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Disability, Personalisation and Community Arts: exploring the spatial dynamics of children with disabilities participating in inclusive music classes

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Abstract

This paper uses personalisation and the capabilities approach to explore inclusive music classes for children with disabilities in Scotland. It provides a unique insight into the impact of participation through the voices of the disabled young musicians, their parents and tutors. The study highlights the power of inclusive spaces to transform lives, to build confidence and intersectional identities. It engages in the spatial dynamic of opening up inclusive spaces, as well as exposing emerging tensions in the liminal space that is created through movement between safe and supported spaces and the antithesis, spaces that disempower and marginalise. The findings suggest good practice around personalisation, when conceived of from a social justice perspective, as a template for working with other marginalised groups and in other professional settings.

Key Words:

Personalisation; Capabilities approach; Inclusive music; Disability; Children; Social justice

Introduction

A discourse of personalisation is disrupting and redefining both the lived experience of disability and professional practice of those working with people with disabilities. As a policy concept, the roots of personalisation are contested, being defined as situated in the social model of disability, human rights and social justice, or neoliberalism, consumerism and marketization (Lymbery, 2014). Personalisation is now embedded in current social policy in Scotland (Scottish Government 2006, 2013a), Europe (Berg, 2005, Christensen and Pilling, 2014), and elsewhere including, North America and Australasia (Pykett, 2009).

Personalisation in Scotland has framed recent developments around direct payments (Scottish Government 2013a) enabling disabled people to choose to receive a personal budget, empowering them to be in control over how their budget is spent. The concept and practice of direct payments stems from the activism of disabled students at the University of Berkeley, USA in the 1970s (Arksey and Kemp, 2008). Central to this changing landscape of social care is an outcomes approach that focuses on service users' strengths and what they can and want to do, rather than what they can't or should be doing as prescribed by others. These policy initiatives are underpinned by theories of self-determination, of individuals having the autonomy to make conscious choices and improve their overall wellbeing and quality of life (Ryan and Deci, 2000; Wehmeyer, 2005; Wehmeyer, *et al.*, 2003). In professional practice these approaches rely on building meaningful relationships with disabled people (Pearson and Ridley, 2016) and the development of inclusive spaces where they can participate in everyday activities that are accessible to the majority population. The alternative is that a shift to personal budgets is leading to loneliness (Pearson and Ridley, 2016) as the geographies of people with disabilities are redefined. A spatial dynamic is

thus situated at the core of personalisation, that of expanding the ‘physical spaces that are available to people who need support, whilst contracting the interpersonal spaces between people and those who support them’ (Needham, 2015:358).

Developments in inclusive arts across Scotland are opening up opportunities and spaces for disabled people that for too long they have been excluded and marginalised from accessing. As the Equality and Human Rights Commission has noted, ‘[d]isabled people are significantly less likely to participate in cultural activities than non-disabled people and continue to face barriers around lack of accessible facilities, services and transport preventing equal participation in cultural life’ (2014:34). Community arts organisations are beginning to disrupt the boundaries of who can engage in the arts through the creation of safe and inclusive spaces where socially constructed boundaries of disability do not (de)limit the freedom for disabled people to be the person they want to be, which for some may be a musician or a dancer. The innovative work of community arts organisations is providing a lens through which personalisation can be explored and lessons learnt for professional practice in other spaces and places. However, transitioning between safe and supportive spaces and the antithesis, less inclusive spaces has the potential to create a new transformative and liminal space. This unsettling of existing norms and the creation of uncertainty over their position and identity within society can displace and reposition disabled people ‘betwixt and between’ (Zukin, 2011).

This paper initially focuses on the changing landscape of disability and social care in Scotland in the context of personalisation and the capabilities approach. Discussion then coalesces around Paragon, an inclusive music and arts organisation, based in Glasgow, Scotland. The background to this qualitative study is discussed along with the study’s methodology and findings before the interconnections and spatial dynamic of disability and inclusive music are considered. Although this paper focuses on Scotland, the findings provide a template for the use of personalisation in community arts based practice that is applicable internationally.

Personalisation and outcomes: making the links to the capabilities approach

The last decade has seen personalisation move centre stage as a policy concept within disability and social care in Scotland (Scottish Government, 2013a). The kernel of personalisation is making services more responsive to individual needs as well as transferring greater choice and decision making to service users. These central tenets of personalisation have been fundamental to the work of the disability movement for decades, and led to the development of a social understanding of disability and the social model of disability (Oliver, 1983, 1990, 2013; Oliver and Barnes, 2012). Personalisation is however a far more complex policy concept with divergent and contested roots and definitions. Tension exists around the axis of social justice and marketization (Lymbery, 2014; Mladenov *et al.*, 2015). From a social justice perspective, personalisation challenges traditional hierarchies of knowledge and oppression and democratises the process of identifying and providing support through the use of an outcomes approach. An approach that focuses on professionals working collaboratively with service users to achieve agreed outcomes that facilitate for choice and agency in the lives of service users. Opportunities for disabled people to access personal budgets to manage their care and support through self-directed support, and specifically direct payments (Scottish Government, 2013a) is a visible articulation of personalisation as a policy concept. However, this same policy concept can be interpreted as a means to achieve ‘more for less’ through market efficiencies shaped by a political discourse of neoliberalism (Ferguson, 2007; Lymbery, 2014); and be no more than a cover for austerity and cost cutting (Morris, 2014; Needham, 2011).

Personalisation and an outcomes approach are conceived of theoretically in this paper through the use of the social model of disability and the capabilities approach (Sen, 1988, 1999; Nussbaum, 2006, 2011; Baylies, 2002). Sen uses the terms *functionings* and *capabilities* to explain his theoretical thinking, with functionings referring to outcomes, the things that a person values doing or being. For example, someone may value learning, performing and/or composing music, however, to achieve that outcome the support and resources required for each person will be different. Capabilities refers to ‘the freedom that a person actually has to do this or be that, things that he or she may value doing or being’ (Sen, 2009:232). For example, if playing music is the outcome (functioning), the capabilities of disabled and non-disabled people to achieve the ‘same end of making music’ (Watts and Ridley, 2012:354) will be different. A disabled person is likely to require access to inclusive music classes along with creative, personalised teaching and support and/or specialist instruments (Watts and Ridley, 2012; Stensaeth, 2013). Without these additional supports, engagement in the arts for disabled people will remain out of reach. For this scenario to change the functionings and capabilities of disabled people need to be visible to social care and arts professionals to enable inclusive arts spaces to become a reality. The narrative that Bowditch, a disabled dance artist, received from social care professionals whilst promoting her inclusive dance classes was simple: ‘our service users are disabled, they can’t dance’ (Personal communication). Sen’s use of ‘adaptive preferences’ (Sen, 1988) helps to understand how individuals adapt, and too often accept social norms. For disabled people this can lead to entrenched inequalities being perpetuated and their freedom to make life choices and fulfil their capabilities being constrained. Adaptive preferences should not however be conceived of as static and unchangeable and nor should individuals be conceived of as inseparable from their adaptive preferences; both can be challenged and transformed.

The capabilities approach provides a lens through which to see and begin to address inequalities and social injustices that are a complex interplay of society’s response to the process of ‘othering’ and entrenched power differentials. A process that has curtailed the creation of opportunities for disabled people, and other marginalised groups, to lead a full and rewarding life. There is a small but growing literature that is situating disability within the capabilities approach (Burchardt, 2004; Nussbaum, 2006; Benbow *et al.*, 2014) as well as work that is using the capabilities approach to explore inclusive music provision (Watts and Ridley, 2012) and theatre and music (Vorhaus, 2015) for disabled people. This study addresses the need for more evidence on the use of the capabilities approach in practice (Burchardt, 2004), and provides a unique insight into community arts practice by capturing the voices of all stakeholders involved: disabled children, their parents and music tutors.

Inclusive music: Paragon and *Play On* programme

The arts are becoming embedded in a range of social policy documents as the context through which the inclusion of people with disabilities is broadened to encompass their integration into a wide range of cultural and leisure activities (see for example, Scottish Government, 2013b). There is a growing literature on arts and inclusion and interest in the impact on disabled people of participating in arts and leisure activities (Darcy and Singleton, 2015), especially in relation to self-esteem and developing a sense of belonging (Parr, 2006; Hall, 2013), of building confidence and dealing with nerves and anxiety (Whitehurst, 2007), of reducing social isolation and promoting health and wellbeing (Stickley *et al.*, 2011; Stensaeth, 2013) and developing a positive identity (Watts and Ridley, 2012). Some of these studies focus on specific disabilities, for example, autism and the arts (Schleien *et al.*, 1995) and autism and music (Molnar-Szakacs and Heaton, 2012).

Three persistent and consistent themes resonant throughout these studies: inclusive arts practices are creating new and inclusive spaces, that these are ‘safe’ spaces for participants, and involvement in the arts can promote wellbeing. These studies are contributing to building knowledge and understanding of ways to integrate disabled people into arts activities by shifting the gaze away from an individual’s disability to identifying ways of creating opportunities for them to fulfil their capabilities and lead lives that have value to them and society.

Originally established in 1980 as a contemporary music ensemble, Scottish based Paragon has evolved into an inclusive music and arts organisation that is driven by the belief that music and the arts can transform lives. The company works on the basis that lives can be transformed when practice is grounded in social justice and is framed by a democratic and empowering approach. Where each individual has a voice, is listened to, supported and integrated into the music making experience. The ethos of Paragon mirrors the essence of personalisation as understood from a social justice perspective and as a mechanism for expanding the physical spaces where disabled people can lead their everyday lives. In 2013 Paragon set up its Play On classes for disabled children and young adults ranging in age from 6 - 20 years. It was designed to create a space for them to be immersed in musical experiences from playing an instrument, composing to performance. The catalyst for these classes was the inequity in music tuition identified by Moscardini *et al.* (2012) whose work exposed the dearth of provision and access to musical tuition in schools for disabled children.

The study aims were twofold, one to explore the impact of participating in an inclusive music programme on the confidence, identity and wellbeing of children with disabilities, and second to examine the use of personalisation in a community arts context. The research questions were:

1. What is the impact of participating in Play On classes on children with disabilities?
2. How does Play On use personalisation in community arts practice?

Methodology

Methodologically the study was grounded within a participatory approach where knowledge is socially constructed between researcher and participants, and participants adopt a co-researcher role in order to inform the research design and analysis of data (Lincoln, Lynham and Guba, 2011). The Play On tutors adopted two roles in this study, as participants and co-researchers working collaboratively with the researchers in three key areas: the design of the methods for data collection, identifying how best to integrate data collection into the Play On classes without disrupting the flow of a Saturday morning session, and data collection with the children with disabilities (referred to as ‘young musicians’ in this study).

Data were collected with three groups of participants: Play On tutors, the parents of the young musicians and the young musicians. Table 1 provides information on the three groups of study participants, the numbers of participants in each group and the methods of data collection used with each group. Few studies have involved and given a voice to the breadth of participants that were included in this study; children with disabilities, their families and tutors (see Stickley *et al.*, 2011). The young musicians participating in Play On had a range of disabilities, including physical and learning disabilities as well as profound and multiple disabilities. When referring to the Play On participants, reference is being made to children within this spectrum of disabilities, rather than a specific disability. This range of disabilities meant that we used data collection methods that would be inclusive and accessible to all irrespective of age and disability. To that end data were collected with the young musicians through participant observation, a Graffiti Wall and informal

conversations, with the researchers paying attention to the contested nature of including children's voices in social research (Lomax, 2012).

Table 1 Study participants

Participants	No. and Gender	Sample	Method
Young Musicians	8* Male: 6 Female: 2	Open to all children/young adults attending the Play On session on the data collection day	<ul style="list-style-type: none"> • Qualitative comments made by participants • Graffiti Wall • Observations
Parents of Play On Participants	11 Male: 4 Female: 7	Open to all parents involved with Play On participants	<ul style="list-style-type: none"> • Questionnaire – available to complete online or as a hard copy during Play On
Play On Staff and Volunteers	7 Male: 5 Female: 2	All Play On staff/volunteers	<ul style="list-style-type: none"> • Focus group
Total	26 Male: 15 Female: 11		

* At the time of the research there were 28 children and young adults enrolled in the Play On classes (20 male and 8 female). Twelve were in attendance on the data collection day, 8 choose to participant in the study.

Qualitative observational notes were collected over a three month period during Saturday morning Play On sessions and one public performance at the Centre for Contemporary Arts, Glasgow. These observations focussed on the interaction and relationships between the young musicians and their music tutors. During one of the Saturday morning sessions data were collected through the creation of a 'Graffiti Wall' for the young musicians to write comments about their experience of Play On, what they liked about Play On or how they were feeling that day at Play On (Figure 1). The concept of the Graffiti Wall has subsequently been adopted by Paragon and is used on a regular basis for the young musicians to express themselves in a visual/written form during the Play On sessions. The researchers also spent time talking to the young musicians at different points during the morning class, developing conversations with the children asking them about what they liked about their Play On classes, how they felt attending classes, the conversations also explored their involvement in other extra-curricular activities. The data collection with the young musicians became a fluid process, allowing for movement between engaging with the researchers and/or the Graffiti Wall, returning to their music and then back again to the researchers. Thus the young musicians participated in the study at different times throughout the morning Play On session. As they moved between activities, the Play On tutors supported them in speaking to the researchers and participating in the study. The use of a familiar person, a 'supporter' to help with participation has been utilised effectively in research with people with disabilities leading to involvement being a positive rather than a stressful experience (Hall, 2013; Nind, 2008). The presence of a tutor/'supporter' during data collection can complicate the process of data collection. Whilst the Play On tutors helped to facilitate participation, their presence may have influenced the children's responses. However, the positive interaction between the young musicians and Play On tutors

observed by the researchers suggested that the children felt very comfortable and at ease with the Play On staff, furthermore the presence of two researchers as observers assisted in the triangulation of the data.

Figure 1: Graffiti Wall



For the parents a questionnaire, using largely open questions, was made available to all of the parents of young musicians to be completed online or as a hard copy during a Play On session, allowing flexibility for completion. The questionnaire covered topics ranging from why their child started attending Play On, what they do during the classes, to the impact of the classes on their child's confidence, independence and identity, as well as the impact on family life and their child's involvement in other activities.

A focus group was held with all Play On tutors, including volunteers, allowing for reflective discussion on their inclusive pedagogy to teaching music as well the social impact of their classes on the lives of the young musicians, in particular on their confidence, motivation, identity and independence.

Ethical approval for the study was provided by the University of Dundee Ethics Committee (UREC). Informed consent was received from all participants in two stages. An initial Participant Information Sheet about the project was distributed to all families and Play On tutors. On the day of data collection with the young musicians, the Play On staff supported the researchers in explaining involvement to them, and on agreeing to take part in the study the young musicians or their parent signed the consent form. To ensure on-going assent during the data collection (Freedman, 2001; Knox, Mok, & Permenter, 2000) the researchers paid attention to the body language of the young musicians making sure they were able to engage throughout the duration of the data collection, with a view to stopping data collection if any discomfort or disengagement with the process was observed.

The data were analysed using thematic analysis (Gilbert, 2011) in two stages. First, the data from each participant group were analysed separately, during this stage initial, broad themes were identified. Second, the full data were analysed under the thematic headings that had been identified in Stage 1. At each stage of analysis the themes were cross checked amongst the researchers for rigour. The three main themes that emerged from the data were the Play On Model (approach to personalisation and pedagogy), Development of Transferable Life Skills (confidence, socialisation, communication, motivation, independence and identity) and Impact on Family Life

(Levy, *et al.*, 2014a). This paper draws on key sub-themes from the Play On Model and Transferable Life Skills themes:

- Safe and Supportive Relationships
- Risk and Safe Physical Spaces.

Pseudonyms have been used to anonymise the participants in the quotations below.

Results and discussion

The study findings presented below explore personalisation as a concept of social justice in a community arts setting. This is interpreted within the context of expanding the physical spaces where the young musicians can feel ‘safe’; at the same time as contracting relational spaces, the spaces where they can develop meaningful and supportive relationships (Needham, 2015).

Safe and supportive relationships

The ethos of Paragon, and the Play On programme, is for the arts and specifically music to be accessible, inclusive and responsive to individual needs. Core to the work of the Play On staff is the valuing of diversity and difference. Play On tutors interacted with the young musicians at an individual, personal level valuing their different experiences, strengths and knowledges.

Mark (Tutor): *The musical skill and expertise of the tutor are essential but are balanced out by what the student brings with them to each session and their needs at any specific moment.*

Alex (Parent): *Creativity is encouraged rather than perfection and tutors are always positive and celebrate all ability no matter how big or small they are successful musically.*

This personalised, person-led approach entailed tutors being open to new ways of working, to be ‘explorative’ and innovative. Their practice required a re-examination of power dynamics through reinterpreting and a levelling of the relationship between tutor and student, as both came to the sessions as musicians, and as the tutors were keen to stress, as ‘equals’. From the perspective of the tutors their teaching method was participatory, through working with the young musicians in a democratic way that was dependent on establishing trusting relationships.

Bill (Tutor): *Yeah it’s always giving and taking from each other a reciprocal thing.*

It is upon a foundation like this that co-production can take place and the creation of positive and meaningful relationships can be established. The salience of the relationship between tutor and student emerged in from participants from across the three groups: young musicians, parents and tutors.

Lisa (Young Musician): *I like the teachers they listen to me.*

Jenny (Parent): *He is comfortable to be there and has a good relationship with the music tutors.*

These narratives were made visible to the researchers in their observations through the way the tutors interacted and supported the young musicians to proactively create supportive and

meaningful relationships and through effective use of communication. Actively listening to what others are saying are the building blocks of socialisation. The Play On tutors innovatively used music as a conduit to develop communication and other skills in preparation for the young musicians to enter the world of music.

Patrick (Tutor): *My primary thing is that I'm working on communication with them. So I'm trying to build the principle skill in music and that is listening. So how do you do that? You have to demonstrate that, so you have to listen yourself, and if they can see you listening and you are listening genuinely to who they are as people then they will listen to you.*

Figure 2: Play On music class



Narratives emerging from each of the three groups of participants intimate that the person centred approach used by the Play On staff is leading the young musicians to layer their identities, for intersectionality to emerge as they begin to move away from a narrowly defined identity centred on disability. This mirrors the process of identity formation for the majority population in a post-modern era, a process that is fluid, interconnected and changing, rather than static and essentialist (Plump and Geist-Martin, 2013).

Robyn (Parent): *He has developed more through Play On than any other activity he has really developed a sense of identity.*

Sally (Tutor): *... when you're talking about identity in a non-medial sense, it's not a condition specific identity it's an identity of being a musician, we are all musicians.*

Tom (Young Musician): *I am a musician at Play On.*

During the tutors' focus group connections were made between identity and a sense of belonging and 'feeling part of something' that allows for other aspects of the identities of the young musicians, that may have been suppressed in other spaces, to come to the fore and flourish (see also Hall, 2013 and Parr, 2006). Throughout the data references were made to examples of small but significant things that were developing the young musicians' confidence and a sense of

belonging. From observing the trusting relationships between staff and students, to the young musicians being ‘welcomed by name’ and in tutors ‘genuinely caring and taking the time to talk.’ Throughout the observations the young musicians appeared relaxed and comfortable in a space where they had a voice, were valued and where their disability appeared to recede and be overshadowed by the other skills they brought to the Play On sessions and their interactions with others. The voices of the parents clearly articulated that Play On is also creating a safe space for them to meet and socialise with other parents and carers, as well as see their children enjoying themselves.

Iona (Parent): *It is something that I also look forward to as I can watch my son thrive in a positive and caring environment.*

Jenny (Parent): *I have found watching him participate very moving. He is able to express a creative side and get a very positive view of himself, also model himself on the tutors socially and musically.*

Risk and safe physical spaces

One tutor described Play On as having ‘a culture of inclusion’ that allows for all the young musicians, irrespective of their ability, to take part and be immersed in music, to play music and, importantly, to enjoy music. The Play On space is one where the development of effective and supportive relationships between tutors and students ensures that the young musicians feel safe and secure and where confidence and independence can evolve. The narratives of the young musicians along with the observations suggest that confidence and happiness are associated with the young musicians attending Play On classes.

Jack (Young Musician): *They (Play On classes) have been good for developing my confidence, I feel more confident here.*

Disabled children, like anyone else, can lack motivation when their personal goals are set at a very low level. Rather than making choices based on their capabilities and what they would prefer to do, disabled children frequently end up acquiring socially accepted norms of what others expect them to be able to do (‘adaptive preferences’, Sen, 1988) rather than what they are capable and aspire to be or do. Such a culture is not conducive to raising motivational levels. In Play On, intrinsic motivation was supported by tutors responding to, and working with the different needs of each young musician at each session, thereby making the sessions highly personalised and outcomes based. It was encouraging for the parents to observe how Play On was helping to motivate their child in a variety of ways, from practicing their instrument at home to raising their expectations and ambitions for a more positive future for themselves.

Callum (Parent): *His motivation has been low and he was getting quite despondent about life. But now he increasingly wants to gain good proficiency in other areas to the best of his ability.*

Figure 3: Play On end of music class performance



Working with risk is a fundamental challenge for professionals framing their practice within personalisation and an outcomes approach. Practitioners are required to balance the transfer of responsibility and leadership in decision making to service users and support them to potentially take greater risks in their everyday lives. Such an approach unsettles and disrupts established norms and understanding of what a disabled person can and cannot do, but is crucial if genuine choice and opportunities are to be opened up for disabled people. For the majority population encountering and managing risk and challenges are part of everyday life, building resilience and coping strategies are central to transitioning from childhood into adult life. Yet too often opportunities are curtailed for disabled children and young adults to encounter risks, face new challenges, to overcome emotional hurdles or to learn how to handle new situations. Play On is a space where the children can be a part of these everyday experiences and in doing so the music classes appear to be building the confidence and resilience of the young musicians. It is often the everyday experiences that can be overlooked and taken for granted, but focusing in on these can help elucidate their significance. The parents talked of how their child felt: ‘excited’ ‘nervous’ and/or ‘anxious’ before their first Play On class, on returning to classes after a break or in relation to performing, yet they could also see the learning that was achieved through music in dealing with nerves (Whitehurst, 2007). Through building resilience and coping techniques the young musicians, in the words of one parent, ‘learnt to deal with the apprehension’ and were developing a readiness ‘to try new things.’ Another parent made sense of how their child managed their apprehension through linking it to previous experiences in other spaces that were less supportive and less inclusive.

Callum (Parent): He was looking forward to it [Play On], but wary as every other club he has attended he hasn't enjoyed as he was treated like a much younger child.

The Play On tutors integrated an element of risk taking into their practice to achieve positive outcomes for their young musicians. This included setting high expectations for the young musicians as well as facilitating for them to take the lead in sessions. Adopting this approach challenges normative assumptions of who can play music and who is a musician. It requires tutors, as one noted, to have the ‘confidence to be creative and to take risks that enable the children and young adults to be immersed in a holistic musical experience.’ Risk taking, or ‘courage’, is required by the tutors to ‘respond to what the child offers you and go with it’. This approach relies on tutors being able to see, value and respond to individual skills, needs and capabilities.

Mark (Tutor): *You kind of have to have a bit of guts to go OK I'm kind of leaving this up to you, I'm going to assist you and work with you rather than work for you in making a piece of music – which is the risk aspect.... So yeah it's made me realise that there are three skills I need: I need to be confident, I need to be able to respond to a situation and go with it and work with them (young musicians) and keep the momentum going and keep it interesting and keep them engaged in the work rather than pile on a lot of other stuff that could make them feel that they don't own whatever it is they're making or creating.*

Lisa (Young Musician): *I like the different experiences to choose different instruments.*

Creativity was central to the Play On staff's pedagogy, to the young musician's experiences and for the parents they saw Play On as providing a space for their child to be creative in a way that wasn't possible in other places and spaces. This connects to an overarching and recurring narrative in our data, that is, the dichotomy between Play On being a 'safe' space in contrast to other everyday spaces in the lives of the young musicians.

Billy (Parent): *He is valued and praised and allowed to shine musically without having to suppress his disability as he would in a mainstream setting.*

Iona (Parent): *He had no access to mainstream music classes. His sense of self-worth and confidence have flourished with Play On.*

Concluding remarks

The capabilities approach and personalisation were used to frame this study to explore inclusive music provision for disabled children and young adults. The work of Paragon, and specifically their Play On classes, appear to be connecting to a discourse of disability and social care embedded in personalisation and an outcomes approach that is changing the lived experience of disability and professional practice. This contemporary and evolving approach requires professionals to work with service users in new and innovative ways to identify outcomes they want to achieve, including things that they may previously not have considered suitable or accessible to them. When the person is prioritised over their disability and their strengths over their weaknesses, the lens through which the world is viewed is transformed allowing for the 'norm' to be unsettled and reinterpreted.

This study highlights the need for new spaces to be opened up that are inclusive, accessible and provide effective communication, supportive relationships, risk taking and creativity. To date limited opportunities for disabled children and young adults have curtailed the freedom they have to make choices and lead a life of their own choosing. The opening up of more accessible and inclusive spaces can contribute to unsettling and challenging the place of disability in society. The capabilities approach along with the social model of disability (Burchardt, 2004) helps to make sense of this lacuna in inclusive arts opportunities for disabled people and the power of space to transform lives. As Massey (1984) argues, spaces should be recognised as 'constitutive of social praxis, rather than being merely sites within which practices take place' (cited in Needham, 2015:357).

Whilst this study provides an insight into how personalisation can create positive change in the lives of disabled children and young adults, it should be noted that the success of the Paragon

approach is time and staff intensive, with tutors offering intensive one-to-one tuition and support. However, it would appear that this inclusive, supportive and democratic practice stands in contrast to how personalisation is experienced and practised in other spaces.

The limitations of this small scale study preclude a causative link being made between inclusive music classes and social outcomes for participants (Levy *et al.*, 2014b). Yet the study does highlight that disabled children and young adults who were involved in the study enjoy music and music making, and their disability has not been a barrier to them exploring their creativity, and being supported to do so in an inclusive and participatory setting. Yet focusing solely on inclusive 'safe' spaces creates a tension and juxtaposes these inclusive spaces alongside the 'other' spaces of everyday life. It problematises the spatial dynamic of what is accepted and valued through the unsettling of roles and identities within society. This uncertainty has the potential to create a new transitional space, a liminal space that is 'ambiguous and ambivalent' (Zukin, 2011), where boundaries need to be renegotiated and redefined.

There are three key areas to have emerged from this study that are ripe for further investigation. First, there is scope for more empirical work to evidence the strengths of the practice of organisations like Paragon that are applying the concept of personalisation from a social justice perspective and broadening physical inclusive spaces at the same time as contracting relational space. Second, professionals working with disabled people need to take cognizance of the intersectionality and fluidity of the identities of the people they are working with. Third, further work is needed to understand the impact of disabled people leading their lives in different socio-spatial settings. Spaces that are participatory and enabling, and where confidence is nurtured and individuals feel valued; and the antithesis, spaces that disempower and marginalise. There is scope to explore the impact of experiencing this liminal space on the lives of disabled people and the inherent tensions of transitioning between inclusive spaces and exclusionary spaces. Whilst this study contributes to the growing empirical work that evidences that participation in the creative arts has a 'transformative potential' (Atkinson and Robson, 2012), it also raises new questions over the spatial dynamic of inclusive spaces and how people negotiate tensions within liminal space that positions them 'betwixt and between' (Zukin, 2011), and in so doing creates the potential to unsettle their place within society.

The findings from this study highlight good practice around personalisation. The Play On approach can be used as a template for working with marginalised groups in a democratic, non-hierarchical way, where individuals are listened to and involved in shaping their own personal outcomes. Our study suggests that the ethos that shapes the work of the Play On music tutors can inform the work of professionals in different practice settings in Scotland and in other countries where personalisation, from a social justice perspective, is embedded into professional practice.

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References

- Atkinson, S. and Robson, M. (2012) 'Arts and health as a practice of liminality: managing the spaces of transformation for social and emotional wellbeing with primary school children', *Health and Place*, 18, 1348-1355.
- Baylies, C. (2002) 'Disability and the notion of human development: questions of rights and capabilities', *Disability and Society*, 17:7, 725-739.
- Benbow, S., Rubnick, A., Forchuk, C. and Edwards, B. (2014) 'Using capabilities approach to

- understand poverty and social exclusion of psychiatric survivors’, *Disability and Society*, 29:7, 1046-1060.
- Berg, S. (2005) *Personal Assistance Reforms in Sweden: breaking the assumption of dependency?*, in C. Barnes and G. Mercer (eds.) *The Social Model of Disability: Europe and the Majority World*, Leeds, Disability Press.
- Burchardt, T. (2004) ‘Capabilities and disability: the social capabilities framework and the social model of disability’, *Disability and Society*, 9:7, 735-751.
- Christensen, K. and Pilling, D. (2014) ‘Policies of Personalisation in Norway and England: On the Impact of Political Context’, *Journal of Social Policy*, 43:3, 479-496.
- Darcy, S. and Singleton, J. (2015) *‘Cultural life’, disability, inclusion and citizenship: moving beyond leisure in isolation*, London, Routledge.
- Equality and Human Rights Commission (2014) *Monitoring the Implementation of the UN Convention on the Rights of Persons with Disabilities*, The UK Independent mechanism list of issues interim report, Equality and Human Rights Commission.
- Ferguson, I. (2007) ‘Increasing User Choice or Privatizing Risk? The Antinomies of Personalisation’, *British Journal of Social Work*, 37:3, 387-403.
- Freedman R. I. (2001) Ethical Challenges in the Conduct of research Involving persons with mental retardation, *Mental Retardation*, 39, 2, 130-141.
- Gilbert, N. (2011) *Researching Social Life*, 3rd Ed., London, Sage.
- Hall, E. (ed.) (2013) ‘Making and gifting belonging: creative arts and people with learning disabilities’, *Environment and Planning A*, 45, 244-262.
- Knox, M., Mok, M. and Permenter T. R. (2000) Working with the Experts: Collaborative research with people with an intellectual disability, *Disability and Society*, 15, 1, 49-61.
- Levy, S., Robb, A. and Jindal-Snape, D. (2014a) *Inclusive Music: evaluating the impact of Paragon’s Play On programme on the lives of young people with additional support needs and their families*, Dundee, University of Dundee.
- Levy, S., Kroll, T. and Jindal-Snape, D. (2014b) *Community-based Music Programmes, Health and Inequalities: Impact on Children/Adolescents and their Families: a systematic literature review*, University of Dundee and Glasgow Centre for Population Health, August 2014.
- Lincoln, Y. S. and Guba, E. G. (2011) ‘Paradigmatic Controversies, Contradictions and Emerging Confluences, Revisited’, in Denzin, N. K. and Lincoln, Y. S., (eds.) *The Sage Handbook of Qualitative Research*, 4th ed., London, Sage, 97-128.
- Lomax, H. (2012) ‘Contested Voices? Methodological tensions in creative visual research with children’, *International Journal of Social Research Methodology*, 15(2), 105-107, DOI: 10/1080/13645579.2012.649408
- Lymberry, M. (2014) ‘Understanding personalisation: implications for social work’, *Journal of Social Work*, 14:3 295-312.
- Mladenov, T., Owens, J. and Cribb, A. (2015) ‘Personalisation in disability services and healthcare: a critical comparative analysis’, *Critical Social Policy*, 35:3, 307-326.
- Molnar-Szakacs, I. and Heaton, P. (2012) Music: a unique window into the world of autism, *Annals of the New York Academy of Sciences*, 1252, 318–324
- Morris, J. (2014) ‘Personal Budgets and Self-Determination’, Jenny Morris blog, 24 April {<http://jennymorrisnet.blogspot.co.uk/2014/04/personal-budgets-and-self-determinatio.html>}.
- Mortimer, H. (2004), Hearing children's voices in the early years. *Support for Learning*, 19: 169–

174. doi: 10.1111/j.0268-2141.2004.00343.x
- Moscardini, L., Barron, D. S., Wilson, A. (2012) 'Who gets to play? Investigating equity in musical instrument instruction in Scottish primary schools', *International Journal of Inclusive Education*, 17:6, 646-662.
- Needham, C. (2015) 'The Spaces of Personalisation: Place and Distance in Caring Labour', *Social Policy and Society*, 14:3, 357-369.
- Needham, C. (2011) 'Personalisation: from story-line to practice', *Social Policy and Administration*, 45:1, 54-68.
- Nind, M. (2008) Conducting Qualitative Research with Learning, Communication and Other Disabilities: methodological challenges, *National Centre for Research Methods, NCRM/012*. Available at: <http://eprints.soton.ac.uk/65065/1/MethodsReviewPaperNCRM-012.pdf> [Accessed: 26/03/15]
- Nussbaum, M. (2006) *Frontiers of Justice: Disability, Nationality and Species Membership*, London, Harvard University Press.
- Nussbaum, M. (2011) *Creating Capabilities: A Human Development Approach*, Cambridge, MA: Harvard University Press.
- Oliver, M. (1983) *Social Work with Disabled People*, Basingstoke, Macmillan.
- Oliver, M. (1990) *The Politics of Disablement*, Basingstoke, Macmillan.
- Oliver, M. (2013) 'The Social Model of Disability: thirty years on', *Disability and Society*, 28:7, 1024-1026.
- Oliver, M., and C. Barnes. (2012) *The New Politics of Disablement*, Basingstoke, Palgrave.
- Parr, H. (2006) 'Mental health, the arts and belongings' *Transactions of the Institute of British Geographers*, 31:2, 150-166.
- Pearson, C. and Ridley, J. (2016) 'Is Personalization the Right Plan at the Wrong Time? Rethinking Cash-for-Care in an Age of Austerity', *Social Policy and Administration*, (doi:[10.1111/spol.12216](https://doi.org/10.1111/spol.12216))
- Plump, B. and Geist-Martin, P. (2013) 'Collaborative Intersectionality: negotiating identity, liminal spaces and ethnographic research', *Liminalities: A Journal of Performance Studies*, 9:2, 59-72.
- Pykett, J. (2009) Personalisation and de-schooling: uncommon trajectories in contemporary education policy. *Critical Social Policy* 29 (3): 374-397.
- Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, 55, 68-78.
- Schleien, S., Mustonen, T., & Rynders, J. (1995). Participation of children with autism and nondisabled peers in a cooperatively structured, community art program, *Journal of Autism and Developmental Disorders*, 25, 397-413.
- Scottish Government (2006) *Changing Lives: Report of the 21st Century Social Work Review*, Edinburgh, Scottish Government.
- Scottish Government (2013a) Social Care (Self-directed Support) (Scotland) Act 2013
- Scottish Government (2013b) *The Keys to Life: improving the quality of life for people with learning disabilities*, Edinburgh, Scottish Government.
- Sen, A. (1988) *Ethics and Economics*, Oxford, Blackwell.
- Sen, A. (1999) *Commodities and Capabilities*, Oxford, Oxford University Press.
- Sen, A. (2009) *The Idea of Justice*, London, Harvard University Press.
- Stensaeth, K. (2013) "'Musical co-creation?'" Exploring health-promoting potentials on the use

- of musical and interactive tangibles for families with children with disabilities', *International Journal of Qualitative Studies in Health and Well-being*, 8
- Stickley, T., Crosbie, B. and Hui, A. (2011) 'The Stage of Life: promoting the inclusion of young people through participatory arts', *British Journal of Learning Disabilities*, 40, 251-258.
- Vorhaus, J. S. (2015) 'Capabilities, human value and profound disability: capability theory and its application to theatre, music and the use of humour', *Disability and Society*, 30:2
- Watts, M. and Ridley, B. (2012) 'Identities of dis/ability and music', *British Educational Research Journal*, 38:3, 353-372.
- Wehmeyer, M. L. (2005). Self-determination and individuals with severe disabilities: Re-examining meanings and misinterpretations. *Research and Practice in Severe Disabilities*, 30, 113-120.
- Wehmeyer, M. L., Abery, B., Mithaug, D. E., & Stancliffe, R. (2003). *Theory in self-determination: Foundations for educational practice*. Springfield, IL: Charles C. Thomas Publishing Company.
- West, K. (2013) 'The Grip of Personalisation in Adult Social Care: between managerial domination and fantasy', *Critical Social Policy*, 33:4, 638-657.
- Whitehurst, T. (2007) 'Liberating Silent Voices – Perspectives of Children with Profound and Complex Learning Needs on Inclusion', *British Journal of Learning Disabilities*, 35:1, 55-61
- Zukin, S. (2011) *Naked City: The Death and Life of Authentic Urban Places*, Oxford, Oxford University Press