

Peter Alheit (Keynote lecture, Amsterdam 6 June 2014)

Researching music and dementia.

A wonderful relationship between science, art and a new way to understand dementia (slide 1)

It is a great honour for me to deliver the keynote address to this symposium on “Music and Dementia”. I am not only grateful to my dear colleague Rineke Smilde for this invitation who initiated the research project with the same name, but also to ‘**Music for Life**’ and its founder Linda Rose, as well as Padraic Garret, staff development practitioner of Jewish Care and contributor to the project, and the three musicians ‘Matthew’, ‘Fiona’ and ‘Annaliese’, whose ‘shadowed names’ accompanied me during the interpretation of the results. I must also give special thanks to the participating carers and symbolically of course also the involved residents, who impressed me and whose real **personhood** once again became very clear in the course of the research process.

I have only been an observer, and not even a participant observer. I was not present at the difficult sessions of the project, nor during the moving moments. I did not take part in the debriefings and I have only read through the written records.

But even though I only really know the text material, and the fascinating stories that have been told to me, these sources have touched me personally – like a “**Book of Life**” in which you read and discover yourself. Working in close co-operation with Rineke

Smilde and Kate Page, I have learnt with the project right from the beginning. I have been part of a **“virtual” Community of Practice**. I was pleased to meet many of those involved in person in Wigmore Hall in September 2012.

I am delighted that today we can present the book which documents our research. It is not only the work of those who have written it down – it is also the work and the learning process of everybody who took part. This is what I would like to talk about now, and not only as a scientist but also as someone who has been moved by this experience and also surprised by the results. **(slide 2)**

I would like to start by presenting the **music and learning dimensions** of our analysis (1). This includes some reflections on the “milestones” or core categories which we identified and also what significance the results could have for the training of young musicians. In the second part, I would then like to consider a **“new understanding” of dementia** (2) and what this could mean for us today – not medically, but in terms of philosophy, ethics and social considerations. Music plays a key role here.

1. The music and learning dimensions of the project

The splendid research material which we had at our disposal, the interviews with the many participants, the group discussions, the field notes, but, above all, the reflective journals of the musicians and the staff management practitioner constitute an exceptionally detailed and moreover highly differentiated source of data about a

co-operative learning process. While this process spanned eight weeks, it also opened much wider horizons as it incorporated long-term professional experiences. It also established links and contrasted between very different perspectives on the undertaken process, for example, by comparing the perspectives of the musicians with those of the care staff, or those of both of these groups with that of the residents.

Thus, it was important for us to illustrate a **complex reality**. We were interested to **understand** what was going on in the research field, not to “measure” it instead. **Learning processes** of individuals and of the whole group should be documented. And we hoped to be surprised by outcomes which we never had dreamed of. **(slide 3)**

Maybe, the final result is a bit more modest. But, nonetheless, we were actually astonished by moments we had never expected before. And our decision to choose a qualitative approach seemed to be legitimate. We could be open for **new insights**. We could correct **preconceived opinions**. And we were allowed to **learn** – even as experienced researchers. The fascinating relationship between ‘Music and Dementia’ is no longer imaginable without a strong idea of learning.

So, I will try to give you a brief overview on our main findings...
Let me start with a strong thesis that benefits from Oliver Sacks’ work who asserts that we can call upon the “self” of people living with dementia, however – he continues – “it is music, and only music, (which) can do the calling”.

This is a wonderful metaphor: music as a special language reaching out to people who have lost their 'normal' capacity to communicate. However, this metaphor does not tell the story that it is hard work to realise this musical communication. It challenges the identities of musicians, it assumes continuous communication and active participation and it makes demands on learning.

The 'Music for Life' project documents this working and learning process. But it also confirms the wonderful metaphor that music can reach a person with dementia. Admittedly, the process is more complicated, but it's worth to be told. It includes musicians and residents, but also carers and managers. It is a learning process of a vital group.

When we looked at this process as researchers, we identified four milestones, as it were, which gave us something like a landmark of our research journey: the milestone "identity", the milestone "communication", the milestone "participation" and the milestone "development". How are these four dimensions connected, and which perspective is created by their association?

Identity, as we know "exists on a personal level as well as on a group level. The musicians' learning process and, in the end, their development towards 'acceptance' lead to an identity that is a constructed version of '**becoming through learning**'. Identity develops according to George Herbert Mead's classical interpretation: *"It is not initially there at birth, but arises in the process of social experience and activity, that is, develops in the*

given individual as a result of his relations to the process as a whole, and to other individuals within that process." In his remarks, Mead draws attention to the process *nature* of the development of identity. On the other hand, he refers to the *social environment* that influences the development of the identity. This social aspect of development has motivated Mead to conceptualise the crucial – **cognitive** – part of our identity as a "*Me-Construction*", as if we are to view ourselves *through the eyes of another*.

Musicians appear to be particularly sensitive in terms of this construction. Their performances are in a specific sense "**public**", even if they occur privately. Part of the professional identity of the musician is also to always have in mind the own musical "teacher", the perspective of the (fictitious) audience, and even the immediate reaction of that with which I, as a musician, am currently working.

This binds musical identity to the context and makes it into a social phenomenon. However, this also confirms the fragility of identity and threatens it yet again. The **stage fright** that every musician knows, the difficult experimentation of successful improvisation, even the insecurity of how to deal with an audience with dementia, show that identity must always be re-established. Musical identity is a struggle with *self-assurance* and *personal development*. And this struggle is a very personal and intimate process, regardless of the concrete context.

If *identity* is therefore key to our data then it primarily addresses the fact that in an encounter between music and dementia a great many

common assumptions cannot be taken for granted. This realisation is an individual challenge for each of the participating musicians. This, of course, applies equally to the care staff, and all participants have to be willing to engage in a *learning process*. “**Identity work**” is therefore in a sense a prerequisite for the shared activity which is initiated by the ‘Music for Life’ project. This “identity work” is not some sort of routine arrangement, but is instead an open process of learning that accompanies the whole project.

Nonetheless, this process of learning is dependent on **communication**, this being the second “milestone” that our data present. Just as we view ourselves through the eyes of another when we try to build our own identity, so we also need to communicate with others to develop our identity further still. This is especially true when we, as musicians, are confronted with people who do not inherently possess that which we call “identity”, and whose reaction to our performance is unpredictable.

The desire to communicate with others, to interpret and understand difficult situations, to design solutions, and to establish contact with people who live with dementia, and to do so with musical sensitivity, is essential and self-evident. The complexity which communication exemplifies in the ‘Music for Life’ project has been presented in detail in the analysis. It deals with the various forms of language: verbal and non-verbal, in essence also the language(s) of music. It is about interaction and interpretation, about *places* of communication and *means* of communication. Occasionally, it is also about overcoming misunderstandings. Communication is a

social activity that relies on *self-assurance* and *social sensitivity*. As such, it moves between the extremes of “personality” and “sociality”.

The dimension of communication is easiest to comprehend by examining again what George Herbert Mead wanted to express in his **game-metaphor**: an intuitive rule-governed anticipation of “players” in relation to the behaviour of other “players”. When musicians (through improvisation and with great sensitivity) respond to people with dementia and the latter become involved in the “playing”, then what results is really a *game* in which each participant reacts sensitively with the other, and where the co-players are “brought into the game” through their efforts. Musical communication is complex and varied, but has little to do with rational planning. It is a means of communication that is based on “**rule-governed intuitions**” that binds tensions which are intimately personal with those which are empathically social.

Our third “milestone” and core category **participation** is already inherent in this concept of communication. The connection of the individual with the social has a concrete focus: the *living group* in which all are participating. Belonging to the group is not, of course, a “status”, it is not a legal title that has always existed. *Belonging* is a process that has to be actively introduced. Participation, therefore, does not only mean *social sensitivity*, as is a characteristic of communication, but also implies *social activity* such as the willingness to integrate and to apply one’s abilities in the group, the desire for tolerance, and to be able to respect and embrace the conceptual ideas of everyone else.

Participation in the 'Music for Life' project takes many forms: creativity and intuition, respect and empathy, responsibility and duty of care. It also has a great variety of participants: the musicians who create a new ambience through their participation, the care staff members who can make use of this ambience in their daily care work, the group members with leadership duties who observe and develop innovative real-life perspectives, and the people with dementia who are motivated to contribute their own potential to the group.

This process is not linear; it is disrupted by conflict and problems. Plans and conceptual ideas have to be reflected upon and, if necessary, amended. However, it is not uncommon that such reflections often form the basis of greater chances for participation that had not been considered before. **(slide 4)**

A symptomatic example is the disillusioning scenery where **Rosamund**, a resident, is lifted from her wheelchair into an armchair by means of a mechanical hoist. The technical process "brutally" disrupts a musical communication scene. The musicians are shocked. In hindsight, however, they realise that it is exactly this which is Rosamund's reality and by recognising this they return her dignity which at first seemed to have been destroyed by the event. It is a dignity that strengthens her participation in the group henceforth.

With this example, a worthwhile bridge has been constructed to the notion of **development**, to the fourth and last “milestone”. The Music for Life project, in actual fact, is not only a group in which a variety of members participate: it deals with a **Community of Practice** as we have learnt from Lave and Wenger, which is itself indeed characterised through participation, i.e. through a development of “*legitimate peripheral participation*” into “*full participation*”.

We should picture this process once again in real terms, and appreciate the pleasant and humane idea of “development” hidden within it. A single participant – symbolically – stands on the edge of a group. She is *permitted* to do so and is, as such, accepted as a peripheral member. Through the interaction with other group members, there is a gradual sense of development whereby she finally becomes a full member of the group. The prerequisite of full membership is not a “status”, but instead it is the learning process she not only willingly enters into, but also one which changes her personally.

‘Music for Life’ is not a “group” in the conventional sense, it is actually a Community of Practice and the transition from group to community is a **transitional learning process**. The single participant (be it a musician, a care staff member, the staff management practitioner, or a person with dementia) becomes a part of the experience that can only be created by everyone – in harmony with one another. In a sense, through this process, the individual turns into “another”, one who develops further and becomes aware of himself in a new way. Our core criteria of

development lies, as it were, between the extremes of *social activity* and *personal development*. Moreover, this category encompasses collective and individual development.

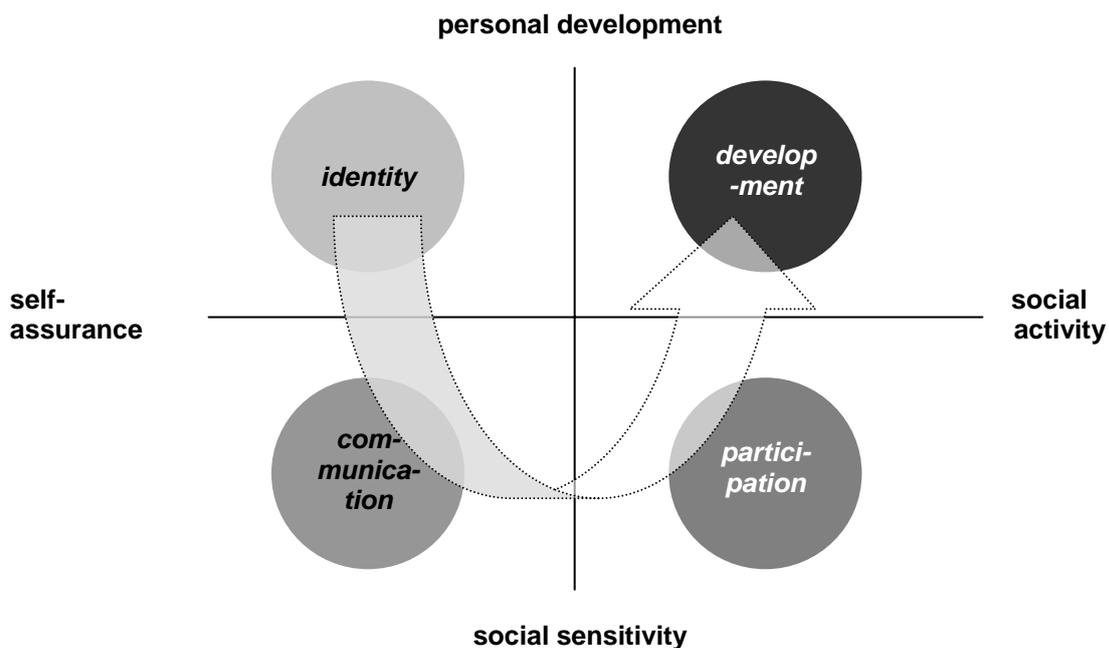
However, this means that the four explored “milestones” or core categories relate to each other. They describe a unique process of learning whereupon the individual participants and the developing community are equally affected. Along the dimension of identity allows the **developmental process** to be seen. Identity is not a static condition, but rather it is a process. This process requires contact with others. It needs communication and reflection where this connection is active and participatory. The development, which necessarily becomes noticeable, also leads to a new level of identity for the participants. It is not a circle which is closed here, but a “**spiral of learning**” is completed, and a new process of learning begins, perhaps one on a higher level.

The space of social learning

This spiral of learning undoubtedly liberates imagination that encourages one to find a more general representation of the described process, without claiming to reveal a pedagogical or psychological “*theory of learning*” that is relevant to every imaginable way to learn. *Grounded Theory*, our methodological framework, is a theory of **practice**, a theory that relates to the investigated field of work and is one that must be accepted by those who are active in that field.

We can therefore place the process of learning (associated with the four core categories of *identity*, *communication*, *participation* and *development*) in a symbolic space that stretches from individual to social experiences, from *self-assurance* to *social activity*, from *personal development* to *social sensitivity*. The first point of contrast relates to the polarity between the extrovert and the introvert. The second is one of inner and outer dimensions of reflexivity. In this way, a surprising **space of social learning** is created which is typical for the ‘Music for Life’ project. **(slide 5)**

Fig. 1: The space of social learning within the Music for Life project



The interesting aspect is obviously that the **implied arrow** does not describe a simple “development”, but it instead describes a spiral of development and learning that continuously leads to new “identities”, “communications” and “participations”. It encourages the participants *to repeat and disseminate* the described process because it is

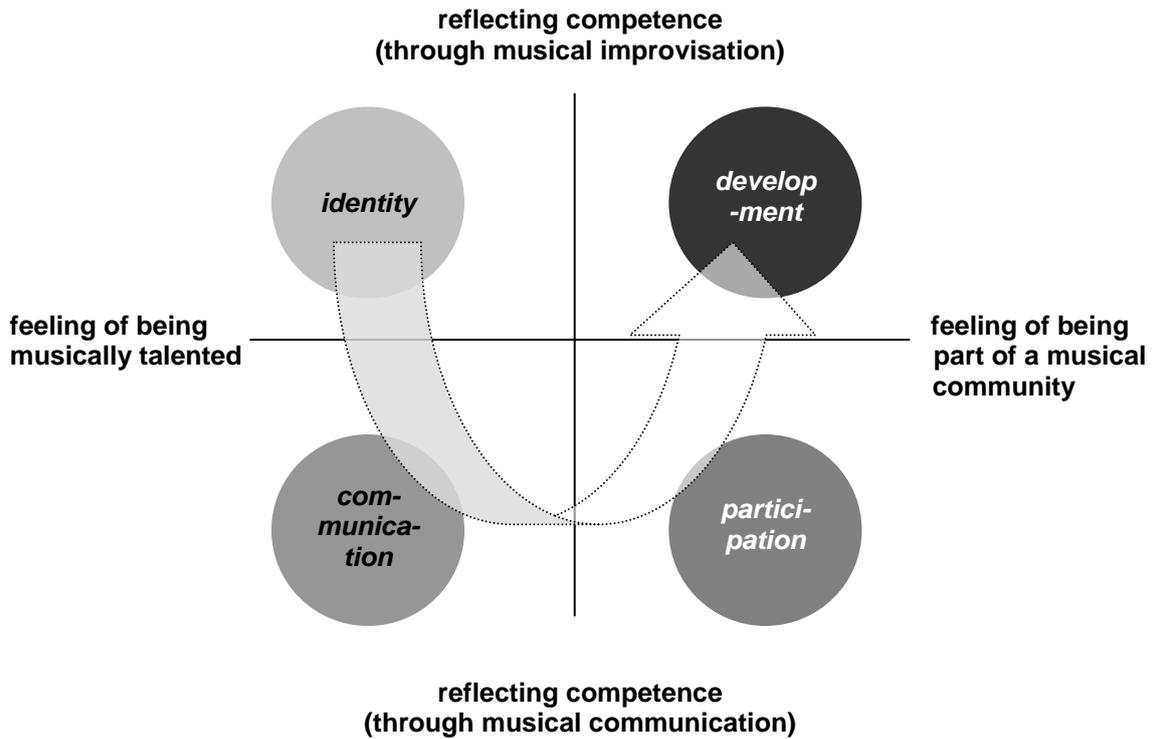
rewarding for all members, yet does not lead to a simple conclusion. Nonetheless, it appears – practically – to be so inspiring that it makes sense to transfer it to the processes of learning for the musicians.

The space of professional learning as a musician

It is especially true of professional musicians that they continually work in the knowledge that they indeed are “**talented**”. Their personal identity relies upon this fact. However, they also need the co-operation of other musicians in order to test and correct what is not apparent during their inward-looking performances: music is a communicative, social activity. It develops into a “*language*” that does not only require listeners, but also partners in order to communicate. Moreover, this musical community is all the more important the more obviously and consistently it depends on co-operation.

Development is thus feasible not only for soloists in large concert halls, but also for musicians who concern themselves with social issues. Perhaps it is this that is the exciting aspect of musical performance today: that music can contribute to the work done in dealing with social problems and which cannot be solved with “classical” methods of social work. This would fit into the following portrayal. **(slide 6)**

Fig. 2: The space of professional learning as a musician

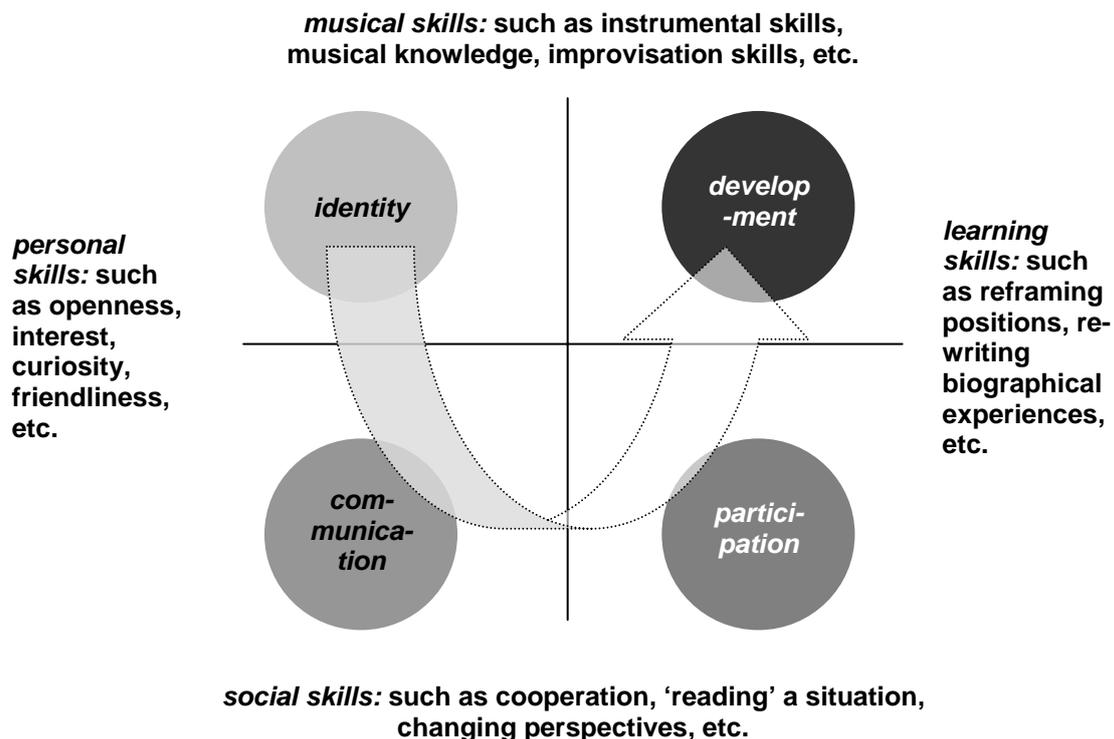


If all these factors make sense, then it would be logical if the experiences of the 'Music for Life' project were embraced by the educational systems in the institutes of music academia. It would then also be clear that the education of a professional musician should no longer encompass only the training required to become a concert soloist, but should instead be applied in a much broader sense, both in the interests of the professional prospects of today's students, and also in the interests of society as a whole.

The space of a basic curriculum of higher education in music

Indeed, this too would drastically change the training to become a musician. *Musical skills* would of course remain the focus, such as studying the actual instrument or musical theory. However, improvisational training should perhaps not only play a greater role in jazz classes. Added to this, would be *personal skills* such as recognising potential for new venues, a willingness to approach others, as well as instilling a sense of inquisitiveness and friendliness. **(slide 7)**

Fig. 3: The space of a basic curriculum of higher education in music



Something similar could be learnt in practical projects that are bound through intensive phases of connection. This is also true of *social skills*, i.e. the familiarisation with co-operative skills or learning to be

able to “read” a situation, to change a point of view and make observations through the eyes of another. The key components are perhaps the *learning skills*, i.e. being able to question one’s own opinion, based on new experiences, by being able to rethink one’s own biographical experiences as a musician. Such conclusions are implied by the investigated core categories of *identity, communication, participation* and *development*. These investigations collectively mean that the personal and, moreover, professional horizon should be extended, and that new challenges should be taken seriously.

These are the provoking results of our research on the music and learning dimensions. *I will come now to my second point: the new understanding of dementia ...*

2. Towards a “new understanding” of dementia

The term **dementia** – as you all know, of course – is used generally to describe a progressive impairment of the structure and chemistry of the brain as a consequence of certain diseases or conditions. The dementia expresses itself in communications and speech difficulties and in impairments to the production, interpretation and retrieval of information. This can involve problems concerning speaking and understanding speech, in the choice of the right words for objects or names, in a failure to recall recent events, in the way in which new

information is registered, the recognition of people, or experience a different reality than the conversation partners.

In the past, definitions of dementia have concentrated on a medically-oriented, pathologising perspective of the conditions of dementia, mostly ignoring the social aspects and the importance of the disorder for the individuals themselves. Such tendencies had created a climate of stigmatisation and misunderstanding.

Even today, the image associated with dementia is often one of dramatic suffering. Scenarios are not seldom painted in which people with dementia have lost all capacity for well-being and taking care of themselves, denied their identity and the change of individual development. As Kitwood puts it: *“A death that leaves the body behind”*.

Kitwood's person-centred approach

And exactly this English social psychologist and psychogerontologist Tom Kitwood is a pioneer of a paradigm shift in the perception of dementia and the provision of care writing the landmark book *Dementia Reconsidered: The Person Comes First*. Kitwood's insights develop a more positive approach which pays more attention to the personhood of the person with dementia.

(slide 8)

'Personhood' means that people who live with dementia are more than their superficial appearance. They are a *“Person with*

dementia” rather than “a person with *Dementia*” – and they have needs like anybody else. This includes the uniqueness of all people and emphasises that every person is valuable, and that we all deserve recognition, respect, and trust, and of course can also express the need to be loved. It also acknowledges that the psychological need for comfort, belonging, integration, activity and identity are important aspects of an individual’s well-being.

These principles form the core of a person-centred approach to care, by means of which the emotional well-being is reinforced and the unique personhood of a person with dementia is acknowledged and celebrated. In the ‘Music for Life’ project, the personhood of all the participants – the people living with dementia, the carers, and the musicians – is accepted as a central principle, and the conditions are created for egalitarian learning and the equality of all relationships.

In order to act out this sort of relationship, to provide truly person-centred care and to develop intensive ties with the care residents, the relationship between carers and patients must become authentic. The carers must have empathy, strong motivation, and a sense of curiosity. It is important that the carers acquire a sort of ‘presence’ in their sensibility for the reality of people with dementia. This involves developing from a ‘state of *doing*’ to a ‘state of *being*’, which could mean that they leave their prejudices and fears behind them and instead take their unconscious experiences and intuitions more seriously.

However, there are challenges in the development of the conditions for person-centred care in institutions at all levels, and the ideal of person-related care could possibly end up as empty phrase. Social and political values, human and financial resources, the organisational culture, the complicated and demanding nature of the work and the personal characteristics, abilities, experience and intrinsic motivation of the carers, are all factors that can influence the ability of an organisation and the individuals in it to become involved in providing person-centred care.

Brian, the staff development practitioner in our project, sees these challenges as unavoidable problems confronting the caring institutions and organisations particularly in the UK: *“I sometimes reflect on the expectations put on care staff generally. We provide them with training and raise their awareness of working in person-centred ways. However, they invariably work in care home situations where they often feel under pressure to have time to do their work according to person-centred principles. The greatest tension is trying to work according to the pace of the person with dementia. This is very difficult in homes with a ratio of one staff member to four residents. Our society hasn’t yet been prepared to value people with dementia as deserving a higher ratio of staff.”*

Brian sees the need to develop a new attitude in society as a whole. The key requirement of a person-centred movement is respect for the personhood of the individual. If we place our trust in the ability of the person with dementia to develop and maintain meaningful mutually supported relationships with others, if we accept the person

behind the dementia, then the vision of mutual respect, love, shared empathy, and understanding can become reality as an orientation for all participants.

Additional aspects in Mead's theory of identity

Kitwood defines personhood as: *“a standing or status that is bestowed upon one human being by others, in the context of relationship and social being. It implies recognition, respect and trust. Both the according of personhood and the failure to do so have consequences that are empirically testable.”*

In this context, Kitwood also mentions the importance of various ways in which biographical knowledge can be integrated in the planning and provision of care. For example, carers can draw on the biography of dementia patients when counselling family members. Tom Kitwood writes: *“In dementia the sense of identity based on having a life story to tell may eventually fade [...] When it does, biographical knowledge about a person becomes essential if that identity is still to be held in place.”*

Kitwood argues that it is decisive to regard personhood in terms of relationships if we want to understand dementia: *“Even when cognitive impairment is very severe, an I-Thou form of meeting and relating is often possible.”*

Perhaps it is appropriate here to mention the classic contribution of George Herbert Mead (who was cited earlier) to the social theory of

mind and identity. Writing a century ago, Mead distinguishes two states of consciousness, namely consciousness as an experience of pain or pleasure, and self-consciousness, which is when *“the individual enters as such into his own experience . . . as an object”*. He emphasises that identity is *cognitive* and must be understood as a social process. We need other people’s view on us in order to be able to see ourselves as an object. It is this *“me”*, writes Mead, which allows a contingent *“I”*. **(slide 9)**

This position contains two ideas with fascinating potential for a new interpretation of dementia:

- Firstly, according to Mead an *“I”* remains – even when the cognitive capacity to see yourself as an *“object”* – is limited.
- And secondly, even when the *“me”* – the ability to see *“myself”* with the eyes of the others – has disappeared, the eyes of the others are still directed towards *“me”*, and by acknowledging *“my”* dignity they take the place of *“my”* reflexive ability to realise a conscious self. *“I”* can no longer ratify myself cognitively, but *“I”* can feel and appreciate the acceptance of the others.

The dignity that others allow *“me”* has its basis in *“my”* biography. It is a history of relationships which do not stop when *“my”* conscious ability to form these relationships is limited or disappears. The *“I”* remains, as Mead makes plain, but also the living memories of the ***“I-in-relationships”***, which the others now have to understand and put into practice in a new way.

These considerations go beyond Tom Kitwood's concept of *personhood*. A no-doubt remarkable ethical option for the care of people with dementia can lead to a sociological insight into the social-biographical context of specific dementia patients. From the person-centred approach, a bridge is created by concrete life histories to a socio-political reappraisal. A very demanding task for all those involved with people suffering from dementia becomes a *societal* challenge affecting all of us. It ought not to be surprising that music has a central role to play in this important redefining of the dignity of individuals.

As final note: a necessary critique

It does not seem to go with the wonderful atmosphere here today, however, before finishing, I have to mention that the study being presented here was offered Routledge publishers but was rejected literally "*with deep regret*", mainly because of a damning assessment by an anglophone musical therapist.

Let me quote from the reviewer's comments: "*My initial, overall reaction was one of outrage. Once again I found myself saying, 'Another group of musicians 'inventing' music therapy, this time for dementia patients.' My second reaction was indignation that these musicians, untrained in working with individuals with special needs, were practicing music therapy without a license.*"

If the reviewer had read the study more carefully, he would know that the musicians had been prepared very intensively for their

special task. And he could also have realised that ‘Music for Life’ is not about “music therapy”, but is a broader project about how the art of music can share in people’s suffering and how it can help to offer alleviation. **(slide 10)**

In a technical sense, dementia is “untreatable”. And however much music is able to contribute, it will not be able to stop the near exponential growth of this disorder through the “ageing process” of modern societies. But music can help us to discover the human dimension in and behind dementia. As Oliver Sacks has been cited before: “*music, and only music, can do the calling*”. This calling, this intrusion and touching is a wonderful gift of the music. But it needs **people** who actually do it: musicians, care staff, managers and facilitators. It needs a Community of Practice which feels responsible. It needs a civil and political framing which documents the readiness of the society to take the problem of dementia seriously. It needs the dissemination of ‘Music for Life’ into an international context.

This is much more than music therapy. It is a very specific plea for a new social ethics in which every life is valuable. It is living recognition of the fact that “*behind the dementia*” there is a person who can be reached. And it means the acceptance of the society – including each of us – that it takes over the responsibility for this.