

Rachel House Coorie Doon Project

A partnership project:
Enterprise Music Scotland
CHAS (Rachel House)
Royal Conservatoire of Scotland

Impact Report

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Report aims

The aim of this report is to explore and summarise the key points concerning the impact and significance of the Coorie Doon project on the parent participants. Viewing the project from a general perspective, it is evident that it had a highly positive effect on those who took part in the programme as individuals, as couples and as members of the wider cohort of CHAS families. The parents' narratives demonstrated a sense of pleasure at being given the opportunity to create a song for their child and most stated that they found the experience to be unique and hugely rewarding. It was apparent that the songs had evoked a variety of emotions and had become an important part of each child's treasured memory box.

The findings of the project have been divided into four main sections with subsections where applicable. These are as follows:

1. Response to the process: *pleasure, challenges, emotions, magnitude, personal approaches*
2. Legacy of the song: *day to day use, joint interaction, memory*
3. Collaboration with the Coorie Doon team
4. Parent recommendations for future projects

Research Objective

The purpose of this research was to investigate the thoughts and perceptions amongst a small group of parents at Rachel House with children who have life limiting conditions, on creating a song for their child. In order to explore the views of the parents, a qualitative methodology was chosen to gain in-depth information on the impact of the project.

Methodology

Nine parents (three fathers and six mothers) were involved in the song writing programme for six children registered with CHAS (Children's Hospices Across Scotland). Five of the children were under the age of five and a sixth was twenty-one years old. All of the parents contributed to the research through individual semi structured interviews, with the exception of one couple who requested to be interviewed together. Due to the idiographic nature of the research responses were highly individual, however, in order to create a structure to the study the interviews followed a flexible format utilising set questions alongside questions that arose from the participant responses. A thematic analysis approach was used in order to uncover key themes. The interview schedule can be found in Appendix A. All of the parents were interviewed after completion of both the project and the sharing event at Rachel House in April. The interviews took place at Rachel House and in the parents' homes according to the convenience of the participants in May/June 2017. Both venues proved to be highly suitable as

they were familiar surroundings, fulfilling the objective of making the interviews relaxed and informal.

Findings

The findings from this research are highly complex and there is much to discuss. Each child involved in the project has specific needs and this impacts heavily on the lifestyle and life choices made by their parents. Many individual thoughts and perspectives arose from the study which were applicable exclusively to each child. Combining this with the individual personalities of the parents and their varying coping mechanisms in addressing their situation on a day to day basis, resulted in multifaceted areas for discussion. The purpose of this report however is to present the key findings which were common to all or to the majority.

In order to respect participant confidentiality, the parents will be referred to as F1 - 3 (three fathers) and M 1 - 6 (six mothers). The children's names are all pseudonyms. Following the transcription and analysis of each interview the following key themes were highlighted:

1. Response to the project
2. Legacy of the song
3. Collaboration with the Coorie Doon team
4. Parent recommendations for future projects

Response to the project

Due to the highly emotional nature of this project there were many different reactions to the process, most of which were extremely positive.

- **Pleasure**

One overriding response was that of pleasure which was expressed using colourful adjectives such as amazing, brilliant and exciting. The parents found the process to be unique and were appreciative of being given the opportunity to create a song for their child. There were many comments that they would recommend the process, with one of the mothers (M1) stating, '*It was absolutely the best week*'(at Rachel House) '*I loved it*'. Satisfaction in having achieved such a positive outcome was also cited from some parents in having created the song themselves and also acknowledging the contribution from their child:

'I felt like I've achieved something, well I've achieved stuff before but it felt special, different, warm, it was good'. (F3)

'I was really excited and Calum was very much involved...his laughter was brought into it..... that's something that he's done and he's achieved he's on it and as soon as his laughter comes up he's like all excited and he can hear himself on it' (M6).

Some parents expressed the fun they had experienced in recording the songs especially those with other offspring as this facilitated feelings of togetherness in being able to accomplish something as a family unit. This is further discussed in a later section of this report on Joint interaction.

'It was good, I enjoyed it. We all got to come together and do something together as a family'. (M3)

'The whole family were involved, it was amazing. To write the whole thing you've done in a day of you and your family and turn it into a song... brilliant, loved it, really did. It was great!' (F3)

In one instance John's ten year old brother Sean had taken ownership of the lyrics and this offered their mother an opportunity to view life more positively through the eyes of her able child. Up until this point she had believed that John had been a burden to Sean as the latter has had to do things that other ten year olds are not required to do and this had instilled unfounded feelings of guilt within her:

'It was quite an upbeat song, more about how John has a positive effect on us as a family. I like that they involved Sean as much as they did. It lets me see his point of view. Hearing the song and seeing that he (Sean) doesn't look at it from that point of view at all just makes things nicer, easier for the family'. (M5)

- **Challenges**

The task of writing lyrics proved to be quite challenging to the majority of the parents and for some, the initial stages of the process were quite daunting. A lack of experience in this field plus the desire to get it right created a degree of apprehension and uncertainty. For example F1 stated that he had looked at the task in hand and thought *'I don't really know what I'm supposed to be doing'*. M1, M2 and M4 in particular expressed their initial anxieties in being asked to write a song. M2 recounted anxiously hiding in the toilet having been asked to pen some notes on her child.

'I went and hid in the toilet and I thought this is like being back at school, although the process of it I found quite nerve-wracking 'cos I didn't know where to go or where to start but as an end product it's really good.....what they (the team) came back with was amazing' (M2).

The reasons for this seem to stem from the sensitive emotions involved and the fear of the unknown in producing a song. Fortunately their fears were quickly alleviated when they realised that they were under no pressure. As can be seen later in this report full support and work from the Coorie Doon team swiftly addressed any initial misgivings.

To a certain extent, a degree of comparison between the families arose but this was described by one mother as a desire to create something perfect for their child as their life expectancy is limited.

'You're aware that it may be the only song you get to do and so for me everything has to be perfect'. (M1)

Despite the initial feelings of panic all of the participants said that they decided on writing words that they felt were suitable at that time and the whole process evolved smoothly and became surprisingly easy and straightforward.

- **Emotions**

Creating a song about a loved one, especially a child with a life limiting illness proved to be a highly emotional personal journey for many of the parents. The lyric writing part of the song in particular seemed to be very powerful and produce a '*rollercoaster ride of different emotions*' (M6) especially when considering the day to day stresses that life holds for these families.

'When you're hearing it and reading it back you're frightened for the future you're frightened of the present everything is scary...nobody knows what the day holds when you've got somebody with complex needs' (M6).

Several stated that it was a cathartic process which enabled them to express their feelings in a way that they would not normally feel able to share. For some, this strong emotional reaction to writing lyrics proved to be a surprising element of the process as it '*brought out thoughts and feelings that maybe I wouldn't have brought out or shared*' (M6). F3 said it was a simpler task to write down his thoughts than actually telling someone and the process helped him to '*get things off his chest*'.

The combination of music and lyrics appeared to produce a strong emotional reaction in the participants and many admitted to crying when listening to the songs. Academic research shows that producing tears can reduce tension by restoring the body to a state of balance and there was evidence here that the parents accepted this as a natural reaction to the song.

'I went through to the bedroom and I listened to it and just sat and cried' (F2).

Positive emotions were experienced by most of the parents who were able to attend the sharing event (concert) in April. They expressed feelings of togetherness and pleasure at hearing each others' songs. However, it is important to note that occasional feelings of negative emotions during the process were also expressed. One mother (M1), despite having felt excited ahead of the event, found the concert too personal. Whilst appreciating that families with other children had much to gain from the event, she struggled in allowing others, even close friends, into her world.

'I didn't expect to feel like this, it's visceral, it's almost protective because it's like it's personal and I almost felt like I don't want other folk to hear that I felt really vulnerable'.

She continued to explain her thoughts by reflecting on the hugely personal nature of the song:

'.....when you have something that's really personal that's put out there especially when played with other people's I found that nerve-wracking ...like the CD that we got I deleted everyone else's songs off it so that what we've got Dan's, it feels like we've taken a bit of everyone else's and I don't want that I just wanted ours does that make sense?'.

- **Magnitude**

Given the fact that writing a song was a new experience for eight of the participants it was not surprising that they had not formulated any prior expectations or thoughts on the finished product. Consequently, they were surprised at the size of the project and significance of the result.

'We didn't realise the magnitude of the thing. We thought, och it'll be arts and crafts, make a dodgy picture and you'll love it forever...but the work that went in...it wasn't what it said on the tin, it was a lot bigger.....Katie's song was fantastic' (F2).

These feelings led to some misgivings on the part of a couple of parents who felt that they had missed an opportunity as they weren't fully aware of what was going to happen in the process and were surprised at the professional recording that they received at the end. Other unexpected aspects included receiving a CD of the recording and a framed picture of their lyrics, both of which were much appreciated by all.

- **Personal approaches**

The non prescriptive approach taken by the Coorie Doon team enabled the parents to create lyrics and input music in a variety of ways, resulting in each family approaching the songwriting process from a different perspective. This can be seen in the moods created in the songs which range from soft and reflective to up beat and energising. The songs appear to have different uses according to the families' needs and wishes and reflect their individuality in a very personal manner. Some participants sought to create a lullaby, others a narrative of their day to day family lives and the remainder a description of their child's personality.

'We did say slow might be good for Katie because at bedtime she has a teddy that plays night time music and that's kind of her routine' (M2).

It was completely us. We had a bit of a mash up so ours started quite slowly and sped up then we had a rap and then it tailed off down at the end and I felt that is like a day in us. Our day can start nice and really calm and then it can go crazy so we wanted a melody that would represent our days' (M5).

Having a child with severe communication difficulties is challenging and some of the parents appeared to use the project as a coping mechanism. One example of this was seeking to create a song as if it had been written by the child, and this appeared to offer comfort by providing an opportunity to speak for them through words and music. This approach was clearly an empowering experience for M6 which offered the chance for Calum to 'speak' in a way which was not readily achievable in their day to day life:

'I feel it's Calum's song..... if Calum could talk I think that's what he'd have thought and I feel it's my tribute to him as well ...when I wrote the song he was with me he was right next to me and I just hope I've captured what he maybe would have said if he'd had verbal communication I feel that's his song and I don't want to take that away'.

The desire to appear as a normal family and not dwell on their child's needs was another common approach. Many of the participants highlighted their wish to be seen not just as 'disability parents' but as families who were able to laugh and joke and they relished the opportunity to convey this through the songwriting process. The need to be seen as people who were still capable of expressing laughter and able to view life beyond the disability was an important thread, and many of the songs were deliberately created to make listeners laugh and to avoid the topic of illness which was viewed as too deep or emotional.

'You don't want to be just the disability parents so having something personal like that where you're just light hearted...parents with kids like ours we make a lot of jokes because it hides how crap it can actually be.... that song we love it the thing that it's funny.... we've got some silly songs that we sing with Dan and tried how can we incorporate that and then tried to make it a bit funnier rather than a bit serious' (M1).

'.....the difficulties the families have to go through because of that (child's disability) and I feel I didn't want this to be the case for us you know because that's not how we live our lives, that's not how I see life you know it's just a part of who she is and just a part of what we have in our lives, so I'm really happy that what we have for her is something that actually is just a lot sweeter you know kind and just funny and a little bit and you know it's not sad, a thing if I listen to it makes me choke up' (M4).

Using the song to represent the interaction between siblings was used by several families who had other children. M4 was a highly artistic mother who was compiling a story book about her

two children through painting and drawing and she intended to use the song as part of the process. She had introduced the use of differing time zones in which her children live but never meet, with each child being represented by a favourite animal, one nocturnal the other diurnal. This story formed the basis of the lyrics for the song.

'They live in two different time zones but never get to play together. My son tries to play with his sister but unfortunately it never really happens the way he would like'.

Legacy of the song

One key advantage in conducting a creative project such as Coorie Doon is that, not only is it an active participatory process but there is also a tangible end product. Having considered the feelings and thoughts of the parents in going through the actual creative activity, their views on the impact of this on their lives moving forward is of paramount importance.

- **Day to day use**

There was clear evidence from the parents' responses that they had benefitted from creating a highly personal song to which they have easy access and which they can listen to at any chosen time. The level of listening engagement with the song varies from on a daily basis to infrequently. Uses include in CD players in cars and children's bedrooms and in living spaces where it is used for singalong purposes. The following quotes help to give a clearer insight into the variety of ways in which the songs are currently being used from a practical perspective.

'Oh we've got it on in the car and we sing it!' (M4).

'We play it in the house for Calum, we tend to.... do you want it on at shower time or do you want your Ed Sheeran on? We tend to use it like that' (M6).

'It's on in Katie's room and when Katie comes out of the bath, Susie (Katie's sister) will say 'can we put the CD on?' so we'll put it on in the bedroom' (F2).

'We listen to it everyday and every birthday it'll get played.....I don't think it'll ever be put on the side' (M5).

Those who interact with the song on a less frequent basis appear to use it for more in depth, emotionally reflective purposes rather than as a song to be sung. Inevitably due to their different approach the song is heard only at specific times when there is a need. When asked what he intended to do with the song F1 expressed his feelings by admitting that he would inevitably '*cry to it in the future*'. He continued by adding that as he rated the song so highly he had '*a thought to use the song*' at his son's funeral. This latter point was also raised by M2 who spoke about her conversations with her own mother and how she had '*kind of got it in*' her '*head that the song will be used when Katie goes*'. The subject of child mortality is clearly ever

present in the lives of these families and whilst some admit that they don't like to think about the topic too often, for some the presence of a personally created song about their child could provide comfort when the inevitable happens. As F2 reflected:

'It's there for ever, that song is yours and Katie's, it's always going to be there forever.... unfortunately Katie is not'.

The addition of a framed picture of the song lyrics alongside the CD proved to be extremely positive, with parents proudly displaying the frame on their walls at home. As a result they frequently form a conversation piece with visiting family and friends as well as being used on a personal level for quiet reflection'.

'I really enjoyed it...I sit down and look at the picture on the wall' (M3).

- **Joint interaction**

Recurring comments about coming together and collaboration relate to the positive effect of working on a project alongside fellow participants. Interaction with others was seen through engagement by all members of the family, meeting other families at Rachel House, working with the Coorie Doon team and also interacting with the outside world externally in taking the songs to the wider community.

The comments below highlight the beneficial effects of full engagement in a creative process which enabled all members of the family to take an active role.

'It's a family song 'cos it's all about the family' (F3).

'There's a bit on it where Katie played the chimes ...which was lovely so there is a part of her in it and Susie got to be in it but she done a picture....it was actually her drawing on the CD cover which was really nice so she's got a part in it as well' (M2)

'Sean (John's brother) wrote the lyrics, he sang in it, he played in it...it was completely us' (M5).

The feeling of camaraderie was strongly held by the participants, not only amongst those who had already formed close relationships but by those who were not acquainted with the other members of the programme group. This was especially evident in the early stages of the project when the parents were left to compile a list of words associated with their child which would form the basis of the song lyrics. Experiencing a unique and to some extent unknown process helped to bring the families together, strengthening bonds and forging new ones. The following comments from some of the parents evidence this positive legacy of the project.

'It's nice that we've got everyone else's songs on the CD and not just ours. I'd never met Andrew's mum and dad before....'cos we've got a connection to the other mums it's nice that you hear their songs as well' (M2).

'It was lovely seeing the other families getting involved and chatting to them about what they did as well' (M6).

'I'm really close to some of the other mums here and to hear their songs and their points of view on their children as well was nice, 'cos we chat and we talk but we don't always talk about those kinds of things. So to hear it in music is lovely' (M5).

Interacting with the wider world through the songs was evident as some parents had taken the songs to their children's schools, community and respite centres where they were well received.

'Our family have listened to it and John's had it to school with him and let his class listen to it so and it's something that we'll have for ever you know it's just there....they played it to the whole school and they had a whole school assembly and the entire school got to listen to it so there were a few tears from parents and teachers and things'. (M5)

The positive impact of Coorie Doon on one mother had inspired her to take the process one step further and encourage other young people at one of Scotland's leading charities for disabled people to write down their own thoughts and feelings.

'We've used it already what we've done is we've taken it up to (charity name) and played it for all the guys there and we've tried to get them to write feelings and different things down, trying to get other people maybe doing similar things.....we've also taken it into respite to let some of Calum's friends and some of the young adults hear it and they loved it' (M6).

- **Memory**

Parents with children suffering from life limiting conditions are encouraged to keep memory boxes. These can consist of varying objects which will help to remind parents and families of their child and offer some degree of comfort after the child has passed away. Creating a memory box can be an emotional experience and for many of the participants on this project, creating a song as a keepsake was a highly important outcome of this process. The legacy of writing a song whilst the child is still alive and incorporating the child into the song, even in a limited way through sound making or shaking a percussion instrument proved to be a key theme. Parents highlighted their pleasure and appreciation of being able to have a memory in words and music which was like no other memory.

'It's when you do something like that through Rachel House with Dan you are very aware that you're memory making.... to hear it at the end and especially to know that Dan had

taken part in it as well & it was Adam (husband) doing that with Dan it's something that you'll always listen to it's just lovely' (M1).

'Yes so put it in there....definitely a memory' (M3)

'...it's a memory, it's a memory that can be in his memory box..... it's really important to have that because we don't know how long Calum's life is, it could be a week it could be 20 years I'm holding all these memories obviously through CHAS you speak about funerals and the future that's my song with Calum, we're playing this song, that's my song with Calum, that's Calum's song so it is important' (M6).

'There's that many things you could do with it.....could go into a memory box, that's his memory, that'll be his box, I think that's what will happen to the CD that will go into his box...if you do want to, or any of us want to listen to it that's the time when the box comes out' (F3).

The parents' narratives are in line with current research which supports the theory that songs can act as memory triggers and assist in reviving thoughts of people, events, places and emotions from the past. M2 recalled conversations with her mother on the topic of memories and highlighted the fact that given Katie's lifespan time she makes different types of memories to those of her able daughter Susie. There is an urgency to acquire as many varied memories as possible knowing that each one could be Katie's last. F2 highlighted the importance of the memory being a song rather than purely words.

'Well because we know the music's there, the music is what it was all about.you remember songs I don't remember poems, I remember songs so the song was a big thing'.

Collaboration with the Coorie Doon Team

Working with the team of creative professionals received unanimous praise from all of the parents. They expressed admiration and gratitude for their hard work and dedication in supporting them through the process. Having the Musician in Residence leading the programme was extremely beneficial as the parents felt more confident working with someone familiar to them. Praise was also given to the quality of the songs which were deemed to be an exact fit as accurate representations of the individual families. The willingness of the team to allow the creative process to move at the participants' speed along with offering full support was much appreciated. The quotes below serve to evidence these comments.

'Oh amazing... I think its lovely you can get to know the team ... I think that's really important because this is an emotional journey, we're in a hospice and we can forget that because this is our happy place, our safe haven' (M6).

'So nice ... it was easy because you know her (Musician in Residence) so it was quite laid back because there wasn't a lot of pressure put on you when you got to the end product it was like minimum effort on our part and maximum effort on the guys behind the scenes who pulled it all together to make something really nice' (M2).

'They were really good, really nice, really friendly, they were brilliant' (M5).

Parents' recommendations for future projects

All of the parents fully endorsed the project and strongly recommended that it should be repeated with other cohorts of parents at Rachel House. The safe environment and familiarity of the hospice made it an ideal environment for this type of emotional journey.

Comments were overwhelmingly positive, however, one thread which ran throughout the narratives was the desire to have had a clearer idea of what was expected in writing the lyrics and to have been given a more detailed idea of exactly what the process entailed. The following view by M4 is representative of the parents' thoughts.

'Now that you have these songs as a concept maybe if you do it again just show people the songs say 'oh this is the kind of thing that other parents wrote but maybe you don't have to do the same but just feel free..... maybe just let people hear a few of the songs that were done in this Corrie Doon project and have them easing into it'.

Discussion and conclusions

This section briefly summarises and discusses the data findings in relation to the participants' involvement in the project, and the significance of the project in their lives now and in the future. These are linked to the key themes: response to the project, legacy of the song, collaboration with the Coorie Doon team and parent recommendations for future projects.

Participation in the project

The findings highlight the importance of being part of the Coorie Doon project for all of the parents. Despite initial feelings of anxiety, they embraced the creative process and reported feelings of pleasure and enjoyment. It was clear that the task of writing lyrics proved to be daunting for some but, despite this, they became aware of the power of the written word in expressing emotions from a therapeutic perspective. The different approaches to songwriting by the parents led to some comparisons being made, however, all felt that they were entirely satisfied with their own song as being an accurate representation of their families and that given the opportunity no changes were needed. The quality and professional recording of the end product along with a framed picture of the lyrics pleasantly surprised most of the participants who had been anticipating a smaller scale project.

Having the opportunity to interact with fellow Rachel House parents on a shared programme brought participants closer together and opened up channels of communication and increased dialogue of thoughts and emotions. The inclusion of siblings where possible was regarded as a positive factor enabling families to engage in and create something as a coherent unit, which resulted in a sense of achievement for all concerned.

It was clear that the safe environment of Rachel House and working with the Coorie Doon team, which included a member already known to the participants, was extremely positive. There were no negative comments concerning the creative and psychological support they received from the professionals with whom they were working. Parents' responses indicated admiration for the hard work of the team to produce a song that was highly personal to each family and their willingness to be flexible and treat each participant sensitively, mindful of individual needs.

Significance of the project

The main impact of the project looking to the future is undoubtedly the provision of a unique and highly personal memory through words and music which is long lasting. This is especially significant to each parent due to the life limiting conditions of their child. The positive role of the song as part of the memory box is considerable as current research demonstrates the power of music to effect mood and provide comfort. Linking this with lyrics that apply to each individual child alone helps to formulate a unique memory and one which is permanent and easily accessible.

Recommendations

A repeat of the creative songwriting process is to be strongly recommended given the high level of positive responses from the participants. The overall therapeutic effect on wellbeing in creating a personal song for a much loved child with a life limiting condition is substantial. In line with parent comments, a more detailed outline of what is involved would alleviate initial misgivings and feelings of anxiety. It is suggested that in future, participants should hear some examples of the bank of songs which have now been compiled. This need not impact on creativity if it is done for example as background music whilst introducing the parents to the process on arrival at Rachel House or given as an online link to access the 2017 songs prior to starting the programme.

APPENDIX A

Coorie Doon Research Interview

Semi-structure interview questions

What has been your experience of taking part in Coorie Doon?

Has anything about the project surprised you?

Have you ever written song lyrics or music before?

How have you found working with the Coorie Doon team?

What have you found challenging about the project?

What has been the most enjoyable aspect?

How will you use your song now that it's finished?

How does having a song that you have written for your child make you feel?

If you could change anything about the project, what would it be?

Explain the value to you of the sharing event?

Is this something you feel should be repeated with others in the future and if so, why?