna (1990) asserts, professionals who adopt a participatory research methodology must be "highly sensitised ... willing to dialogue ... on more or less equal terms" (p. 3). Participatory research involving individuals with VI/MD, especially when disorders of communication are involved, is therefore a particularly challenging pursuit where more concrete pre-cognitive multisensory forms of communication are utilised.

### Vision Impairment and Multiple Disabilities (VI/MD)

The term vision impairment and multiple disabilities (VI/MD) describes a set of conditions where the individual has vision impairment and more than two other

disabilities. These may include intellectual, physical and sensory disabilities but most often involve disorders of communication. These individuals may find it challenging to maintain their awareness of environmental events. Their ways of communication are therefore likely to be highly idiosyncratic and strongly influenced by context. This is particularly the case for individuals with vision impairment. In addition to their disabilities these individuals frequently have medical complications such as seizure disorders that further exacerbate active participation (Vlaskamp, Coeter, Huijsmans & Smit, 2003).

According to Kitchin (2000, p.25) the concept of those with disabilities becoming partners in research brings with it the danger of omission of those with the most severe combinations of disabilities. These individuals may be outside research efforts because they are perceived as too difficult to include, especially when vision impairment and disorders of communication are involved. Any form of participatory research with individuals with VI/MD therefore is highly ambitious but none the less worthwhile.

In participatory research, working together is a central component. However, as Walmsley (2004, p. 66) observes "Remarkably little has been written about what supporters (or non-disabled researchers) do when supporting people with learning difficulties in a number of contexts including participatory research". The author's stratagem therefore was to try to identify a set of incremental steps employed in the research literature that demonstrate some movement towards the practice of more inclusive research.

Two contexts, which seem to have some potential to involve the individual with VI/MD in the research process are snoezelen® and MSEs. The authors therefore decided to survey this literature to assess how such participatory research might be happening in these environments and in what arrangements. The authors were guided by Kemmis and McTaggart's (2000, p. 595) recommendation that: "The criterion of success is not whether participants have followed the steps faithfully, but whether they have a strong and authentic sense of development and evolution in their practices, and the situations in which they practice."

### Snoezelen® and Multisensory Environments (MSEs)

The word snoezelen®, created by combining two Dutch words for 'sniff' and 'doze', is a term introduced by Hulsege and Verheul in 1974 (Verheul, 2003). Working at De Hartenberg in the Netherlands, they used snoezelen® to describe their purpose built environments for people with disabilities. The emphasis was on facilitation of interpersonal relationships through multisensory stimulation (Hutchinson & Haggart, 1994). As Hulsege and Verheul (1987, p.11) explain:

One could give many descriptions of what precisely 'snoezelen' is, but through word and image it is only partly possible to give an exact representation of what happens. Ultimately, personal experience alone can provide an overall picture.

The radical feature of snoezelen® was its emphasis on client led leisure choices and the accompanying notion that it be nondirective, lacking specific educational or therapeutic aims predetermined by those facilitating access to the multisensory experiences (Hogg, Cavey, Lambe & Smeddle, 2001). Personal experience has been closely aligned to leisure and leisure it is argued possesses its own potential for self-development and self-realization (Hogg et al., 2001). According to Hulsege and

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Verheul [1987] Snoezelen® clients were to choose what they wanted to do. They were invited to participate and be active in ways that were personally suitable and relevant. Furthermore in the original concept, a session's duration depended more on the clientele's responses than external limits imposed by the carer [Lai, 2003]. As a leisure approach then, snoezelen® provided a welcome option to the care environment culture of the time [Barns, Cox & Plant, 2000].

In response to the word 'snoezelen®' becoming a registered trademark, a new term 'multisensory environment' (MSE) was coined [Pagliano, 1999]. The original snoezelen® concept was reinterpreted in more complex terms as an open-minded or multifunctional space [Pagliano, 1998]. Pagliano [1998, p. 107] argued that the MSE "can take a variety of physical, psychological and sociological forms" including a "dark room" [Pagliano, 2001, p. 25] for individuals with vision impairment. For Pagliano [2001] "The MSE is designed from the ... [individual] out" [p. 63]. Such a blueprint works at many levels from the physical to the emotional. As such the MSE becomes an incubator to support the very beginnings of exploration of the environment with the individual as participant action researcher [Pagliano, 2006].

For the remainder of this paper the word MSE is used as an umbrella term to include both the MSE progenitor the snoezelen® and the MSE itself. This is because both the snoezelen® and the MSE provide a similar array of lights, sounds, aromas, vibrations, movements and tactual stimuli within an enclosed and controlled space. They both promote safe opportunities for individuals to participate in their own research. The clients' own needs, or sensory diets delineate what the snoezelen® or MSE are and how they are experienced [Messbauer, 2005].

### Inclusive Research Goes Beyond the Either/Or

For Pagliano [2006]: A common criticism of Multisensory Environments (MSEs) relates to the lack of available research to validate its use. This criticism often highlights the point that most published research is of fairly poor quality, qualitative in nature or employs a case study methodology with little or no opportunity for generalisation. (p. 23)

He further argues: "such criticism does not seem to demonstrate an adequate understanding of the enormous complexities and fine nuances associated with this emerging area", and in particular the idea that the MSE is a purpose built environment specifically designed to involve the client in research, for the individual to gain insight into how to increase and develop levels of engagement with the outside world.

A key concern regarding this quest to increase the legitimacy of social research by involving people with VI/MD in the research is the interface between subjectivity and objectivity.

Yet I know, as Elliot Eisner discusses, that it will be difficult to wean scholars and the ... public from a view that measuring, comparison, and outcomes are all that matter. ... We've opened a space to ... stimulate more discussion of working the spaces between subjectivity and objectivity ... [Ellis & Bohner, 2000 p. 761]. Inclusive research goes beyond the either/or.

MSE literature is diverse in its scope. This is because MSEs are for both children [Shapiro, Parash, Green & Roth, 1997] and adults with disabilities [Vlaskamp *et al.*, 2003], for individuals with dementia, of which 70% have a vision impairment [Sisal, Pinkney & Roane, 2003], for people

with mental health problems [van Diepen, Bailion, Redman, Rook, Spencer & Prettyman, 2002], and those in palliative care [Schofield, 2003], for leisure, relaxation, interaction, development, learning and intervention [Messbauer, 2005]. MSE research similarly involves disciplines as varied as education, nursing, psychology, psychiatry, occupational therapy, physiotherapy, speech language pathology and allied therapies (art, aroma, music).

### Method of Analysis

The authors wished to find a way to sort the MSE literature to ascertain what, if any, research could be described as being participatory, even if only in rudimentary ways. They searched for an all-encompassing approach, a model that would allow examination to occur across a broad range of research methodologies and types. It was therefore decided to use Kemmis and McTiggar's [2000, pp. 575-578] five aspects of practice as a basic framework for organising the literature. The five aspects of practice are:

1. "Practice as individual behavior, to be studied objectively"
2. "Practice as group behavior or ritual, to be studied objectively"
3. "Practice as individual action, to be studied from the perspective of the subjective"
4. "Practice as social action or tradition, to be understood from the perspective of the subjective"
5. "Practice as reflexive, to be studied dialectically"

The fifth aspect recognises that the study of practice is a political process because the process of examination involves change. This view of practice challenges the dichotomies or dualisms that separate the first four views from one another, i.e. the dualism of the individual versus the subjective. It attempts to see each of these dimensions not in terms of polar opposites, but in terms of the mutuality and relationship between these different aspects of things. (p. 578)

The goal of aspect five is to regard MSE practice as a reflexive process involving an ongoing procedure of directing one's thinking about the practice back upon itself. As Lather [1991] explains a reflexive process "focuses on our too easy use of taken-for-granted forms" and its use "might lead us towards a science capable of continually demystifying the realities it serves to create" [Lather, 1991, p. 15]. Studying practice dialectically involves the process in which two apparently opposed ideas, namely subjective and objective plus individual and group become combined into a unified whole. MSE practitioners therefore employ an epistemological perspective, which Kemmis and McTiggar (2000) describe as "never either, always both" (p. 575). For the MSE the fifth aspect attempts to understand practice from all four perspectives. They all provide vital information to inform practice.

### Results

The results are reported in two parts. Part one consists of an overall analysis of the studies and their allocation to the five aspects according to methodology, discussion and recommendations for future research. Part two provides a more in-depth analysis of studies located under aspect five.

### Overall Analysis

Of the 42 MSE studies analysed, 23 focused on disabilities and 19 on dementia or other health issues. The disability studies



covered a range of difficulties but mostly centred on multiple disabilities. The dementia studies were included because of similar challenges regarding difficulties with communication, their relative high quality and their relevance regarding research methodology. Inclusion of these studies was further justified from the perspective of the high incidence of vision impairment and the increased risk of people with disabilities such as Down syndrome developing early onset dementia [Stratmann, van Schrojenstein Lantman-de Valk, Schellevis & Dinant, 2007].

For the first aspect "Practice as individual behavior, to be studied objectively" research reporting on "practices seen 'primarily from the outside'" was identified [Kemmis & McTaggart, 2000, p. 575], using "quantitative, correlational-experimental methods" (p. 581). Research practice is "seen in terms of performances, events and effects" (p. 576). For example, the Houghton et al. (1998) empirical evaluation to examine the effects of MSE use on 17 individual children with severe disability fits this characteristic. Their study used ANOVA to reveal a statistically significant increase in a number of particular skills exhibited by the participants from pre- to post-MSE. Further disability studies that fit under the first aspect include Thompson and Martin (1994), Ashby et al. (1995), Shapira et al. (1997), Slevin and McClelland (1999), Vlaskamp et al. (2003), Matson et al. (2004), Chan et al. (2005) and Kaplan et al. (2006) (see Table 1).

The second aspect "Practice as group behavior or ritual, to be studied objectively" similarly "views practice 'from the outside' but sees it in terms of the social group" rather than the individual [Kemmis & McTaggart, 2000, p. 576]. A study by Moffat et al. (1993) was located under both the first and second aspects. The study, which followed a multiple baseline research design, investigated the effects of anecdotal on people with dementia, with several hypotheses written in terms of the group of 12 patients. For example, hypothesis one was "Patients and staff enjoy successful sessions" (p. 23). Other dementia studies matching both the first and second categories were Moffat et al. (1993), Pinkney (1997), Hope (1998), Baker et al. (2001), van Diepen et al. (2002), Baker et al. (2003), Bailon et al. (2004), Bailon et al. (2005) and van Weert et al. (2005, 2006) (see Table 1).

For the third aspect "Practice as individual action, to be studied from the perspective of the subjective", the authors identified research that reported on "attempts to understand practice 'from the inside'" [Kemmis & McTaggart, 2000, p. 576], using "qualitative methods (including autobiographical, idiographic, and phenomenological methods)" (p. 577). One study that fits this aspect was by Bakker (2003) who describes her experiences with her father who has Alzheimer's disease. In the paper she "evaluates the relevance of good environment, including interesting sights, smells, sounds, tastes, and tactile sensations, in increasing functional abilities and comfort of older people with dementia" (p. 46). Further studies that match include Hutchinson and Hagar (1991), De Dunsen (1994), Hope (1997), Kenyon and Hong (1998), Martin et al. (1998), Pulsford et al. (2000), Andersson and Johansson (2003), Kwok et al. (2003) and McCormack (2003) (see Table 1).

The fourth aspect "Practice as social action or tradition, to be understood from the perspective of the subjective" similarly "attempts to understand practice 'from the inside'" [Kemmis & McTaggart, 2000, p. 577] and likewise uses qualitative methods. The difference however is on understanding practice "as part of a social structure that contributes to forming the way in which action (practice) is understood by people in the

situation" (p. 577). A fascinating example is by Pulsford et al. (2000) which was previously included under aspect three. It appears under aspect four as well as aspect three because of the authors' focus on a group activity. As the authors state "Most researchers prefer MSEs as a setting for individual patients to experience either sensory stimulation or relaxation. Woodlands therapy (WT) builds on this approach. In WT, the multi-sensory environment becomes an adjunct to small group recreational activity" (p. 65). Notwithstanding there being no disability research, several other dementia studies correspond to aspect four: Zinn (2000), Bakker (2003), Staal et al. (2003), Cox et al. (2004), Hope and Waterman (2004), Hope et al. (2004), van Weert et al. (2004) and van Weert et al. (2006) (see Table 1).

The fifth aspect "Practice as reflexive, to be studied dialectically" [Kemmis & McTaggart, 2000, p. 578] provides a broader classification that transcends "each of these two dichotomies individual-social and objective-subjective by seeing both in dialectical terms for a taxonomy of different approaches to the study of practice" (p. 575). Aspect five most closely fits participatory research. The authors were not able to identify any research that could be described as participatory. It was only possible to distinguish research that contained rudiments of participatory research, a process described in the following section.

#### Rudimentary Aspects of Participatory Research

Sorting literature into the first four aspects was reasonably straightforward. Sorting literature into aspect five was more difficult. As stated previously the first sort did not identify any MSE literature that explicitly matched aspect five. It was therefore decided to conduct a new search for what was called rudimentary aspects of participatory research. This involved scanning the literature on participatory and participatory action research, to compile a list of possible elements that could be described as participatory [Kemmis & McTaggart, 2000]. Those identified included a focus on:

- Clients' preferences or individual needs
- Family members' participation or interaction
- Staff training, participation or interaction
- Values of participatory research in developing environments and methodology [evaluation, reflection, development or need for change]

Once the list had been compiled the MSE literature was re-examined to see if these elements were present. Identifying these elements was more complicated than the original sorting into the first four categories because all details of each study including the discussion, recommendations and conclusion needed to be carefully considered.

Following the new less stringent allocation process using the four elements 25 of the 42 studies were located under aspect five (see Table 1), 13 disability and 12 dementia. The best examples identified were in the dementia area by van Weert et al. (2004) and van Weert et al. (2006). The studies reported on how the research "effected a change from task-oriented care to resident-oriented care" [van Weert, Kerleira, van Dulmen, Bensing, Peter & Ribbe, 2004, p. 397] or "showed ... [an] increase in 'Positive Person Work' and decrease in 'Malignant Social Psychology'" [van Weert, Jansen, van Dulmen, Spreuwemberg, Bensing & Ribbe, 2006, p. 656]. Furthermore both studies involved attempts at staff training. The other studies that contained some elements of participation, particularly with regards to future plans, can be found in Table 1.

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**Table 1**  
MSE research sorted into Kemmis & McTaggart's (2000) five aspects of practice

Focus: Perspective:	Individual	Social	Both
Objective, Quantitative	(1) 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13, 14, 16, 17, 19, 20, 21, 22, 23 [21]  24, 26, 27, 30, 31, 32, 35, 36, 39, 40, 41, 42 [12/33]	(2) 2, 6, 7, 11, 13, 14, 17, 21 [8]  24, 26, 27, 30, 31, 32, 35, 40, 41 [9/17]	2, 6, 7, 11, 14, 17, 21 [7]  24, 26, 27, 30, 31, 32, 35, 40, 41, [9/16]
Subjective, Qualitative	(3) 1, 3, 10, 11, 15, 16, 18 [7]  25, 28, 33, 39, 42 [5/12]	(4) [0]  28, 29, 33, 34, 36, 37, 38 [7/7]	[0]  28, 33 [2/2]
Both	1, 3, 10, 11, 16 [5]  39, 42 [2/7]	[0]  [0/0]	(5) Participation 1, 3, 4, 6, 10, 13, 15, 16, 18, 19, 20, 22, 23 [13]  24, 25, 27, 28, 29, 33, 34, 36, 37, 38, 39, 42 [12/25]

(1-5) Five aspects of practice (Kemmis & McTaggart 2000, pp. 575-9)  
[x/y] Total number of studies: 1st disability (top), 2nd dementia, 3rd both  
Listed chronologically with categorization given after year of publication.

**MSE disability research:**

- 1) Hutchinson & Haggart (1991): 1, 3, 5
- 2) Long & Haig (1992): 1, 2
- 3) De Buman (1994): 1, 2, 5
- 4) Thompson & Martin (1994): 1, 5
- 5) Ashby, Lindsay, Pitcaithly, Broxholme & Geelen (1995): 1
- 6) Withers & Ensum (1995): 1, 2, 5
- 7) Lindsay, Pitcaithly, Geelen, Bunton, Broxholme & Ashby (1997): 1, 2
- 8) Shapiro, Parush, Green & Roth (1997): 1
- 9) Houghton, Douglas, Brigg, Langford, Powell, West, Chapman & Kellner (1998): 1
- 10) Kenyon & Hong (1998): 1, 3, 5
- 11) Martin, Gaffan & Williams (1998): 1, 2, 3
- 12) Stevin & McClelland (1999): 1
- 13) Cuvo, May & Post (2001): 1, 2, 5
- 14) Lindsay, Black, Broxholme, Pitcaithly & Hornsby (2001): 1, 2
- 15) Andersson & Johansson (2003): 3, 5
- 16) Kwok, To & Sung (2003): 1, 3, 5
- 17) Long, Woodward, Stokes, Swan, Wareing & Baker (2003): 1, 2
- 18) McCormack (2003): 3, 5
- 19) Vlakamp, Geeter, Huijsmans & Smit (2003): 1, 5
- 20) Matson, Bamburg & Smalls (2004): 1, 5
- 21) Singh, Lancioni, Winton, Molina, Sage, Brown & Groeneweg (2004): 1, 2
- 22) Chen, Fung, Tong & Thompson (2005): 1, 5
- 23) Kalpan, Clopton, Kaplan, Messbauer & McPherson (2006): 1, 5

**MSE dementia or other health issues research:**

- 24) Moffat, Parker, Pinkney, Garside & Freeman (1993): 1, 2, 5
- 25) Hope (1997): 3, 5
- 26) Pinkney (1997): 1, 2
- 27) Hope (1998): 1, 2, 5
- 28) Pulsford, Rushforth & Connor (2000): 3, 4, 5
- 29) Zinn (2000): 4, 5
- 30) Baker, Bell, Baker, Gibson, Holloway, Pearce, Dowling, Thomas, Assey & Wareing (2001): 1, 2
- 31) van Diepen, Baillon, Redman, Rook, Spencer & Prestyman (2002): 1, 2
- 32) Baker, Holloway, Holzkamp, Larsson, Hartman, Pearce, Scherman, Johansson, Thomas, Wareing & Owens (2003): 1, 2
- 33) Bakker (2003): 3, 4, 5
- 34) Smaal, Pinkney & Roane (2003): 4, 5
- 35) Baillon, van Diepen, Prestyman, Redman, Rook & Campbell (2004): 1, 2
- 36) Cox, Burns & Savage (2004): 1, 4, 5



- 37) Hope & Waterman (2004): 4, 5  
 38) Hope, Easby & Waterman (2004): 4, 5  
 39) van Weert, Kerckstra, van Dulmen, Bensing, Peter & Ribbe (2006): 4, 5  
 40) Bailon, van Diepen, Pratsyman, Rooke, Redman & Campell (2005): 1, 2  
 41) van Weert, van Dulmen, Spreuwwenberg, Ribbe & Bensing (2005): 1, 2  
 42) van Weert, Janssen, van Dulmen, Spreuwwenberg, Bensing & Ribbe (2006): 1, 3, 5

For full details see Reference list

Details outlining why each of the 25 studies were allocated to aspect five are presented in Table 2.

**Table 2**

MSE research located under aspect 5 further sorted according to four rudimentary elements of participatory research

<p><b>Research focus on:</b></p> <p><b>Clients' preferences or individual needs:</b></p> <ul style="list-style-type: none"> <li>Identify preferences, future cooperation with snoezelen staff and other staff (4)†</li> <li>Research on participants' favourite activity (13)†</li> <li>Future plans for developmental work, evaluation of individual needs and staff's working habits (15)†</li> <li>Effectiveness of the activity the participants had already chosen, discussion of individual needs in MSEs (19)†</li> <li>Implications of findings, future assessment and treatment discussed in a developmental way, enjoyment as goal, looking for the most reinforcing equipment (20)†</li> <li>Future plans and questions (patient-led, preferences, sensitive and planned application) (27)†</li> <li>Developing new assessment of stimulus preferences in MSE (34)†</li> <li>Conduct a stimulus preference screening, prepare an "individual snoezel care plan" (p. 659) (42)†</li> </ul> <p><b>Family members' participation or interaction:</b></p> <ul style="list-style-type: none"> <li>Task goals were selected by either the family or the residence" staff (p. 446) (23)†</li> <li>Relative's mood and stress scales, plans to study carer-patient interaction more deeply in the future (24)†</li> <li>Free choice to participate, attention to family-client relation (29)†</li> <li>Improving and maximizing well-being in multisensory environments, caregivers and visitors</li> <li>Opinions are valued, solving a problem in a participatory way (36)†</li> <li>Individual "lifestyle history interview with family members" (p. 659) (42)†</li> </ul> <p><b>Staff training, participation or interaction:</b></p> <ul style="list-style-type: none"> <li>Ideas of developmental work, staff training (10)†</li> <li>Staff members' participation in reflecting their work, developing a new tradition (37)†</li> <li>Collaborative group development, democratic action research, staff has an active role in the research changing culture of care (38)†</li> <li>Changing care from task oriented to resident-oriented by staff training and implementing a new intervention (39)†</li> <li>Staff "trained in snoezelen showed a statistically significant increase in the total number of verbal utterances ... duration of resident gaze ... affective touch ... and smiling" (p. 665) (42)†</li> </ul> <p><b>Values of participatory research in developing environments and methodology (evaluation, reflection, development or need for change):</b></p> <ul style="list-style-type: none"> <li>Multiple methods, dialectic way of planning developmental work in future (1, 3)†</li> <li>Need to develop a new treatment method, need for change (6)†</li> <li>Multiple methodology, intentions to develop the environments and the method (16)†</li> <li>Developmental ideas to bring a treatment method to Canada (18)†</li> <li>Evaluative and developmental attitude, values that fit PAR (22)†</li> <li>Author engaged in the evaluation process, staff's monthly improving meeting, change in the culture of care environment (25)†</li> <li>Ethnographic analysis, comparison to well-being, person-centred principles in communication (28)†</li> <li>Suggestions for a better multisensory environment (33)†</li> <li>"... suggested a reflexive and sensitive approach was considered something that a positive user of the room should possess" (p. 54) (37)†</li> <li>Aim to "effect a change from task-oriented care to person centred care according to" Kitwood's Dialectical Framework (p. 657) "participant observation" (p. 666) (42)†</li> </ul>
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† For key to numbers see Table 1.

## Discussion

According to Whyte (1991) the goal of participatory action research (PAR) is to increase the relevance of research, by placing individuals or groups being studied at the centre of the decision-making process, in order to empower them [Twey, 1997]. Those involved participate in the conduct of

all phases including design, execution and dissemination of research that affects them [Brown, 2001]. PAR "has emerged from a significant shift of perspective in social and educational research to research which aims to avoid privileging the perspectives of professional researchers in favour of the perspectives of the ordinary participants in social settings" [Kemmis & McTaggart, 2000, p. 566].

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In this survey of the literature the authors were not able to identify any MSE related PAR studies, nor could they find any participatory studies. They therefore decided to delve deeper into research types by subdividing participatory research into four rudimentary elements. This strategy located 25 studies.

From Table 1 it can be seen that the majority of the 42 MSE studies focused on the individual (aspect 1 objective 33, and aspect 3 subjective 12, shared 7, which gives a total of 38 or 90% of the studies) and on the objective (aspect 1 individual 33, and aspect 2 group 17, shared 16, total 34 or 81%). Of the 23 disability studies the majority similarly focused on the individual (aspect 1 objective 21, and aspect 3 subjective 7, shared 5, total 22 or 96%) and on the objective (aspect 1 individual 21, aspect 2 group 8, shared 7, total 22 or 96%). Greater balance was found in the 19-dementia studies with the focus on the individual (aspect 1 objective 12, and aspect 3 subjective 5, shared 2, total 15 or 79%), and on the objective (aspect 1 individual 12, and aspect 2 group 9, shared 9, total 12 or 63%). Least overall attention was given to aspect 4 the subjective-social, with no disability studies and only seven (37%) dementia studies or 17% of the overall total.

Table 2 lists four elements of participatory research and describes why each of the 25 studies (13 disability and 12 dementia) were included, see Table 1 Aspect 5). Decisions regarding the categorisation were informed by research title, stated aims, research methodology and future plans, some of which merely hinted at a desire to increase levels of participation of clients, family members or staff in forthcoming research. Still the results do indicate that at least four elements of participatory research are currently in practical use in MSE research.

**Conclusion and recommendations for future research and practice**

Even though the idea of participatory research for people with VI/MD, particularly those with extreme disorders of communication, might at first seem preposterous, given the extreme vulnerability of this group, it is even more important that the issue continue to be explored both in research and in practice. As Kemmis and McTaggart (2000) argue:

... participatory research ... emerged more or less deliberately as ... [a form] of resistance to conventional research practices that were perceived by particular kinds of participants as acts of colonization – that is, as a means of normalizing or domesticating people to research and policy agendas imposed on a local group or community from central agencies often far removed from local concerns and interests. (p. 572)

In this paper the authors surveyed the MSE literature and identified a number of studies that reveal that some characteristics of participatory research are being employed. Figure 1 serves as a summary of the analysis of current MSE research literature and in the process demonstrates that it is possible to use a range of elements of participatory research in the MSE involving people with VI/MD and/or dementia. Key strategies to endorse participation identified were trans-disciplinary teamwork where the person with VI/MD is included as a team member, staff education that focuses on participatory research know-how and the application of an ongoing reflexive-dialectical perspective on practice.

According to Kemmis and McTaggart (2000) practice should be researched in reflexive-dialectical ways and this may mean the need for more deliberate and well-coordinated participatory research involving individuals with VI/MD to be

done in co-operation with international research teams. The authors hope the proposed model (see Figure 1) will facilitate this process.

This research survey helps to demonstrate that it is not only possible to conduct research into MSE practice where individuals with VI/MD are included as research participants, it also suggests strategies to help make it happen. The MSE provides an exciting opportunity to connect with individuals with VI/MD using more concrete, pre-cognitive forms of communication that enable these individuals to express their likes and interests.

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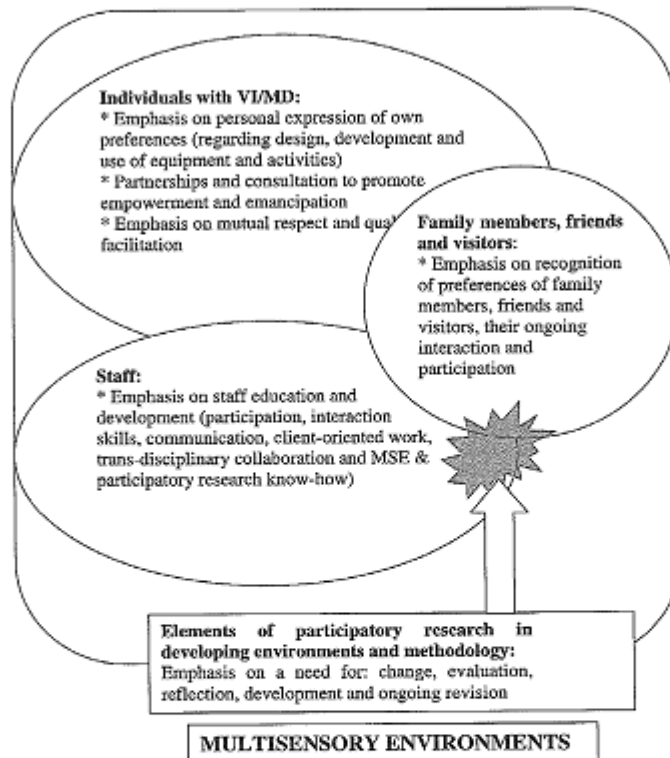
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**Figure 1**  
Participatory elements used in MSEs with individuals with VI/MD to promote more social and historically constituted, critical and dialectical research



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Appendix 4, (1/2)  
Joint authorship of journal articles



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During Marja Sirkkola's enrolment in the Doctor of Education I joint authored the following journal articles:

Sirkkola, M., & Pagliano, P.J. (2009). Increasing the level of participation of individuals with vision impairment and multiple disabilities: An analysis of the Multisensory Environment research literature. *Journal of the South Pacific Educators in Vision Impairment*, 4, 1, 15-24.

Sirkkola, M., & Pagliano, P.J. (Submitted for peer review 14.04.2009). Empowerment in three Finnish Multisensory Environments: Experiences of 12 interdisciplinary staff members working as service providers for adults with profound and multiple disabilities. *Scandinavian Journal of Disability Research*.

My involvement in each paper was less than 30%.

Yours faithfully

A handwritten signature in cursive script that reads "Paul Pagliano".

Paul Pagliano PhD  
Associate Professor Education

Appendix 4, (2/2)  
Joint authorship of journal articles

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1 (1)

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Sirkkola, M. & Ala-Opas, T. (Submitted for peer review 26.06.2009).  
MusaSaurus II: a multisensory environment creative activity project  
involving adolescents with learning disabilities. *British Journal of  
Learning Disabilities*.

My involvement in this paper was less than 30 %.

Yours faithfully



Tuomas Ala-Opas  
Lecturer at HAMK