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ORIGINAL ARTICLE



Musical preferences of people with profound intellectual and multiple disabilities: A participatory design with proxies

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Abstract

Background: Inclusive research advocates for the involvement of people with intellectual disabilities to be more than passive participants within the research process.

Methods: This study used a participatory design with proxies to consult with 13 people with profound intellectual and multiple disabilities, on their musical preferences. Four instrumental listening tracks were created for consideration. The expected outcome was that people with profound intellectual and multiple disabilities would contribute to the codesign and development of a Musical Play framework. The study took place in England.

Findings: Proxy reports suggested that elements of music such as the tempo, tonality and instrumentation influenced the participants' responses. Responses were mixed across all tracks, indicating that the musical preferences of people with profound intellectual and multiple disabilities are variable and individualised.

Conclusion: Further exploration of how people with profound intellectual and multiple disabilities can contribute to inclusive research is recommended.

KEYWORDS

coresearchers, inclusive research, musical preference, participatory design with proxies, profound and multiple learning disabilities (PMLD), profound intellectual and multiple disabilities (PIMD)

Accessible summary

- Everyone should have the chance to contribute to research.
- It is difficult for people with profound disabilities to contribute to research.
- Using creative research methods and involving a parent/carer can support people with profound disabilities to contribute to research.
- By using an online listening experience some people with profound disabilities could contribute their experiences to research.

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1 | INTRODUCTION

Recently, there is an increasing acknowledgment of the responsibility that researchers have to include people with profound intellectual and multiple disabilities within the research process (de Haas et al., 2022; Nind & Strnadová, 2020). In the last 25 years, the expansion of the movement 'Nothing about us without us' (Charlton, 1998; Shakespeare, 2006) has led to the understanding that best practice research, which includes participants with intellectual disabilities, should also include people with intellectual disabilities within the research process (Nind & Vinha, 2014; Walmsley et al., 2018).

This study used a participatory design with proxies (PDwP) approach (Frid et al., 2022; Hamidi et al., 2017) to consult with people with profound intellectual and multiple disabilities on their responses to four instrumental tracks, composed specifically for this study. An exploratory listening experience survey (adapted from Sue & Ritter, 2012) was developed. To set the context, a brief overview of inclusive research, including research with proxies is provided, followed by an outline of the role of music, and a description of the listening experience used within this study. The findings of the consultation with people with profound intellectual and multiple disabilities are then presented and discussed. At the end of the paper, the advantages and limitations of codesigning using this approach are considered.

1.1 | Background

Including people with intellectual disabilities within the research process aims to highlight and reduce the imbalance of power between the researcher and the researched. People with lived experience of disability can contribute to research that may directly influence their population, providing insights that may previously have been overlooked (Aldridge, 2007; Shakespeare, 2022). Although there are various levels of participation people with intellectual disabilities may have within the research process, most research that includes people with intellectual disabilities as more than participants, for example, in the role of coresearcher (Riches et al., 2020), codesigner, author, and so forth (Haigh et al., 2013), involves people with mild and/or moderate intellectual disabilities (Cluley, 2016). People with profound intellectual and multiple disabilities adopting additional roles other than participant within research is relatively very limited, possibly due to the complex ethical and practical considerations researchers must navigate when working with this population (de Haas et al., 2022).

People with profound intellectual and multiple disabilities often have a profound intellectual impairment combined with physical disabilities, sensory impairment/s and/or complex medical conditions. Although there is no universally agreed definition for this population (Nind & Strnadová, 2020), most people with profound intellectual and multiple disabilities use idiosyncratic, non-formalised methods of communication (Colley & Tilbury, 2021). The profound cognitive

disability, and individualised communication methods of this population mean that it is often perceived to be particularly difficult to involve them in the research process (Beail & Williams, 2014). Informed consent from people with profound intellectual and multiple disabilities is also compromised due to their level of cognitive functioning. Therefore, it is necessary to identify a consultee, or proxy, who can act on behalf of the participant, and establish a medium of determining ongoing assent from the person with profound intellectual and multiple disabilities, throughout their period of involvement (Mietola et al., 2017). Additionally, conventional research tools used to generate feedback in the participatory design process, such as interviews and questionnaires, are unsuitable for use with this population. Instead, novel and creative approaches are necessary if people with profound intellectual and multiple disabilities are to be present and active contributors to the research process.

Inclusive research has the possibility to reposition and reshape the relationships of individuals involved within the research process. Potential passive subjects of research can be involved as active contributors (Walmsley et al., 2018), in turn co-creating knowledge that is representational and inclusive of the perspectives of the population. In a review of inclusive research with people with profound intellectual and multiple disabilities, Gjermestad et al. (2022), reported that all nine reviewed studies used proxies or significant people within their study design. This need for researchers to utilise pre-established relationships when researching with this population acknowledges the complex communication methods people with profound intellectual and multiple disabilities use, and the significant amount of time and familiarity needed to comprehend these (Frid et al., 2022). McCormack (2020) discussed the role of the proxy within the context of distributed competence (Goodley, 2001, cited in McCormack, 2020). Using this approach, a significant person, such as a parent or carer, is viewed as an expert in interpreting the communications of the key participants to make their communications discernible to the researcher. This viewpoint supports the understanding that all communication, regardless of ability, is 'co-constructed' (de Haas et al., 2022, p. 159), and that the use of proxies does not necessarily negate the data generated. Therefore, including people with profound intellectual and multiple disabilities in participatory design will inevitably involve contact with a significant person or proxy, such as a parent, sibling or advocate, and an acknowledgement that feedback will likely be coconstructed, through alternative communication methods (Frid et al., 2022; de Haas et al., 2022).

1.1.1 | Music

Emotional responses to music are highly individual and context specific. Listening to music may elicit both affective and/or cognitive-emotional responses (Carlson, 2015; Hynes & Mason, 2016). Music can influence the emotions and behaviour of the listener, regardless of their cognitive abilities or age (Solms, 2022; Trevarthen, 2002), and

is reported to be motivating for children and young people with profound intellectual and multiple disabilities (Rushton & Kossovaki, 2022). However, understanding how, and why these responses occur continues to present ambiguity.

While some research has been conducted into the effect of listening to music on typical adult populations (Lamont, 2011; Västfjäll et al., 2012), and those with less profound intellectual disability (Hooper et al., 2011), these studies used self-reporting data collection methods, which are unsuitable for people with profound intellectual and multiple disabilities. The above studies found that participants reported certain characteristics within music elicited specific emotional responses and preferences (Juslin & Laukka, 2004; Lundqvist et al., 2009). Findings from a previous study (Rushton & Kossovaki, 2022) suggest that some people with profound intellectual and multiple learning disabilities have musical preferences which can be communicated to parents/carers. However, it has to be mentioned here that Rushton and Kossovaki (2022) gathered viewpoints and perspectives from parents/carers, without including individuals with profound intellectual and multiple disabilities in the research process directly. In contrast to this, the exploratory listening experience and participatory design with proxies methods used within the present study allowed people with profound intellectual and multiple disabilities to express their responses and perspectives as active consultants.

1.2 | Aims of the research

This study formed part of a larger research project investigating the introduction of a Musical Play framework on the play experiences of young people with profound intellectual and multiple disabilities. The Musical Play framework includes principles of practice and suggested musical stimuli, to facilitate opportunities for playfulness with people with profound intellectual and multiple disabilities; see Rushton and Kossovaki (2020) for an earlier version of the Musical Play framework.

Combining prerecorded instrumental backing tracks with percussion instruments, the Musical Play framework is intended to be used to support nonmusic specialists to facilitate opportunities for feelings of playfulness, with and for, people with profound intellectual disabilities. The larger research project, of which this study is the first phase, investigated the effect of introducing Musical Play sessions with children and young adults with profound intellectual and multiple disabilities, and their supporting staff, in two educational

settings in England. In writing this paper the authors wish to draw attention to the contributions of people with profound intellectual and multiple disabilities, which influenced the development of the musical content used in subsequent research. The findings of this phase of the study influenced the musical stimuli used during later Musical Play sessions and further Musical Play research.

Specifically, the three main aims of this study were:

- To consult with people with profound intellectual and multiple disabilities and their parents/carers.
- Reduce researcher hierarchy as part of a larger study.
- Develop awareness and understanding of the responses of people with profound intellectual and multiple disabilities to different elements within prerecorded instrumental music.

1.3 | The instrumental tracks

To consult with individuals with profound intellectual and multiple disabilities on different musical elements, such as modality, tempo, rhythm, instrumentation and so forth, four instrumental tracks, lasting around 1-min each were created by the first author, who has a musical background. A review of studies that looked at the effects of music on emotion found the average length of stimuli was around 30–60 s (Eerola & Vuoskoski, 2013). The longer length, of around 60 s was thought to be most suitable for listeners with profound intellectual and multiple disabilities, who often need more time to respond to external stimuli (McCormack, 2020). It was not intended that the tracks prove, or disprove the effect of a particular musical element, rather the aim was to gather opinion; considering if there were any trends, or commonalities, in the preferences of those taking part.

The instrumental tracks were piloted with both musicians, and professionals working with people with profound intellectual and multiple disabilities, such as teachers, teaching assistants and personal assistants, who were not necessarily musicians ($n = 14$). Feedback was gathered on the musical content, general mood of the track, and personal preferences. After piloting the tracks, several changes were made including, adding additional harmony lines to consolidate the modality of each track, dynamics, and the structure of the tracks.

A basic description of the four instrumental tracks used in the online exploratory listening experience are presented in Table 1.

TABLE 1 A basic description of the four instrumental tracks* used in the online survey.

Track No.	Basic description of musical elements	Tempo (speed) (beats per min)
1	Major tonality, simple melodic line, and a I, IV, V chord progression, typically used in Western pop music. Marimba and brass instrumentation with shuffle rhythm.	125
2	Unpitched, percussion instruments, strong pulse	70
3	Modal, South Asian, Bollywood style. Bells, percussion, and sitar instrumentation.	98
4	Minor tonality. Chimes, clarinet, and mark-tree instrumentation.	76

*The audio of all four tracks can be found using the following link: <https://www.youtube.com/@musicalplayresearch>.

2 | METHODOLOGY

2.1 | Ethics

Ethical approval for this study was granted by the Research Ethics Committee, England (REC 21/LO/0674) as part of the wider research project it fell within. It also abided by the British Educational Research Association's guidelines for educational research (BERA, 2018). All parents/carers acted as proxies and gave written consent for the person with profound intellectual and multiple disabilities to take part. Further, to reduce potential distress, parents/carers were encouraged to skip any of the listening tracks, or stop the listening experience, if they felt this was causing distress to the individual with profound intellectual and multiple disabilities, thus establishing a process of ongoing assent from the participants.

2.2 | Methods

The study used a participatory design with proxies approach (Frid et al., 2022; Hamidi et al., 2017). Participatory design is a methodology that supports shared learning, through the codesign of a future intervention, product, or concept, where research includes and learns from those for whom the concept is intended (Cumbo & Selwyn, 2022). Participatory design with proxies is an adaptation of participatory design, in which proxies are identified and included to relay knowledge generated from the participant (potential future user) to the researcher. An online exploratory listening experience survey (adapted from Sue & Ritter, 2012) was used to collect data. Due to the sensory-based disposition of participants with profound intellectual and multiple disabilities (Grace, 2017), participatory processes needed to be facilitated through tangible or auditory means. The 'real' examples, objects or sounds under consideration needed to be presented to gather feedback from this population. For this reason, the first author created four exploratory listening tracks which provided audible musical elements for the participants, people with profound intellectual and multiple disabilities, to consider. These methods were used with the aim to codesign and further develop elements of a framework (see Rushton and Kossyvak, 2020 for an earlier version of this design) with people with profound intellectual and multiple disabilities.

The online exploratory listening experience survey gathered both quantitative and qualitative data and included 18 questions in total, 12 open-ended and 6 close-ended questions, as well as four exploratory instrumental tracks. The survey was created using Qualtrics, an online survey platform, which enabled the researcher to embed both video and audio content into the survey. The survey was available for a period of 4 weeks, after which participation was likely to cease (SurveyMonkey, n.d.). A link to the online survey was shared by the three authors with gatekeepers, including schools, parent-carer groups, and on social media platforms (i.e., Twitter and Facebook).

The survey was developed in three sections (see Supporting Information: Appendix 1 for a blank copy of the survey). Section 1 collected demographic information on the participants. Section 2 was designed to prompt parents/carers to consider the communicative behaviours of the participant. This section was developed with the aim to guide parents/carers to think about the interactions and behaviours participants had previously used to communicate their views, before acting in the role of proxy (Cobb, 2018). It was hoped that this approach could support the accuracy of the proxy reporting during Section 3 of the survey. For example, parents/carers were first asked:

'Thinking about the communication of the person with PIMD contributing to this research please answer the following questions. They communicate their mood using actions and sounds? (These might be big or small)'.

This was followed by more detailed questions regarding the communication of their child/young person's specific mood, for example;

'How do they communicate their good mood? (What does this look like in their actions and sounds)'

How do they communicate when they are upset? (What does this look like in their actions and sounds)'.

In Section 3 the parents/carers acted as a proxy for the participant during the listening experience and noted the responses of their child/young person.

The survey questions were piloted with parents/carers of people with profound intellectual and multiple disabilities ($n = 4$), who were known to the first author. Consideration was given to the grammatical person used in the survey (i.e., first or third person) to address 'who' was being identified as the participant within the study. As the study was being conducted using proxy methods, but with the view to ascertain the responses of the participant with profound intellectual and multiple disabilities, two versions of the survey were created, in first and third person, and piloted. Third-person language was selected by all parents/carers who were part of the pilot. Further, to improve understandability a video guide, explaining how to take part in the exploratory listening part of the survey, was created and added at the beginning of the survey.

2.3 | Sample

A self-selected purposive sampling method was used (Emmel, 2013). Participation was limited to individuals living in England due to the ethical approval obtained (Research Council England). Potential parents/and carers of participants were provided with the following description to help ensure that their child/young person met the criteria to contribute to the research.

TABLE 2 Inclusion criteria for the online listening experience purposive sample.

Inclusion criteria young person (participant)	Inclusion criteria adult (respondent)
Aged 5–25 years.	The primary caregiver or parent of an individual with PIMD as defined by the Core and Essential Standards (Doukas et al., 2017).
An individual with PIMD as defined by the Core and Essential Standards (Doukas et al., 2017).	Regular access to the internet to access the survey.
	Adequate computer literacy skills to complete the survey.
Male or female.	Male or female.

'People with Profound [Intellectual] and Multiple disabilities are a heterogeneous group of people with a profound intellectual disability, often combined with additional disabling conditions such as physical disabilities, sensory impairments and complex medical needs.' (Doukas et al., 2017).

The characteristics of the sample are described in the inclusion criteria in Table 2.

3 | FINDINGS

A total of 50 respondents (parent/carers) completed some part of the survey (beyond the consent page). Twenty-six respondents (52%) completed over 70% of the survey. However, most of these respondents failed to complete the exploratory listening experience part of the survey (Section 3). Thirteen surveys were fully completed. Quantitative data generated by the completed surveys were visually analysed using Microsoft Excel. Qualitative data for each track, generated from the free-text-box responses, was thematically analysed (Braun & Clarke, 2006).

The results of the 13 complete surveys, in which the responses of participants with profound intellectual and multiple disabilities were reported via proxy, are presented for discussion within this paper. Demographic details of the participants are provided in Table 3.

There could be numerous reasons parents/carers did not complete Section 3 of the survey. However, after further consideration using the Qualtrics platform, the timings in which the surveys were completed suggests that the individual with profound intellectual and multiple disabilities may not have been present when parents were accessing and responding to the survey. Data showed around half ($n = 6$) of the 13 respondents, who completed over 70% of the survey, but did not complete Section 3, accessed the survey between 21.00 and 23.30 h. Likely the person with profound intellectual and multiple disabilities was not available during this time. This may suggest that some parents/carers access online surveys and contribute to research when their child/young person is asleep, as they then have fewer active responsibilities. Further, it may highlight an attitudinal viewpoint of parents/carers who must often advocate or represent their child/young person independently of them (Wright & Taylor, 2014).

TABLE 3 Demographic information of participants with profound intellectual and multiple disabilities, who participated in the exploratory listening experience survey (Section 3).

Age (years)	Gender	Ethnicity
5–10	$n = 4$	Female $n = 7$
11–16	$n = 6$	Male $n = 6$
17–25	$n = 3$	White $n = 10$
		Asian $n = 1$
		Black Caribbean $n = 2$
		and White

To gather the perspective of people with profound intellectual and multiple disabilities, parents/carers were asked to describe how their child/young person responded to each of the four tracks. This produced both quantitative (see Figure 1) and qualitative data. Key themes for each track were generated from thematic analysis of the qualitative data provided in the open-ended textboxes (see Table 4). Responses to specific musical elements within the tracks, such as instrumentation and rhythmic elements, were also highlighted in the descriptions provided by parents/carers in their role as proxies.

The proxies reported mixed feedback from participants across all four tracks (see Figure 1). There were positive responses across all tracks, however, there were a greater variety of responses to tracks 2 and 4.

The feedback for tracks 1 and 2 was mixed. Although generally gaining positive responses ($n = 9$), track 1 caused one participant to be 'startled when music started playing', and for another participant, it was 'not what he wanted to listen to'. As track 1 was the initial musical stimulus within the listening experience (Section 3), and environment and preparation that each participant experienced before taking part were unknown, it is understandable that introducing a novel stimulus into their environment (track 1) may have been disruptive or startling. Perhaps if the order of tracks had been different for each participant these responses may have been different as well. Future consultations, in which the order of the stimuli participants are presented with is randomised would further develop understanding of the impact of this.

Track 2 was unpitched, and percussive with a strong beat and a deliberate absence of any melody line. Seven participants responded positively to the track, however, four proxies reported that participants gave 'no clear response' to the track and one reported a negative response. The lack of clarity in response may have been due to the absence of any melody line or pitched instruments.

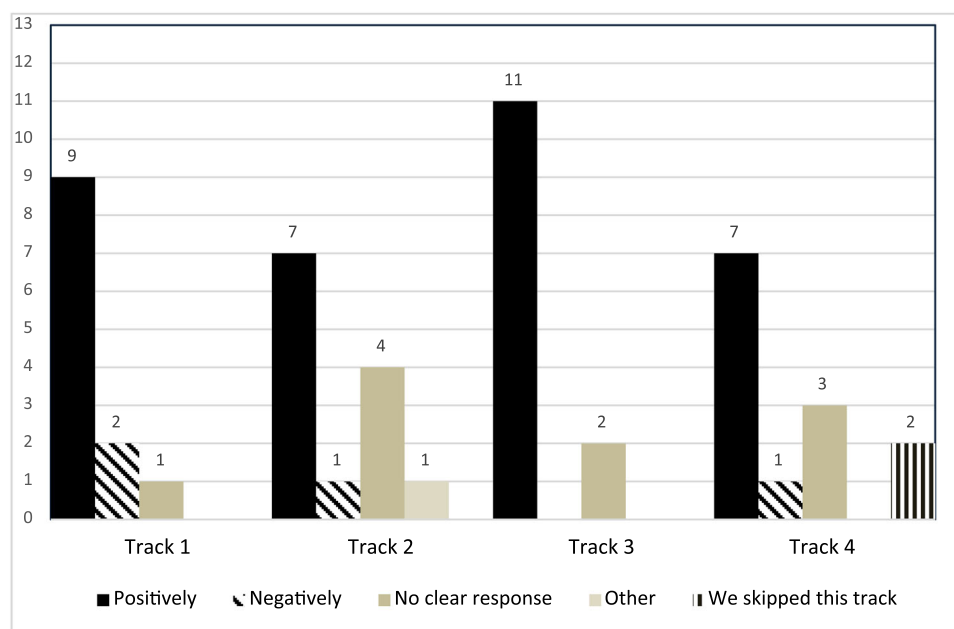


FIGURE 1 Participant responses to instrumental tracks as recorded by proxy reporting. [Color figure can be viewed at [wileyonlinelibrary.com](https://onlinelibrary.wiley.com/doi/10.1111/ndd.12524)]

Track No.	Basic description of musical elements	Key themes
1	Major tonality, simple melodic line and popular I, IV, V chord progression. Marimba and brass instrumentation with shuffle rhythm.	'Smiling' 'Alert'
2	Unpitched, percussion instruments, strong pulse	'Smiling'
3	Modal, South Asian, Bollywood style. Bells, percussion, and sitar instrumentation.	'Increased movement'
4	Minor tonality. Chimes, clarinet, and mark-tree instrumentation.	'Calm, stilling'

TABLE 4 Key themes generated for each track using thematic analysis.

Two participants responded positively to the beat. This was evidenced in comments such as; 'liked the "boom" beat', and 'seemed to like the beat'.

'She loved this! I was surprised by such an instant reaction. For the first few seconds she listened intently, then she rested her mouth, chin and then cheek on the speaker to feel the vibrations. She then started smiling, followed by lots of giggles. She was chuckling and giggling out loud for the whole of the track. We played it 2 more times and had the same response. We were all laughing out loud!' (Response to track 2)

Track 3 received the most ($n = 11$) positive responses. Track 3 had South Asian musical influences, was at a relatively upbeat tempo (98 bpm), and used bells and percussion in the instrumentation (see Table 4). This track received no negative responses from the participants (see Figure 1). The descriptions, provided through proxy reporting,

suggested that some participants ($n = 2$) responded to the specific instrumentation of the track. This was evidenced in comments such as; 'noticed the bell sounds,' and 'she appeared to like parts of the track especially the bells.' Interestingly, specific attention to musical instrumentation was not noted for the other tracks.

Two participants requested to listen to this track more than once.

'He didn't get cross - which is very unusual when listening to something for first time. Stayed silent and curious no vocalisations. Hands opening on lap and relaxed. Managed to listen to the whole piece. Also smiled at listening for the second time. Staying silent (was shouting when no music was playing). When asked if he wanted it again, he said yes (single vocalisation and smiled)' (Response to track 3)

'When the music stopped, she prompted it to be played again by lifting her head up and down on the speaker.' (Response to track 3)

The findings suggest that track 4 gained fewest positive responses. Two proxies reported that they skipped track 4, and a negative, or 'no clear response' was recorded for four of the participants (see Figure 1). One participant communicated their dislike of the track by 'remov[ing] hearing-aids'. The musical differences in Track 4, which was created in a minor modality and at a slower tempo were clearly identified by the participants, and when tolerated received 'calm', 'contemplative' and 'stilling' responses.

4 | DISCUSSION

The aim of this research was to consult with people with profound intellectual and multiple disabilities, using participatory design with proxies, to inform the design of the Musical Play framework, in doing so reducing researcher hierarchy. The methods used co-created knowledge inclusive of the perspectives of people with profound intellectual and multiple disabilities. As far as the authors are aware, this is one of the first studies to include people with profound intellectual and multiple disabilities in the codesign and development of an innovation intended for use with, and by, this population. Additionally, this study directly consulted with people with profound intellectual and multiple disabilities on their musical preferences, using a format which was accessible and relevant.

The study proposed ways to develop inclusive research practice to involve people with profound intellectual and multiple disabilities. Consideration was given to the development of the survey to support parents/carers in their role of proxy. This included an explanatory video, followed by guided prompt questions, before parents/carers and participants with profound intellectual and multiple disabilities accessed the four listening tracks. The exploratory survey was designed to be an easy and convenient method of consultation, as the time-demands of parents/carers supporting people with profound intellectual and multiple disabilities are high (Tadema & Vlaskamp, 2010). This study required the person with profound intellectual and multiple disabilities to actively contribute to the survey (Section 3). However, findings suggest that some parents/carers were completing surveys on behalf of their child/young person without them being present. The response rate, and drop-out point, of parents/carers completing the exploratory listening experience (Section 3) with the participant with profound intellectual and multiple disabilities was notable. Parents/carers may not be familiar with their child/young person actively participating in research. This perception may be a result of historic research cultures, which have excluded people with profound intellectual and multiple disabilities as active contributors (Cluley, 2016; de Haas et al., 2022). Additionally, the need and familiarity for parents of children with disabilities to advocate or act as proxy for their child, without them being present (Boshoff et al., 2016), may also have contributed to the low response rate in the exploratory listening experience (Section 3) of the survey. Alternative in-person data collection methods may have increased participation, further research is recommended to investigate this.

Considering the knowledge coconstructed from this study, findings suggested that people with profound intellectual and multiple disabilities are responsive to various elements within music. This includes the instrumentation and rhythmical components. The results for each track were mixed, suggesting that musical preferences are variable and individualised. However, overall tracks which were composed using modal or major tonality were preferred over minor tonality. More positive responses were expressed for the tracks which were at a faster tempo (tracks 1 and 3). Further to this, track 2, which included strong rhythmical elements, also received positive responses from the participants according to their parents/carers. Feedback from the proxies, in response to the music elements included within each track, goes some way to echo the findings of previous self-reporting studies conducted with nondisabled populations. These studies found that 'happy' music was associated with being in a major tonality, faster tempo (speed) and louder volume, such as tracks 1 and 3. In contrast, music was perceived to be 'sad' when it was quieter, at a slower tempo and with minor tonality, components which were included in track 4 (Juslin & Sloboda, 2013; Juslin & Laukka, 2004; Lundqvist et al., 2009).

Building on this consultation phase, elements of the Musical Play framework should include instrumental music composed in a major key, at an upbeat, faster tempo as part of the musical playlist. Additionally, music which has strong rhythmic elements, and uses instruments such as bells could also be included. Further to this, there should be an option to vary the musical stimuli used within the Musical Play framework to the individual preferences of each of the participants with profound intellectual disability.

Following this consultation phase, Musical Play sessions were implemented across two educational settings in England. The Musical Play playlist provided for practitioners to use in the delivery of these sessions was developed from the findings of this phase of the study. The playlist included instrumental music which had similar elements to those highlighted as preferences. For example, one track had no melodic line, but a repetitive strong pulse at a relatively upbeat tempo. Tracks that included pitch were in a major key, and most tracks were at a faster tempo. Some additional music and/or artists which had been noted as preferences by parents/carers, were also included in the Musical Play playlist. The playlist remained malleable to the musical preferences of the individuals with profound intellectual and multiple disabilities and the practitioners taking part in the Musical Play sessions. Tracks could be added to, or removed from, the playlist throughout the period of implementation.

4.1 | Limitations

There are several limitations when considering the participatory methodology and findings of this study. Participants with profound intellectual and multiple disabilities took part in this consultation because of their parents/carers' self-selection. Although quite unlikely, some parents/carers may have taken part in the survey despite their child/young person failing to meet the inclusion criteria.

This is a common limitation for surveys (Gravetter & Forzano, 2015). Despite this, the wide demographic and geographical reach, as well as the convenience of an online self-selective survey (Evans & Mathur, 2005), combined with the constraints imposed by Covid-19, meant that the online survey was the most appropriate tool for this study.

Participatory design with proxies relied entirely on the interpretation and documentation of the parent/carer. The design of the study assumed that this accurately reflected the communication and contributions of the person with profound intellectual and multiple disabilities. However, as previously discussed, communicative responses may have been misinterpreted, over-interpreted or unrecorded (Nind, 2013; Ware, 2012). The relationship of the proxy to the person with profound intellectual and multiple disabilities, along with their home situations (i.e., family home, residential housing) was not collected. The difference in these relationships and roles may have affected the interpretation and documentation of individual responses. Using multiple proxies for each participant, such as teachers or personal assistants, alongside parents/carers, and combining these, may have increased the reliability of the findings, and offered alternative interpretations of participants' responses. A further limitation regarding engaging parents/carers as proxies was that due to the anonymity of participation, and time constraints of the wider research project, it was not possible to consult with parents/carers after their participation to discuss their experiences of the survey. As a result, there was no further data gathered to enable the researcher to understand how the data collection methods could be altered or improved.

It may have been possible for the preference and responses to the musical stimuli to be collected directly from the participants with profound intellectual and multiple disabilities, through direct observation by the researcher. Due to the subtle and idiosyncratic means of communication, researchers working with people with profound intellectual and multiple disabilities require prior knowledge, understanding and experience of the population to gather accurate data (Ware, 2012). Additionally, extended periods of time to establish and develop relationships with participants is necessary (Mietola et al., 2017). This was not possible due to time limitations. So, to gain a breadth of responses in this consultation phase the researcher utilised the knowledge of pre-established relationships (Frid et al., 2022). Furthermore, this research was conducted during the Covid-19 pandemic, as such direct observations may have posed a risk to the participants and the researcher and would likely have been disrupted.

There was limited musical content within the four tracks, and a range of devices may have been used to listen to the tracks, varying the experience of each participant. However, the aim of this study was not to prove, or disprove the effect of a particular musical stimuli received in a controlled way. Rather, the study was undertaken as participatory inclusive research, to gather feedback from people with profound intellectual and multiple disabilities, via proxies who know them well, and create a more collaborative research process to inform decisions made at later stage of this study.

5 | CONCLUSION

People with profound intellectual and multiple disabilities have numerous routines, many of which are often life-sustaining (Tadema & Vlaskamp, 2010), that are conducted to, and for them daily (Doukas et al., 2017). As subjects of research, done 'to' or 'about' them, people with profound intellectual and multiple disabilities may continue to fulfil this passive role. However, attitudes and perceptions towards this population continue to shift, and individuals with profound intellectual and multiple disabilities are beginning to be recognised as active contributors within their interactions, relationships (Nind & Strnadová, 2020), and more recently within research (de Haas et al., 2022).

Communications between people with profound intellectual and multiple disabilities and those that know, love, and support them may always be ambiguous and reliant on interpretation. However, the same is true for communications between all people; all communication is open to misinterpretation, may be unrecognised, or successful (Mietola et al., 2017). Whenever possible, utilising the knowledge and experiences of multiple proxies during participatory design with proxies, such as parents, siblings or personal assistants, may generate a more objective and co-constructed viewpoint (Lyons et al., 2017). Nevertheless, the limitations of understanding, interpreting, and reporting the communications of people with profound intellectual disabilities should be acknowledged (Cluley, 2016).

Still, devaluing the communicative responses of people with profound intellectual disabilities because they may require the interpretation of proxies further marginalises, isolates, and silences this population. Using creative research methods to include people with profound intellectual and multiple disabilities within participatory design may enable researchers to develop greater understanding of their preferences, and an increased awareness of the usefulness and relevance of the product/concept being designed. Opportunities for people with profound intellectual and multiple disabilities to contribute to the development of the products/concepts they may access in the future, acknowledges their viewpoints and perspectives as valid and worthwhile, and repositions them as active contributors rather than passive subjects within research.

People with profound intellectual and multiple disabilities will never be able to conventionally analyse data, comprehend or write for journals such as this. However, with consideration and creative methods they can shape, contribute and codesign the research that they are a part of, and we as researchers can continue to learn from the lived experiences and expertise they share.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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