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Impacts of Participating in a Choir on Health and Wellbeing of Adults with Intellectual Disabilities

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Article Info.	Abstract

Background: An estimated 1.4 million people in the United Kingdom (UK) have an intellectual disability. Research in these populations has advanced over the last 40 years, and there is now evidence for the beneficial use of music interventions (for example Hall, 2010). However, there is still insufficient good quality evidence on the most effective interventions to support health and wellbeing.

Method: This paper presents the results of a study looking at the impact of participatory singing for people with intellectual disabilities, assessing the impact of a choir, and collecting quantitative and qualitative data at three time-points.

Results: This paper shows that the choir had a positive impact. The qualitative results were particularly strong, with quantitative results (Rosenberg Self-Esteem Scale (RS-ES) and Personal Wellbeing Index (Intellectual Difficulties) (PWI-ID) more ambiguous.

Conclusion: The results of the study suggest that choir singing has a positive impact on wellbeing.

## 1.	Introduction

In the UK, there are an estimated 1,400,000 people with an intellectual disability (Mencap, 2020). Life for this group can have challenges, for example discrimination and stigma, social exclusion, health inequalities and financial burdens (Mencap, 2020; Ali, Hasiotis, Strydom & King, 2012:2122-2140; Bates & Davis, 2004:195-207; Coleman, Sykes & Groom, 2013; Emerson & Hatton, 2008; NHS Digital, 2019; Sense, 2017; Taheri, Perry & Minnes, 2016:435-443). There is a need for more research to

gather evidence, support impactful interventions and help build connections with the wider community (Department of Health, 2010).

Definitions and key concepts

In the UK the term 'learning disability' has been defined as 'a significantly reduced ability to understand new or complex information, to learn new skills, with a reduced ability to cope independently which started before adulthood' (Department of Health, 2001:14). More recently the term 'intellectual disability' is gaining usage (Cluley, 2017:24-32), particularly in the international context. The definition of intellectual disability provided by the World Health Organisation (WHO) (2019) is similar to the Department of Health definition but with a focus on social and environmental dimensions. In the questionnaire used for this study, the term 'learning disability' was used, as participants were most familiar with that term, but this paper uses 'intellectual disabilities'.

Notions of self

Self is a complex notion. The role that the perspectives of other people play in one's sense of self has been widely discussed. Prescott (2006:7) states 'self-perception is possible because the individual is able to compare his Self with others and is also able to interpret the feedback from others on his Self'. There has been disagreement regarding the strength of self-concept amongst individuals with intellectual disability. Harter (1982:87-97) found that children with intellectual disability had a less developed sense of self than children with typical development, however others (for example Lewandowski & Arcangelo, 1994:598-605; Reschly & Christenson, 2006:103-113; Pestana, 2014:16-23) failed to find any differences between people with intellectual disabilities and others in terms of global self-concept.

The rating scales used in this study presuppose that people with intellectual disabilities have a sufficient sense of self to assess themselves.

Research with people with an intellectual disability

Historically, intellectual disability research has been informed by the biomedical model, and carried out primarily in psychology and biomedicine. More recently, however, research has drawn upon a socially-based model which aligns with the position of the UK Government strategy document, *Valuing People* (Department of Health, 2001) and with the WHO's definitions (2019). Recent studies have taken a qualitative stance, with participants sharing their own perspectives (Walmsley, 2001:187-205). However, while such smaller-scale studies offer depth and texture, they may not provide the evidence required for widespread change. More, and larger, research studies are needed from a social perspective. However, there can be challenges, such as issues with mental capacity and informed consent (Beauchamp & Childress, 2009:77-81). For example, the requirement for consent can lead to the exclusion of people with intellectual disabilities (McClimens & Allmark, 2011:633-639).

The impact of participative arts on health for people with an intellectual disability

Despite challenges, the evidence base is growing, and research has shown that participating in meaningful social and leisure activities yields benefits (Hall, 2010:24-40) including a sense of belonging, connectivity, and improved wellbeing (Wilson, Jacques, Johnson & Brotherton, 2017:847-858). This is particularly true for music activities (Nordoff Robbins, 2020; British Association for Music Therapy, 2017). This synergises with research amongst the general population on the positive impacts of arts and music on health and wellbeing. For example, Clift and Hancox (2010:79-96) found improvements in physical, psychological, social and environmental wellbeing amongst choir singers in Europe and Australia; Clift, Skingley, Page, Stephens and Hurley (2017) found that participation in *Singing for Breathing* groups were beneficial for people with COPD; while Clift, Gilbert, R. and Vella-Burrows, T. (2016) discuss the value of singing for older people in terms of health and wellbeing.

New research into the benefits of music for people with an intellectual disability has emerged. Music therapy improves social and communicative skills (Graham, 2004:24-29), while longer-term therapy reduces isolation and boosts self-esteem and belonging (Pavlicevic, O'Neil, Powell, Jones and Sampathianaki, 2014:5-19). Kennedy and Brewer (2016:35-42) found benefits to communication, while Baumgarten and Wheeler (2016:118-127) found improved social behaviours and social skills development. These studies indicate the value of music as a way of working with people with intellectual disabilities, but most of the studies have been small-scale and qualitative. There is a need for more quantitative evidence. There is also little evidence about the specific benefits of group singing. It is hypothesised that group singing offers additional benefits concerning community and shared experiences which may enhance the beneficial impacts, but more investigation is needed.

2.   Methodology

Research design

A longitudinal observation study design was used. The aim was to examine the group in their setting when exposed to a particular influence (Thyler, 2010:166-167). The choir ran for a year, over three terms, meeting weekly for an hour. It was led by a trained leader and modelled on an existing choir for people with intellectual disabilities. Data was collected immediately before the start of the choir (T1), at mid-term (T2) and after the choir ended (T3). The questionnaire included demographics, two rating scales, and some 'short-answer' textual questions (see Appendices One to Six). Data was also collected in focus groups. The rationale for using mixed methods was to allow a rounded picture (Clark & Ivankova, 2015:120-123). Quantitative data offered the opportunity to test responses for statistical significance, and the use of established rating scales meant responses could be compared with other studies. Textual data allowed a richer understanding of experiences (Patton, 2014:119).

A group of people with intellectual disabilities who work as co-teachers in educational contexts was consulted by the research team to get feedback on the rating scales in the questionnaires, particularly about how easy they were to understand. The group's founder also trained interviewers for this project in a session which covered, for example issues associated with acquiescence and the importance of not 'leading' respondents to particular answers.

The Intervention

The choir evaluation was delivered in collaboration with a local service organisation whose membership attend regular activities at their local centre. The choir itself was managed by the service organisation whilst the evaluation was conducted by the researchers. The choir was advertised internally within the organisation and members signed up for it voluntarily. These members formed the body of the choir. The choir also included volunteer participants recruited from local choirs and also some of the service organisation's own support workers. The role of these volunteers was to model responding to the facilitator and to support the sound. Potential volunteers and support workers attended a one-day training event led by a choir leader of an existing choir for adults with a learning disability. This training included introduction to the framework of community choirs, warm up exercises and some repertoire, as well as some discussion about practical matters such as timing, use of instruments/percussion, uniform, managing performance etc.

The choir facilitator is experienced both in working with people with a learning disability as well as in supporting the management of local choirs. The repertoire was designed by him and included warm up exercises, some material provided by him and some requested by the choir members themselves. The choir chose a name for themselves and t-shirts were produced for them. The singing was mainly in unison. The role of the support workers who were already known to the group was to support the members and take responsibility for the building and the facilities.

Study participants were drawn from current users of the choir. All users of the service were invited to join the choir, but only those assessed as having capacity to give consent were asked if they wanted to join the study. In total, 35 people joined the choir: over the year it ran, new participants were recruited, while others left. Twenty-two participants agreed to take part in the evaluation at T1, of which data was collected for 19. At T2, 16 interviews were carried out, and 14 at T3.

Data collection

Choir participants were interviewed face-to-face, by trained interviewers. Interviews took place in private rooms within the service centre, and responses were recorded on paper. Support workers were present in some cases, to help respondents understand the questions, but not to answer for respondents.

One focus group took place during on the day of the final data collection, interviewing three support workers and volunteers. A further focus group with two carers was held two months later. Both groups were semi-structured with open questions about various themes relating to the choir. The interviews were audio-recorded and transcribed. A researcher present in the room, also made observational notes.

Questionnaire Design

The questionnaire was made up of two rating scales, demographic questions and short answer (qualitative) questions (see Appendices One to Five). The two validated rating scales used to collect quantitative data are summarised in Table 1.

Table 1.   Validated rating scales

Tool	Outcome
Rosenberg Self-Esteem Scale (adapted) (Rosenberg, 1982)	• Global self-worth • Self-esteem
Personal Wellbeing Index- Intellectual Disability (Cummins & Lau, 2005)	• Quality of life • Wellbeing

The Rosenberg Self-Esteem Scale (RSES) has been found valid and reliable (for example Park & Park (2019), however there has been dissent, including Davis, Kellett, Beail and Turk (2009:172-178) who argue that validity and reliability have not been established for groups of people with intellectual disabilities. Indeed, in this study, testing the data from T1 returned a Cronbach Alpha score of 0.579 (negative items four and six recoded). By contrast, the PWI-ID returned a score of 0.824 at T1. Despite this, the scarcity of quantitative tools meant an adapted version of RSES was used. Each item was presented in large print on a single, A4 page with blocks of increasing size to act as visual cues alongside the written answers.

The Personal Wellbeing Index-Intellectual Disability (PWI-ID) (see Appendix Two) (Cummins & Lau, 2005, *passim*) was found to show good reliability (Cronbach alpha coefficient of 0.76) and validity by McGillivray, Lau, Cummins and Davey (2009:276-286). These results were supported by Yousefi, Mozaffari, Sharif and Sepasi (2013:68-72). The answer options form a 5-item Likert scale, which was presented to respondents in this study as smiley faces in different colours (see Appendix Two). The PWI-ID was originally designed with two pre-test stages to determine acquiescent responding, but this study did not use the pre-test, due to its length. Instead, the research team asked support staff at the service centre to assess capacity. Qualitative data was gathered through four 'short answer' questions about intellectual disabilities at T1, T2 and T3, with additional questions about experiences of the choir asked

at T2 and T3. The short answer questions elicited information about feelings of social inclusion and stigma, and about life experiences.

Sampling and consent

Consent was requested in two stages. First, participants were invited to an information session and given an Easy-Read information sheet to take home and discuss with family and carers. A week later, participants were asked to sign a consent form (in Easy-Read English) after further explanation from interviewers.

Ethics

Ethical approval was requested from the London HRA Social Care Research Ethics Committee. Consent was granted on 16th October 2018 (Reference 18/IEC08/0027).

Confidentiality, voluntary nature of participation and data protection

Participation in the study was voluntary and did not affect participants' involvement with the service or choir. The study was carried out within the terms of the General Data Protection Regulations (2018). Consent was obtained for data collection. No identifying details of participants, only a unique ID number were attached to the electronic data. One paper copy of name and unique ID number was created, this was held securely, and kept in a locked cabinet in a locked room when not in use. Participants were informed what data would be held, what it would be used for, and their rights.

Data analysis

The focus groups were audio-recorded and transcribed. The data from face-to-face interviews was entered into IBM SPSS 24, and analysed, primarily descriptively. Due to small participant numbers and lack of respondent continuity, statistical significance tests were not used. Qualitative data from short answer questions, individual interviews and focus groups was coded. Simpler questions were coded into categories, more complex information was analysed thematically (Clark & Braun, 2013:120-123).

3.   Results

Quantitative results

In total, 22 participants consented to the evaluation (PID001 to PID022). Table 2 (Appendix Six) summarises participation at each time point. Only 11 respondents were present for all three time-points, which explains some discrepancies between demographic variables.

Demographics

Roughly equivalent numbers of men and women took part in the study. Ages ranged from 18 to 64. The full demographic data can be found in Tables 3 to 8 and 15 to 17 (see Appendix Five).
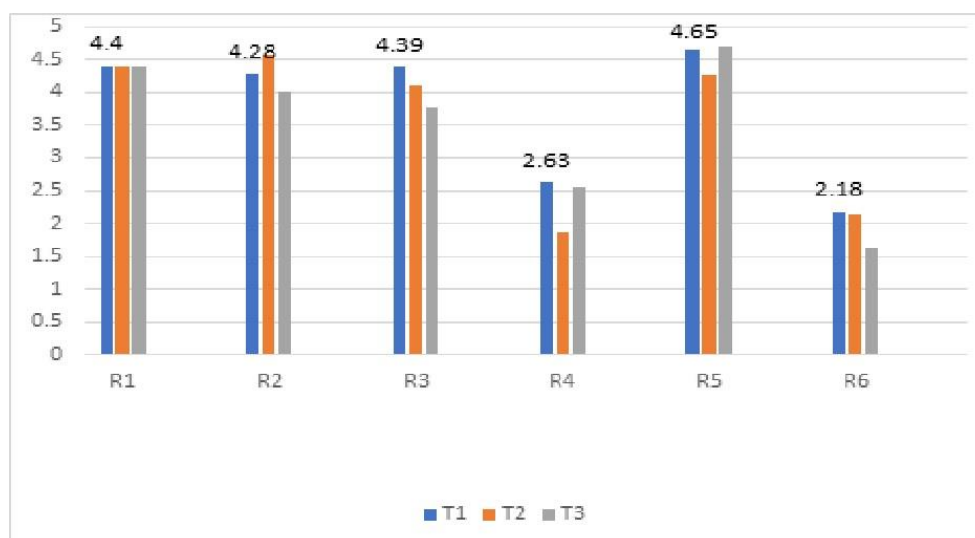
Rosenberg Self-Esteem Scale

The results are summarised in Table 9 (mean score calculated from Likert scale in which 'Never True' is '1' and 'Always True' is '5'):

Table 9.   Mean, standard deviation and number of respondents on each of the Rosenberg items by time point

Rosenberg item	T1 (start of choir) M (SD)	T2 (midpoint) M (SD)	T3 (end of choir) M (SD)
1. I feel that I am a good person, as good as others	4.4 (1.042) n=18	4.4 (1.031) n=16	4.38 (0.870) n=13
2. I feel that I have a lot of good qualities	4.28 (1.074) n=18	4.56 (0.629) n=16	4.00 (0.953) n=12
3. I am able to do things as well as most other people	4.39 (0.778) n=18	4.12 (0.957) n=16	3.77 (1.013) n=13
4. I feel I haven't done anything worthwhile	2.63 (1.408) n=16	1.87 (1.204) n=16	2.54 (1.506) n=13
5. I like myself	4.65 (0.786) n=17	4.25 (1.000) n=16	4.69 (0.630) n=13
6. At times I think I am no good at all	2.18 (1.380) n=17	2.14 (1.512) n=14	1.62 (0.870) n=13

Figure 1, below, shows that all items score relatively highly, with relatively little difference between the scores overall:

Figure 1.   Rosenberg items (x axis) by time period (mean scores) (y axis).

As illustrated in Figure 1, respondents seemed consistent in their answers to the Rosenberg: mean scores for the 'negative' items (four and six) were notably lower than those for the 'positive' items (items one, two, three and five). However, statistical tests do not support this. Table 10 summarises the

Cronbach Alpha scores for T1, T2 and T3 (with the negatively expressed items (four and six), being recoded onto the scale for items one, two, three, and five).

Table 10.   Cronbach Alpha for Rosenberg at various time points (recoded for negative items)

T1	T2	T3
0.579	0.614	0.617

If the negative items are entirely removed from the scales and Cronbach Alpha calculated, the results demonstrate greater internal consistency for T1 and T2, but only T2 scores over 0.7 (an indication of internal consistency) (see Table 11).

Table 11.   Cronbach Alpha for Rosenberg at various time points (negative items removed)

T1	T2	T3
0.586	0.788	0.362

A total score for all elements of the Rosenberg was calculated. Answers for the 'negative' items (four and six) were recoded ('1' became '5', '2' became '4', '3' remained '3', '4' became '2' and '5' became '1'). The results of this also failed to show a clear pattern (Table 12):

Table 12.   Total mean scores for Rosenberg at T1, T2, T3.

T1	T2	T3
24.1333	25.4286	24.5833

It might be predicted, given the literature on the positive impact of participative arts activities on wellbeing, that mean scores for Rosenberg items one, two, three and five would increase from T1 to T3, and that mean scores for items four and six would decrease. However, this is not the case: there is no clear pattern. R1 stayed relatively constant, R2 increased then decreased, R3 decreased. Any changes were small. More data is needed to clarify this.

Personal Wellbeing Index (Intellectual Difficulties)

The PWI-LD scale is described above and is included in Appendix Two. The results are presented in Table 13 (means calculated from a 5-item Likert scale in which 'Happy nearly always' is '1' and 'Hardly ever happy' is '5'):
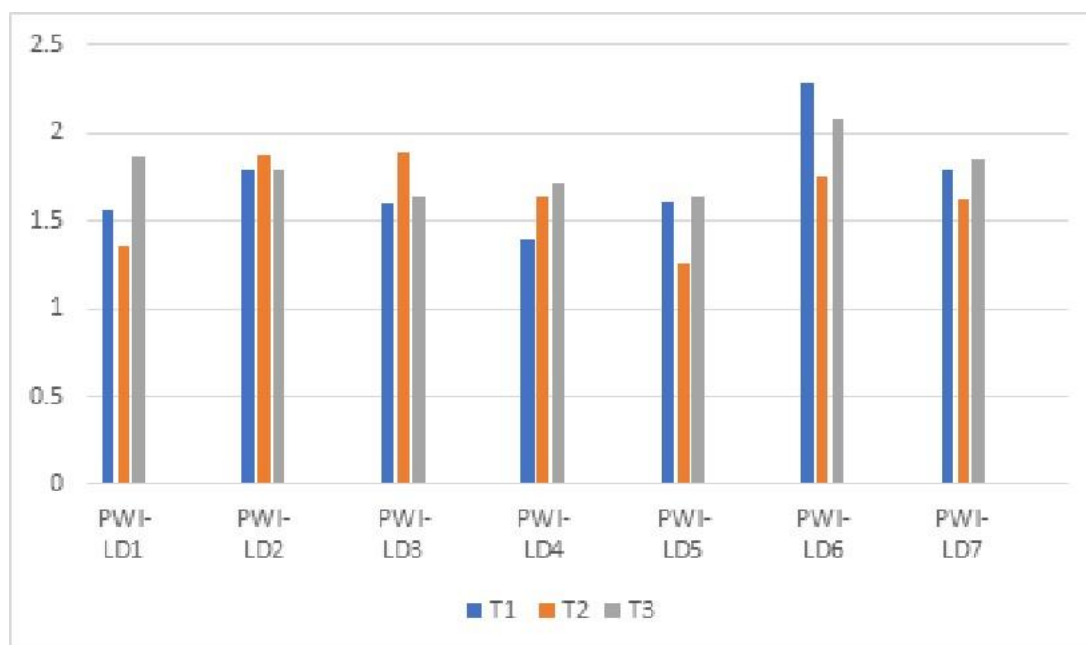
Table 13.   PWI-LD items by time point (mean score, SD)

PWI-LD item: Happiness felt about…	T1 M (SD)	T2 M (SD)	T3 M (SD)
1. … your life as a whole?	1.56 (0.81) n=16	1.36 (0.50) n=14	1.86 (1.10) n=14

2. … the things you have (Like the money you have and the things you own)?	1.78 (0.88)	1.88 (1.09)	1.79 (0.89)
	n=18	n=16	n=14
3. … how healthy you are?	1.59 (0.71)	1.89 (1.01)	1.64 (0.84)
	n=17	n=16	n=14
4. … the things you make or things you learn?	1.39 (0.61)	1.63 (1.15)	1.71 (0.61)
	n=18	n=16	n=14
5 … getting on with the people you know?	1.61 (0.85)	1.25 (0.44)	1.64 (0.84)
	n=18	n=16	n=14
6. … how safe you feel?	2.28 (1.18)	1.75 (1.24)	2.08 (1.19)
	n=18	n=16	n=13
7. … doing things outside your home?	1.78 (0.94)	1.62 (0.96)	1.85 (0.90)
	n=18	n=16	n=13

The results in chart form are shown in Figure 2. Here, some items scored less highly at T2 than T1, then increase again at T3. Others increase from T1 to T2, then fall. Overall, no clear picture emerges. As with the Rosenberg, there is relatively little difference between the mean scores at each time point.

Figure 2. PWI-ILD items (x axis) by time period (mean scores) (y axis)

The total scores for PWI-ID were also calculated for T1-3. No clear pattern is revealed (Table 14):

Table 14.   Total mean scores for PWI-ID at T1, T2, T3 (lower score – happier response).

T1	T2	T3
14.67	12.15	14.54

Qualitative results

Short answer questions about intellectual disabilities

Respondents were asked three questions about perceptions of intellectual disabilities. The first asked the respondent if they thought they had a learning disability (see Table 18, Appendix Five). Most respondents said they thought they did, but frequently qualified this. Some respondents described their medical diagnoses ('Yes I have, Down Syndrome. IBS. Epilepsy – stress') (PID001), while others explained how they experienced their intellectual disability: ('Yes. Sometimes it takes me a while to process the question of things') (PID002). Others simply said, 'I have' or 'Yes'. Each respondent's answers were broadly consistent across time-points, although responses differed in detail.

The second question asked, 'Do people treat you differently because you have a learning disability' (see Table 19). Some answers describe being bullied or mistreated.

'Yes. People like to talk to other people and ask what I like to eat - that really annoyed me because I can speak' (PID002).

'Yes - at school someone wasn't very friendly to me and the children called me names because I was in a group for disabled children, but I'm just the same as everyone else - I just have a disability' (PID006).

The third question asked, 'What do you think people think about people with a learning disability?'. Interviewers commentated that some respondents found this difficult to understand. Of the 47 total answers across T1 to T3, only 21 answered the question. Some of the answers which did answer the question include: 'I think some people avoid them like the plague - get treated different' (PID002), 'I think people think in good terms about people with disabilities and they try to help them' (PID004). Examples of answers which do not answer the question include: 'I don't talk to strangers. Stay safe' (PID001), and 'I like old people. They are sweet' (PID018). Some of the answers partially answered the question, but also included non-relevant information. Respondents also sometimes changed their answers to this question between time-points. One respondent, for example, stated at T1 'cruel to people with a learning disability', at T2 'in the middle' and at T3 'don't know' (PID005). These mixed responses may indicate limited understanding of this question.

Short answer questions about singing and the choir (T2 and T3 only).

Respondents were asked 'how does singing make you feel?'. Here, the responses were overwhelmingly positive: 23 people over T2 and T3 mentioned 'happy'. Other responses included 'proud' (2) 'confident' (1) and 'makes me feel better' (1). One respondent said that singing made them 'sad', but the wider context of the remark indicated a nuanced emotional reaction to music: 'sometimes happy and sometimes sad - happy songs make me happy and sad songs make me sad' (PID006). Some other examples include: 'I am happy to sing my heart out' (PID002) and 'really bad mood because my disability

holds me back sometimes - and all I did was sing and it made me feel better. I sing a lot now. I sing around the house and drive my mum crazy'. There were no negative responses to this question.

Next, respondents were asked 'what did you like most about the choir?'. The answers here were also entirely positive (see Table 20, Appendix Five). Verbatims from this question include: 'Confidence. Happy. Really helped me with depression' (PID005) and 'It's good, like being part of a group, like that everybody smiles' (PID002).

The group performed at Christmas 2018. Q3 asked 'How did you feel about performing in front of people? (Table 21, Appendix Five). Verbatim quotes include: 'My nieces and nephew came to watch - they were like, that's my auntie - Auntie did good!' (PID002) and 'It's great. I'm not scared of nothing' (PID008).

Most participants were positive about practical arrangements for the choir, although a couple of people had minor reservations, for example noise. The final question in this section asked, 'What do you think could be made better about the choir'. Responses are summarised in Table 22 (see Appendix Five).

Focus groups

The results from the focus groups were coded by two researchers, using thematic analysis (Given, 2008) and the results compared. Clear themes emerged:

- Enjoyment of choir
- Community and belonging
- Progressions and growth
- Group cohesion and equality

These themes are discussed below.

Enjoyment of choir

People enjoyed the choir: (SW = 'support worker', V = 'volunteer'): SW3 'I think the choir has a lot of energy, which is a good thing, people come with a lot of energy and they put a lot of their heart and soul into it. The people that come here, they've got, they enjoy it' and, from V2, '[NAME] was always quiet but he'll come in now and he'll do that [action] to everyone, he'll touch you and he might not always want to take part but he is there and he enjoys it in his own way'. In the latter example, the volunteer links enjoyment of the choir to greater participation and increased social interaction, thus underlining a connection between attending choir regularly and social engagement and inclusion.

Commuity and Belonging

People who regularly attended the choir were also actively involved with the choir, participating, engaging with the music and each other, as this response indicates: 'I think people like having instruments like the shakers and the tambourines for people who can't take part in the singing so much they have slowly got involved with music and got really like more involved with that' (SW1).

The following comment, from a volunteer (V1), expresses the increased sense of community and belonging observed for some participants:

'It's also a great leveller actually you know…we're all there to sing and we're all there to sing together and everybody contributes sometimes in very different ways but it doesn't really matter…because we're all there with a common purpose and that's a great leveller'.

One participant, during the course of the choir, 'really opened up his connection with people and that's really lovely to see' (SW2), whereas V1 reports that another participant 'smiles, she joins in, and she's actually started talking to people'.

Progression and Growth

Another theme concerned participants' progression and growth in confidence. The stories of individuals who had made changes during the choir were interesting: '[NAME] has helped lead it on occasions when [FACILITATOR] has not been here…his timing is absolutely impeccable and we all know the words and we know the melody but he'll know when to start singing and it is absolutely fantastic…it is lovely to see his confidence within the choir has grown' (SW2). 'She has been kind of observing on the side-lines and she's gradually been getting more involved, last week she volunteered to hand out the tambourines to everybody' (V1).

Group Cohesion and Equality

Those interviewed also mentioned being part of something bigger than the personal. SW2 stated that the choir is a 'very good levelling ground' in which no one person is dominant: 'they recognise that it is a group activity and more so those people that during the day probably have quite dominant personalities and take over a lot are allowing other people to come and be on the same level as them'. Others reported how considerate choir members were of each other. The choir also seemed to empower quieter members: SW2 reported that the choir gave opportunities for members to stand up in front of the group and lead, and that this opportunity, with the support of others, helped more introvert participants to take a more active, leadership role. A sense of ownership also grew: 'it is their choir, they choose a lot of the things and they decide a lot of the things' (SW3).

Singing, particularly, was felt to be key in the levelling of differences: 'It's also a great leveller actually you know people whether they're members of the choir or volunteers or support workers... we're all there to sing together and everybody contributes sometimes in very different ways' (V1).

4.   Discussion

In terms of the quantitative results, no clear picture emerges. Both Rosenberg and PWI demonstrated no obvious impact of the choir on health or wellbeing of participants, although mean scores from T1 were already relatively high (for example, typically 4.2 or more for the positive items of the Rosenberg scale). Of course, this could also have been because the choir had no impact on the participants, however this seems unlikely because the qualitative results do show a very positive impact (on participant's feelings, sense of community and of belonging) on the choir's participants, as reported by choir members and by family, carers and support workers. The choir also seemed to aid progressions and growth amongst participants, as well as promoting equality and respect. A number of specific benefits were discussed above. The qualitative results also offered insights into the experiences of people with intellectual disabilities, for example how they felt they were perceived by others, instances of bullying and social exclusion. Not all feedback was entirely positive. Several volunteers mentioned a need to improve communication, and to reduce confusion. This feedback will be used to better manage future projects.

As mentioned above, the quantitative data did not show a clear picture about the impact of the intervention, with no clear progression between T1 and T3. There are a number of possible reasons for this. As indicated above, it could be that the choir had no impact on the variables measured, although this seems unlikely given the qualitative data. Other reasons will be examined in more detail in a separate paper (in preparation). Possible causes include that the scales were difficult to understand, or that other variables influenced respondent answers (for example acquiescence). Additionally, questions were raised about the sense of self assumed by the rating scales. Although the rating scales were selected because of

their established use and seeming effectiveness with people with intellectual disabilities, the results suggest that respondents had some difficulties understanding questions about how people with intellectual disabilities are perceived by others, which might be interpreted to support Harter (1982:87-97, 1985, *passim*), who argued that learning disabilities can be associated with a less developed sense of self.

Due to respondent numbers, no statistical testing was done. It is anticipated that the next phase of the study will gather further data, possibly from a larger cohort, as this may clarify whether the issues found in this study regarding the rating scales are indicative of a more general situation. As far as the quantitative results suggest anything, they indicate a relatively high average score for questions relating to self-worth and self-awareness and relatively low score for negative measures. While the scores fluctuate between time-points, there is no clear pattern. Despite some reduction in mean scores for the 'negative' items, statistical testing revealed a lack of internal consistency, although the change in average score between the 'positive' and 'negative' items seems to indicate that the scale was generally understood by participants (however, see discussion above of Cronbach Alpha scores). Similarly, for the PWI, the scores indicate a generally high level of satisfaction, both with participants' lives and with specific elements of their lives (possessions, health, creativity and so on). In the qualitative data, a clear picture emerged of the perceived positive impact of the choir (for example, participants became more sociable and confident), and also into the prejudice faced by people with an intellectual disability, and the way participants see themselves.

Turning to the wider implications of our results, there seems to be a need to address inequalities in health and wellbeing for the substantial group of people with intellectual disabilities in the UK and beyond. A report by researchers at University College London finds that people with intellectual disabilities are more likely to live in poverty, less likely to be in work, and more likely to suffer bullying and discrimination (Rikard & Donkin, 2018). There is also a need to expand research to include more people with intellectual disabilities as participants. Indeed, a consensus statement has recently been published on approaches to conducting inclusive health research (Frankena, Naaldenberg, Cardol, Iriarte, Buchner, Brooker, Embregts, Joosa, Crother, Schormans, Schippers, Walmsley, O'Brien, Linehan, Northway, de Valk & Leusink, 2019:1-11). This contains useful pointers around four key themes (attributes of inclusive research; potential outcomes; reporting and publishing, and future research directions).

The background literature also highlighted benefits of participation in music amongst the general population: a sense of belonging, feeling more connected, better health and wellbeing, and engagement (Wilson et al., 2017: 847-858; Hall, 2010:24-40; Nordof Robbins, 2019; Clift & Hancox, 2010:79-96; Clift et al., 2017; Coulton et al., 2015:250-255). These benefits were also found amongst our participants, particularly in regards to a sense of belonging, feeling more connected and engagement, as discussed in the results section above. For example, Wilson et al. (2017:847-858) report that a study of the impact of a supported social group for adults with intellectual disabilities boosts engagement, and through this wellbeing, and develops social belonging and connectedness. This chimes with our results, but it should be noted that Wilson et al.'s study had only 10 participants. Similarly, studies looking at music interventions amongst people with an intellectual disability (for example Graham, 2004:24-29; Pavlicevic et al., 2014:5-19; Baumgarten & Wheeler, 2016:118-127) find numerous benefits, which broadly concur with our findings.

5.   Conclusion

In summary, while the quantitative results fail to show a clear picture, the qualitative results clearly indicate the positive impact of group singing as delivered by this project for people with an intellectual disability. The possible reasons for the unclear quantitative results have been discussed above, and further studies including a larger number of participants might throw further light on the matter. Arguably it may be important not to see lack of proven statistical significance as a 'failure', but rather as a call for future consideration of what health and wellbeing mean for people with intellectual disabilities,

and of how this group of people can be best researched in order that their positions be most adequately represented. Indeed, our long-term aim is to influence practice in the field. Further reflections on issues which arose in data collection and analysis form the subject of another paper (in preparation), and in this we will share further thoughts about improving research practice. Aside from issues with the quantitative data, the qualitative results give a vivid picture of the widespread impacts of the choir on its participants.

As empirical research, which involves people with an intellectual disability as participants is in its relative infancy, it is hoped that this study will contribute to the body of knowledge around health and wellbeing in this group. The methodological issues which arose during data collection have prompted further reflection amongst researchers, and it is hoped that wider dissemination will be of interest to other researchers and improve research methods. We had planned a dissemination event; due to the impact of the Coronavirus this has been postponed.

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Appendices

Appendix One: Adapted Rosenberg Scale

Rosenberg Self-Esteem Scale

Please read each statement. Then circle the number indicating how much you believe the statement to be true.

	Never true	Hardly ever true	Sometimes true	Often true	Always true
1. I feel that I am a good person, as good as others	1	2	3	4	5
2. I feel that I have a lot of good qualities	1	2	3	4	5
3. I am able to do things as well as most other people	1	2	3	4	5
4. I feel I haven't done anything worthwhile	1	2	3	4	5
5. I like myself	1	2	3	4	5
6. At times, I think I am no good at all	1	2	3	4	5

Appendix Two: Adapted PWI Scale

Appendix Three: Personal Wellbeing Index (PWI-ID)

Test Question: Using the scale, how do you feel about eating ice cream?

Part I: Happy with Life as a Whole

    1. "How happy do you feel about your life as a whole?" _____

Happy nearly always	Happy most of the time	Happy about sometime	Not often very	Hardly ever happy

Part II: Personal Wellbeing Index – Intellectual Disability

Happy nearly always	Happy most of the time	Happy about sometime	Not often very	Hardly ever happy

"How happy do you feel about…?"

    2. the things you have? Like the money you have and the things you own? _____

    3. how healthy you are? _____

    4. the things you make or the things you learn? _____

    5. getting on with the people you know? _____

    6. how safe you feel? _____

    7. doing things outside your home? _____

    8. how things will be later on in your life? _____

Appendix Four: Demographics

Demographics and Initial Information

Gender	Male	Female	Prefer not to say

Age	18-24	25-29	30-34	35-39	40-44
	45-49	50-54	55-59	60-64	65+

Ethnicity	_____

Marital Status	Married	Divorced	Separated
	Widowed	In a relationship	Single
	Prefer not to say		

Employment/ Volunteer Status	Full-time paid	Part-time paid	Volunteering
	Student	Unemployed	Prefer not to say

Living Situation	Living alone	Living with family	Living with spouse/partner
	Supported accommodation	Other:_____	Prefer not to say

Other Service Engagement	_____ _____ _____ _____

Other Arts/ Music Involvement	_____ _____ _____ _____

Appendix Five: Short Answer Questions

How does singing make you feel?

_____

_____

_____

_____

What did you like most about the choir?

_____

_____

_____

_____

How did you feel about performing in front of people?

_____

_____

_____

_____

Is the time of the choir convenient to you?

_____

_____

Do you feel comfortable coming to the room and the building for the choir?

_____

_____

What did you not like about the choir?

_____

_____

_____

_____

What do you think could be made better about the choir?

_____

_____

_____

_____

Researcher Only – Reflection on data collection

_____

_____

_____

_____

_____

_____

Appendix Six: Supplementary Tables

Table 2.   Respondent consistency over time points

Respondent	T1 (n=19)	T2 (n=16)	T3 (n=14)	Respondent included in all 3 data collections?
PID001	X	X	X	Y
PID002	X	X		
PID003	X	X	X	Y
PID004	X	X	X	Y
PID005	X	X	X	Y
PID006	X	X	X	Y
PID007	X			
PID008	X	X	X	Y
PID009	X	X		
PID010	X	X	X	Y
PID011	X		X	
PID012	X	X	X	Y
PID013	X	X	X	Y
PID014	X	X	X	Y
PID015	X	X	X	Y
PID016	X			
PID017	X	X	X	
PID018	X	X	X	
PID019	X	X		
PID020				
PID021				
PID022				

Table 3.   Gender at all time points

	T1	T2	T3
Male	8	7	6
Female	9	9	8
Prefer not to say	1	0	0
Missing	4	6	8
Total	22	22	22

Table 4.   Age groups by time points

	T1	T2	T3
18-24	0	0	0
25-29	6	7	4
30-34	4	2	3
35-39	1	1	0
40-44	0	0	0
45-49	4	3	3
50-54	1	1	2
55-59	2	2	1
60-64	0	0	1
65+	0	0	0
Prefer not to say	0	0	0
Missing	4	6	8
Total	**22**	**22**	**22**

Table 5.   Ethnicity by time points

	T1	T2	T3
Born in UK, Jamaica heritage	1		
White British (and variants)	16	9	9
White British / half Egyptian	1	1	

Black African	0	1	
British (and variants)	0	4	1
White	0	0	2
Black	0	0	1
Missing	4	7	9

Table 6.   Marital status by time points

	T1	T2	T3
Married	1	1	1
In a relationship	4	7	6
Single	11	7	6
Prefer not to say	2	1	1
Missing	4	6	8
Total	**22**	**22**	**22**
Missing	4	7	9

Table 7.   Work status by time points

	T1	T2	T3
Full-time paid	1	0	2
Part-time paid	1	3	6
Volunteering	8	5	1
Unemployed	7	5	4
Prefer not to say	1	2	0
Missing	4	7	9
Total	**22**	**22**	**22**

Table 8.   Living situation by time points

	T1	T2	T3
Living alone	0	1	1
Living with family	8	8	4

Living with spouse / partner	1	1	1
Supported accommodation	6	5	6
Other	2	0	1
Prefer not to say	0	0	0
Missing	5	7	9
Total	**22**	**22**	**22**

Table 15. Other 'service' use, across all time points. Multiple responses per respondent.

Activity	Number of mentions
Other Mencap	5
Church	5
Sport	4
Dance / disco	4
Web / internet / computer	4
MAPS in deal	4
Choir / singing	3
Fitness	3
Maths	2
Riverside club – youth club	2
Gateway club	2
Other single mention (for example film night, slimming world, bingo, bird watching, drama)	14
Don't know	2

Table 16. Other arts involvement

Activity	Number of mentions
Dancing / disco	10
Art / colouring	8
Other choir /singing	7
Music	4
Fitness	4

Karaoke	3
Painting	2
Bingo	2
Tambourine	1
Drums	1
DJing	1
Listen to Elvis	1
Swimming	1
Bocca	1
Outdoors	1
Drama	1
Writing	1
Photography	1
Cooking	1
Folkestone Hall events	1
Shopping	1
Quiz	1
Bowling	1
Monday club	1
Tuesday MAPS	1
Everything	1
No / none	4

Table 17. Other arts involvement (summary codes)

Activity	Number of mentions
Music	18
Fitness / movement	17
Arts	13
Other	10
No/none	4

Table 18. Summary of responses to question about whether respondent thinks they have a learning disability

	T1	T2	T3
Yes and variations	14	13	11
No and variations	3	1	1
Don't know		1	1
Other response	1	1	

Table 19. Summary of responses to question about whether respondent thinks they were treated differently because of their learning disability

	T1	T2	T3
Yes – treated badly / worse	4	6	2
Yes – treated better / well	1	1	2
Yes – not specified how / not clearly better or worse	3	2	6
No – not treated differently	5	2	4
Other	4	2	5
No response	1	3	

Table 20. What did you like most about the choir? (Summary)

Summary code	Mentions
Singing / enjoyment of singing / music	17
Socialising / being with friends	10
Happy / makes me happy and variants	2
Other	6

Table 21.   How did you feel about performing in front of people? (Summary)

Summary code	Mentions
Enjoyed it / happy / other positive	22
Nervous	5
Not nervous	3
Mentions of family	2
Confident	1

Table 22.   Improvements to the choir

Code	Responses
Different / more songs	5
Performing with other choirs	2
Dancing / disco	2
Warmups / drama games	2
Performing at other venues	1
More people in choir	1
Toilet break	1
Singing workshops	1