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The role of music within the home-lives of young people with profound and multiple learning disabilities: Parental perspectives

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Accessible summary

- Music is often part of our lives.
- We asked parents what music is like for children and young people with profound learning disabilities at home.
- People listened to music more than they made music at home.
- Music is used for different reasons.
- Music can help families feel more connected.

Abstract

Background: Music is weaved within our cultures; it is ever-present within daily-life and can considerably influence our mood, well-being and relationships. This study explores parental perceptions of the role of music in the home-lives of children and young people with profound and multiple learning disabilities in the UK. It considers parental views of how listening to and making music can shape the mood and behaviours of their child and their relationship.

Methods: Using a mixed-method explanatory sequential design and cross-sectional survey methodology, the study collected data from parents and carers of children and young people with profound and multiple learning disabilities. Data were collected from an online questionnaire ($n = 48$) followed by online one-to-one interviews ($n = 10$).

Findings: Parents reported that children and young people with profound and multiple learning disabilities more frequently listen to music than make music within the home. They also stated that music is used for enjoyment, to support mood-regulation and to add structure to the lives of young people with profound and multiple learning disabilities. Parents finally reported that listening to music together helps families feel more connected and strengthened their relationships.

Conclusion: This paper outlines the positive role music may have in the home lives of people with profound and multiple learning disabilities and their families.

KEYWORDS

home, music, parents' perspectives, profound and multiple learning/intellectual disabilities

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1 | INTRODUCTION

Music is an intrinsic part of human life; its presence is weaved within our cultures, and it can have a considerable emotional effect upon all individuals (MacDonald et al., 2017). Ever-present within our daily lives, it fulfils both an individual and social need (Clayton, 2009), experienced as a solitary and social activity. Music connects us to people, places and events; it can evoke powerful personal responses (Hallam & MacDonald, 2013). Its informal presence within the home and its impact on child development throughout the early years has been of growing research interest (Young, 2008). However, although music has been identified as a medium to engage and motivate people with profound and multiple learning disabilities (Ockelford, 2008), little is known of its presence and use within home-life.

Readily available (Krause et al., 2015), technological advances mean that the accessibility, ease, and variety of music to listen to are ever-increasing (Sloboda et al., 2009). The prominence of music within daily life continues to increase (Krause et al., 2015). Studies reveal that psychological and physiological effects of music can be experienced by all humans, from the earliest stages of life (Juslin & Sloboda, 2013), regardless of an individual's physical or mental ability (Trevvarthen, 2002). Listening, responding and making music provide accessible and vital platforms for communication (MacDonald et al., 2017) creating opportunities for self-expression, social connectedness and individual empowerment (Murphy & McFerran, 2017). Individuals are empowered through creating music, which can influence their environment. Personal responses to music, which develop and support individual preference, also offer opportunities for empowerment. Considering these qualities, music has the potential to hold a valuable place in the lives of children and young people with profound and multiple learning disabilities.

The definition of profound and multiple learning disabilities, as provided by the Core and Essential Service Standards (Doukas et al., 2017), is adopted within this article. The term profound and multiple learning disabilities is used to describe a heterogeneous group of people with a profound intellectual disability, often combined with physical disabilities and sensory impairments (Doukas et al., 2017). The complexity of these needs often means that the children and young people are dependent on adult support to take part in most everyday activities. As a result of this, and disabling barriers within society, people with profound and multiple learning disabilities are likely to spend the majority of their free time at home (Petry et al., 2005). Better understanding of how to engage children with profound and multiple learning disabilities within home-life is therefore essential. Identifying and making these strategies explicit may enhance participation (Axelsson et al., 2014) and strengthen relationships and resilience within the family (Luijkx et al., 2019).

Parent-child musical interactions are a traditional part of family life throughout the world (Custodero & Johnson-Green, 2003). These musical experiences (e.g. exchanges of song, rhythmical movement and vocal imitation) facilitate intimate parent-child interactions, without the need for the understanding of formal language (Zeedyk,

2008). The innate nature of these musical exchanges has been observed globally (Custodero & Johnson-Green, 2003). However, there is limited research on the prevalence of music in the everyday home-life of young children (Mehr, 2014). Further, the impact of informal shared musical experiences, on the social behaviours of children, remains largely unexplored (Williams et al., 2012). Previous studies of typically developing children (Mehr, 2014; De Vries, 2009; Young, 2008) all reported a high prevalence of pre-recorded music within the home. Spontaneous singing with parents also occurred frequently (Mehr, 2014; Young, 2008), making music and using instruments was less likely to occur. Young (2008) reported on the significance that attending external groups had on the musical repertoire parents were using at home, suggesting that parents may be "relying heavily on baby and toddler groups to learn the song and rhyme repertoire they use at home" (Young, 2008, 39). Whilst these studies capture the musical experiences of typically developing children, there are few studies which attempt to explore and quantify these experiences for children with disabilities (Thompson et al., 2014). Literature documents the impact of music therapy sessions, delivered in the family home, for children with disabilities (Nicholson et al., 2008; Pasiali, 2004; Williams et al., 2012). However, these interventions do not capture informal musical experiences, such as listening to music and spontaneous singing. Moreover, the studies do not baseline the musical encounters of their participants prior to the interventions resulting in little evidence of typical day-to-day musical experience of individuals with learning disabilities.

Previous studies reveal music to be highly motivating for people with profound and multiple learning disabilities (Ockelford, 2008), providing a platform for individuals to communicate without the need for formal language (Corke, 2002), through structured interactions (Ockelford, 2008) or spontaneous exchanges (Corke, 2012). Music influences environments, affecting the arousal and emotional levels of listeners and participants with profound and multiple learning disabilities (Corke, 2002), provides opportunities for playful interactions (Corke, 2012) and supports prolonged communications (Prevezer, 2000). Music also offers a platform to build relationships and facilitates the sharing of emotions and intentions (Hallam & MacDonald, 2013) which are all fundamental to effective family functioning (Luijkx et al., 2019).

The multiple and often conflicting roles that parents of individuals with profound and multiple learning disabilities fulfil within family life such as nurse, advocate, physiotherapist and emergency response (McCann et al., 2016) may impact on their physical and mental health (Whiting, 2014). Time-poor parents report that they are juggling schedules, relationships and responsibilities in order to meet the daily needs of their child (Mactavish & Schleien, 2004), creating strains within family relationships (Whiting, 2014). Despite this, studies show that play activities, between parent and child, are highly valued (McCann et al., 2016) and support feelings of unity within the family (Mactavish & Schleien, 2004). Whilst it is widely acknowledged that recreational activities, and the social opportunities these provide, are an important element to improving quality of life (Schalock & Felce, 2004), it remains a neglected area of

both disability and relationship studies. Research into the impact of these activities, for families with children with profound and multiple learning disabilities has been given minimal attention. Improved understanding of the factors which contribute to positive family relationships and effective family functioning (Mactavish & Schleien, 2004) may enhance family well-being.

The paper focuses on the musical experiences children and young people with profound and multiple learning disabilities encounter at home. More specifically, parental perspectives are explored to consider how these musical experiences influence the behaviours of children with profound and multiple learning disabilities and the parent-child relationship. The aims of the study were to investigate parental understandings of:

1. how children and young people with profound and multiple learning disabilities encounter music at home
2. how music influences the behaviours and mood of children and young people with profound and multiple learning disabilities
3. the role of music within the parent-child relationship

2 | METHODS

This study followed a mixed-method explanatory sequential design (Tashakkori & Teddlie, 2010). Within a cross-sectional survey methodology, both questionnaire and interview methods were used to collect data. Quantitative data via questionnaires were collected first, followed by qualitative data collected via follow-up online interviews with participants from the same sample. In this way, the research questions were explored with a larger sample, before expanding and exploring the findings in more detail, collecting qualitative data from a few cases (Creswell & Creswell, 2005). The quantitative and qualitative data are then integrated during the discussion section of this paper, a further characteristic of the mixed-method design.

2.1 | Sample

The population of people identified as having profound and multiple learning disabilities is relatively small, forming <0.1% of the general population of the UK (Emerson, 2009). A nonprobability convenience sample of parents/carers of people with profound and multiple learning disabilities aged 0-25 years was generated from the online questionnaire. Potential participants were provided with the Core and Essential Service Standards (2017) descriptor of people with profound and multiple learning disabilities on the research information form to help ensure their child/young person met the criteria for the study.

The questionnaire was distributed as an unrestricted, self-select survey, which was open to the public for anyone to access

for a period of five weeks (June-July 2020). The link was placed to reach the targeted population through social media networks. Organisations which work with people with profound and multiple learning disabilities in the UK were also contacted, and a request was made to share the link with their networks. A number of UK special schools known to the authors were contacted and asked to share the link with parents. The sample of interview participants was generated from individuals who had completed the questionnaire and indicated a further interest in contributing to the study.

2.2 | Data collection

2.2.1 | Questionnaire

The questionnaire, which was developed by the two authors, as to their knowledge, there was none pre-existing relevant and appropriate tool, aimed to establish trends in the musical experiences of children and young people within their homes and considered how these experiences influence behaviours and relationships. The online questionnaire, conducted using the Qualtrics survey platform, contained forty-two items, including open and close-ended questions. Five-point Likert scales were used to collect data on frequency, likelihood and attitudes (see Appendix S1 for a blank copy of the questionnaire). Questions were derived from existing literature on musical encounters at home and, family leisure experiences, as well as the authors' experience of working with families with profound and multiple learning disabilities. Within the questionnaire, music-making was defined as: "may include vocalising, singing, playing with musical instruments, playing with musical toys etc."

2.2.2 | One-to-one interview

One-to-one online interviews were conducted to increase the depth of qualitative data and gain a greater understanding of the impact of music in the home. Interviews lasted between 20 and 40 minutes, with a mean average of 26 minutes (see Appendix S2, for a blank copy of the interview schedule). The interview schedule was developed from existing literature on family home-life and music in the home, the questionnaire responses, as well as the authors' experience of working with families. The interview schedule gathered information on participants' home-life, behaviours of their child, importance of music on the parent-child relationship, parental experiences of music and parents' confidence levels in using music at home. Semi-structured interviews allowed for more flexibility to follow-up on themes which were believed to be important by the interviewees (Brinkmann, 2013). The semi-structured interview method was particularly appropriate for this study due to the diverse nature of children and young people with profound and multiple learning disabilities, allowing the uniqueness of each family's circumstance and experiences to be captured.

2.3 | Ethics

This research was undertaken with ethics approval from the University of Birmingham. It also abides by the British Educational Research Association's guidelines for educational research (BERA, 2018). All participants were provided with a description of the study and a consent form to indicate whether they are happy to participate. There was no incentive provided to any of the participants. All data sets were anonymously labelled and securely stored.

3 | RESULTS

Data were generated from questionnaires with over 70% completion; this level of completion was felt to include significant and valuable data (Lavrakas, 2008). Data from 48 individuals with parental/carer responsibility were analysed. Twenty-six questionnaire respondents indicated that they would be interested in being interviewed, and they were contacted by email. Ten responded to the email and agreed to take part in online interviews. Each interview was recorded and fully transcribed.

3.1 | Descriptive information on the participants

Descriptive information of the participants and the children/young people with profound and multiple learning disabilities are presented in Tables 1 and 2. Pseudonyms have been used throughout.

3.2 | Coding

Quantitative data obtained from the questionnaire were visually inspected and analysed. Transcribed data from the open-ended questions from the questionnaire and the interviews were coded using an abductive approach (Timmermans & Tavory, 2012a,b). The abductive approach allowed the first author to analyse the data using predetermined categories derived from the literature, whilst also remaining open to emergent themes and concepts within the data. Abductive analysis emphasises that, whilst data should be analysed with a broad knowledge of theory, the researcher should not be limited to pre-conceived concepts.

After familiarisation with the data, through reading and re-reading the transcripts, data were preliminarily coded using Nvivo 12 (NVivo, 2018). Data were first analysed deductively using literature-driven predetermined categories: frequency, resource and purpose. Data were then analysed inductively using the six-step process described by Braun and Clarke (2006) (see Appendix S3, for the code-trees). Quantitative and qualitative results are presented in themes aligned to the study's research aims.

TABLE 1 Demographic information of questionnaire respondents

Demographic information	N (%)
Role of respondent	
Mother	43 (90%)
Father	1 (2%)
Carer	3 (6%)
Grandparent	1 (2%)
Child/Young person's age in years	
Under 5 years	0
5–11	27 (56%)
12–18	14 (29%)
19–25	7 (15%)
Child's sex	
Male	29 (60%)
Female	19 (40%)

3.3 | Musical experiences of children and young people with profound and multiple learning disabilities at home

Data were collected on the parents' experiences of listening to music and making-music. The questionnaire was used to collect data on the *frequency* of these experiences, the *types of resources* used and their *purpose*. Interviews provided an opportunity to expand on the data and further explore these main themes. For example, interviewees were asked; "Is music part of the home-life and to what extent?".

3.3.1 | Frequency

In the questionnaire, parents/carers reported that children were more likely to listen to music at home than take part in active music making. Most children ($n = 44$; 92%) were reported to listen to music daily, and however, less than half ($n = 20$; 42%) were reported to make music daily. Further, some families ($n = 4$) reported that they "never" make music with their child at home (Figure 1).

In the interview, families ($n = 9$) discussed the high frequency in which listening to music occurred within the home, commenting: "an incredible extent, every day, several times a day" (Lisa) and "listening to music is a massive part of his day" (Melissa).

Making music at home happened less often. However, eight parents commented positively on the frequency of music-making experiences, such as:

...well my brother got him a guitar and he's been absolutely loving that really...he can sit for hours just playing.

(Melissa)

TABLE 2 Descriptive characteristics of interview participants (parents) and their child/young person

Parent	Parent Sex	Child/YP	Child/YP Age	Child/ YP Sex	Parental description of disability ^a
Lucy	Female	Minnie	9	Female	"Similar to cerebral palsy...affects everything. Her body and her learning, her cognition and her speech." "Not compatible with life kind of diagnosis."
Hannah	Female	Libby	9	Female	"Medical complexity" "her wheelchair" "profound needs"
Karine	Female	Lily	9	Female	"KAT6A Syndrome" "Severe learning disability, hypertonia and hyper flexibility... she uses a wheelchair."
Tracy	Female	Logan	9	Male	"PMLD...from brain conditions polymicrogyria and microcephaly"
Melissa	Female	Harry	10	Male	"Fox G1 syndrome...as a result of that he's got profound and multiple learning disabilities and a complex form of epilepsy, that's life threatening and life limiting and he has a visual impairment as well and is tube fed, and he's a wheelchair user"
Sue & Dave	Female & Male	Joe	11	Male	"PMLD it's a rare genetic condition called SCN2a" "epilepsy and autism, but his is more epilepsy" "uses a wheelchair"
Kevin	Male	Simon	12	Male	"Blind, four limb cerebral palsy and global development delay." "Completely dependent on adult support for feeding, personal care and everything else."
Helen	Female	May	15	Female	"Cri-du-chat syndrome" "quite a few medical problems and developmental issues" "like deaf...with bone-anchored hearing aids"
Sarah	Female	Dom and Henry	16	Male	"Disabilities and complex needs" "Henry has complex needs, autism, ADHD, other mental health issues and physical issues" "Dom's a spastic quadriplegic, with epilepsy and a rare condition called Schizencephaly; about a third of his brain's missing."
Lisa	Female	Elliot	24	Male	"Seizures" "uses a wheel chair" "complex needs"

^aAll parents were provided with the Core and Essential Service Standards (2017) descriptor of people with profound and multiple learning disabilities on the research information form to help ensure their child/young person met the criteria for the study. Parental descriptions were also asked as it was felt that these would be most reflective of their perception of their child's disability.

A sub-theme which was generated from the interviews was the limitations parents ($n = 7$) experienced. The main limitation parents highlighted was the behaviours and physical limitations associated with their child's disability: "dribbling," "chewing things," and "throwing." Two parents commented on both the physical and cognitive abilities of their child as a limit to music-making:

In that way he's limited in terms of what he can do, and that's because of his physical limitations, and... potentially his understanding. So I guess...if he was able to, we may have explored [music-making] a bit more.

(Tracy)

Other limits to music-making at home included "time." Parents ($n = 5$) commented on a lack of time to make music at home, due

to their child being "exhausted" after arriving home at the end of a school day. For these families, music-making was typically limited to a weekend activity. Parents also reported being time-poor due to the "care demands," "physical care," and "stress" of looking after a child with profound and multiple learning disabilities. Meeting these care needs impacted on the time available for activities such as music-making to take place at home.

3.3.2 | Types of resources

In the questionnaire, parents were asked to select the types of music their son/daughter listened to at home. Figure 2 shows that children and young people with profound and multiple learning disabilities listen to a wide range of musical styles within the home.

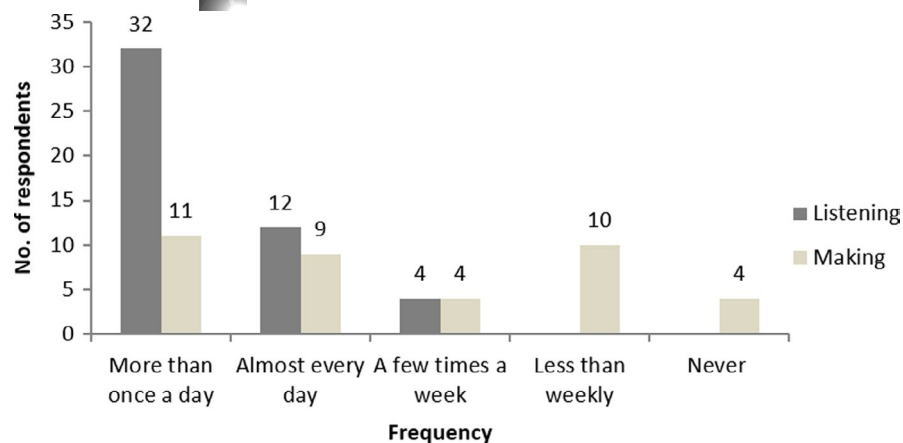


FIGURE 1 Frequency of listening and music-making experiences

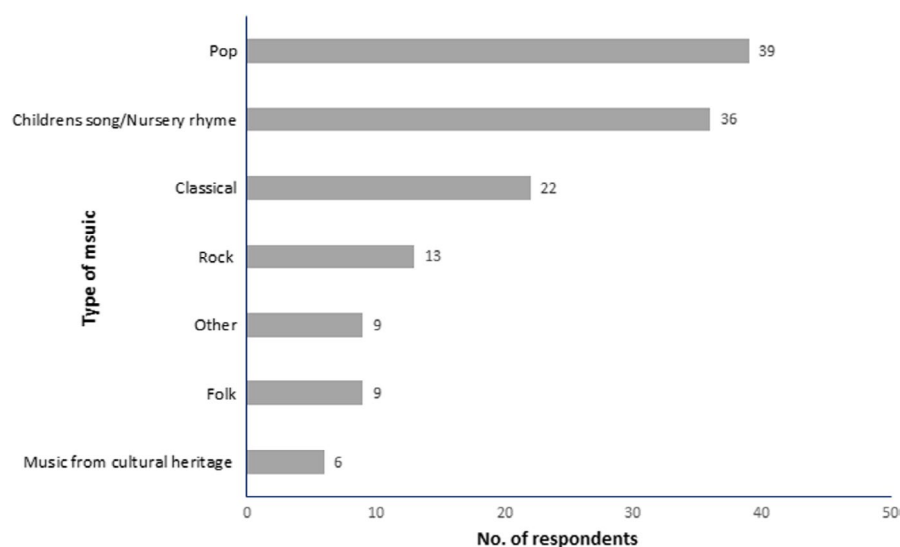


FIGURE 2 Types of music children and young people listen to at home

Parents reported that their children most frequently listen to Popular music ($n = 39$; 81%) and Children's Song and Nursery Rhyme ($n = 36$; 75%). "Other" types of music described by respondents included "Musicals," "Rap" and "PMLD disabilities specific resources". Parents were also asked in the questionnaire whether they often chose music they preferred to listen to, or that they thought their child would like to listen to. Thirty-six parents "strongly agreed or agreed" that they often chose music their child would like to listen to.

In the interview, eight parents were able to comment on the musical preferences of their child. These parents were confident that their child had preferences when listening to music and they were able to describe them with comments such as.

She does seem to have a particular love for the flute and the penny whistle. I think because of the pitches.
(Karine)

And she always has choices she knows what she wants to listen to and it. I always find it interesting, but it isn't always the same thing....
(Lucy)

Two of the parents said they were unable to comment on their child's musical preferences.

He doesn't recognize it, pieces of music or anything.
(Sue and Dave)

It's difficult to tell, I don't see, you know, with different styles of music we play, I don't see any different kind of reaction with him.
(Tracy)

Alongside considering the types of music listened to within the home, interview participants were asked whether there were any resources which supported the music opportunities that their child experienced at home.

Interview participants commented on having access to a range of musical instruments at home. All families spoke about untuned percussion instruments such as the tambourine, shaker and ocean-drum. A number of families ($n = 8$) spoke about tuned instruments,

most commonly the ukulele ($n = 4$), other tuned instruments included guitar, bass-guitar and piano.

Whilst parents felt that having access to instruments at home supported music-making, they also discussed the importance of “inspiration” and “resources” which came from both learning resources, and experiences gained from attending music classes with their child. Parents reported using a range of specific and nonspecific resources and classes for people with profound and multiple learning disabilities. A number of participants ($n = 7$) spoke about attending “music classes” or “music groups” which supported them to make music at home with their child. Speaking about attending a music-group specifically for children with profound and multiple learning disabilities one participant commented:

it's certainly been a fantastic support because it's given us ideas on how best to use the instruments and you know, tapping on the instrument and tapping on her body...feeling the rhythm... giving us some direction and some pointers really in terms of what to do.

(Hannah)

Some parents ($n = 4$) also spoke about attending music-classes which were not specifically for children with disabilities when their child was younger. Attending music-classes supported music-making in the home, motivating parents. One interview participant reported that:

Once I realized through the class that that's something that's going to work for her... that definitely motivated me to do that.

(Lucy)

3.3.3 | Purpose

The questionnaire collected data on the main reason that the respondents' child listened to and made music at home. Thirty-five families (73%) selected the main reason their child listened to music was because it was enjoyable. Enjoyment was also the primary reason families made music with their child. Twenty-seven respondents (56%) selected “they/we enjoy making music”. One respondent wrote, “We sing to be silly and have fun”.

Within the interviews, parents provided rich descriptions of the purpose of listening to music and music-making with their child. Most ($n = 9$) agreed that music was “enjoyable” and was able to expand and explore the reasoning behind this, commenting:

It's a way that she can kind of communicate and join in and it's a source of enjoyment. It's something that we can kind of all enjoy and do together.

(Helen)

Enjoyment was also attributed to the sense of togetherness of listening to and making music, with comments such as.

You remember that with pleasure, because it's like as a family, you are truly together at that point.

(Lisa)

Interviewees ($n = 6$) spoke about music being purposed to add routine and structure to the day. Music, both recorded and parental singing was used to signify activities within the day. Melissa described how music was used within the daily routine;

So, we have a good morning song, then there's a washing your face, I'm going to brushing your teeth song, I mean, they're not exactly a high quality... Then the hoisting song... He absolutely loves that, he proper anticipates that he's being hoisted because of that... songs are part of his routine anyway.

3.4 | Parental perceptions of how music affects the behaviours and mood of children with profound and multiple learning disabilities

The majority of respondents “strongly agreed/agreed” that they felt that listening to music increased the communication attempts ($n = 41$, 85%), alertness ($n = 38$, 79%) and playful behaviours ($n = 43$, 90%) displayed by their child (Figure 3). Within the questionnaire, “alertness” was described as: “they seem more aware and responsive to their surroundings” and “playfulness” as “they seem to have a lift in mood and appear happier/more animated.”

When asked to describe, in their own words, how listening to music influenced their child's behaviour and mood the main theme which was developed from the questionnaire data was a “calming and relaxing” ($n = 31$, 65%) effect. Comments included “she relaxes, calms and concentrates on the sounds.” Respondents also reported a range of ways music may alter their child's behaviour or mood depending on the type of music being listened to: music “engages him, calms him, excites him” and “it brings out different emotions and reactions.”

The questionnaire also collected data on parent and caregiver perceptions of how music-making at home may play a role in the mood and behaviours of their child. These are displayed in Figure 4.

All respondents who claimed to make music at home with their child ($n = 43$, 90%) “strongly agreed/agreed” that music-making experiences increased their child's playfulness, having a “lift in mood” and appearing “happier/more animated.” This playfulness is captured in questionnaire comments such as “she usually expresses pleasure,” “more vocal noises. Attempts hand actions. Laughter, excited behaviour,” and “action songs usually lead to giggles and laughter”.

Supporting the questionnaire data, interviewees commented on a range of behavioural and emotional responses their child displayed when listening to music.

[Music] can soothe if he's feeling distressed, but it's also the thing that brings him great joy.

(Lisa)

Parents highlighted the communication opportunities that they felt music provided, such as their child communicating musical preference, or taking part in turn-taking exchanges. Describing these opportunities parents commented:

They're quite quick to show you what bit of the...music they like, well you can tell what music they like by the time they start singing and, you know, dancing...

(Sarah)

It's kind of communication, sort of my turn, your turn kind of thing.

(Karine)

Almost all parents ($n = 9$) reported that listening to or making music played an important role in influencing their child's mood and behaviours. The primary theme generated from interview data which discussed parents' views on the importance of listening to music on their child was that of mood enhancing ($n = 9$). Parents commented on the changes in their child's behaviour and response:

when [music] comes on, maybe she'll just still for a little while and then she'll join in with the banging and the shaking... she's quite noisy... always kind of making like, squealing and making funny noises.

(Karine)

He will just sit in there in his chair and just listen, and you can hear him kind of making, just because he can't speak, but just happy noises

(Kevin)

A secondary theme generated was the calming influence of music ($n = 7$). This is evidenced in comments such as.

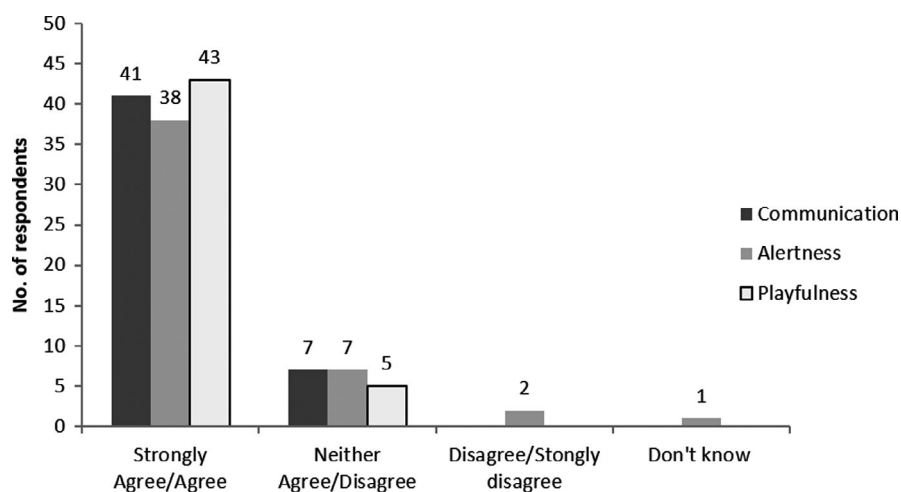


FIGURE 3 Parental perspectives on the increased display of *communication attempts*, *alertness* and *playful behaviours* when listening to music

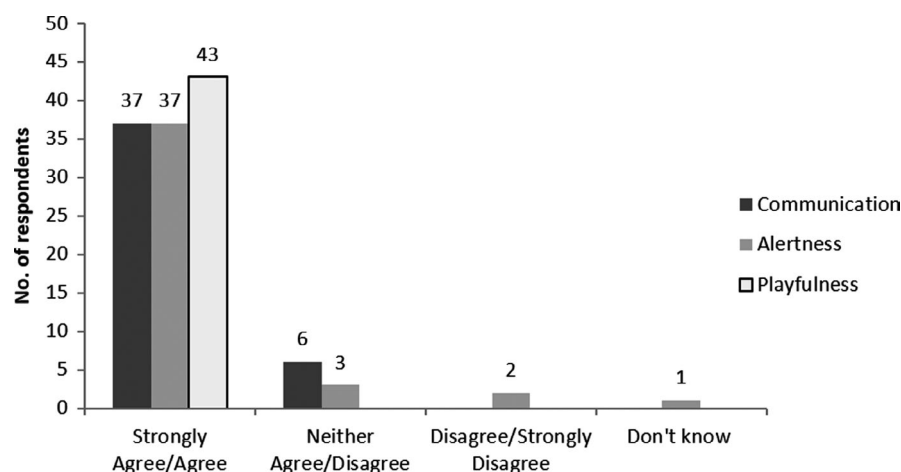


FIGURE 4 Parental perspectives on the increased display of *communication attempts*, *alertness* and *playfulness* when music-making

He can self harm quite a bit, he can get quite upset with various issues. So like I said... it [music] brings him down to another level regarding his anxieties, it calms, it brings him down to quite a calming level.

(Sarah)

Discussing the role of music-making in the behaviours and mood of their child the main theme which was developed from the interview data was engagement ($n = 8$). This engagement was described in changes of behaviour such as.

She'll be more giggly, she's much more focused. If you put things on her mat and there's one of her musical and buzzer toys. She will make a beeline to it.

(Hannah)

She will clap and vocalize... I think that's a sign of her engagement, it is her efforts, her attempts to take part.

(Karine)

Although most interviewees ($n = 9$) commented on the considerable role both listening to, and making music played in the behaviours of their child, it must be noted that one parent felt musical encounters did not influence their child, commenting:

No, I don't feel like music has a big impact on [his] life... if we didn't do [music] he wouldn't miss it, and he doesn't necessarily respond to that, so no, I guess it doesn't.

(Tracy)

3.5 | The role of music on the parent-child relationship

According to the questionnaire data, parents "strongly agreed/agreed" that they enjoyed listening to ($n = 45$; 94%) and making-music ($n = 41$; 85%) at home with their child. Music was evidently recorded as an enjoyable activity for parents to share with their child. Parents were also asked whether they felt more connected to their child when listening to or making music together. The results of this are displayed in Figure 5.

A higher percentage of parents "strongly agreed/agreed" that they felt more connected to their child when making music than when listening to music. When asked to describe in their own words how listening to music with their child made them feel parents said "happy" ($n = 25$; 54%), "calm" or "relaxed" ($n = 12$; 26%) and "connected" ($n = 11$; 24%). Parents were also asked how they felt when making music with their child. When describing this in their own words, 23 comments (52%) included "happy".

The impact of music on the relationship between parent and child/young person was also discussed in the interviews.

It's almost like a survival actually to me. It is survival for us. I don't, I can't, without music everything would crash.

(Lisa)

The most prominent theme that was generated from the data was that of shared connection ($n = 9$). The majority of interviewees ($n = 9$) spoke about the positive influence they felt music had on the relationship they have with their child. Parents described the ways in which music "helped the relationship" (Lucy), facilitated "moments of connection" (Lisa), provided opportunities for

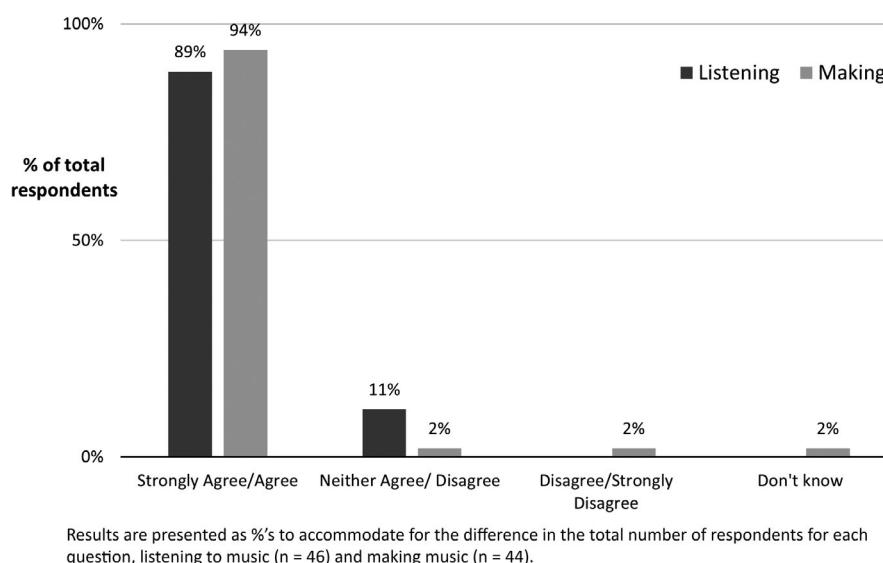


FIGURE 5 Connected; listening to ($n = 46$) and making-music ($n = 44$) positively impacts on parental feelings of connectedness. Results are presented as %'s to accommodate for the difference in the total number of respondents for each question, listening to music ($n = 46$) and making music ($n = 44$).

communicating and was something they could “all get involved in” (Kevin). Interviewees reported how music facilitated opportunities for them to do something together with their child. Parents described that listening to ($n = 6$) and making music ($n = 3$) were activities that meant as a family they could all be together, evidenced in comments such as

It's a way that she can kind of communicate and join in and it's a source of enjoyment and it's something that we can kind of all enjoy and do together. So I think it is very important for us.

(Helen)

Speaking about the connection they felt with their child when listening to music together parents ($n = 5$) also commented on how they felt these opportunities helped their child to “feel the connection” with them, and “strengthen relationships” with other family members (Melissa).

4 | DISCUSSION

The study found that according to their parents'/carers' reports children with profound and multiple learning disabilities were more likely to listen to music than make music at home mirroring the findings of studies with typically developing children (De Vries, 2009; Young, 2008). The ease of listening to music and the minimal effort required to facilitate shared enjoyment may lead to its increased prevalence in home-life. Listening to music was reported to have a “calming” effect on the children within this study in keeping with previous studies (Västhjäll et al., 2012). Findings of this study suggest that some children/young people with profound and multiple learning disabilities have musical preferences and these can be communicated to, and/or interpreted by their parents. However, the musical preferences of some children/young people with profound and multiple learning disabilities, within the study, remained unclear for their parents'/caregivers. Whilst children with profound and multiple learning disabilities may not be able to initiate, or select their listening experience independently, the effects of listening to music were found to be similar to the literature (Murphy & McFerran, 2017) supporting the argument that the effects of music can be experienced by all humans, regardless of their stage of development (Juslin & Sloboda, 2013).

This specific study revealed that parents use a wide range of instruments and musical resources. The resources, and experiences parents obtain from attending music groups/classes, are important in supporting them to facilitate music-making at home. In line with previous studies (Barrett, 2009; Young, 2008), these resources, skills and ideas are transferred into the home life of the families, long outliving attendance at the classes. These skills and modelled interactions, especially in groups for children with disabilities, may be of particular importance for parents of children with profound and multiple learning disabilities, as typical parent-child responses may not always occur (Ware, 2004).

Parents also reported that during music-making activities the communication attempts, alertness, and playful behaviours of their child increased. The connection between music and playful behaviours is also documented within the literature (Corke, 2012; Prevezer, 2000). However, this study also revealed that positive music-making experiences were sometimes restricted. This was due to the time limitations and caring responsibilities of parents of children with profound disabilities, also described in previous studies (McCann et al., 2016), and the physical and behavioural characteristics of some children with profound and multiple learning disabilities.

Within the home, parents reported that music was used to provide enjoyment and to support daily routines. Literature highlights the importance of enjoyment (Axelsson et al., 2014), routine and structure, within daily life. Structure is seen as an effective method of communication, for individuals who have profound and multiple learning disabilities (Doukas et al., 2017). Using music to support routines and add structure may be valuable as a powerful and engaging multi-sensory stimulus (Altenmüller & Schlaug, 2013). Melodies provide rhythmic, pitch and interval indicators, alongside formal language; these cues are frequently accompanied by an emotional response, all of which increase opportunities for understanding. Further, the mutual enjoyment documented between both parent and child within this study is important, as activities which generate shared enjoyment are likely to be more motivating for both parent and child functioning (Axelsson et al., 2014; Luijckx et al., 2019). Creating opportunities to facilitate mutual enjoyment and feelings of togetherness, through shared musical experiences may begin to overcome some of the difficulties that people with profound and multiple learning disabilities have in forming relationships as reported within the literature (Corke, 2012; Ouvry, 2013).

4.1 | Limitations of the study and recommendations for future research

This study was conducted with a self-selected sample of parents'/carers who regularly access the internet, this type of nonprobability sample is not likely to reflect the wider population (Fricker, 2012). Additionally, key demographic information on the participants (e.g. parent age, gender, education level, family size) was not obtained as this study aimed to focus on the parents' experiences rather than generalise the findings to the wider population. Data on the role of music in the behaviours and mood of people with PMLD relied on parental interpretation and reporting, which may not have reflected the emotional experiences of the child/young person (Nind, 2013). The time period, in which the research was undertaken, during the COVID-19 pandemic, created unique circumstances for respondents. These circumstances may not accurately reflect typical home-life experiences. The pandemic restrictions also prevented the direct involvement of people with profound and multiple learning disabilities within the research or the data collection. Recommendations for further research include investigation into the listening experiences

and musical preferences of people with profound and multiple disabilities, the impact of attending external music groups on musical experiences in the home, the availability and access of this provision. Further exploration and understanding of the impact of music within the home on sibling interaction and wider family functioning are also recommended.

5 | CONCLUSION

This study is one of the first to provide evidence to support the positive role music can play within the home-lives of children/young people with profound and multiple learning disabilities as experienced by their parents and carers. Although preference, ability and need differ between individuals, music is frequently reported to have a strong presence and purpose within daily life. For some families, music appears to be a lifeline whereas for others a medium to communicate, an enjoyable past-time or part of a routine. The accessible, inclusive and emotive nature of music supports relationships between many individuals with profound and multiple learning disabilities, their caregivers and their wider family. Music unites, connects and bonds. Whilst there may be barriers to the musical experiences children and young people with profound and multiple learning disabilities encounter at home, the findings within this study evidence the value of musical experiences have for both individuals with profound and multiple learning disabilities and their parents and carers. Highlighting music and its important role in the well-being of parents of children with profound and multiple learning disabilities is essential. Supporting, equipping and empowering parents to provide these experiences may be fundamental in fulfilling the social and personal needs of an individual with profound and multiple learning disabilities and their family.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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REFERENCES

- Altenmuller, E., & Schlaug, G. (2013). Music, brain and health: Exploring biological foundations of music's health effect'. In R. MacDonald, G. Kreutz, & L. Mitchell (Eds.), *Music, health and well-being* (pp. 12–24). Oxford University Press. <https://doi.org/10.1093/acprof:oso/9780199586974.003.0002>.
- Axelsson, A., Imms, C., & Wilder, J. (2014). Strategies that facilitate participation in family activities of children and adolescents with profound intellectual and multiple disabilities: parents' and personal assistants' experiences. *Disability and Rehabilitation*, 36(25), 2169–2177. <https://doi.org/10.3109/09638288.2014.895058>
- Barrett, M. (2009). Sounding lives in and through music: A narrative inquiry of the 'everyday' musical engagement of a young child. *Journal of Early Childhood Research*, 7(2), 115–134. <https://doi.org/10.1177/1476718X09102645>
- BERA (British Education Research Association) (2018). *Ethical guidelines for educational research*. <https://www.bera.ac.uk/publication/ethical-guidelines-for-educational-research-2018>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp0630a>
- Brinkmann, S. (2013). *Qualitative Interviewing (Understanding Qualitative Research)*. Oxford University Press.
- Clayton, M. (2009). The social and personal functions of music in cross-cultural perspective. In S. Hallam, I. Cross, & M. Thaut (Eds.), *Oxford handbook of music psychology* (2nd edn, pp. 47–63). Oxford University Press. <https://doi.org/10.1093/oxfordhb/9780199298457.013.0004>
- Corke, M. (2002). *Approaches to communication through music*. David Fulton Publishers.
- Corke, M. (2012). *Using playful practice to communicate with special children*. Routledge.
- Creswell, J., & Creswell, J. D. (2005). Mixed methods research: Developments, debates and dilemmas. In R. Swanson, & E. Holton (Eds.), *Research in organisations, foundations and methods of inquiry* (pp. 315–325). Berrett-Koehler Publishers Inc.
- Custodero, L., & Johnson-Green, E. (2003). Passing the cultural torch: Musical experience and musical parenting of infants. *Journal of Research in Music Education*, 51(2), 102–114. <https://doi.org/10.2307/3345844>
- de Vries, P. (2009). Music at home with the under fives: what is happening? *Early Child Development and Care*, 179(4), 395–405. <https://doi.org/10.1080/03004430802691914>
- Doukas, T., Fergusson, A., Fullerton, M., & Grace, J. (2017). *Supporting people with profound and multiple learning difficulties*. Core and Essential Service Standards.
- Emerson, E. (2009). Estimating future numbers of adults with profound multiple learning disabilities in England. *Tizard Learning Disability Review*, 14(4), 49–55. <https://doi.org/10.1108/13595474200900040>
- Fricker, R. (2012). Sampling Methods for Web and E-mail Surveys. In J. Hughes (Ed.), *SAGE internet research methods*. (pp. 195–216). SAGE Publications.
- Hallam, S., & MacDonald, R. (2013). Introduction: Perspectives on the power of music. *Research Studies in Music Education*, 35(1), 83–86. <https://doi.org/10.1177/1321103X13488485>.
- Juslin, P. N., & Sloboda, J. A. (2013). Music and emotion. In D. Deutsch (Ed.), *The psychology of music* (pp. 583–645). Elsevier Academic Press.
- Krause, A. E., North, A. C., & Hewitt, L. Y. (2015). Music-listening in everyday life: Devices and choice. *Psychology of Music*, 43(2), 155–170. <https://doi.org/10.1177/0305735613496860>
- Lamont, A. (2012). Emotion, engagement and meaning in strong experiences of music performance. *Psychology of Music*, 40(5), 574–594. <https://doi.org/10.1177/0305735612448510>
- Lavrakas, P. (2008). *Encyclopedia of survey research methods*. Sage Publications Inc.
- Luijckx, J., van der Putten, A., & Vlaskamp, C. (2019). A valuable burden? The impact of children with profound intellectual and multiple disabilities on family life. *Journal of Intellectual & Developmental Disability*, 44(2), 184–189. <https://doi.org/10.3109/13668250.2017.1326588>
- MacDonald, R., Hargreaves, D., & Miell, D. (Eds.) (2017). *Handbook of musical identities*. Open University Press.
- Mactavish, J., & Schleien, S. (2004). Re-injecting spontaneity and balance in family life: Parents' perspectives on recreation in families that include children with developmental disability. *Journal of Intellectual Disability Research*, 48, 123–141. <https://doi.org/10.1111/j.1365-2788.2004.00502.x>
- McCann, D., Bull, R., & Winzenberg, T. (2016). Brief report: Competence, value and enjoyment of childcare activities

- undertaken by parents of children with complex needs. *Journal of Pediatric Nursing*, 31(2), 127–132. <https://doi.org/10.1016/j.pedn.2015.10.018>.
- Mehr, S. (2014). Music in the Home: New Evidence for an Intergenerational Link. *Journal of Research in Music Education*, 62(1), 78–88. <https://doi.org/10.1177/0022429413520008>.
- Murphy, M. A., & McFerran, K. (2017). Exploring the literature on music participation and social connectedness for young people with intellectual disability: A critical interpretive synthesis. *Journal of Intellectual Disabilities*, 21(4), 297–314. <https://doi.org/10.1177/1744629516650128>.
- Nicholson, J., Berthelsen, D., Abad, V., Williams, K., & Bradley, J. (2008). Impact of music therapy to promote positive parenting and child development. *Journal of Health Psychology*, 13(2), 226–238. <https://doi.org/10.1177/1359105307086705>.
- Nind, M. (2013). Inclusive research: where does it leave people with PMLD? *PMLD Link*, 25(1), 23–26.
- NVivo (2018). *NVivo qualitative data analysis software; Version 12*. QSR International Pty Ltd.
- Ockelford, A. (2008). *Music for children and young people with complex needs*. Oxford University Press.
- Ouvry, C. (2013). Making relationships. In P. Lacey, & C. Ouvry (Eds.), *People with Profound and Multiple Learning Difficulties – a collaborative approach to meeting complex needs* (pp. 66–75). David Fulton Publishers.
- Pasiali, V. (2004). The use of prescriptive therapeutic songs in a home-based environment to promote social skills acquisition by children with autism: three case studies. *Music Therapy Perspectives*, 22(1), 11–20.
- Petry, K., Maes, B., & Vlaskamp, C. (2005). Domains of quality of life of people with profound multiple disabilities: The perspective of parents and direct support staff. *Journal of Applied Research in Intellectual Disabilities*, 18(1), 35–46. <https://doi.org/10.1111/j.1468-3148.2004.00209.x>.
- Prevezer, W. (2000). Musical interaction and children with autism. In S. Powell (Ed.), *Helping children with autism to learn*. David Fulton Publishers.
- Schallock, R., & Felce, D. (2004). Quality of life and subjective well-being: conceptual and measurement issues. In E. Emerson, T. Thompson, T. Parmenter, & C. Hatton (Eds.), *International handbook on methods for research and evaluation in intellectual disabilities* (pp. 261–280). Wiley.
- Sloboda, J.A., Lamont, A., & Greasley, A.E. (2009). Choosing to hear music: Motivation, process and effect. In S. Hallam, I. Cross, & M. Thaut (Eds.), *Oxford handbook of music psychology* (pp.431–440). Oxford: Oxford University Press.
- Tashakkori, A., & Teddlie, C. (2010). *SAGE handbook of mixed methods in social & behavioral research*. SAGE Publications.
- Thompson, G., McFerran, K., & Gold, C. (2014). Family-centred music therapy to promote social engagement in young children with severe autism spectrum disorder: a randomized controlled study. *Child Care Health and Development*, 40(6), 840–852. <https://doi.org/10.1111/cch.12121>.
- Timmermans, S., & Tavory, I. (2012a). Theory construction in qualitative research: From grounded theory to abductive analysis. *Sociological Theory*, 30(3), 167–186. <https://doi.org/10.1177/0735275112457914>.
- Timmermans, S., & Tavory, I. (2012b). *Abductive analysis: Theorizing qualitative research*. University of Chicago Press.
- Trevarthen, C. (2002). Origins of musical identity: evidence from infancy for musical social awareness. In R. MacDonald, D. Hargreaves, & D. Miell (Eds.), *Musical Identities* (pp. 21–38). Oxford University Press.
- Västfjäll, D., Juslin, P. N., & Hartig, T. (2012). Music, subjective wellbeing, and health: The role of everyday emotions. In R. MacDonald, G. Kreutz, & L. Mitchell (Eds.) *Music, health & wellbeing* (pp. 405–423). Oxford University Press.
- Ware, J. (2004). Ascertaining the views of people with profound and multiple learning disabilities. *British Journal of Learning Disabilities*, 32(4), 175–179. <https://doi.org/10.1111/j.1468-3156.2004.00316.x>.
- Whiting, M. (2014). Children with Disability and Complex Health Needs: The Impact on Family Life: Analysis of Interviews with Parents Identified Time Pressures, the Need for Carers to Adopt Multiple Roles and Being a ‘Disabled Family’ as Major Influences on their Lives. *Nursing Children and Young People*, 26(3), 26–30.
- Williams, K. E., Berthelsen, D., Nicholson, J. M., Walker, S., & Abad, V. (2012). The effectiveness of a short-term group music therapy intervention for parents who have a child with a disability. *Journal of Music Therapy*, 49(1), 23–44.
- Young, S. (2008). Lullaby light shows: everyday musical experience among under-two-year-olds. *International Journal of Music Education*, 26(1), 33–46. <https://doi.org/10.1177/0255761407085648>.
- Zeedyk, S. (Ed.) (2008). *Promoting social interaction for individuals with communication impairments*. Jessica Kingsley Publishers.

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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