Beyond Words Project Report

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Acknowledgements

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1   Executive Summary

Beyond Words was funded by the Arts Council England Research Grants programme. It brings together researchers from Plymouth University's Plymouth Institute of Education and award-winning community music organisation Plymouth Music Zone. The research team combined expertise in social science, music and visual art bringing a strong interdisciplinary perspective to the study.

The research builds on previous joint projects to focus on how those who face problems communicating with words are included in music making, including those with learning difficulties, autism, stroke, brain damage or dementia. This is a neglected group who have never been brought together in this way. Although commonly called 'non-verbal' the research shows they should be termed 'post-verbal', as in going beyond words to other forms of communication.

The study is significant and innovative, being an eighteen month multi-method longitudinal ethnography which employs a post-human theoretical lens. This lens is appropriate because post-humanism challenges the common view of 'the human' as one who must be able to speak and articulate their thoughts.

The research involved a researcher being embedded in Plymouth Music Zone for eighteen months observing music sessions they run with post-verbal people. She also observed a range of other sessions. The study followed 25 post-verbal people over the eighteen month period and the Principal Investigator interviewed 44 of their family members and carers. Four focus groups were held with Music Leaders and volunteers.

To allow the post-verbal participants to communicate their own feelings about music sessions, 30 bespoke arts workshops were run by an experienced artist in collaboration with a Music Leader and fieldnotes and art works were collected. Interim findings were presented at a participative seminar with representatives from participants, Health and Social Work and other agencies. Data from all these sources

were analysed by the research team. Finally, a highly successful international conference was held for academics and artists interested in post-humanism.

The report presents a detailed account of existing literature on the post-verbal and arts and wellbeing, with a particular focus on music. It explores the data using a post-human approach and post-human conceptual tools. Findings were multi-faceted and it proved generative to think of them in the form of a fern with multiple fronds, opening and closing and moving backwards and forwards.

The following summarises the Research Questions and Main Conclusions of the *Beyond Words* project.

Primary Research Question:

1. How do we include and make music with those whose communication is non-verbal, such as those with dementias, strokes, autism, learning difficulties or brain damage? What benefits do they and networks around them gain in terms of wellbeing/social inclusion?

- Post-verbal people need music for full wellbeing: as a form of voice; to make bonds with others; as part of their speaking through their bodies; as a form of self-soothing and self-care; as a release for creativity; as access to unspoken feelings of both pleasure and pain.
- Including post-verbal people in music making requires: respect, autonomy and real choices: focusing primarily on the post-verbal person themselves, but also drawing knowledge from families and carers. The right environment needs appropriate and integrated organisational, cultural, social, musical and emotional strategies, such as those in Plymouth Music Zone.
- Families and carers of post-verbal people also need music. It shows them the being they love is still there or is emerging. It gives them joy and pleasure both directly and indirectly and creates new social and support networks. It gives them practical tools to take away and use at home and surprises them with what their loved one can do.

Research Question 2

2. What role does the 'unspoken' play in inclusive music leadership overall?

- The unspoken is invaluable across all inclusive music making. Music Leaders deliberatively use unspoken elements to promote inclusion which run across all aspects of music, such as rhythm, dynamics, pulse, pitch and harmony. Music Leaders attend carefully to space, time, and things. They are sensitive to unspoken emotions and gauge the mood of sessions, making musical choices to best support participants.

Research Question 3

3. What are the implications of addressing the 'unspoken' for inclusive practice across the Arts sector, how can this help practitioners in the fields of Health/Education?

- The research has lessons for other forms of arts practice: This is a group with a capacity and appetite for arts work, but who tend to be marginalised. PMZ's inclusive practices can help inform the work of other organisations. Understanding and respecting post-verbal ways of being is essential: communicating via the body, being in the now, self-calming, the need for real choices and creative potential.
- The research is useful to practitioners in other fields such as Health and Education. This is a group of people who can be very isolated and misunderstood. The sample we saw are the privileged ones, as in they already have access to music. Not speaking doesn't mean there is nothing going on, learning is always possible. Opportunities to access music and other arts should be a priority in their education and care to promote wellbeing.

Research Question 4

4. How does post-human theory help illuminate this process: what does this study add to the field of post-human theory?

- Post-human theory has proven essential to this project, providing key analytic tools and ways of thinking and has great potential for future studies of inclusive arts practice. The research contributes to post-humanism in significant ways,

showing how post-human theory can be used in a substantial longitudinal empirical study.

The research also had the following unanticipated conclusions:

- The term post-verbal not non-verbal should be used for this group

- Music can facilitate speech for post-verbal people

- Music helps post-verbal people to teach important lessons to others

- Policy makers need to pay more attention to post-verbal people

Report Recommendations

- Policy makers should recognise post-verbal people as a neglected and vulnerable group that requires specific care and attention.
- The term 'non-verbal' should not be used. It seems pejorative and inaccurate. 'Post-verbal' is a better way of respecting and working with their capacities beyond words
- Arts funding and consistent provision should be increased for this group
- All organisations working with post-verbal people should consciously develop and apply inclusive organisational, social, cultural and emotional principles relating to this group
- Accessibility should be understood as not just meaning physical access to buildings / resources - organisations, services and facilities should continue to develop and improve the experiences offered to post-verbal people in terms of different types of communication and information offered to them
- Community music organisations should apply the musical strategies outlined in this report combined with full liaison with families and carers and gather as full knowledge as possible about post-verbal participants, in order to plan for the highest possible quality provision
- Partner organisations should agree clear guidelines about co-operating in music sessions to ensure dignity and agency of post-verbal people

- Music should be an integral part of care after stroke (particularly early interventions for speech recovery) or in early dementia, rather than an add-on that families need to secure for themselves
- Music interventions should be live, creative and interactive
- Community music organisations that work successfully with post-verbal people and their families should receive better and more sustained levels of funding
- Music organisations should consider developing collaborative, cross-arts approaches in order to maximise the variety of creative opportunities offered to post-verbal people, thus opening up wider opportunities for expression
- Further international research should be undertaken looking at the 'unspoken' and post-verbal people across multiple arts activities
- Further research should be undertaken with post-verbal people and their networks of intimacy, including those who don't access arts activities, to ascertain what facilitates persistence, communication and creativity and what prevents it
- Research should be undertaken with those who 'abandon' family members living with dementias to help understand their perspectives

2   Aims of Project & Report

This report presents the findings of the *Beyond Words* project, funded by Arts Council England (ACE) from 2015 to 2017. The project was one of eight national projects funded by ACE's first Research Grants Programme. The aim of the programme was to fund research projects between arts organisations and academic researchers to deepen knowledge and understanding of the impact of art and culture, and the complex role it plays in our experience as individuals and as a society.

Beyond Words involved researchers from Plymouth Institute of Education, Plymouth University (PIOE) and award-winning community music organisation Plymouth Music Zone (PMZ). The *Beyond Words* research team consisted of: Principal Investigator, Professor of Education, Jocey Quinn and Research Assistant Claudia Blandon, with musician and Training and Research Manager at Plymouth Music Zone, Anna Batson as well as visual artist Karen Abadie. This produced a distinctive interdisciplinary approach combining social science, music and visual arts. Findings will be valuable to a multi-disciplinary audience and the wider arts/culture sector as they span important interlinking outcomes in areas of education/health and wellbeing/culture/society.

The study built on their earlier partnership research exploring the impact of music making with older people in care homes and families escaping domestic violence (Quinn and Blandon, 2014A, 2014B). Both previous studies were informed by post-human theory which is interested in breaking down the dominance of the 'ideal human' as someone who expresses themselves through speech. Both studies had a focus on the generative power of 'things' and took an ethnographic approach which proved successful in exploring how much and in what ways Plymouth Music Zone worked together with participants to improve wellbeing. The unspoken emerged as an important issue in music sessions, both in terms of participants (some older people had suffered strokes and could not speak and some women in the domestic refuge refused to speak), and also in terms of what helped music leaders to work well and include people in the sessions. The partnership thus identified the 'unspoken' as an area that would build on these former studies.

The *Beyond Words* project takes advantage of the diversity of participants available within the context of Plymouth Music Zone's vibrant community music organisation to explore how people who face problems communicating with words are included in music making and what the benefits might be for their families and carers. The groups included in the study are diverse; they include children and young people with severe disabilities, autism and elective mutism, adults with strokes, aphasia and brain injury, and also older people with different types of dementia. Rather than positioning them as 'non-verbal', the study conceptualises them as 'post-verbal' and concentrates on how communication and inclusion happens beyond words.

This eighteen-month longitudinal ethnography is the first to bring these groups together in this way. Focusing on post-verbal people and inclusive music practice fills a gap in knowledge about the arts and social benefit for marginalised groups, and the study's innovative post-human approach makes an important contribution to theoretical and methodological developments in this sphere. It will also heighten awareness of a group who are growing in number, but neglected in the literature, and not addressed in terms of policy. As such, the project is very much in line with the priorities set out in the Arts Council England *Equality, Diversity and the Creative Case* report (2016): identifying a group who need to be included to ensure arts funding is fully equitable and diverse.

Thus the aim of *Beyond Words* is to explore the following research questions:

The primary question is:

1. How do we include and make music with those whose communication is non-verbal, such as those with dementias, strokes, autism, learning difficulties or brain damage? What benefits do they and networks around them gain in terms of wellbeing/social inclusion?

The sub-questions are:

2. What role does the 'unspoken' play in inclusive music leadership overall?

3.   What are the implications of addressing the 'unspoken' for inclusive practice across the Arts sector, how can this help practitioners in fields of Health/Education?

4.   How does post-human theory help illuminate this process: what does this study add to the field of post-human theory?

We have found the answers to these questions to be multi-faceted and find it generative to think of them in the form of a fern with multiple fronds; furling and unfurling, moving backwards and forwards. It may be useful to keep this image in mind when reading the report.

This report provides a detailed review of the background literature, research methodology and findings. It presents conclusions and recommendations that should prove useful to a range of arts, community, health and social work practitioners and to researchers. A shorter version of this report will also be widely available.

3   The Partners

From left to right:

Debbie Geraghty, Executive Director, PMZ

Karen Abadie, Visual Artist

Professor Jocey Quinn, Plymouth Institute of Education (PIoE)

Anna Batson, Training & Research Manager, PMZ

Claudia Blandon (PIoE)

Plymouth Institute of Education (PIoE)

Plymouth Institute of Education forms part of Plymouth University and is the locus for life-wide and life-long educational research and teaching within the university.

The Institute focuses on understanding and transforming education and learning at all ages, from babies to elderly people. This includes formal and informal contexts: nurseries, schools, colleges and universities, but also communities, nature, work, arts and families.

The Institute's perspective is global with networks and funded projects across the world including Marie Curie Fellowships, ESRC international networks and research for the Council of Europe. Institute staff publications, impact and research culture were recognised as world-leading and internationally excellent in the 2014 REF.

Plymouth Music Zone (PMZ)

Plymouth Music Zone (PMZ) is an award-winning community music charity dedicated to reaching out to bring people together to transform lives through music. PMZ works with vulnerable adults and children using highly skilled Music Leaders who deliver a diverse range of innovative and tailored creative music-making activities that develop skills and enhance wellbeing.

The charity also offers specialised training for music professionals as well as health and social care professionals. It also gives volunteers and apprentices bespoke opportunities for career development. Much of PMZ's work sets out to tackle loneliness and isolation among a diverse range of groups and aims to empower individuals, families and communities to have a voice to develop and grow through the life-changing power of music.

4 Literature Review

An initial scoping study of the literature revealed the following gaps:

Arts provision for what are commonly termed 'non-verbal' groups appears to be neglected and under-researched, even though people who struggle to communicate with words, such as those with dementia, strokes and autism constitute a growing group with concomitant demands on health/social care and with impacts on the networks and communities around them. There is some limited research on the 'non-verbal' and music practice, with the most commonly researched areas being autism (Hillier et al, 2012, Reschke-Hernandez, 2011) and dementia (Sherratt *et al.*, 2004, Sakamoto *et al.*, 2013). Additionally, the emphasis in the literature seems to be on music therapy with verbal participants (Aldridge, 2000; Goodall and Etters, 2005; Lou, 2001; Raglio and Gianelli, 2009; Ridder, 2003 - as cited in Hara, 2011, 36). 'The role and importance of music as means of communication with 'non-verbal' people, or people who struggle to be understood, has been neglected' (Hara, 2011, 36).

Unspoken aspects of Arts practice like body language, spatial and visual environments, culture and ethos appear to be important aspects of inclusive music practice with applicability in all contexts across the Arts sector, yet these aspects have not been widely researched or understood. There seem to be limited longitudinal qualitative studies of the unspoken in music and other arts practices (Bishop, 2012, 6).

Existing theoretical approaches to the 'non-verbal' in inclusive music practice seem to be based on what might be perceived as deficit models which see silence simply as a problem to be overcome.

The *Beyond Words* study was designed to fill the above gaps. As part of the project a comprehensive literature review was undertaken to bring together literature which explored conceptions of the non-verbal and inclusivity in arts interventions, particularly music. This review draws on literature found using a systematic search (terms: non-verbal, nonverbal, s/elective mutes, communication difficulties, music interventions, inclusive practice, Arts interventions) in SocIndex, Sage Journals Online,

and Google Scholar. Also, the following journals were key resources: *Disability & Society, British Journal of Learning Disabilities, Journal of Nonverbal Behaviour, Journal of Creativity in Mental Health, Medical Sociology, Arts & Health: an international journal for research, policy and practice, Art Therapy: Journal of the American Art Therapy Association, journal of Applied Arts & Health, Cultural Sociology, Sociology, Discourse, International Journal of Qualitative Studies in Education, Body & Society Qualitative Enquiry, and the British Journal of Sociology of Education*. Additionally, the following sources were consulted: Arts Alliance Evidence Library, Arts for Health at Manchester Metropolitan University, CReaTE Canterbury, Culture, Theory and Critique, Music Education Research.

This review is divided into three main sections. The first critically explores interdisciplinary conceptualisations and theoretical frameworks of the 'non-verbal'; the second addresses arts-based interventions with what we term 'post-verbal' people. The third looks specifically at music making used for inclusion and wellbeing purposes.

Being 'non-verbal': facing difficulties communicating with words

Terminology

The term 'non-verbal' immediately causes difficulties. It could be perceived as pejorative, focusing simply on what is not there, and, as we shall discuss in our findings, it is also a misnomer. Thus, as already explained, the *Beyond Words* project has created the term 'post-verbal', as in the post-human sense of 'going beyond' words. Nonetheless, since the existing literature uses the term 'non-verbal' this term will be used in describing prior research.

Non-verbal communication

We found no previous research which brings non-verbal people together across conditions. In her 2008 review of the literature. Nind found that qualitative research with people with communication difficulties was relatively limited; the bulk of it concentrating on people with learning difficulties (2008, 4).

A simple working definition of non-verbal communication 'refers to communication affected by means other than words'; this definition, however, does not account for all complexities of this phenomenon (Knapp & Hall, 2002, 5). Non-verbal communication theory and research 'focus on three primary units: the environmental structures and

conditions within which communication takes place (proxemics: architectural style, lighting conditions, colours), the physical characteristics of the communicators themselves and the various behaviours manifested by the communicators' (Knapp & Hall, 2002, 5).

Bodies

Thus, non-verbal communication can occur through gestures, facial expressions, eye contact, pupil dilation, distance, vocal features, movements, posturing and smell. Researchers have suggested that a cultural relativist approach is important when interpreting this form of communication, since it is typically learned implicitly and may be culturally specific (Duffey & Hodges, 2003, Sue & Sue, 2003, as cited in Silverman, 2008, 5).

Empathy

Some scholars claim that non-verbal communication is part of social competence, because some people are more alert to non-verbal cues and are better at interpreting their meaning (Knapp and Hall, 2002, 71). They have more empathy with others and as Bazalgette discusses in *The Empathy Instinct* (2016) empathy is the key to inclusive arts practice, including music. Moreover, researchers have explored whether non-verbal communication is a skill that could be developed and provided evidence to demonstrate the positive effects of training (Ekman & Frieses, 1975, as cited in Knapp and Hall, 2002, 74-75). In one study, researchers developed training to develop people's abilities to send non-verbal cues using the 'social skills model' developed by Argyle (1988). According to this model, social skilled behaviour is analogous to skilled motor behaviour and can be trained by active role playing that includes positive use of smiles, head nods, looking at the other, touching and certain body gestures (Knapp and Hull, 2002, 76).

Environments

Interestingly, however, there has been a shift in non-verbal research from its emphasis on the persons communicating, to the influence of non-human factors (proxemics) on human transactions (Knapp & Hall, 2002,8). Evidence suggests that environments can affect people's moods, choices of words and actions. Thus, proxemics study the use and perception of social and personal space and its effects of people's behaviour. As

we shall discuss, a focus on space is also characteristic of post-human research and in our study we actively explore the effects of space on our participants' experience of music-making.

Objects

Correspondingly, anthropological research offers further insights on how objects convey silent meanings. Lemonier sheds some light on the 'role of objects and material actions in non-verbal communication, both in non–ritual and ritual situations '(Lemonier 2012, 13). According to Gell (1996 as cited in Lemonier, 2012, 18), understanding the agency of objects blurs the border between art and utilitarian objects. This idea of making the unfamiliar familiar may be applied to inclusive practices in the arts. Interventions that create different relationships with an object (e.g. a musical instrument) may be building a bridge between two different cultures, which in turn may contribute to an element of inclusion. This is highly relevant to our later discussion of the agency of musical instruments.

Sociological Perspectives

From a sociological perspective, research on the non-verbal highlights that 'when the body does not speak, read or write; it still retains and reproduces a social and cultural memory' (Carozzi, 2005, 25). In fact, sociological research since the mid-1960s has criticised 'methodological practices that separate discourse from the actions that produce, surround and make discourse possible' (Carlson 1996 as cited in Carozzi, 2005, 35). Furthermore, sociologists argue that 'too often all communication is understood to be linguistic or amenable to analysis in linguistic terms' (Black, 2011, 3). The body 'as a material substrate of communication is a dynamic entity which produces a multiplicity of perceptual interactions within itself and the world' (Black, 2011, 3). This agency of the body is a point that we will also take up in our analysis.

It is claimed that humans are able to control their faces because of the development of speech. However, 'chimps have relatively fine muscle control, but are incapable of speech, suggesting that speech is not necessarily the driver of such physical changes... The face, and communication more generally, are not brought into being by language or culture' (Black, 2011, 9). As we shall discuss, post-humanists such as Barad and Bennett have taken this further arguing that the role of the material world, (including animals), in producing communication has been neglected.

Silence

It is also important to explore the significance of silence. Philosophers have argued on 'the virtues of silence as an ontological principle' (Picard, 1948 as cited in Glenn, 2004, xi). Glenn, who has written widely on silence, sees silence as 'rhetoric', as a 'constellation of symbolic strategies that (like spoken language) serves many functions, including a strategic position of strength' (Glenn, 2004, xi). In this light, silence is as important as speech. 'Like speech, the meaning of silence depends on a power differential that exists in every rhetorical situation: who can speak, who must remain silent, who listens and what those listeners can do' (Glenn, 2004,9). Glenn claims that when silence is unexpected it is unsettling, just as, for example, the silence of an elective mute in our study perturbed his teachers. The question is not whether speech or silence is better, more effective or more appropriate. Instead the question is whether our use of silence is our choice or that of someone else. 'When silence is our choice, we can use it purposefully and effectively' (Glenn, 2004,13). Consequently, it is important to find out how people 'inhabit their silence' (Glenn, 2004,15) and to understand what barriers they face.

In terms of music, the gaps and pauses are what makes sense of the sound. They need to be there, otherwise sound would be 'continuous'. This is a function in itself. The gaps and the pauses aren't necessarily a complete absence of sound either. The point of John Cage's famous piece: 4'33" was not to generate 'silence' but to inhabit what happens in any sonic space. Cage even went on to try and create 'true' silence by creating an anechoic chamber, which proved unsuccessful because he then could only hear his own body sounds.

Agency

Regardless of the reasons why people face difficulties communicating with words (biological, social, psychological), issues of agency, access and participation are highly relevant. Agency is generically defined as 'an action or intervention producing a particular effect' (Oxford Dictionaries). Within social science there are further debates about agency. On the one hand, it is argued that 'people exercise agency when they can act to influence their own personal circumstances' (Giddens 1991, Madhok, Phillips, and Wilson 2013 as cited in Boyle, 2014,1131). In this context, agency depends heavily on rationality, language, intentional action and goal orientation

(Shilling 1999, Velleman 2000, Hemmings and Treacher Kabesh 2013, as cited in Boyle, 2014,1131). There is an assumption that those without these characteristics, such as people with dementia, possess weak or no agency at all.

However, in a study with people with dementia, Boyle (2014) argues that current definitions of agency in social science need to be revisited and informed by the experience of cognitively disabled people. In her study, Boyle observed five people with severe dementia and interviewed their carers. Boyle focused on participants' everyday decision-making, aiming to identify the role of social factors in influencing their decision-making. This study is significant because it revealed the potential for at least basic agency in people with dementias on everyday decision-making. Boyle found evidence to suggest that people with dementia, who lack deliberate capacity, can nonetheless demonstrate 'imaginative agency' (Boyle, 2014,1140). The research also identified when agency was manifested as 'habituated, embodied or emotional' (Boyle, 2014,1140); suggesting that they can exercise agency, albeit in somewhat different forms than currently defined. Again this is important as this broader notion of agency will be demonstrated in the research findings of our study.

Access

To address these challenges, Law et al (2005) interrogate the duty to facilitate communication with those who have difficulty using words. The social model of disability recognises the need to 'introduce ramps (real or metaphorical) into the social environment, strategies that support communicative access and participation regardless of individual capacity. Just as a physical ramp addresses the barrier of stairway access for the person who uses a wheelchair, so the use of gesture may reduce the need to understand the spoken word in isolation. In this way, the playing field of communication is levelled out and the opportunity for the individual to make his/her contribution is enhanced.' (Law et al, 2005, 171). Music might be considered a form of ramp allowing access for everyone.

In this vein, research in linguistics can contribute to the understanding and developing of the 'metaphorical ramps' mentioned above. Sperber and Wilson (1986, as cited in Grove *et al.*, 1999,193), propose that every act of communication involves two dimensions: linguistic encoding and decoding, and inference (interpreting meaning in the context of participants' prior knowledge and assumptions). They suggest that inference is part of the human condition, 'so the issues faced by people with

communication difficulties may not be qualitatively different from those that we encounter daily in negotiations with others' (Grove et al, 1999, 194). Everyone daily faces the problem, do others understand what we mean to say?

This is an important point for our study: people who are 'post-verbal' are not a different species and their struggles to be understood are shared ones. One of the things the literature review shows is that barriers to communication are common and that the potential for non-verbal communication exists in all human encounters. However, there is something particular about people who do not have the easy option of communicating with words and this needs to be understood and researched.

Theoretical frameworks

Post-humanism

Existing approaches to the non-verbal in inclusive music practice seem to be rather inadequate, based on deficit models which see silence simply as a problem to be overcome and the 'non-verbal' person as someone who has not attained those elements that are considered essential to being a high-functioning human, namely articulacy and agency. Thus the issue poses a significant theoretical challenge, with opportunities for significant innovation. It was decided at the initial stage of the project that a post-humanist approach would shift the terms of engagement in a fundamental way. Rather than focusing on the inviolate individual who possesses a 'self' that s/he can communicate through words, post-human theory moves away from the articulate human to focus on acts and bodies (Braidotti, 2013) on materiality (Barad, 2007) and the agency of things (Bennett, 2010). It validates and explores the significance of silence Mazzei (2016) and focuses closely on space and the visual in its methodology (Taylor & Hughes, 2016). As such it provides the ideal approach to this issue. Taking this approach can validate the participants and recognise the other things they are doing that are not about speech but are equally important. The focus of attention is on what happens when the participant and the musical instrument or song comes together, what is created and what effects this has.

Post-human theory moves away from 'mental, discursive and spiritual values that have placed man as the measure of all things', from an ideal of bodily perfection, and from seeing difference as 'pejoration'. According to Braidotti, humanism has a

restricted notion of what counts as human', it reduces the others, 'the different', to a less than human status of 'disposable bodies' (Braidotti, 2013,15). Thus the person who struggles to speak is the ultimate 'disposable body' as s/he seems to have no place in the world of words.

Taylor & Hughes (2016) propose using post-human research practices in education to critique 'fundamental assumptions underpinning dominant ways of doing education research' (Taylor & Hughes, 2016,5). By questioning humanist binaries (body/mind, theory/practice, self/other, emotion/reason, human/nature, human/animal), post-human theory seeks to challenge old 'certitudes regarding identity and subjectivity, binaries and boundaries, language and representation, methodology and methods' (Taylor & Hughes, 2016,7). Post-human practices call for new ways of finding out; to this end, post-humanist researchers lean towards data collection techniques that include arts-based, visual, sensory, movement, sonic and creative writing practices (Taylor & Hughes, 2016,19).

Despite the above, there is comparatively little in the form of longitudinal empirical studies using post-human approaches, with the exception, for example, of Renold and Ivinson (2016). In terms of our study, the theoretical works of Braidotti, Barad and Bennett are particularly important and to some extent the ideas of Mazzei are applicable.

Bennett focuses on what she terms 'vibrant matter' (2010). Her argument is that both humans and non-human animals and matter all share the same vibrant materiality and are teeming with life. Moreover such matter cannot be understood in isolation but as part of what she calls an 'agentic assemblage'. Thus instead of the isolated individual who speaks, the focus of meaning is on an assemblage which may include the human, but within which the human may not be the most important element. Instead of positioning some matter as active and some as inert, it is more realistic to see and respect them all as having forms of agency. Bennett's work shows how even material considered waste is 'vibratory' teeming with life (Bennett, 2010,5). This is very important when considering people with dementia who are too often perceived as detritus. Another important aspect of her work is what she calls 'thing power', 'Things too, are vital players in the world' (Bennett, 2010,4). This too is helpful in unpicking the

power of songs and instruments and recognising the significance of the objects which surround the person who does not speak and trouble or delight them.

Barad (2007) is a post-humanist thinker who has proven very influential. One of her key concepts, drawing on quantum physics, is intra-activity. This places the focus of attention not on the human but on the phenomena generated when different forms of matter are brought together: for example a human and a musical instrument. "Matter is agentive and intra-active-generative not merely in the sense of bringing new things into the world but in the sense of bringing forth new worlds" (Barad, 2007,170). This is very useful when the focus is not on words but on moments of communication, sparks of new life.

Finally, Mazzei follows on from other feminist writers such as Lewis (1993) in considering the function and nature of voice and silence in research contexts (see for example, 2007, 2016). Thus she draws attention to the silences that always occur in research interviews or the silences participants choose. She challenges the primacy of words as a mode of communication, and with them the notion that they tell us something essential and uniquely personal about the person who speaks them. Moreover, voice does not belong to the individual but is distributed across the assemblage.

'Because "voice" cannot be thought as existing separately from the milieu in which it exists, it cannot be thought as emanating "from" an individual person. There is no separate, individual person to which a single voice can be linked…there is no present, conscious, coherent individual who speaks the truth of her present or her past.' (Mazzei, 2016,158)

Potentially this is helpful for our study as we need not search for the individual voice or lament its lack, but can trace how the participants speak without words in their entanglements with other matter in the assemblage. Nevertheless, despite her interest in voice, Mazzei does not address those who cannot speak or who struggle to communicate with words. We have not found many studies, including post-human ones, that do so and in this research we are treading new ground. As previously discussed, taking a post-human position where 'post' is conceptualised as 'going beyond', we have adopted the term 'post-verbal' for our participants. This helps to

capture the sense that there are other ways of being and communicating that move past words.

From a post-humanist perspective, Guattari sees art as 'a process of becoming: a fluid and partially autonomous zone of activity that works against disciplinary boundaries, yet it's inseparable from its social field' (Guattari as cited in Bishop, 2006, 79). This too is useful for *Beyond Words.*

Personhood

However, other theoretical frameworks have more commonly been used to evaluate, explore and understand issues of non-verbal behaviour, arts interventions and inclusion. A widely cited framework is Kirtwood's theory of personhood; this framework has emerged as a potential framework for music therapy research. The most important aspect of the theory of personhood (Kirtwood, 1999) is that 'key components such as social interaction and wellbeing are overt behaviours and are therefore observable' (Sherratt *et al.*, 2004,10).

Public sociology

Finally, in an innovative study with people with early onset dementia (EOD) and their families, Jenkins et al (2016) explored a public sociological approach to person-centredness in dementia by using theatrical vignettes about living with EOD. Vignettes are a method of data collection defined as 'short hypothetical scenarios involving fictitious protagonists and situations' (Bloor and Wood, 2066 as cited in Jenkins et al., 2016,79). In qualitative research, vignettes seek to represent (rather than elicit) qualitative data and seek to give voice to individuals whose voice has been marginalised (Jenkins *et al.*, 2016, 80). In addition, researchers also used Image Theatre (Boal, 1979) methodology which uses 'dramaturgical techniques to facilitate marginalised groups finding collective power to challenge oppression' (Boal as cited in Jenkins *et al.*, 2016, 79-81). In this study Jenkins et al propose a 'sociologically informed model of person-centredness based on the core ontological belief that the self is transactive and multifaceted, as opposed to discrete and unified' (2016, 88).

In all, theoretical approaches to researching the 'non-verbal' appear to have been minimal. For this reason we feel that *Beyond Words* is making an important step forward in making the contribution of theory to the study, and the contribution of the study to theory, one of its core research questions.

Arts-based interventions and the 'non-verbal'

Process and Product

Debates on inclusion and socially engaged practice (Bishop, 2012) and dialogic art (Kester, 2004) have shed light on important methodological issues for the *Beyond Words* project. One side of the debate emphasises the process in participatory arts practice (Bishop, 2004), whereas the other side emphasises the importance of the end product (Kester, 2004). Artists interested in the process of making participatory arts believe that inclusion is central to their practice, and consequently use sociological models of analysis, where the process is part of the method (Bishop 2012). Bishop argues: 'In today's context participatory art is often at pains to emphasise process over a definitive image, concept or object. It tends to value what is invisible: a group dynamic, a social situation, a change of energy, a raised consciousness; therefore highlighting the importance of longitudinal studies' (Bishop, 2012, 6). This type of longitudinal sociological approach is the one adapted in *Beyond Words*.

Kester warns against paternalistic relationships between artists and participants. Instead, active listening and intersubjective vulnerability should be central 'as the artist does not always occupy a position of pedagogical or creative mastery' (Kester, 2004, 151). In Plymouth Music Zone, Music Leaders are facilitators not teachers and a similar form of intersubjective vulnerability characterised the research process of *Beyond Words.*

Quality of Evidence

Arts interventions consulted in this review have different objectives (therapeutic, inclusion, wellbeing, to manage anger, anxiety, depression) and target people whose non-verbal behaviour might be a side effect of other conditions as in dementia (Camic

et al., 2014, Rusted et al, 2006, Sherratt *et al.*, 2004), stroke and brain injury (Magee & Davidson 2002, Nayak et al, 2000, Bradt et al, 2010), autism (Epp, 2008, Wigram & Gold, 2006, Emery, 2004), cognitive impairments (Dykens et al, 2005, Gregory, 2002) and other complex communication needs (Goldbart & Caton, 2010). However, the quality of evidence for some trial studies in specific conditions is poor because 'of high risk of bias and limited number of studies' (Bradt et al, 2010, 8).

The *What Works Wellbeing Evidence Review* (2016) provides the most up-to-date review of quality of evidence in terms of arts interventions and wellbeing. In volume 2 (Daykin *et al.,* 2016) the review included participants from different countries with a variety of health conditions (including stroke, fatigue and anxiety) but no mention of non-verbal behaviour specifically. The music interventions were described as music therapy, singing and choral singing, and music singing. Only two projects reported using instruments as part of the intervention (Daykin et al, volume 2, 2016, 8-9). There was evidence to show that for adults with chronic conditions, such as stroke, arts interventions had reduced stress and increased wellbeing (e.g. personal wellbeing: mood, self-awareness, self-esteem, efficacy; artistic and cultural dimensions of wellbeing: achievement and confidence; social dimensions: group dynamic, social support, relationships and connections with others) (Daykin et al, vol 2, 2016, 42).

In a review conducted by Beard (2011) evaluating different arts therapies (music, visual arts, drama, and dance/movement) between the years 1990-2010 on individuals with dementia of the Alzheimer's type, it was found that studies properly designed, documented and evaluated were scarce (Beard, 2011,12). Information on research design, operational concepts, measurement tools and methods of analysis were vague, thus making replication and/or validation of results impossible (Beard, 2011,3). Evidence is further divided between studies focusing on the product versus the process of art. Beard argues that the field of arts therapy has been fragmented by two opposite ontologies; one approach focuses on traditional arts therapy's values of being process oriented and an opposite approach focuses on outcomes to manage symptoms (Beard, 2011,4).

In a 2011 review of the impact of participatory arts (music, singing, drama, visual arts, dance, storytelling, festivals, mixed art forms) on older people, the Mental Health Foundation found evidence that 'engaging with participatory art can improve the wellbeing of older people and mediate against the negative effects of becoming older'

(Mental Health Foundation, 2011,4). This finding is relevant to those with dementia in our study.

Drama Interventions

We found few arts interventions that focused particularly on non-verbal communication. One relevant study involved drama interventions with people with profound disabilities, Vorhaus (2015) looked at the place of theatre and comedy in uncovering someone's potential. He showed that interventions that offer interactive, multi-sensory experiences to people with profound disabilities 'might draw out and enliven a previously inert and apparently 'unreachable' child' (178). Furthermore, the use of comedy may offer a different window into cognitions. Theatre directors made use of humour to encourage profoundly disabled children to 'revel in sketches that are in some way 'naughty' or 'ridiculous', on the assumption that humour can help to reach people, and draw them out of themselves, even in the absence of verbal communication and other basic human capabilities.' (Vorhaus, 2015, 179). Indeed in our study Music Leaders often used humour successfully to facilitate communication.

Another important aspect explored here was the individual contribution in a performance. 'There is a collective aspect to a group performance, a relational aspect to the good-humoured interaction, and the significance of the spectacle as a whole – which includes what the children reveal themselves to be capable of in their own right and also as members of a group' (Vorhaus, 2015,181). Again this shared performative element was also important in our study.

Drama interventions have also been used with support workers in dementia care homes (Bolmsjö et al, 2012, Konto et al, 2010). In one study, the drama sessions with staff involved exercises directed and led by a professional theatre director and actors followed by reflective group discussions. The authors found that the intervention allowed care workers to reflect on their practice, facilitated awareness and allowed them to 'gain a new understanding of the residents' experience, something that they could use as a base for nursing provision' (Bolmsjö et al, 2012,187). On the other hand, Kontos et al's (2010) study aimed to introduce the notion of embodied self-hood (defined as non-verbal self-expression) to care workers They found that drama was an effective educational tool: support workers reported having new awareness of the significance of residents' body language (body movements and dispositions) (Kontos

et al., 2010, 165 & 159). Whilst PMZ sessions are not training as such, our study showed that their music sessions did raise this awaremess of body language amongst care workers.

Rapport

Research highlights the importance of body language in arts interventions generally, especially in therapeutic encounters, and how it can be used to establish rapport (Duffey & Hodges, 2003, as cited in Silverman, 2008). This suggests that an important element of inclusive practice is how comfortable participants feel with intervention leaders; the way intervention leaders 'speak - as much as what they say - communicates confidence and favourable expectations' (Silverman, 2008,6).

Impact

In terms of measuring the impact of arts interventions, Daykin & Joss (2016) have developed a framework which takes into account the need of a range of approaches and methodologies to assess the use of arts in health interventions. They propose minimum standards of reporting to document impact; in addition, they find that 'creative arts methods (e.g. photography, visual arts, artworks) and outputs can be 'effective for uncovering hidden perspectives, adding emphatic power and strengthening participants' voices' (Daykin & Joss, 2016, 10). We have designed our study to meet these standards and to use such creative arts methods.

Music elements and activities used to promote inclusive practice and improve wellbeing

Objectives

Music activities may have different objectives, but there can be problems in defining what those objectives are. Raglio and Gianelli (2009) claim that one difference between music therapy and musical activity is in the goal of long term effects in the former and the absence of such a goal in the latter. 'This has direct implications for an understanding of underlying processes; are they immediate responses that do not last, do they involve learning or, especially in the case of dementias, do they function in such a way as to slow deterioration?' (As cited in Spiro, 2010,896). The problem with

this distinction is that inclusive music making, whilst not being individualised therapy, *does* have a goal of longer effects, such as wellbeing, confidence, feelings of belonging. Moreover, in our study we found that even if an effect only lasted for a moment it could be highly meaningful.

Definitions of Health and Wellbeing

Definitions of health and wellbeing are varied and contested. The What Works Wellbeing Review (2016) "identified three dimensions of subjective wellbeing reported in qualitative studies, this included personal wellbeing, social and self-identity" (Victor et al, V3, 26). A working definition of health provided by the World Health Organisation defines health as 'a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity'. Thus the concept of wellbeing has become an integral part of health. McDonald et al (2012) point out that what matters is not only how poorly we feel, but also how well we feel and which cultural resources are available to sustain and develop people's sense of coherence (McDonald et al, 2012, 6). Different approaches to health and wellbeing place different emphases on the extent to which individuals can influence their own health condition. In terms of the effects of music on people's wellbeing, there is evidence to show that 'music is an intrinsic and important part of human development. Thus it needs to be considered as a universal resource, from which implications for health and wellbeing emerge.' (McDonald et al, 2012, 6).

Sociological Perspectives

From a sociological point of view, DeNora conceptualises music as a social force (McDonald et al, 2012, 5) and as a temporal medium: 'music moves through time' (Denora, 2010, 66). For DeNora, music conveys 'signification through non-verbal means. Music might influence how people compose their bodies, how they conduct themselves, how they experience the passage of time, how they feel about themselves and others' (DeNora, 2000,17). From her research DeNora has found that 'music is active within social life, it has effects because it offers specific materials to which actors may turn when they engage in the work of organising social life. Music is a resource because it provides affordances for world building' (DeNora, 2010, 44); people turn to music in order to 'regulate themselves as aesthetics agents, to regulate their feelings and thinking' (DeNora, 2010, 62).

Philosophical Perspectives

From a philosophical perspective, Adorno's work on conceptualisations of music explains the role of music in people's social consciousness and its potential effects on wellbeing. Adorno 'conceives of music as formative of social consciousness: musical organisation is a simulacrum of social organisation, music is a 'force' in social life, a building material of consciousness and social structure' (as cited in DeNora, 2000, 2). Moreover, 'one of the primary functions of music is to communicate (Miell et al, 2005)… providing a means by which emotions and ideas can be expressed, communicated and shared both locally and globally, even when communication by language may be impossible' (Hargreaves *et al.*, 2005 as cited in McDonald et al, 2012).

Philosophers have also questioned both the 'nature of music and the nature of the human 'self' that music is being engaged to heal' (Elliot & Silverman, 2012, 25). Elliot and Silverman point out the shortcomings of defining music from a Westerner's point of view where there is a distinct divide between performer and listener (Davidson & Emberly, 2012, 142). Furthermore, in the West music tends to be defined as 'a matter of humanly organised musical sounds and silences, in the sense of deliberately designed patterns of melody, harmony, rhythm, tone, colour and texture. However, all these elements are not features of all musical products (e.g. Zuni Indians, Kete drumming, etc), not every musical culture in the world conceives of music in terms of musical products , pieces or works of music. As a result, thinking of music in terms of musical features and products is at best incomplete' (Elliot &Silverman, 2012,26). This is supported by the emphasis on process rather than product within our research findings.

If music is conceived as social praxis: as something that people do instead as something that is contemplated; it would have 'profound implications for anyone committed to the beneficial integration of music, health and wellness' (Elliot & Silverman, 2012,29). The concept of music-as-action acknowledges and welcomes any and all forms of musical-social participation included in the term 'musicking' (Small, 1998). In this sense, music depends on active doing and thus involves embodied knowledge and experience (Bourdieu 1990, Regelski 2006 as cited in Elliot & Silverman, 2012,30).

'In contrast to the dualistic separation of mind and body …, the paraxial concept reunites the dualisms implicit in the 'fine art' concept of music: body and mind become body-mind, thinking and feeling become thinking-feeling, knowing-doing, etc. Conceived as praxis the musical body-mind is holistically integrated' (Elliot &Silverman, 2012, 31). Praxial music education emphasizes social, ethical, embodied, musical 'particip-action' in musicking and listening for deeply felt musical experiences, experience self-growth, happiness, health, democratic fellowship, intercultural understanding and the construction and reconstruction of self-efficacy in broader social-cultural-political affairs' (Elliot & Silverman, 2012,31). This is very much in tune with the post-human lens used in our research.

Addressing the question of 'what or where is the self' that we are concerned to heal, revitalise, rehabilitate or educate with music, Neisser (1988) responds that 'the individual self may be thought of as a combination of several simultaneous selves or dimensions: ecological self (the self in its physical environment), an interpersonal self, an extended self (defined by its personal memories), a conceptual-cultural self (I-awareness) and a narrative self (the self-portrait one creates about oneself over time) (Neisser,1988 as cited in Elliot & Silverman, 2012, 31). Elliot and Silverman argue that 'the self might be compared to a huge jazz ensemble whose many millions of players (self-processes) are so expert at improvising collaboratively in relation to continuous changes in environmental circumstances that 'beautiful music' - meaning you and your unique experience of reality - flows continuously'(Elliot & Silverman, 2012,32). Whilst this discussion of music and 'the self' is interesting, we have discussed previously that post-humanism does not focus on the individual self but on agentic assemblages. This has proven more useful for our study as we shall discuss in the Findings section.

Ecological Perspectives

Although a firm connection between practice and theory in regards to the effects of music interventions and wellbeing has never been really established, (Ansdell & DeNora, 2012, 102, McDonald et al, 2012,3) it seems that 'interdisciplinary understanding of health and wellbeing as 'ecological' phenomena meshes perfectly with a similarly developing ecological understanding of people, music and context.' Together these perspectives show how music 'can provide a resource for cultivating wellbeing, understood as the positive flourishing of identity, relationship and community (regardless of objective health status)' (Ansdell & DeNora, 2012,97,

McDonald et al, 2012,6). Furthermore, Ansdell & DeNora point out that 'notions of being well are cultural constructions, linked to matters that take shape or emerge in relation to socio-cultural practices' (2012,107).

Evidence

One of the challenges in establishing a firm connection between practice and theory is the question of what should be considered appropriate evidence and how this can be demonstrated (Ansdell & DeNora, 2012, 104). To address the complexities in measuring wellbeing that comes from different sources (e.g. skills, practices, relations, habits), Ansdell & DeNora suggest that the only one thing to be done is to 'consult the participants themselves and trust their self-insight'. This approach has at its core a truly client centred method and it 'poses a radical challenge to conventional modes of evidence based medicine' (Ansdell & DeNora, 2012, 105). The notion of being person- centred is central to the work of Plymouth Music Zone, as evidenced in the evaluation of their practices conducted by Lonie et al (2016). Of course evidencing this becomes more challenging when participants cannot verbalise these insights. Research such as ours in *Beyond Words* has to find a way to be client-centred beyond words.

According to Ansdell & DeNora (2012) challenging the conventional notions of evidence-based medicine will require two key shifts. First, it will be necessary to move away from a dichotomy between health and illness to focus on 'the mechanisms and processes of moving along a continuum of wellness to illness'. This change will imply a focus on how these shifts are effected by both clients and therapists. It also means 'a theoretical conception that enable us to perceive the most minute of changes, as a composite of social/musical/psychological' (Ansdell & DeNora, 2012, 105).

To that end, anthropological research of cross-cultural music could provide new understandings on how to affect this change. Cross cultural research of music and music practices are providing new grounds to think about music as 'music in action or 'musicking' in relation to people, context and culture: 'the outcome of the dynamic interdependence of human and non-human phenomena and resources (sounds, agents, actions, forms, 'habitats')' (Ansdell & DeNora, 2012, 106).

Moreover, research on cross-cultural perceptions of emotion found that it is possible to identify emotion in music from an unfamiliar tonal system. In Balkwill & Thompson's

(1999) study, thirty Western listeners rated the degree of joy, sadness, anger and peace in 12 Hindustani pieces from India. These pieces were intended to convey one of four moods rated by listeners. In addition, listeners also provided ratings of tempo, rhythmic complexity, melodic complexity and pitch range (psychophysical cues). Results from this research suggest that listeners are sensitive to emotions expressed through music in an unfamiliar tonal system; they found evidence to support that 'relationships between emotion judgements and psychophysical dimensions of music is preserved across cultural boundaries' (Balkwill & Thomson, 1999,59).

Music as a Bridge

Music can 'serve as a bridge across communicative restrictions …because people can relate better to the non-verbal aspects of music' (Bruscia 1991,6, in Silverman 2008, 7-8). In fact, research in music therapy has suggested that music therapists can establish personal relationships with clients who resist other personal contacts because of the non-verbal characteristics of music (Silverman, 2008,8).

However, as DeNora (2000,16) points out 'using music as a resource for creating and sustaining ontological security and for entraining and modulating mood and levels of distress, is not unique to music therapy. In daily life many of us build and use music as a strategy 'for coping and generating pleasure, creating occasion and affirming self and group identity' (DeNora 2000,16). In our research we found that music was such a significant part of daily life, and not confined to PMZ sessions.

Paralinguistics

Silverman (2008) offers an interesting discussion on the relationship between 'paralinguistics' and music. 'Paralinguistics is a facet of nonverbal communication that includes vocal and musical elements such as tone, pitch, rhythm, timbre, loudness, and inflection. Awareness and variation of these elements may have the ability to maximize interest and effectiveness in communication' (Silverman, 2008,8). Further, the rhythmic qualities of music can be used to develop nonverbal communication (Redinbaugh, 1988 as cited in Silverman 2008,8) and music can be particularly helpful as a form of expression for people who have limited or no verbal communication skills. 'Although verbal interaction was found to be the preferred type of communication,

music can increase non-verbal social behaviour with patients diagnosed with Alzheimer's disease' (Pollack & Namazi, 1992 as cited in Silverman 2008,9). Interestingly, Redinbaugh (1988) noted that non-verbal communication progressed faster than verbal communication.

Eye-contact

In terms of body language, Antonietti et al (1991) found that 'eye contact is an important way of communicating non-verbally, that it promotes more efficient learning and affects people's behaviours' (Antonietti et al, 1991,91) This quantitative study explored how a musician's eye-contact with the audience can improve musical perception. It also assessed emotional responses from participants, particularly joy. In the experiments conducted 'joy was the emotion which under baseline condition reached the highest scores. Results showed that the number of times the musicians looked at the listeners determined the changes only in joy.' (Antonietti et al, 1991,102). Thus, increasing eye contact between musicians and the audience created: 'feelings of co-presence that can make people feel more involved in communication and has a positive impact on the amount of attention people pay to information given' (Antonietti et al, 1991,91) In our study we also found that the extent to which a Music Leader used eye-contact related to how successful they were at including people who faced problems communicating with words.

Cognitive Impairments/Stroke

Music appears to have significant effects for people with cognitive impairments. 'Many of those with Alzheimer's disease, despite aphasia and memory loss, continue to remember and sing old songs, and dance to old tunes' (Braben 1992; Brotons 2000, as cited in Sixsmith & Gibson, 2007,128). Further, those who were able to play instruments prior to the onset of dementia could still do so, indicating that musical abilities may be spared in the progression of the disease (Crystal et al,1989; Cuddy and Duffin, 2005, as cited in Sixsmith & Gibson, 2007,128). Such research has also indicated that musical abilities and memories may not be connected to deterioration in the brain relating to speech and language, raising the possibility of music as a non-verbal form of communication for people with dementia (Aldridge, 2000; Brotons, 2000; Hubbard *et al.*, 2002, as cited in Sixsmith & Gibson, 2007,128). Our research confirms that indeed it can function in this way.

Cognitive and neuropsychological research suggest that music interventions may also 'enhance a variety of cognitive functions, such as attention, learning, communication and memory', both in healthy subjects (Wallace, 1994; Thomson et al, 2001; Thompson et al, 2005; Schellenberg et al,*2007, 2005* as cited in Särkämö et al, 2008, 867) with clinical conditions such as, autism, (Gold *et., al,* 2006) and dementia (Brotons and Koger, 2000; Foster and Valentine, 2001; Van de Winckel *et al.,2004*, as cited in Särkämö *et al.*, 2008, 867). In stroke rehabilitation, music interventions have previously been used as a part of physiotherapy (Thaut *et al.,*1997) and speech therapy (Belin *et al.,1996)* to 'enhance the recovery of motor and speech functions' (Särkämö *et al.,* 2008, 867).

Särkämö et al (2008) conducted a randomised controlled study with people who had suffered a stroke. Participants were divided into three groups: a music group, a language group and a control group. Results showed that 'verbal memory and focused attention improved significantly after being part of a music group intervention compared to control groups. The music group also experienced less depressed and confused mood than the control groups. These findings demonstrate for the first time that music listening during the early post-stroke stage can enhance cognitive recovery and prevent negative mood' (Särkämö *et al.*, 2008,872). As we shall discuss in the Findings, this matches insights from both Music Leaders and participants in our study.

Dementia

Dementia is an umbrella term for a wide range of conditions and is the term we are using in this study, as in the academic literature generally. Music therapy for individuals with dementia focuses on communication, memory, behavioural management and facilitating interactive relationship with therapists and carers. Music is seen as a tool to achieve those goals (Hara, 2011,37), not as a medium to communicate with people as they are. Lately, there has been much research documenting the specific language deficits that people with dementia may experience: 'vague and empty speech, diminished vocabulary, faulty linguistic reasoning, changes in word association patterns and disordered discourse' (Hubbard et al, 2002,156).

In a study of people with dementia and music interventions, Spiro (2010) explored which musical characteristics enable observed improvements in dementia and what aspects these musical elements are acting on. Spiro found that 'memory for linguistic information contained in songs was superior but not limited to memory of old songs'

(Spiro, 2010,893). Prickett and Moore (1991) found that individuals with dementia remembered the words of songs they had sung during therapy sessions better than spoken material, and the percentage of recall was better for older than for newer songs' (as cited in Spiro, 2010, 893).

Spiro's results echoed previous research findings in that tailoring music to individuals' preferences seems important. In addition, 'live', as opposed to pre-recorded music has been suggested to have the additional benefit of promoting arousal and social engagement (O'Connor, Ames, Gardner, & King, 2009a; Sherratt, Thornton, & Hatton, 2004b); and levels of agitated behaviours seem to decrease more with individually tailored music than generic 'classical relaxation music'' (Clark et al, 1998; Gerdner, 2000; Groene, 1993; O'Connor et al, 2009a; Ragneskog, Bra°ne, Karlsson, & Kihlgren 1996, as cited in Spiro, 2010, 895). Spiro asks: 'is the main driving mechanism one of arousal, memory, mood or attention or a combination of the four? Some responses to different music types could be based in the same processes (such as arousal or attention) but others may be music specific: affective valence being related to mood and emotion, familiarity being related to memory and predictability' (Spiro, 2010, 896).

There is evidence to suggest that 'the power of music as a therapy for dementia may lie in a number of sources: superior retention, attention, arousal, by-passing or triggering failing capacities, and underlying physiologically, neurologically or socially driven emotional effects. Indeed, though distinctions are made between music therapy and activities, the boundaries seem more flexible than suggested by the definitions' (Spiro, 2010, 897).

Sixsmith and Gibson (2007,133) found that music had a 'communicative and stimulating effect' on people with severe dementia. 'Music also provided opportunities to be with other people and to take part in meaningful activities with others, often engaging with them using non-verbal forms of communication and interaction, such as touch.' (Sixsmith & Gibson, 2007,133) Thus 'providing a medium for physical and emotional bonding between a person with dementia and his or her family and carers' (Gotell et al, 2000, Hubbard et al, 2002 as cited in Sixsmith & Gibson, 2007,136). The sociocultural context of the music listening experience (which is itself linked to the individual and musical histories) is often left out of the analysis. 'A sociological approach would seek to address this drawback by looking in depth at individual experience with music in dementia care' (Hara,2011,35). To some extent *Beyond*

Words fills this gap because it looks sociologically at both the person with dementia and families and carers.

Autism

Another condition for which arts therapies has been widely used is autism. In autism music has been effective mostly because of the non-verbal aspect. It is also a predictable phenomenon in an unpredictable world, this predictability stems from the rhythm, melodic and harmonic structures inherent in music and the structured forms it employs (Silverman, 2008,10). Research on music interactions with children with autism in early stages of language development suggests that there is a potential impact of music on the children's wellbeing (Ockelford, 2012, 291). In particular, Deci and Ryan (1985, 2000 as cited in Ockelford 2012, 291) 'have demonstrated that a powerful connection can exist between autonomy, competence, and relatedness on the one hand and a sense of wellbeing on the other'. Evidence from music interventions highlighted the importance of consistency of approach, the use of familiar routines, short phrases and staff positive attitude (Goldbart & Caton, 2010,19). Furthermore, the study also offered evidence on the importance of a reflective approach to practice and the ability to form relationships, especially with those who are 'non-verbal' (Goldbart & Caton, 2010, 20). All of these factors have been observed when Music Leaders work with small children with autism in the *Beyond Words* study.

Magic Moments

In this light, conducting research in southern Africa, Pavlicevic (2012) identifies 'Magic Moments' as key elements of how participatory group musicking transforms people and places. In her research, she explored Magic Moments as part of a 'social, musical, temporal, and spatial map that spans various connecting events before, during and after as well as in and around these moments' (Pavlicevic, 2012,197). She observed magic moments in sessions that despite lasting no more than seconds – appear to signal participants' experiences of shared meaning, pleasure, dignity, and collective belonging in the 'present moment'. Pavlicevic argues that such Magic Moments are key to music's transformative work. She describes magic moments as 'optical moments in group musical flow and coherence; the musicians constantly ebbed and flowed towards and away from Magic Moments. Discussions of such moments reveal that identities to do with being ill, marginalised or expert musician are dissolved or shared in the interest of being people together in music in this place and in this time'

(Pavlicevic, 2012, 197). Although this work is not specifically with those who are post-verbal this is possibly the closest concept we have found in the literature to match the work we have done in *Beyond Words.*

Reflection on Literature Review

In sum, a systematic exploration of interdisciplinary conceptualisations of being 'non-verbal' have shed light on its developmental, social, cognitive, physical and psychological dimensions. Awareness of these different dimensions have infomed fieldwork, data analysis and discussions in the *Beyond Words* project. Although a variety of studies proposed different approaches to facilitate communication, there is still an underlying perception within the literature that being 'non-verbal' is a problem to be overcome. This is something we have consistently addressed and challenged, beginning by creating the term post-verbal.

In addition, there seems to be little in the form of longitudinal empirical studies of post-verbal people, and arts interventions, particularly music. We have found no evidence of any post-humanist studies on this subject. *Beyond Words* seeks to fill that gap in the literature. By taking a post-humanist approach, this research focuses not on the human but on the phenomena generated when different forms of matter are brought together, its focus is not on words but on moments of communication, sparks of new life.

In this light, this study also seeks to contribute towards debates on the agency, power and inclusion of those who are post-verbal. Some scholars, especially in the social sciences, propose a re-assessment of definitions of agency that would allow for more holistic understanding of contexts where post-verbal people exist. *Beyond Words* holistically explores the power of things, temporal, visual and spatial landscapes; the unspoken that facilitated communication and decision-making with post-verbal people. Systematic reviews of literature on arts-based interventions have reported that rigorous studies are few, and thus findings are difficult to replicate/validate. In addition, there is also a schism between the importance of focusing on the process or the outcome of interventions. Nonetheless, research on arts interventions (e.g. drama, music, singing) have identified a number of essential elements of inclusive practice, for example: humour, eye contact, visual spaces, and body language. With this

longitudinal study, *Beyond Words* seeks to contribute to an interdisciplinary dialogue about becoming client-centred beyond words.

There is cross-disciplinary research documenting the importance of music as means of communication. However, we did not find studies that included a diverse sample of post-verbal participants (aphasia, dementias, stroke, brain injury, developmental conditions, elective mutes) to explore how music can be used effectively across conditions to facilitate communication. This project aims to also fill that gap in the literature.

The report will continue to explore the research methodology of the project, including reflections on methodological and ethical concerns raised in the literature.

5   Methodology

The literature suggests that a major obstacle precluding theory building in the field of music and wellbeing is a lack of coherence: there is a diversity of approaches and findings, heterogeneity of methods, participants, outcomes, and interpretation of findings (McDonald et al, 2012,4). Hence there is no pre-agreed methodological approach for a project such as *Beyond Words*.

DeNora argues for the benefits of conducting ethnographic research with music: 'only ethnographic research has the power to elaborate our conceptualisation of what such processes entail (how to understand the mechanisms through which cultural materials work)' (DeNora, 2000, 39). We concur that the foundation of our project needed to be ethnographic.

It is always important to acknowledge the power relationships between the researcher and participants. According to the literature (Nind, 2008,5), this is less realistic for people with profound difficulties, for people who may lack the required communication and social skills and flexibility of thought, making active participation rare (Beresford et al., 2004 as cited in Nind 2008, 5). It was thus extremely important to build in ways by which our participants could actively express their feelings about music-making.

With these insights in mind, *Beyond Words* Project developed a mixed methods qualitative methodology with five key data collection tools. First, the project conducted a longitudinal eighteen-month ethnography of Plymouth Music Zone (PMZ) music sessions. Some of these sessions took place at PMZ headquarters and some at other venues such as care homes for people with dementia, assisted living for elderly people and centres for people with learning difficulties. As discussed in the literature review, space is a crucial element in PMZ's work.

The people studied were diverse; they included children and young people with severe disabilities, autism and elective mutism, adults with strokes, aphasia and brain injury, and also older people with different types of dementia. The groups observed shared

the common denominator that people who had difficulty using words to communicate attended the music sessions regularly. The Research Assistant (RA) was a 'researcher in residence' with PMZ for four days a week, acting as a participant observer and filming selective practice.

She attended sessions in different venues and with different groups and took detailed field notes. Initially, the project aimed to follow fifty participants who had difficulty communicating with words, however, reaching this number of participants proved to be difficult because of some gatekeepers' (such as partner organisations) reluctance to participate in the research. It was also found that the data being gathered was so rich that a smaller number was advisable. The target was changed to twenty five which was then achieved thanks to tireless team efforts by the RA, support care workers and Music Leaders, made possible by relationships developed over the longitudinal study. These twenty five participants are given pseudonyms in this report. In addition to observing them in the music sessions, and the ways in which they participated with others, the RA also observed the Music Leaders and the interactions (especially unspoken interactions) between Music Leaders and post-verbal participants. She also observed other music sessions with verbal participants to see how the unspoken was used in general music practice.

It is notoriously difficult to observe and describe what happens when music is made and to understand the multiple relationships that take place. In addition, no comparable post-human ethnography of music-making exists. Over the course of the project the research team developed a series of prompts to use to help this process of observation. This ensured that a post-human lens was employed and that a focus on music-making was maintained. The researcher was prompted to notice the following:

Bodies, Silence, Beyond Words Communication, Interaction with Things, Time, Space, Group Interaction, Responsiveness, Respect, Music making:

Rhythm (regular/irregular), Pulse (steady beat), Tempo (fast/slow),Timbre (timbral effects),Texture, Pitch (low/high), Melody/tune (angular, playful, simple, soaring), harmony (major/minor - how music makes people feel sad/happy/unsure), Inclusion, Becoming. Not all of these elements would be present all the time, but overall they form a useful approach for anyone exploring music from a post-human perspective. Combined with more qualitative field-notes they provide a unique longitudinal data-source.

The second method of data collection was four focus groups. These focus groups were fundamental in informing fieldwork and data analysis; focus groups with Music Leaders were conducted at the beginning, the middle and the end of the project; one additional focus group was conducted with PMZ volunteers and apprentices. The focus groups contributed greatly to a successful approach to fieldwork; for instance as a result of the initial focus groups, the research team agreed to change the use of the term 'non-verbal' to the expression 'people who have difficulty communicating with words'.

The third method of data collection drew on the concept of 'networks of intimacy' (Heath, 2008, 220) which recognises that people who have difficulty using words to communicate are part of a network, that their networks can help to illuminate their lives and that benefits for them also impact on family, friends and the wider community. The Principal Investigator aimed to interview two people per participant, either family members or support care workers. The in-depth interviews explored the lives of participants from the perspective of their families and carers and addressed music's role in the participant's life and in the network as a whole. However, because of challenges reaching support care workers and some participants' relatives, only forty four out of fifty interviews were conducted. However, every participant had at least one network interview and most had two. The majority of interviews took place with families. The most problematic aspect was arranging interviews with professional carers as they had limited availability and were sometimes reluctant to speak. Most interviews happened on the phone, several were held at PMZ, the university or the person's home. Telephone interviews proved very useful, as many people were able to say things that they might have found difficult face-to-face.

As a fourth method of data collection, the project also used visual methodologies in different ways. A visual artist with experience working with community groups designed and delivered thirty tailored arts workshops to participants in collaboration with a Music Leader, some in groups, some individually. The workshops were experimental and there are no similar examples in the research literature. They were designed to allow a voice to those who have difficulty using words to communicate: the main objective was to elicit responses from the participants about the music sessions they attended. The artist chose materials to match the interest and capabilities of the participants: this included paint, pastels, clay, shadows, textiles and film and this was matched by music making/musical stimuli from the Music Leader.

The artist delivered the workshops in collaboration with the Music Leader and kept reflective notes. The artistic outputs produced by participants and the reflections of artist and musician were used in data analysis. As part of the visual methodology, the Research Assistant and the artist also filmed random music sessions to assist with longitudinal observations, data collection and artistic outputs.

The fifth key data collection tool was holding a participative stakeholder seminar organised and delivered half way though the project to share interim results with participants, families and practitioners across different disciplines (education, health, social work, psychology). This interactive seminar proved useful for data analysis and informed further fieldwork and consent practices. A very successful final international conference was organised at the end of the project for an audience of academics, artists and community practitioners interested in post-humanist approaches.

Data gathered included eighteen months of fieldnotes and film, transcripts of 44 in-depth interviews and 4 focus groups and data from 30 arts workshops including fieldnotes from the artist and the musician and art works created by the participants. Data was analysed initially by researchers Professor Jocey Quinn and Claudia Blandon, Plymouth Music Zone's Training and Research Manager and musician Anna Batson, and visual artist Karen Abadie in a series of six research away days focusing on each participant in turn and drawing on multiple disciplinary perspectives. It was then further thematically analysed by Professor Jocey Quinn and Claudia Blandon using post-human theory.

In sum, the research methodology used in this project has been innovative and effective but quite difficult to organise:

- Our qualitative ethnographic approach with multiple methods was needed to approach these complex issues.
- Identifying the right people, gaining access to their families, encouraging consent and monitoring assent was a very long process.
- Organising network of intimacy interviews was logistically difficult but highly rewarding.
- Multiple things happen or have happened below the 'surface' of the person who does not speak and so the interviews have been a revelation.
- The arts workshops are crucial because they have helped to challenge preconceptions that might have carried over from interviews and observations

and have given opportunities for agency to the participants themselves. They have been much more diverse and challenging than anticipated in order to meet the needs of different participants. They add access for and to participants, providing additional windows into participants' subconscious and imagined responses to music, indicating its power to release capacities and potentials.

Working with these participants and their networks stirred up difficult emotions for the research team. We had to acknowledge and work with these feelings and seek support in addition to the ongoing pastoral support on offer at each of our respective organisations.

Ethical Considerations

The *Beyond Words* research team used an ethical approach that allowed for continuous revision of ethical approaches in conducting research. Ethical procedures were approved by the Education Research Ethics Sub-Committee and revised several times throughout the research. Because this research project worked with people who might be considered 'vulnerable', special measures were put in place. For instance, risk assessments were conducted throughout the research, both for participants and researchers; special efforts were made to create and manage good relationships with family members, carers and partner organisations.

From the onset, the research team made the decision to follow PMZ's child protection policy and procedures, should they be needed during the life of the project. Information and consent forms used clear and appropriate language to explain how images and footage were going to be used as part of the research dissemination. Although PMZ's registration procedures include consent forms to authorise the use of visual material, the research project asked participants to consent whether they wanted their visual data used for research purposes.

It became evident early on in the research that the project would present ethical challenges at different levels. In essence, the project faced three main ethical obstacles: first, gaining informed consent and respecting assent, second, filming random music sessions and third interviewing support care workers.

Firstly, there were two main challenges in gaining informed consent from both participants and from their carers. The initial ethics protocols were lengthy and wordy,

but included all necessary elements for ethical approval. They included several textual forms tailored to different participants and a visual consent form with images that captured key concepts: right to ask questions, participation is voluntary, right to withdraw, etc. These visual forms were aimed at young children or adults who preferred visual representations (as reported by their carers/family members). The research team discussed at length the type of images that should be chosen to convey the meanings the textual consent forms described.

Foreseeing ethical challenges in the project, the research team added a request to approach the ethics committee throughout the life of the project to clear any potential changes to consent forms or any other ethics protocol. This request aimed to take into account participants' feedback as fieldwork developed. Furthermore, one of the Chairs of the ethics committee was invited to be a member of the project's Steering Group.

However, as evidenced by family members' lack of response after the information and consent forms were sent to participants, it was clear the forms were not being effective in inviting people to take part in the research. Some family members reported they found the consent forms 'intimidating'. The research team consulted further with care workers in dementia care settings to explore what exactly was perceived as intimidating, and the feedback was illuminating. It was reported that family members receive a lot of official post, and the frequency and content of this correspondence is often overwhelming. Family members and gatekeepers found the project's consent forms looked and sounded similar to correspondence they dread to read. With this feedback in mind, the research team went back to the drawingboard several times throughout the project to accommodate all participants and their needs. For instance, for participants who suffered stroke or aphasia, the forms were designed with their needs in mind; they included short sentences with key words in bold. This proved a very useful principle in designing consequent consent forms for other groups.

There is substantial discussion in the literature surrounding informed consent from people who are perceived as vulnerable or as having cognitive impairments. For instance, challenges of conducting research with people with dementias because of the progressive destruction of their cognitive functions (Hara, 2011,35) have been widely discussed and explored (Proctor 2001, Reid *et al.* 2001, as cited in Hara, 2011, 35). As a result, discourses about revised meanings of agency have emerged (Boyle

2014). The Beyond Words project seeks to contribute towards discussions advocating redefining concepts of agency.

Thus, in terms of informed consent, Scott et al (2006) 'outline the three key issues: the person's competence to give consent, the extent to which the research is in the person's own best interests, and the balance with public interest' (Scott et al, 2006 as cited in Nind, 2008,6). With regards to competence to give consent, historically people with learning difficulties have been considered unable to make decisions for themselves (e.g. healthcare, education). Attitudes to this have changed however, as reflected in legal changes marked in the Mental Capacity Act. According to this Act, in legal terms, a child is 'Gillick/Fraser-competent' to make decisions when s/he 'achieves a sufficient understanding and intelligence to enable her or him to understand fully what is proposed' and has 'sufficient discretion to enable him or her to make a wise choice in his or her own interests' (Morrow & Richards, 1996, 96, as cited in Scott et al, 2006, 277). This implies the capacity to make decisions and understand the consequences of that decision. However, this notion gets convoluted when short memory is affected as a result of dementias or other type of brain damage.

From a gatekeeper's point of view, especially in the *Beyond Words* research context, discussions about the benefits of research participation were fundamental to allow access to participants. In this context, participants are 'protected' by the decisions made for them, and thus their capacity to make decisions is 'under-developed'.

Thus, research exploring notions of capacity of people with communication difficulties has found that while emphasis is usually put on intellectual capacity to make decisions, social and environmental factors are also important (Harris 2003 as cited in Nind, 2008,7). It is important to take into account that people with learning difficulties often live in settings where choices are restricted, where they are unaware of choices denied to them, and where they have little experience of making decisions because of inadequate information and poor communication. Consequently, if one does not have previous experience and/or familiarity with choice-making these conditions will affect one's ability to make choices. And thus, for these group of people, 'information may need to be absorbed over time with understanding reached in 'the doing' (Brooks & Davies, 2008, 130, as cited in Nind 2008, 7). In this project, after initial reluctance from some gatekeepers to grant access to invite participants to take part in the research,

the information sheet included two separate sections to explain potential personal benefits of taking part in the research and potential benefits of public interest.

Research addressing consent from 'vulnerable' populations has identified different elements that can be interpreted as positive indicators of consent; namely high level of engagement (eye contact, body language), relevant elaboration (verbal comments) and positive non-verbal responses (nodding). In contrast, doubtful indicators of consent include 'low engagement and ambivalent nonverbal responses.' (Cameron & Murphy, 2007 as quoted by Nind 2008,8). In addition, in conducting research with people who face difficulty communicating with words, 'ongoing processes of assent together with proxy consent may be also needed' (Beresford et al, 2004 as cited in Nind, 2008, 8).

In this vein, research has also highlighted that the 'need for consent is distinct from the need for assent (Scott *et al.*, 2006, 282; Whitehurst, 2006,35). In research ethics, there is a distinction between consenting to take part in a specific research project 'versus assenting to the particular procedures to be used' (Scott et al, 2006, 282). The *Beyond Words* project incorporated these principles as part of the procedures of seeking consent both from participants and from Music Leaders. Special effort was made by the research team to remind all participants at the beginning of all music sessions about the research project. Music leaders orally reminded people that the music sessions were going to be observed for research purposes and that participants had the right to approach the Music Leader to object to being observed. This oral procedure aimed to give participants an opportunity to exercise their rights as research participants, to have their wishes known, and in several occasions, research participants and non-participants exercised that right. With this practice, the *Beyond Words* project aimed to have strong 'ethics of representation' by having clarity about whose 'voice' is being communicated in the study' (Booth, 1996 as cited in Nind, 2008, 8). The researcher conducting fieldwork played close attention to participants' body language for any sign of dissent, despite the fact that there were consent forms signed on their behalf.

In sum, and taking all of the above into account, shortening the sentences and making key words bold in each sentence made the consent forms looked less crowded and more readable. The use of colours, and a larger font size (14) also helped. Effectively,

consent forms were personalised, which implied previous basic knowledge of the person to whom the form will be delivered (e.g. full name, and the name of the participant they were related to); in these forms proper names were used throughout the form and clear instructions were given in short and concise sentences.

Moreover, Music Leaders were also reminded often of their rights as research participants. Printed posters of the *Beyond Words* project were placed in key places of the partner organisation. The poster included an outline of the research, initial references and contact details of university researchers. The poster, and all communications with music leaders, included a reminder of their rights not to take part in the research without any repercussions. A few Music Leaders exercised their rights throughout the research; they objected to being observed or have a researcher involved in music sessions, especially when they were working with a new group of people.

The second ethical challenge involved an element of the visual methodologies used in the project: filming random music sessions. The objective of filming random music sessions was to complement participant observations. As a result of the first focus group with Music Leaders, the research team was advised not to take notes during the music sessions because it would cause distraction and possibly some anxiety to some participants. Consequently, all field notes were written after the sessions, and thus having additional visual data was useful to complement longitudinal observations.

When music sessions were scheduled to be recorded, Music Leaders asked participants' permission to be filmed, or whether anyone had any objection to being filmed. These two ways of asking the question also posed ethical dilemmas, given the nature of some of the groups or the participants, they were not actually given the right choice to consent or object. Once again, participants' assent became very important.

Additionally, some participants became very distracted by the filming, and this in turn, disrupted the music session for others. In one case in particular, the participant made it quite clear that he liked being filmed and took to perform for the camera which defeated the purpose of the filming.

The third element of ethical concern was brought about by conducting interviews with support care workers (SCW) who were nominated by sole members of participants' network of intimacy. As discussed in the findings session, some of the participants

and their families reported being isolated and thus they only had support care workers as part of their immediate network. These SCW experience high turnover at their workplace and only a few knew the participants well. However, because the project did not offer any financial reward for taking part in the interviews, SCW were asked to volunteer their time to be interviewed. This proved quite problematic and resulted in several interviews being re-scheduled several times and some not being conducted at all.

The Beyond Words project includes a wide range of participants with different conditions that leads them to not being able or wanting to use words to communicate. Therefore, 'ethically important moments' (Guillemin & Gillam, 2004) have been a fundamental element in conducting fieldwork for this project. This approach allowed for the notion of reflexivity to be considered as a resource and a bridge to the procedural ethical issues that cannot predict all possible scenarios on social research. The 'researchers should constantly take stock of their actions and their role in the research process and subject these to the same scrutiny as the rest of their data' (Mason, 1996, as quoted in Guillemin & Gilliam, 2004, 274).

6   Findings & Discussion

In our research we followed the lead set by families when they said "I think *with* her" or "You have to enter into *their* world". The perspective that we tried to take in our analysis was that of the participants.

Working with post-verbal people

Post-verbal not non-verbal people

We often heard the phrase 'classed as non-verbal' to describe the restrictive, deficit category into which our participants were placed. Our research shows that the term non-verbal is a misnomer as well as seeming pejorative. None of our participants was completely silent, in fact some were challengingly noisy. Nor were they without words, even if they were used selectively in certain contexts or to animals rather than humans, or were rare utterances never to be repeated. In many cases it was more that they spoke but that others did not have the patience or the capability to decipher what they said. In our research we did not position people negatively because they faced problems communicating with words, instead we use the term 'post-verbal', as in the post-human sense of moving beyond words to recognise all the other ways they were able to communicate: with their body movements, eyes, touch, expressions, art and with music itself. Indeed, as we shall discuss, the research reveals all the ways in which they taught others important lessons.

The research is a process of unlearning, mirroring the kinds of unlearning Music Leaders need to do. For example, who is to say that the noise Freya makes, which is piercing and constant, is awful? Who is the arbiter? Music Leader practitioners often describe unlearning/ deconstructing and challenging their own perceptions in order to elicit others' experiences of their sessions and deepen communication and connection with their participants. Creative exploration in turn can then be stimulated through challenging and often' undoing' what we think we 'know' or feel most comfortable with.

Within carefully designed parameters, PMZ is a free space where people are enabled to step outside the bounds of categorisation.

Creating the right environment for inclusion

Inclusion of post-verbal people requires respect for difference, the promotion of autonomy and room for choice, otherwise it is simply lip service. Music is an equaliser between post-verbal and speaking people, however, music alone is not enough. Parents in our study had taken their children to private music sessions that charge money, such as group music sessions designed for babies and young children and felt excluded because their different needs were not respected or accommodated. Ed is a five and a half year old boy with a combination of autism and other sensory conditions which mean that certain noises and bright lights overwhelm him. He does not speak but makes high pitched expressive noises that sound like he is singing. Making music requires a great deal of effort and motivation on his part, yet PMZ managed to make this possible for him:

> *"With a lot of sessions you have to fit in. PMZ was just about what they could do to calm him, building his confidence, encouraging him to explore instruments. helping him to communicate… With music a set structured session is very difficult for a child with high needs to conform… He couldn't sit still or in a circle to do specific songs… It would end up with him being so distressed we'd have to leave after 5 minutes"*
> (Interview Ed's mother)

Our ethnographic approach enabled us to find an answer to our first research question: PMZ effectively included our participants by adopting deliberate and well-thought out social, cultural, musical and emotional and organisational strategies. The organisational element is key, as in management organises and promotes what Lonie et al (2016) call their person-centred and assets-based approach, and this shapes the social, cultural, musical and emotional strategies. However, our research found that it is the embodiment of the strategies in people's daily material practice that makes them vital and alive and that working with intuition is essential with post-verbal people.

Listing the strategies in a linear way does not do justice to the way in which they form an integrated whole. They might better be understood as multiple layers where participants are at the centre surrounded by families and carers and then emotional, social, cultural and organisational strategies:

Organisationally: PMZ is exceptionally well-organised, having very effective leadership with a clear understanding of what their mission is and how it might best be achieved. That mission focuses on inclusion and social justice for all via music, and it suffuses all the decisions which shape organisational practice; including those which have resulted in working with growing numbers of post-verbal people. There is a solid organisational foundation that invests in training and opportunities for reflection and celebration with the aim of producing high quality impactful work. To work in this way is expensive. It requires a longer-term approach, extra funding and often requires more than one Music Leader per session. Participants in our study gained tremendously when given the opportunity of individual sessions, which is sometimes possible for PMZ, and was also facilitated by our arts workshops. In order to gain funding for its work the organisation has to be highly strategic and ensure that it will deliver outcomes that have a wide impact.

As with all charities, funding is an ever-pressing issue and our participants noted negative effects on the few occasions when music sessions had to stop for financial reasons. PMZ has a strong ethos of sharing. It works hard to be strategically embedded in local and national contexts and to meet current health and social care priorities. It has systematically sought external evaluation and review to enable it to demonstrate the quality and impact of its work.

Socially: It provides a safe, welcoming, environment with "*stress-free*" non-judgemental staff who are loving and caring but also keen to have fun, who dedicate time and patience to understanding post-verbal people, enabling them to make music at their own pace in their own way. It models an inclusive community by combined celebrations and performances bringing people together who would never normally meet, making and remaking a community where words are not paramount or even necessary. The research has contributed to this modelling with a friendly and ethically sound research team embedded in PMZ, making the university/academic setting seem more accessible and comprehensible to research participants and their families, to Music Leaders and to external staff and organisations involved in the study.

Culturally: It proceeds by clear principles of inclusion and equality with a commitment to promote social justice via a clearly defined strategic approach: all are equally valued, but special efforts are made to meet different needs as defined and driven by the charity's organisational values. Collaborating in research focusing specifically on their post-verbal cohort is an example of this culture of inclusion and learning. Training, including bespoke designed Music Leader 'skills pods' for collaborative learning, creative development and discussion, supervision, snapshot observations, evaluations by external researchers, links with other organisations with the same values, are all based on a shared mission and work to generate and further embed a shared ethos. Diverse Music Leaders are recruited, including as volunteers and apprentices, and race, disability and class and other inequalities are addressed, with diversity fully valued and celebrated. PMZ is very good at branding itself and sharing examples of its work, for example through high-quality films, social media and its website, but this would be less meaningful without the strong sense of ownership and connection and the emotional validity of these documents, as they celebrate the lives of their participants.

Musically: Inclusion for post-verbal people relies on Music Leaders' ability to adapt music to the needs of the individual/group and to facilitate autonomy and choice. Attention to small signals and fleeting moments is crucial; this requires a broad repertoire and flexibility. Music Leaders have to be able to build up relationships and read and respond to signs and signals:

I noticed in this session that Louise is making an effort with the gestures of the 'Red Feathers' song. In a previous session, the ML teased her about pointing to her right hand side to indicate the location of her heart. She had responded at the time that she could not reach to the right place because of her lack of mobility. Today, I noticed that she was using her left arm and she was making the appropriate gestures.

(Researcher fieldnotes)

Music Leaders are matched carefully with groups. Across different groups we observed helpful strategies such as using: repetition and familiarity for those with strokes or sensory impairments; calm and soothing songs with evocative lyrics with those living with dementias; tapping into pleasure in performance and dance with the younger people with learning difficulties; using electronic and digital media to enhance physical access for those with brain injury. However, these are mixed and varied according to the mood and needs of the group. No one type of music 'fits' post-verbal people: careful reflection, patience and trial and error is needed and not all MLs can do this all of the time. Lessons learnt about non-verbal signals, bodies and time are also used consciously:

"*You have to rely on a whole other raft of things …when you haven't got speech to rely on. "The ability to tune in and use your instincts and to kind of evaluate what's happening in the moment, assess it, adapt it and change.*"

"*I think as musicians we are quite good at doings lots of things at the same time simultaneously, …but we have got an additional sort of layer of things of awarenesses, that I think we take for granted quite a lot really. But with the nonverbal side to it we kind of have to really rely on those resources quite heavily.*"

"*And believe in them have faith in the fact that you're responding appropriately and you're picking up on these keys or accepting that it's wrong and adapting again, being very flexible and adapting.*"

(Music Leaders focus group)

At PMZ, although all Music Leaders are reflective and skilled, their development and cohesion in terms of working beyond words relies on a creative hub at the centre. This combines musical expertise across a range of instruments and musical styles and genres with an open and experimental approach and dynamically demonstrates creativity and reflexivity. Such a hub whether it be one person, or a group combining these attributes, is essential.

When working with partner organisations in their own venues, such as private care homes, it is less possible to control the environment for music making. Observations showed that sometimes carers were noisy or disruptive whilst music was happening, or unceremoniously took participants away from music sessions without their consent. Conversely sometimes carers were too attentive, intervening in music sessions and arts workshops trying to manipulate what participants should do; trying to be helpful but spoiling the flow of the sessions and reducing their free choice. Music Leaders often rely on carers to help them plan and access sessions appropriately and therefore these relationships are invaluable. PMZ provides a Code of Conduct for those who support participants in sessions. Expectations of partnership working, including the kind of support needed from the external organisation is also laid out as part of the contracting process. Keeping track of this is more possible when working in the main PMZ building, but more challenging, particularly in settings where there is a high turnover of staff, or when new staff are supporting an individual who doesn't know what to expect. Appropriate support can make the difference in terms of providing genuine opportunities for people to flourish and grow together.

> "*In PMZ they talk to her and sit opposite her. When there's a choice the child chooses not the parent, that's really nice, including them. Quite often as a parent or carer you are asked 'what do they like?', but not in PMZ. It involves all of us but the children are at the forefront which is how it should be.*"
> (Interview, Cara's mother)

Throughout the research the notion of being present, riding the wave of the moment seems the most significant factor in working with post-verbal people. The emphasis on process rather than product fosters creativity and inclusion for everyone. This is not to say that taking part in celebratory events or producing CDs are not motivators or highly enjoyable. Indeed we found that two of our participants were both hoping to win

the same coveted PMZ prize in the organisation's annual award celebration event. Nevertheless there are those, for example with advanced dementia, for whom product is meaningless, but making music is intensely meaningful. They are moments of celebration in themselves, but it would be interesting if PMZ found a way to memorialise them, as in the arts workshops videos and as in their wider use of film. Through the research, particularly filming tender moments and interactions between Music Leaders and people living with advanced stages of dementias, there have been moments that are utterly precious in terms of showing connections made through music interactions. Not all families want to acknowledge 'windows' of hope when they have begun to accept their family member in a new way of living, but by contrast, others may perhaps find great comfort in holding and preserving some positive 'moments' as captured beautifully during some of the arts/music workshops.

Emotionally: Working with post-verbal people is a positive challenge in which the word *"love"* was often used. It is also emotionally draining, particularly in working with people with advanced dementias. In many ways the Music Leaders provide emotional support to participants and they in turn need support, which is provided by a member of staff who is a trained counsellor as well as by line managers. Emotional and peer support also happens informally across the MLs but a designated time for shared debriefing is essential. PMZ offers designated 'support hub' time for small groups of MLs (often working with similar groups of participants) who can come together and share experiences in an open and supportive way. This is particularly important when they need to talk about emotional elements raised in their workshops. This differs from the 'skills hubs' which tend to focus more on the creative and practice elements of music leading. PMZ sought assistance in designing these pastoral support sessions from an experienced group facilitator who had worked in a range of NHS settings. The sessions are being embedded in PMZ training and are becoming more valued by MLs, particularly as PMZ engages with increasingly intensive settings and participant groups.

MLs differ in their attitudes to providing respite or catharsis through music. Some want to provide a space without pain, others actively 'stay with the trouble' (Haraway, 2016) helping people to work in and out of their pain through music. This provides an invaluable resource beyond words.

Music and Verbal communication

As discussed, it is a mistake to view post-verbal people solely in terms of needing more words. However, the research also indicated that music can facilitate speech. This was demonstrated on numerous occasions and in different ways. For example, stroke survivors, those with brain injuries and dementias who could say few intelligible words could sometimes sing the full lyrics of songs.

"We noticed definitely in the dementia care home people who struggled to communicate hugely have retained an ability to sing most of the songs."

"Yes, and sometimes with increasing stimulation with music will then be able to have some sort of conversation and it might even communicate using a line of the song."

"Little music conversation where they are kind of engaging socially, but not necessarily in a chit-chat way, but they are singing to each other."
(Music Leaders focus group)

Observations showed participants gradually increasing their vocabulary across the duration of the study.

"Since she has been coming there have been improvements (in her speech) that I can only put down to PMZ."

"So why can you only put it down to PMZ?"

"Because we don't do a lot of other communication. When you leave hospital and Early Care Support everything stops. Physio stops, speech and language support…she's had her quota. No PMZ has helped a lot because there is nothing else."
(Interview Louise's husband)

Music was also the agent which broke through the silence of an autistic teenager, allowing him to speak freely whilst at PMZ. The intense experience of music in some

of our arts workshops seemed to facilitate speaking even more and to illustrate how words might be generated in synthesis with other forms of communication:

> *I observed that the longer the duration we sang for the more words started to emerge in between other more babbled phrases where Bill used the sounds that were most easy for him to form "bi bi bi beebie doo - ra laaaaaaa" alongside big dramatic gestures and lots of rolling back his eyes into his head, fluttering his eyelashes and at one point laughing and flicking out his hand.*
> (Music Leader Bill Arts workshop, notes)

Drawing on their experiences, Music Leaders and family members felt that if music were provided sooner post-stroke, or in an early stage of dementia, speech might be restored or preserved.

However, not relying on words seemed to create a certain freedom. Post-verbal people are already in the zone of creativity without holding back; they don't need to put concepts into words. As Rosi Braidotti says, "there is nothing to say but everything to do" (2013, 190). Cara is a teenager with Down's Syndrome who doesn't speak with words but by her movements, her laughter and her happy responses to music, in doing so, she also influences the responses of those around her:

> *"I'm not the best dancer, I've always felt self-conscious. Cara has made me. She has to get up and dance. We might be the only ones on the dancefloor"*

> *"Would you have done it before Cara?"*

> *" No, no way, never."*

> *"It's quite a bit because she doesn't speak makes her different…Because she can't speak she doesn't care. She just enjoys it and she does it."*
> (Interview, Cara's mother)

Families and carers

Including 'networks of intimacy' in the research in the form of families and carers, has been integral to the success of this project. It has given us a deep understanding of our participants and the contexts in which they are living and what they add to the richness of a diverse community. We have learned of creative hidden lives and fascinating histories. PMZ builds on an existing engagement with and love of music rather than always creating it from scratch and provides a vehicle to share and develop this love of music with others. It is cascading wellbeing throughout the wider community through their work with post-verbal people. Families get respite and feel secure that their family member is safe and happy. Increased levels of confidence and happiness spread through households and networks. Participants re-enter the wider community and make their own different contribution with and through music, making the community more diverse and vibrant. The community in turn then has an opportunity to contribute to the participants' lives through a shift in their values and awareness, bringing potentially more meaningful interactions with previously marginalised people and valuing their contributions more fully.

Most striking in our research is the love and devotion shown by families and the persistence of this over many years; a persistence that demands the fullest life for their loved one, including the opportunity to make music. This is not a self-sacrificing love but a joyful love, in tune with music:

"Cara has taught me a lot, I love her to bits she's just uncomplicated. I like the simplicity of it, it's lovely. The take it in the minute, the now"
(Cara's mother interview)

However, we have also learnt of isolation, frustration, feelings of loss and abandonment: years of sleepless nights, overcoming aggression and dealing with *"the looks"* of strangers in the street. Support from health and social care is patchy and unconnected. There are no holistic links across services and the right information is sometimes impossible to find. More painful still is having to take on all the responsibility alone as friends fade away or families split:

"*The family, the family I thought I had now doesn't exist, so I have no support from them.*"
"*Was there a reason why they just turned away from her?*"
"*I have no idea. Someone will say: "We don't do illness" or "We'd rather remember mum as she was". But you know at the end of the day they weren't even, I was getting no support, not even a telephone call saying 'how are you doing?' It's been a very bitter pill to swallow to be honest.*"
"*Yes, I can imagine.*"
"*In fact I'm still swallowing that one.*"
(Interview Sarah's husband)

In response to instances such as the above, PMZ has facilitated support networks within and across different groups, often working beyond its 'music' remit. In some specific instances, they have given families tools they can use at home:

"*I've found more than anything I could use music at home when he was having a severe meltdown. The PMZ track from Zoobie Doo, track 5-the owl session. The ML says he liked the tone, the repetitive beat. Autism fuels repetition. I play it to calm him down. He associates it with 'calming me down' and leads me to the CD player. Just to have that time a week to see him happy in a group; at that time he was often distressed having meltdowns, very overwhelmed with anxiety and he couldn't cope. If it was something like football you'd go to the session and wouldn't bring anything away from that. With PMZ there were*"

things we could bring home, calm him down in 10 minutes instead of up to 2
hours with us at a loss how to calm him. PMZ spilled out to the rest of the week."
(Interview Ed's mother)

Families were excited and moved to see what their loved one was capable of doing. We found that even in their nineties people have the capacity to surprise others and that this was experienced as a real gift.

The research also involved a small number of interviews with carers, whether carers involved in residential twenty-four hour care, assistance for children with learning difficulties or support workers at centres for people with learning difficulties or care homes for the elderly. Our research made us aware of the emotional challenges involved in care and the need for better support of care workers. Those who had had an opportunity to develop long-term relationships often demonstrated great attachment to our participants and were very aware of the value of the music sessions. Generally the music sessions helped the process of care because they gave happiness and pleasure to participants and this in itself lightened some of the load of care.

Music through a post-human lens

As previously discussed, *Beyond Words* is breaking new ground by taking a post-human approach. It has enabled us to move beyond finding answers to the initial questions of the research and to enter new territory. In presenting our findings we have found that post-humanism offers a fresh and innovative way of thinking and writing about post-verbal people and music making, but that using words alone has many limitations. The image of ferns, as introduced at the beginning of the report, opening and closing, many fronded and moving backwards and forwards helps to convey the multiplicity and mutuality of researching with post-verbal people.

Learning from post-verbal people

 "Are there advantages in working with people who have problems
communicating verbally?"
"It's wonderful."

"It is wonderful?"
"It is wonderful."

"…you can go on these like amazing journeys, it's non-linear if you know what I mean… every time I think about him I just smile because he's just a laugh to be with and I just have to say that's wonderful because it makes you think about the world a bit differently."

(Volunteers' Focus Group)

By seeing life through the perspective of a post-verbal person, it is possible to shed many limiting perceptions of what is important. We can tune in to a different way of seeing where material textures come alive and can be appreciated through the body: where Cara "*licks a wall to see what it tastes like.*" They are active post-humanists and don't have the problem of shedding humanism that verbal people do:

"*For us having a child like Ed makes you appreciate things more makes you notice all the little things before you didn't notice. It's made me realise that the little things are so important. Ed looks at the world in a different way than we do, when we are out for a walk he notices the detail in something, picks things up*" (Interview Ed's mother)

ML's often talk about 'little details' making a difference within a musical context. Finding 'meeting points' where objects, textures, sensory exploration are juxtaposed with musical exploration and experiences. Meeting points might include, for example playing a musical instrument in an 'unconventional' way that perhaps feels more intuitive or interesting / rewarding to a participant. It's always worth exploring when these little things can become more significant - change happens and that can then be slowly built upon.

Music and becoming

Our research helped us to understand our participants as emerging and re-emerging beings. Nothing and nobody is ever fixed, everything is always changing. We are all part of what Karen Barad calls "the ongoing dynamism of becoming" (2007,142). Music highlights this and prevents post-verbal people from seeming stuck in a negative place. It comforts and strengthens family members, revealing that the person they love is developing, re-emerging or changing in ways that are still valuable. For example Andy, an eleven year old child with Down's Syndrome and other sensory issues, mainly communicates by touch or by making noises like a baby animal. Although his gentle demeanour is very appealing, it may seem that his capacities are quite limited. However, in music sessions he engages and challenges the Music Leader, repeating and embellishing phrases on the piano and building them to a crescendo until he is simply challenging himself. He responds with joy and wonder to his own musical ability, the instruments and the people around him.

For his mother, music is not an extra, but a vital form of communication with her growing child:

"For him it's a deeper thing, because we don't have verbal communication music is a much more level playing field. He's challenging you. His appreciation of music is different, it's his voice in a lot of ways…You see the world in a

different way when it comes to him….Other people miss things, there's so much pleasure in the interacting with him."
(Interview mother Andy)

At the other end of the spectrum, participants living with dementia were changing too. Although research suggests the emphasis of interventions with people with dementia tends to be on their retrieving the past, PMZ uses music to encourage them to live fully as they are now. Sarah lives in a care home and has advanced dementia. She is smiling and friendly and talks freely but her speech seems to make no sense:

"What do you think that the music sessions would give Sarah that other types of activity don't, or is there no difference?"

"…you can have quizzes and you can have games and this and that but it's not the same. It doesn't attach doesn't integrate with so many senses as music does. And again you know because her mind is different from what it was, the music that she used to like or dislike that doesn't exist anymore…. You know there's no point, everything changes. My every preconception has to be thrown out of the door, it's a new, she is living in a different world, so therefore it's all new to her."
(Interview, Sarah's husband)

Music helped families to accept that all was not lost through this process of change, as it helped them see traces of the old re-emerging and positive elements within the new.

Music, community and belonging

In contrast to much qualitative research, post-human approaches are not individualistic. It is not helpful to view people in isolation, instead they need to be understood as part of what Jane Bennett (2010, 23–24) calls an "agentic assemblage". This means that at any point they are part of a grouping of different things and other people and it is the grouping as a whole that has the force, whether negative or positive. For example, the regular PMZ music session for the Stroke Association is made up of stroke survivors and their partners, some of whom are living very isolated and difficult lives, rarely leaving the house and feeling abandoned by old friends. The stroke survivors themselves are limited in their movements and speech and in interviews it was sometimes difficult for their partners to express themselves too. However, bring the group together with their songbooks, music-stands, songs and movements, the Music Leader and his guitar and corny jokes, the tea and the homemade cakes, the friendly, accessible and welcoming space with easy parking and convenient toilets and they are all happy and powerful.

> "*You leave your stress at the door, you leave any negative feelings at the door and you come into this hall with people who are all in the same boat. You are equal all of a sudden and you just let the music do the work… As a carer it has taken the stress away on a weekly basis. I feel invincible after a session, I could cope with anything and it has made me be able to pass on to family and friends just what he is capable of doing and how the music has helped with that.*"

Art and music together in a series of workshops seemed to build this cohesion and to permit an expressiveness that was very different from the restraint of speech:

The drawing, the people and music seem to become one
effortless flow between each other.

The music played with the group, who then played with
Each-other in creating the large piece (of art).

(Artist field notes)

Music and Time
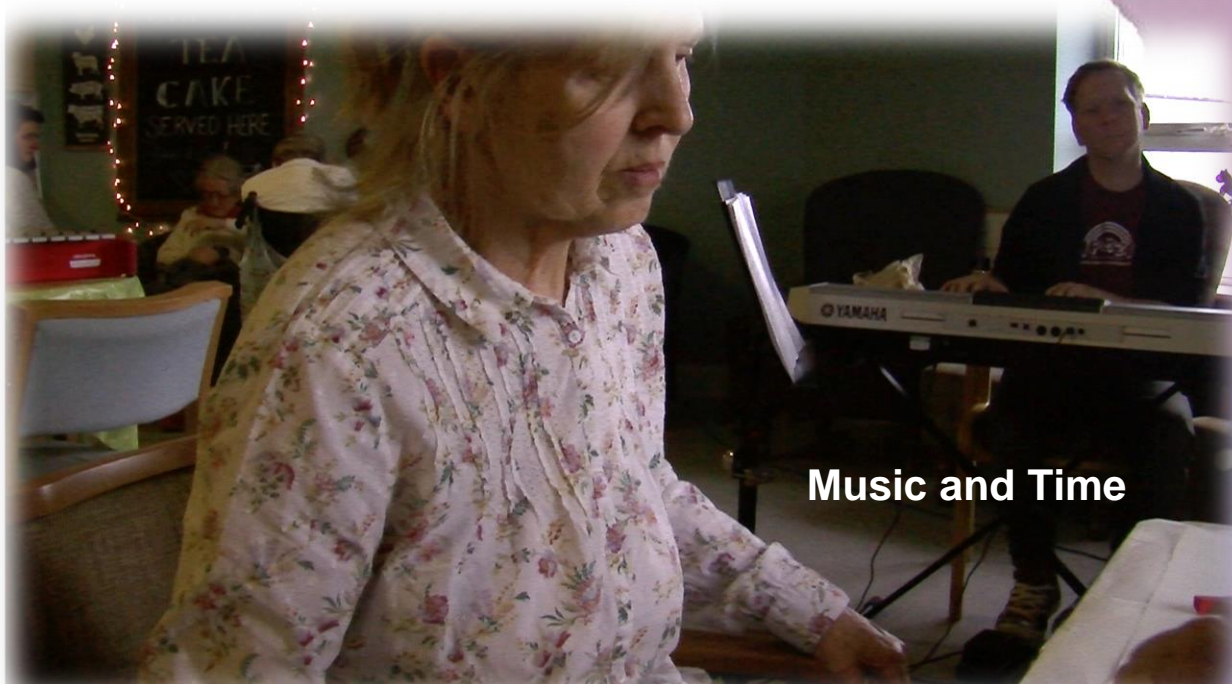
The research demonstrates a fresh perspective on time. Our experience of time is not linear, stretching forward to the future, but more a spiral where our memories go backwards and forwards and loop back on themselves. The arts, including music, can make time stand still, creating what Deleuze and Guattari call "the eternity that exists for that short duration" (1986,166). Musicians are particularly adept at anticipation and looking backward and forwards at the same time. In our research we found that music creates such powerful moments of intense meaning, and by studying these moments we can gain access to our participants without words. On numerous occasions the

researcher noted a moment when music broke through an impassive surface and made a connection. By approaching each person individually with an instrument, music leaders enabled participants to move from apparent absence to consciousness. By providing a musical focal point, such as a piano, they promoted movement and focus towards the music making, instead of immobility. For those with dementia in particular it was important to understand time on their terms, so that these moments can be appreciated and validated. The husband of one of our participants puts this perfectly:

> "*Why give up? You shouldn't give up. I think the potential that they still have a quality of life. Surely we have gone past the days when we just zonk them out with drugs and leave them. I mean we have moved on from that surely. We don't, you just never know what the, the benefit, how you quantify the benefit that they derive from these (music) visits is just impossible, apart from that moment in time when perhaps they may just react, that is excellent and then an hour later or minutes later they won't remember that someone was there and they reacted to it, but in the moment, that bubble, why not stimulate that bubble?"*
> (Interview, Jane's husband)

Learning how to live with transience, working with people who might shortly die and measuring success in different temporal terms is a philosophical and emotional leap for the MLs. Just one session can be very powerful and important for some participants, reconnecting them to the past, bringing to the present what they once were, giving a sense of future and past and that they have a place in it. It can be very full of 'magic moments'.

Music and new worlds

Conveying what happens when music is made is very difficult, but post-humanism offers some useful tools. When people and instruments come together they create a spark, not only something new, but producing what Karen Barad calls "new worlds" (2007, 170). Robert has advanced dementia and is normally extremely agitated. He is in a wheelchair and is constantly rising up or reaching out to touch something, just out of view. He sings very loudly and tunelessly all day. He appears to be in what his stepdaughter calls a "*hard place*", where he mimes shooting aggressively at everyone around him. As he is so disruptive he cannot join the group sessions, but sometimes had an individual session when possible. His stepdaughter was present at such a session where the Music Leaders quietly played gentle traditional songs of the sea and escape like the Skye Boat Song, lulling and rocking him and taking him to another place and time. They then invited him to engage with something new:

'He was very, very calm when they were there. There was an engagement at quite a deep level… I was amazed - they have a laptop which allows you to play musical instruments.…It was this moving his hand across the laptop to make a sound there was almost a fleeting 'Isn't that wonderful' on the face…That is brilliant you are doing something creative in a way you can't be creative anymore.'

'How did you feel when you saw this?'

To be quite honest I was almost in tears, I feel tearful now'
(Interview stepdaughter Robert)

She went home and contacted all her family members to tell them what had happened and share her joy at this, the ripple effect lasting far longer than the session itself.

Music and listening and speaking with the body

Post-humanism is bodily and material. By seeing humans only in terms of what they think and say we neglect the significance of the body and, as Rosi Braidotti says, nobody knows what a body can do (2013). "When Cara listens to music it's very sensory. She twiddles her hair round and round, bangs her head." Holly, a woman in her twenties with learning difficulties, with a sweet face and childlike smile, blows kisses and gives thumbs up when she wants to show how much she enjoys performing:

"They like to sometimes threaten us as Music Leaders by driving at us at high speed with their powered wheelchairs! Although this is hilarious and builds rapport with us, in all seriousness, it's a form of physical expression."

(Music Leaders focus group)

For Carl his body and brain had been shattered when he fell from the roof of a building on his eighteenth birthday. He is in a wheelchair with limited use of one hand and

acute memory loss, yet when he enters the room he is powerfully charismatic, mainly because of his expressive face and eyes and the rock star image he cultivates with his clothes, hair and jewellery. He does speak, although many people are too embarrassed to know how to talk to him beyond an initial greeting, and it takes focus and determination to include him meaningfully in music sessions. He often uses music technology, such as IPads when accessing music. The arts workshops where he painted huge canvases or worked closely with clay, allowed him to demonstrate with his body just how much music and his engagement at PMZ means to him:

> *"He painted what he felt the music was saying and he was so intense so focused, he loves that expressing himself I think getting out what's inside"*
> *"Has seeing his love of music helped you to understand him any better?"*
> *"Well I suppose so because it does solidify something in you that was there that you see it in the depths of him, the depths of music and the importance of it in his life, yes and it's a huge thing."*
> (Carer Carl)

> "Carl said that the activity of making visual art whilst being surrounded by music allowed him to express himself "*with his mind's eye and heart*"
> (ML notes arts workshop)

Music releases both pleasure and pain in the body, so that in painting sessions Carl repeated that he longed for a partner and through the experience of working with clay that he was "*feeling free".* Those around him were enabled to see and understand the depth, and, indeed the beauty, of his mind.

Music as a form of voice

Our research confirms that "voice" is…entangled" (Lisa Mazzei, 2016, 158), it doesn't exist in isolation from everything around it. Our participants demonstrate how certain musical spaces facilitate speech and others don't. Sean is a teenager who has autism: tall and gentle with his long hair often hiding his face. At home and at PMZ he speaks freely, if he is familiar and comfortable with the people around him, everywhere else he is mute. Private flute and guitar lessons did not break down this barrier, but with time, patience and music PMZ has transformed his life. His devoted parents have struggled to disentangle this history:

> "*He went within himself, he closed down, he speaks to us but not to others. We ask 'Why can't you speak?' He says 'Well something closes in my throat, I just, I want to speak but I can't I just can't…I can talk with my music. The music talks to me, if other people are playing I know how they are feeling*"
> (Interview, Father, Sean)

> "*he was a very introverted child for whom the world was a really scary place and it's not quite so scary now…PMZ have built his confidence. They've given him a sense of identity that he's a musician. Before he was just a child who wasn't good at anything but now he's a musician and that's something to be really proud of*"
> (Interview, Mother, Sean)

During the course of the research tragically his mother died and the way that he has spoken about this is naturally through music: "*He made his way over to me and said: "I've started making my own songs at home. When I'm feeling sad, I just get the guitar out and it really helps me to get my feelings out. A lot of my stuff comes out sounding like the sea – like waves.*" (Music Leader notes). This image of making and riding waves was recurrent in our research data and analysis.

With the identity of a musician and music as his voice Sean can operate very successfully within PMZ, and the hope is that he will ultimately be able to transfer this to other spaces. His voice is celebrated but his silence is also respected. Similarly silence was not something that phased or unsettled the Music Leaders. They accepted that some people would not speak and still actively included them, whilst allowing them freedom to retreat as they chose. They trusted that nobody would chastise them for not eliciting verbal responses.

The Power of Things

In our research we paid close attention to things, such as instruments and objects in the room and to songs as things too. Observations revealed that instruments had palpable amounts of what Jane Bennett calls "thing power" (2010,4). The same instrument, such as the saxophone, could evoke a strong sense of disgust in a stroke survivor or enthral and captivate a child with sensory impairments. Touching a vibrating instrument, putting ears to strings, banging large drums and shaking small

compact shakers all generated waves of communication and connection. Things were integral to musical choices:

"The 'things' needed to improve or augment physical access can be the starting point for musical planning – ways in which a participant is able to make purposeful movements and express preferences for particular sound qualities. The meeting of those two factors might specify an instrument or piece of equipment, and then the creative possibilities around and within that can be explored."

(Music Leader notes)

PMZ uses a very wide range of unusual instruments and musical expertise to provoke tactile and emotional responses. For example, in the arts workshops the Music Leader carefully chose instruments for their diverse impacts/stimuli including:

Piano accordion: for both harmonic and melodic influence
Flute: higher pitches, use of 'articulation' through tonguing and slurring notes, flutter tongue and effects using 'key clacks'
Bassoon: wide range of pitches, articulations possible as well as 'tonal' colours and contrasting timbres.
Double bass: can be plucked or bowed
Casio mini synth keyboard: harsh, repetitive rhythmic electronic sound with a mixture of beats
Miniature steel pan: for melodic phrases (staccato - short, percussive pitched notes)
Tongue or slit drum: resonant wood played with beaters (melodic and rhythmic)
Acme Siren whistle: for comedy whizzing whirring sound
iPad Garageband 'Smart Strings': well sampled orchestral string sounds
Cuica: samba drum: high pitched squeaky timbre
 (Music Leader, notes)

Effects of the instruments were multiple and diverse, for example as demonstrated in this arts session with stroke survivors:

The tongue drum, percussive and bobbly sound-rhythm patterns played. Sam said he found this "more intense" to work with and described the containment of

the small area of clay Sally used two chains pressed into the clay. Harry was 'playing' the clay with a stick-poking it in. "That's it". Molly and Sam produced very primal/pointillist marks. Harry was fascinated by the instruments themselves as objects.

(Music Leader notes, arts workshop)

It was sometimes very difficult for people to make the leap to touch and engage with the objects, particularly for those with learning difficulties or dementias and this requires a calm and patient approach from the Music Leaders. Nevertheless the right object has the power to move things forward. Tim is a middle-aged man with Down's Syndrome, the only creature he really speaks to is his dog. He is constantly moving his hands as if they are puppets talking to each other. However, during observation the researcher saw this encounter:

"*He held the tablet on his lap and turned it gently round. He got his hand close with a long finger, like daring to touch something that was hot…He gave the impression of wanting to touch the tablet desperately but being immensely terrified at the same time. At one point a Music Leader came over and stood there playing his guitar, he saw that he hesitated to play with the tablet but did not say anything or push him. After he touched the tablet for the first time his face conveyed some sort of fearlessless. It was wonderful to observe the tension in his body in his hands, how much he wanted his fingers to touch the screen. It was powerful to see his leap too. He just trusted another person's encouragement and went for it and he could not go back afterwards, he continued touching the screen and exploring the sounds it made*"

(Researcher, field notes)

Instruments enable and provoke responses from those who may appear affectless and unresponsive and allow them to make new connections. Digital technology such as tablets can allow for flow and this is particularly useful for post-verbal people.

Looking below the surface: creativity in the home

By focusing on words and dismissing those who don't speak, we are only ever able to skim the surface of human possibilities. In contrast, Stacey Alaimo urges researchers to "follow the submersible…descending rather than transcending" (2010,283). Mark is a middle-aged man who had brain damage as a child following a vaccination. He is very quiet and seemingly placid, restrained and self-contained and has some speech that is difficult to understand. Across observations he seemed to take instruments because he was expected to, not through desire, although his capacity to make choices seemed to increase over time. By observing him in music sessions alone there is no hint of the rich and creative life he lives with his parents at home:

> *"On a Saturday he likes to do a play OK? So one week I do it with him and then the following week my husband does it with him OK? And this has gone back for years and years … And er so he'll we'll do the play and then he has to have the title for the following week, OK? Then he'll get the props out and then he will draw the picture."*

> *"And does he act it out with you?" "Yes he does and sometimes you lose the plot half way and he corrects you [laughs]… it is great fun, it really is great fun and some of the things that he comes out with during the play is like 'Oh my god I never thought of that!'"*
> *"But that is amazing, so he has taught you how to do plays?"*

"Yes"

"Would you have ever done anything like that without him?"

"No, absolutely not"

(Mother of Mark)

Rather than being passive, Mark, like other of our participants, is able to initiate and take the lead in creative work, but neither Music Leaders nor support workers knew about his playwriting. This was only one example of creativity and learning in the home that the research revealed. Other participants played music on the internet, had been master weavers, organists or ballroom dancers or learned the guitar and languages. So, although it is vital to focus on the post-verbal and on the participant themselves, learning what we can through words with their families facilitates a deeper understanding of their history and home life. By working with this knowledge and with other arts PMZ, which is already a stimulant could be even more of a fulcrum for creativity, a public space where it can be shared, demonstrated and validated.

The unspoken across music making

Finally, one of the aims of *Beyond Words was* to explore the important role of the unspoken across all the Music Leaders practice, not just their work with post-verbal people. Drawing on the data and reflection, a complex picture emerges as expressed in this fern image...

At a basic level, the Music Leader encourages people to participate/listen or both and may choose to model an activity or instigate a musical conversation without using words or verbal instruction. Conducting using bodies or 'things' may be explored by either the music leader or participant(s) using arms / hands / lights / objects with clear signals for 'Stop'.

Repertoire and genres are carefully considered. Music Leaders make choices about musical material that may be most appropriate to work with. This overlaps with 'things' and which instruments and tools are available. Songs and lyrics are considered carefully and adapted (removing inappropriate words or insensitive content). Choices are made about whether to work with familiar repertoire or to create new original work. Attunement – linking and connecting with one another's musical expression by using a combination of musical elements is particularly useful when working without words.

Music

Music leaders draw upon different unspoken elements within music itself:

DURATION: short or long notes - the length of time a sound / note is played for, or the length of time within a whole song / piece of music.

RHYTHM: How notes of different durations are organised next to one another within time. Rhythm can be described as 'regular' or 'irregular'. It is linked to 'pulse' but not the same thing.

DYNAMICS: "loud or quietness" and can include accentuation of parts of the music in small measurements of time – for example to emphasise a particular beat of the bar or part of a phrase (perhaps comparable to speech and phrasing / breathing / emphasis placed on parts of words to express them in slightly different ways).

PULSE: the underlying steady 'beat' (literally like a heart-beat) that denotes the tempo or speed of the piece of music. This can be changeable – speeding up or slowing down. It's a key component that musicians learn to 'lock' into when playing 'in time' with one another. Often musicians practice 'feeling the pulse' before they commence performing, and will provide cues for other musicians to keep one another working together, for example one of the key roles of a conductor.

TEMPO: fast and slow

TIMBRE: This describes the quality or characteristics of sound or tonal 'colour'. This helps us to distinguish musical instruments from one another, and further to this, the way that this may change when playing the same instrument in different ways to create different effects using its physical characteristics. The materials that instruments are made from causes them to produce different qualities within their sounds. (for example, 'metallic') which also enables us to identify different instruments.

TEXTURE: layers within music and the way that different things are combined to create different effects.

PITCH: frequencies that may be described as 'low or high'. They can be arranged to form melodies. These frequencies are measured in Hz (Hertz).

MELODY or 'TUNE': is related to pitch and how notes are organised (high, low, stepping or jumping). Their contours and combinations of different pitches elicit different emotional responses according to how they are positioned or juxtaposed with one another. For example, different modes and scales can imply different cultural references. Descriptions of melodies could include words such as 'angular', 'playful', 'simple', or 'soaring'.

HARMONY: is created when more than one pitch is layered on top of one another (polyphony means more than one sound). Harmony has a strong influence on how music may make us feel happy / sad / unsure. It may be described in a number of ways including: major, minor, dissonant, complex, simple. It may contain predictable or unpredictable changes and can have significant effects on the listener's cultural reference points as to what feels comfortable or uncomfortable, conventional or unconventional in terms of its use within different types of music.

Harmony is formed of 'chords', which are more than one note played simultaneously. Groups of chords can create harmonic 'tension'. When this is released with a calm chord or one without tension, we say that it's been 'resolved'. Our ears are familiar with specific resolutions e.g. moving between chords 4 and 5 and returning to 1 (the root) at the end of a piece. This is strongly influenced by the way that 'Western' music has evolved. Harmonic 'language' varies hugely in the music of different cultures. (Many contemporary composers may challenge our comfort zones around what may

be harmonically or melodically familiar – good examples of this are found in film music where the composer will try to induce particular feelings alongside the story of the film).

TONALITY: This relates to harmony and is the organisation of all the tones and harmonies of a piece of music in relation to the tonic (or 'root' – the main key that the piece is based in. For example, the 'tonic' could be the key of C. We often heard music leaders saying – "*I'm going to play this one in the key of C or G .*"

STRUCTURE: the way sounds, or different sections of a song or piece are organised in time and put together overall.

The following gives an example from the research about how these unspoken musical choices affect inclusion:

> *"One of the MLs changed the tempo of one of the songs they use. He played it very slowly and this gave time for the group to sing and relax into the music, there was a sense of anticipation and expectation. The other ML asked the ML to speed up the tune and he did it quite rapidly (accelerando); which changed the mood of the children involved. Afterwards, the ML explained that the song had been written to create that sense of expectation in the children, in order to encourage participation/engagement. The MLs also talked about the importance of changing pitch when singing, depending on the age of the children they are working with. The older the children the lower the pitch should be, otherwise it may be considered 'uncool'; high pitch is associated with children. And therefore, changing the pitch may engage certain groups depending on their cultural milieu."*
>
> (RA fieldnotes)

Space

The physical accessibility of a 'space' is considered and adapted. Music Leaders consider how to best prepare the 'space' for a workshop – preparing the territory, whether it is familiar or new.

> "*We feel as Music Leaders that we work very much to 'invite' people in to the space, and then gradually encourage them to take ownership of it, thus empowering them. Sometimes we also need to let them invite us into their*

spaces, particularly if you're working in 'their space' or home setting, like a residential place."

"Contrary to this, sometimes we may not have choice about the space we get to work in and this might feel less possible, but we may try and do the best we can within it."

(Music Leaders Focus Group)

Size, shape and layout are important in relation to the size of the group or an individual's needs. They may choose to use more or less of the physical space, as required. The ML will arrange the space for comfort – invite people to be seated, stand. S/he will explore their own position and that of their participants within a space. This is, of course, adaptable unless there are particular restraints caused by the space itself. This includes exploring different layouts (e.g. circle / semicircle / linear / facing towards or away from one another). Acoustics and how 'sound' behaves within a space can have a significant effect on those working within it. Distractions surrounding the space (e.g. noise pollution) can be detrimental to the success of a workshop (or conversely could be used as inspiration).

Physical

Both Music Leader and participants either make choices to keep still or move around. S/he considers their own physical 'position' within the space and adjusts accordingly. (e.g. gradually hands over ownership and control of an activity to participants). In some instances it may take some time for a participant to feel comfortable to inhabit the same space and needs gradual introduction). The Music Leader considers their own presentation of body language and facial expressions used throughout the session – e.g. expansive or 'closed' gestures to elicit different responses and enhance communicating without words. Participants' present different physical / body language, and Music Leader looks for changes. Music Leaders instigate or avoid eye-contact depending on the situation. Sometimes they may suggest closing eyes to help focus on activity and listening, for example.

Time

The MLs plan with consideration for the different amounts of time spent with participants. They consider time spent on different activities, for example, where repetition is required or a decision to try something new. Being "in the moment" and being 'present' is a recurrent theme. The ML considers and (where appropriate) communicates the 'distance travelled' from a particular starting-point in time, to help encourage participants.

Things

MLs make selections about tools, instruments, technology, furniture and other resources needed within their session(s), including non-musical items e.g. parachute, pens and paper, or balls. They consider choosing and adapting 'things' to improve or augment physical access, for example for participants who have additional needs (mounting equipment on stand / using electronic instruments and / or gestural controllers). Things work on participants' bodies in unspoken but potent ways:

The following week, the ML asked if anyone was interested in playing the giant marimba, but there were no forthcoming answers. However, this changed as soon as the marimba was rolled out to the main floor. Everyone gravitated towards the instrument, almost in awe.

(RA fieldnotes)

Here the spoken word gets no response but the object propels them to it.

Emotions

Music Leaders use intuition and questioning as their emotional 'barometer'– they attempt to gauge and assess the "mood" or emotional dynamics within the group or perhaps how an individual may be feeling at any given time and 'within the moment.' They adapt their planning to be flexible and understanding of their participants' emotional need. When appropriate, they elicit information from participants themselves and their support network about how best to support them emotionally and prepare activities appropriately in response. MLs may deliberately acknowledge (or

ignore!) certain responses and behaviour depending on the situation (perhaps to help regulate emotional response). They aim to offer choices to participants about whether to avoid or encourage using different kinds of musical material that may provoke particular emotional reactions, both positive and negative. For example, considerations are made whether to change tack or to 'remain' with less comfortable emotions and work through them:

> *"At the beginning of the music session, when the MIs were about to start, a support worker (a manager?) came in to talk to the MLs and make an announcement. Quite unceremoniously, she informed the residents, that one of the residents had passed away in hospital that week. The support worker added that she had passed away peacefully and she wanted the group to know because the deceased resident enjoyed the music sessions a lot. There was silence at first, and then after the worker left, people made some comments. The MLs allowed space for this silence and the conversation that ensued to happen. They allowed the residents to reminisce and express their thoughts about death. Then, the MLs suggested that they should sing a the deceased person's favourite song in her honour; people agreed and sang the song."*

(RA fieldnotes)

7   Conclusions

As we have demonstrated in the discussion section, the research has enabled us to answer the four key research questions effectively. The methodology, a multi-method ethnography, whilst not easy or straightforward, provides a successful model for similar research on inclusive arts practice.

The inclusion of a musician in the research team and the development of observational prompts helped to tie the research firmly to music-making. Post-human theory proved an invaluable conceptual tool for understanding the ineffable and complex aspects of music making with post-verbal people. The research showed that valuable lessons can be learned by working across different groups of people who may face problems communicating in words (such as those with learning difficulties, autism, dementia, brain injuries or stroke), rather than seeing each group in isolation.

Significantly, the research also demonstrated that the term non-verbal is redundant and that post-verbal should be used to recognise and respect all the ways that they can communicate beyond words. It has also opened up a much richer picture of their lives and music, becoming a celebration as well as an investigation. We found words are not the only way to communicate or be fully human and working with post-verbal people can be a joyful and eye-opening experience. They helped us to re-define what a human is and to attune to communications manifesting in a different way; and for this we are very grateful to all of our participants.

The following is a summary of the conclusions we have drawn.

Research Question 1

How do we include and make music with those whose communication is non-verbal, such as those with dementias, strokes, autism, learning difficulties or brain damage?

What benefits do they and networks around them gain in terms of wellbeing/social inclusion?

Post-verbal people need music for full wellbeing:

- as a form of voice
- to make bonds with others
- as part of their speaking through their bodies
- as a form of self-soothing and self-care
- as a release for creativity
- as access to unspoken feelings of both pleasure and pain

Including post-verbal people in music making requires:

- Respect, autonomy and real choices in a safe environment
- Focusing primarily on the post-verbal person themselves, but also drawing on knowledge from families and carers
- Social factors: welcoming, stress-free, non-judgemental, patient, open
- Cultural factors: ethos of equality plus positive attention to difference
- Musical factors: patience, timing, riding the wave, adaptability, flexibility, signal-reading
- Emotional factors: loving, caring, to families and participants, well-supported
- Provision of: appropriate and accessible tools eg. a wide range of musical instruments, technology and sensory non-musical resources
- Organisational commitment and investment in skills and support and an inclusive approach
- Partnership development skills and a responsive approach to be able to successfully develop and sustain work with other organisations who support these groups
- Intuition and material embodiment of all these factors

Families and carers of post-verbal people also need music:

- Music shows them the being they love is still there or is emerging
- Gives them joy and pleasure both directly and indirectly

- Creates new social and support networks

- Gives them hope that conditions will improve, or acceptance of what is

- Gives them a medium for communication with their loved one

- Gives them practical tools to take away and use at home

- Gives them respite, comfort and belonging

- Surprises them with what their loved one is capable of

- Supports them in their grief at losses of their loved one or of the family as it was

Research Question 2

What role does the 'unspoken' play in inclusive music leadership overall?

The unspoken is invaluable across all inclusive music making:

- It informs decisions in planning sessions: how to introduce them, what repertoires, instruments and genres to use and how

- MLs carefully use unspoken elements which run across all aspects of music, such as rhythm, dynamics, pulse, pitch and harmony

- Space plays a crucial role: access, comfort, positioning, acoustics and distractions are all considered, modified and used

- Unspoken physical elements are key, such as moving or keeping still, body language and eye contact

- Time is considered: how long to spend on different activities, being in the moment, 'distance travelled' in a session

- Things, not just instruments, but also parachutes, pens and paper, balls are all chosen and adapted to improve sessions

- MLs are sensitive to unspoken emotions and gauge the mood of sessions and make musical choices to best support participants

Research Question 3

What are the implications of addressing the 'unspoken' for inclusive practice across the Arts sector, how can this help practitioners in fields of Health/Education?;

The research has lessons for other forms of arts practice:

- This is a group with a capacity and appetite for arts work, but who tend to be marginalised. In some instances they may be offered only tokenistic opportunities to engage in arts activities.
- PMZ's inclusive organisational, social, cultural, emotional and musical practices can help inform the work of other organisations
- Principles of music can be adapted in other arts eg flexibility, responsiveness, attention to small signs and fleeting moments
- Understanding and respecting post-verbal ways of being is essential: communicating via the body, being in the now, self-calming, need for real choices, creative potential

The research is useful to practitioners in other fields such as Health and Education:

- This is a group of people who can be very isolated and misunderstood
- They have all experienced problems accessing information about services
- Their experience is that services are currently patchy and non-holistic
- The sample we saw are the privileged ones in the respect of being in families or contexts where music has been sought or agreed - there are many in much worse situations and who are even more difficult to 'reach'
- Not speaking doesn't mean there is nothing going on, learning is always possible
- 'Unlearning' what we have been 'told' is 'normal' for some individuals and can be helpful in terms of progression – gentle challenges to what can often get 'fixed' through a need to remain 'safe'
- 'Unlearning' can also embrace 'regression' and the creative opportunities that can exist alongside this, when participants are perhaps living with a degenerative condition
- Patience and time are needed to work with them
- Choices, respect and autonomy are crucial
- Opportunities to access music and other arts should be a priority in their education and care to promote wellbeing

- Music can provide vital stepping-stones, for example in development of children and improvement of conditions associated with stroke
- As a result there is less pressure on other services

Research Question 4

How does post-human theory help illuminate this process: what does this study add to the field of post-human theory?

Post-human theory has proven essential to this project:

- Post-humanism has provided many useful analytic tools e.g. thing power, agentic assemblages, intra-activity
- Post-humanism is in sync with the ways of being of post-verbal people and fits this project
- Post-humanism has great potential for future studies of inclusive arts practice

The research contributes to post-humanism in significant ways:

- It places the human without a voice at the centre of enquiry, bringing critiques of humanism to life
- It has helped us to simplify post-human ideas so that they can be conveyed successfully to a non-academic audience
- It shows how post-human theory can be used in a substantial longitudinal empirical study
- By combining posthumanism with critical attention to structural inequalities it helps address some critiques of post-humanism

Unanticipated Conclusions

The research also reached some important but unanticipated conclusions:

Post-verbal not non-verbal people:

- Non-verbal is a deficit category it should not be used to describe people

- Post-verbal, as in moving beyond words, is a better term
- It captures the many other ways they communicate beyond words

Music also facilitates speech

Music helps post-verbal people to teach important lessons to others:

- Small moments of time can mean everything
- Time is not linear or future-directed
- The important moment is now
- Small details, colours and textures need attention
- Identity is not fixed it is fluid
- Being a human does not rely on words

Policy makers need to pay more attention to post-verbal people:

- This group is growing, for example increasing numbers of those living with dementia and strokes
- They are often marginalised with inconsistent support and no holistic provision
- Their families are under great pressure and lack information and advice
- Music is extremely valuable in their development and an improvement of their conditions
- It increases wellbeing and quality of life
- Access to music is not a luxury and can reduce pressure on other services
- It needs to be the right provision that understands their needs. Many music sessions organised for profit implicitly or explicitly exclude these people
- There is a strong economic and moral argument for retaining and increasing funding for community music organisations

8   Recommendations

- Policy makers should recognise post-verbal people as a neglected and vulnerable group that requires specific care and attention

- The term 'non-verbal' should not be used. It is pejorative and inaccurate. Post-verbal is a better way of respecting and working with their capacities beyond words

- Arts funding and consistent provision should be increased for this group

- All organisations working with post-verbal people should consciously develop and apply inclusive organisational, social, cultural and emotional principles relating to this group

- Accessibility should be understood as not just meaning physical access to buildings / resources – organisations, services and facilities should continue to develop and improve the experiences offered to post-verbal people in terms of different types of communication and information offered to them

- Community music organisations should apply the musical strategies outlined in this report, combined with full liaison with families and carers, and gather as full knowledge as possible about post-verbal participants in order to plan for highest possible quality provision

- Partner organisations should agree clear guidelines about co-operating in music sessions to ensure dignity and agency of post-verbal people

- Music should be an integral part of care after stroke (particularly early interventions for speech recovery) or in early dementia, rather than an add-on that families need to secure for themselves

- Music interventions should be live, creative and interactive

- Community music organisations that work successfully with post-verbal people and their families should receive better and more sustained levels of funding

- Music organisations should consider developing collaborative, cross-arts approaches in order to maximise the variety of creative opportunities offered to post-verbal people, thus opening up wider opportunities for expression
- Further international research should be undertaken looking at the 'unspoken' and post-verbal people across multiple arts activities
- Further research should be undertaken with post-verbal people and their networks of intimacy, including those who don't access arts activities, to ascertain what facilitates persistence, communication and creativity and what prevents it
- Research should be undertaken with those who 'abandon' family members living with dementias to help understand their perspectives

9   Looking Forward

We see this report as a starting point and opening up of debate, rather than a fixed endpoint. In our interim seminar and ensuing workshops we have linked with practitioners such as Social Workers, Psychologists and Health Professionals and we intend to continue with a range of bespoke workshops introducing practitioners to the research and unpicking the implications for their work with post-verbal people.

Via our final international conference we opened up attention to the idea of the unspoken across other contexts beyond the university and across other disciplines, academics and students, making waves for the future. We linked with a range of arts theory and practices across visual arts, sound, theatre, photography, film and installation. Feedback called for more seminars and conferences on Beyond Words and we are planning a range of activities, including participation in the ESRC Festival of Social Science.

By working with a post-human lens we are connecting Plymouth Music Zone's music practice to debates across the arts and social sciences, for example in articles such as a forthcoming one on lifelong learning in dementia in *The International Journal of Lifelong Education.*

Finally, we intend to use the research as a tool to inform policy makers about the unacknowledged needs of post-verbal people and their families and the vital importance of inclusive music making and other arts to their lives.

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