

BBC Children in Need Project 2021

Evaluation Report

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I. Introduction

This project, funded by BBC Children in Need, was implemented by the Muscle Help Foundation between January and March 2021.

The overall objective of the project was to contribute to the social inclusion of children and young people with Muscular Dystrophy and allied neuro-muscular conditions under the age of 18 years old in the UK. The specific objective was to develop sustainable models of social support for these children and young people.

Children and young people with muscular dystrophy and their families are extremely vulnerable to high levels of social exclusion. The social exclusion they experience is characterised by feeling remote from peers and the communities they live in and have few opportunities to meet with each other. This leads to poor mental wellbeing and a loss of hope for their immediate future. This has been exacerbated by the effects of the global coronavirus pandemic, as these children and young people are shielding.

To achieve these objectives, the project had two pillars for the intervention:

- Community engagement
- Virtual Muscle Dreams

With each pillar, the outcomes were to:

- reduce isolation through online communication and engagement
- stay connected with each other and the outside world
- support good mental wellbeing and restore hope for the future

This was an innovative pilot project which was delivered virtually to children and young people across the UK. The project was set up and implemented over a three-month period; the project implementation team was recruited during month one.

The project implementation team worked on the project part-time and consisted of:

- Project Manager (Chief Muscle Warrior)
- Project Officer (Community Engagement Lead)
- Project Officer (Virtual Muscle Dream Maker)
- Social Media Lead
- Evaluation Lead

This evaluation report has been produced using data collected by the Project Officers during the course of the project. The Project Officers identified progress measures based on their assessment of levels of engagement from beneficiaries during the course of the project.

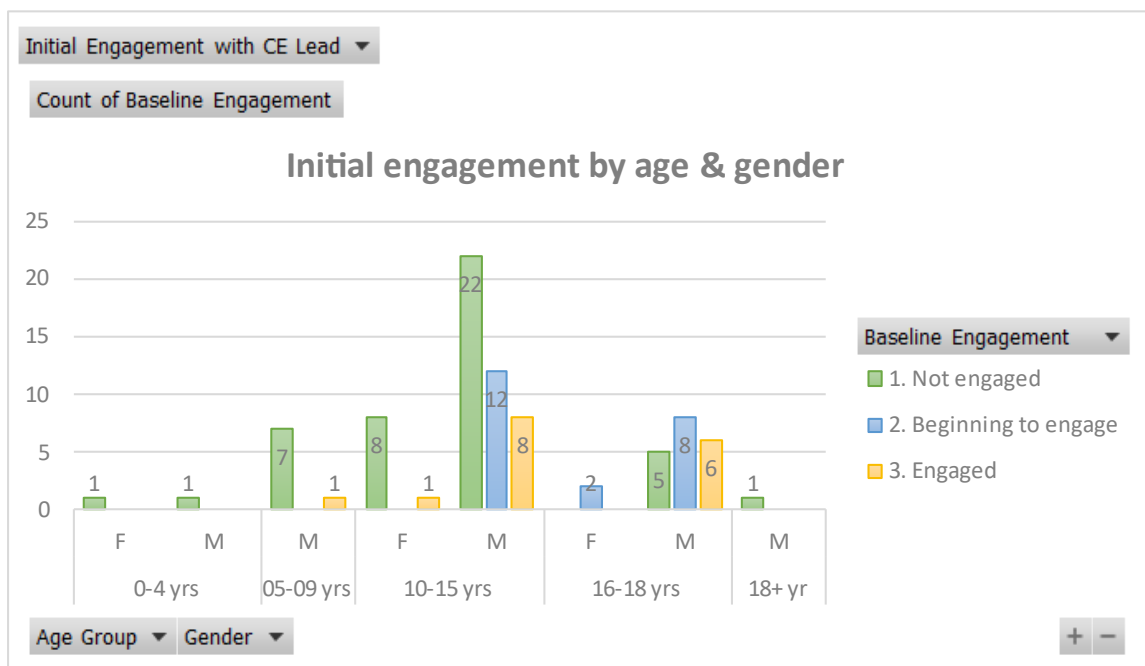
2. Key Findings

2.1. Community engagement

The Community Engagement Lead personally contacted 73 families; these were all current beneficiaries and their families as well as those on the wait list to receive a Muscle Dream. The largest group were boys aged 10-15 followed by boys aged 16-18. The largest group of girls were aged 10-15.

The purpose of the community engagement was to make contact with vulnerable families: to carry out a social needs assessment, to find out how families were coping and to provide practical support and mental health signposting. In addition, the families were offered access to Virtual Muscle Dream programmes (see section 2.2) and were referred to the Chief Muscle Warrior for a virtual conversation to provide inspiration.

Their baseline engagement, as identified by the Community Engagement Lead, was as follows:



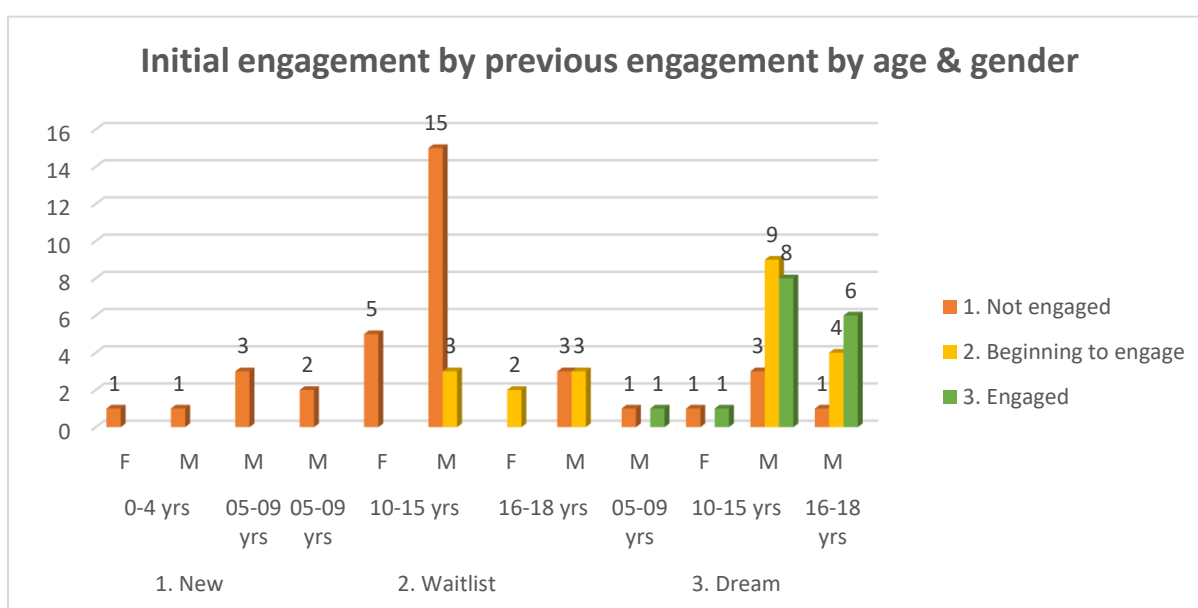
Over 50% were not engaged at the beginning of the project. Those aged 16-18 years were the exception, where over 75% were beginning to engage or engaged. 75% of girls were not engaged at the beginning of the project. Due to the small number of girls participating this may or may not be significant.

All families who were contacted (not including those who didn't respond to the initial contact) were sent an inspirational book, *The Boy, the Mole, the Fox and the Horse* by Charlie Mackesy, to support well-being and to foster engagement with the activities being offered by the Muscle Help Foundation as part of this project.

The Community Engagement Lead kept in close contact with families, including providing information on upcoming relevant events of interest and encouraging children and young people to take part in virtual activities on offer. There were pre- and post-event phone calls and a final follow-up phone call towards the end of the project to understand families' experience and to evaluate the impact of the interventions.

Of the 73 beneficiaries contacted, 35 (48%) had experienced a Muscle Dream previously and of these:

- 13 beneficiaries were assessed as beginning to be engaged and 16 beneficiaries were assessed as engaged
- six beneficiaries were assessed as not engaged; i.e., the families did not respond



Unsurprisingly 41% of those beneficiaries who were new or previously on a waitlist were assessed as not engaged. However, 16% of those who were assessed as not engaged had experienced a Muscle Dream and it would be interesting to understand the reasons for this potential disengagement.

2.1.1 Reduction of isolation

The indicators of signs of change from community engagement activity were:

- the sense of belonging to the Muscle Warrior community, as reported by the child/young person and their family.
- number of children/young people taking part in the virtual conversations with the Chief Muscle Warrior, and their feelings as reported by them.

Families provided feedback to the Muscle Help Foundation which showed some impact from community engagement on feelings of isolation. Some examples are provided here:

“So appreciative of the [Muscle Help Foundation] to check in on us and be thought of during this time. Everyone has been so supportive.” (2018 Muscle Dream recipient)

“Overall, so so pleased to have been in touch with the [Muscle Help Foundation] and amazing that everything can be so flexible.” (2020 Muscle Dream recipient)

In addition, eight beneficiaries took part in the Coffee & Catch Up with the Chief Muscle Warrior. The Chief Muscle Warrior reported that the conversations highlighted the importance of these discussions to families:

“The scourge of isolation was (and remains) a driving motivation for these kinds of conversations in encouraging more of a sense of belonging to the Muscle Warrior community. Beneficiaries and families were at pains to say just how grateful they were in ‘being remembered’ in this way.”

2.1.2 **Staying connected**

The indicators of signs of change from community engagement activity were:

- number of participants & feedback who took part in a Virtual experience
- engagement with the Mackesy *Muscle Masterpiece* Competition prize draw
- number of drawings and responses across the charity’s social channels

There were 28 Virtual Muscle Dream sign-ups, across three activities.

There was positive feedback from families on engagement with the charity.

“We are really looking forward to the families catch-up this weekend as it is so important to do. We get ideas of how to help each other and know what each other are going through as we are all shielding. I would love this to happen more regularly.” (2020 Muscle Dream recipient)

There were nine entries for the Mackesy *Muscle Masterpiece* Competition, with good engagement in this activity from the Muscle Warrior community, resulting in 616 votes across the charity’s social media channels.

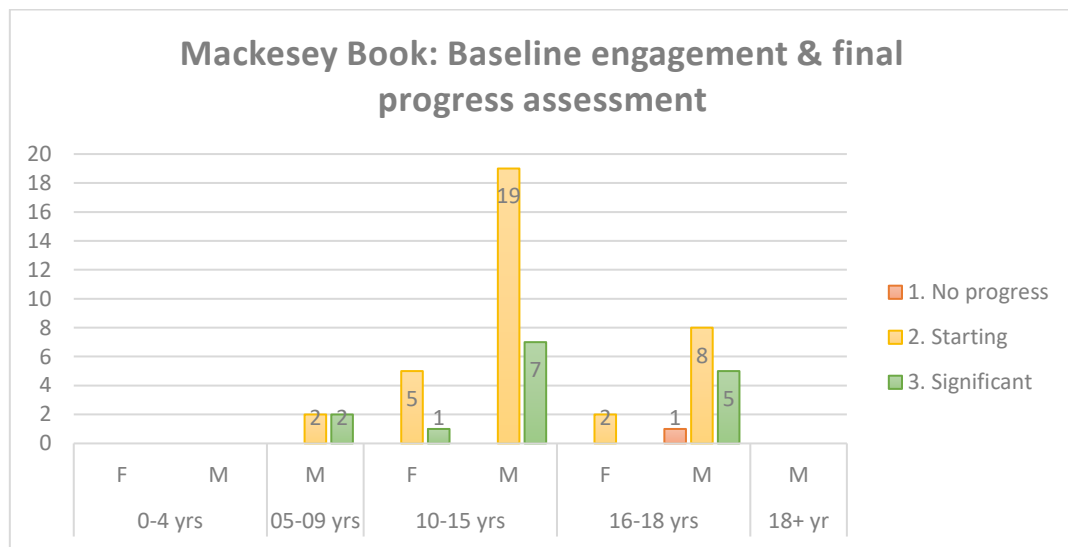
2.1.3. **Supported good mental well-being & hope for the future**

The indicators of signs of change from community engagement activity were:

- using Charlie Mackesy’s book ‘The Boy, the Mole, the Fox and the Horse’ as a well-being platform to create their own drawing and message of hope

All beneficiaries (except one) who received & read the book were assessed as having started to show or having shown significant progress:

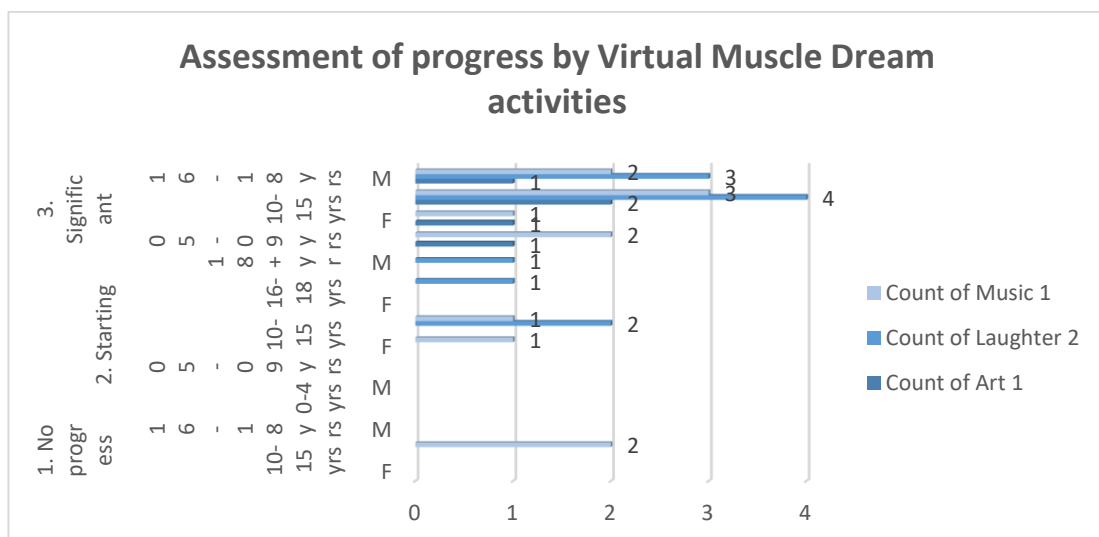
- 69.2% - 36 out of 52 were assessed as starting to show progress
- 28.8% - 15 out of 52 were assessed as showing significant progress
- 50% - 26 out of 52 who were assessed as starting to show or having shown significant progress were boys aged 10-15



2.2. Virtual Muscle Dreams

Of those who took part in Virtual Muscle Dream experiences, the assessments were:

- 100% of those attending Art Virtual Muscle Dream showed significant progress
- 66% of those attending Music Virtual Muscle Dream showed significant progress
- 64% of those attending Laughter Virtual Muscle Dream showed significant progress



As the numbers of beneficiaries participating were small, and there was only one session of each Virtual Muscle Dream, it may be difficult to draw conclusions of the long-term impact.

2.2.1 Reduction of isolation

The indicators of signs of change from Virtual Muscle Dreams were:

- sense of belonging to the Muscle Warrior community (reported by young person/family), through baseline and end of event polls, and post-event surveys
- commitment to joining the Muscle Warrior online community e.g. Facebook, Instagram, YouTube and sharing their experiences (reported by young person/family)

The baseline (start of event) and end of event polls for the **Art Muscle Dream** showed a clear shift of 3 points in the reported feelings of beneficiaries as a result of the event:

Let us know how you are feeling by rating the following statements from 1 (Feeling down & isolated) to 10 (Feeling happy & engaged)



Let us know how you are feeling by rating the following statement from 1 (Feeling down & isolated) to 10 (Feeling happy & engaged)



The baseline (start of event) and end of event polls for the **Laughter Muscle Dream** showed a clear shift of 3.4 points in the reported feelings of beneficiaries as a result of the event, and the feelings described at the end of the event were largely positive:

Let us know how you are feeling by rating the following statements from 1 (Feeling down & isolated) to 10 (Feeling happy & engaged)



Let us know how you are feeling by rating the following statement from 1 (Feeling down & isolated) to 10 (Feeling happy & engaged)



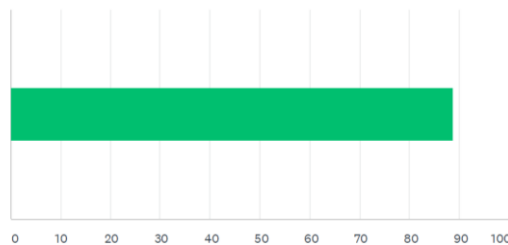
Add a word or phrase to describe your feelings right now?



Engagement on social media platforms to share experiences was assessed from the Art Virtual Muscle Dreams, although the sample size was small:

Q6 On a scale of 1 to 10, since the event, has yours or the beneficiary's engagement increased with Muscle Help Foundation via our social media platforms?

Answered: 3 Skipped: 0



There was positive feedback from some families on feelings of reduction of isolation:

“Looking forward to future activities and would do laughter again. Feeling so supported by the [Muscle Help Foundation] and watching the ‘In Conversations’ on Facebook are great”. (2015 Waitlist)

“These sessions really help with isolation and they are fun but also bring skills, which are so important. Really excited to see what the MHF do next!” (new)

2.2.2 Staying connected

The indicators of signs of change from Virtual Muscle Dreams were:

- sharing experience with classmates or another wider group of friends and family e.g. drawing, presentation, with support from MHF
- story-telling using blogs, vlogs or drawings to share how they felt about their experiences

Unfortunately, there was not an opportunity to gather data on sharing of experiences by beneficiaries with their own personal communities, due to the length of this project. This would be a useful follow-up exercise for a longer project. Story-telling using drawings for the Macksey competition did take place; again, with a longer project

duration the charity would be able to work with beneficiaries and families to support them with drawings, blogs and vlogs.

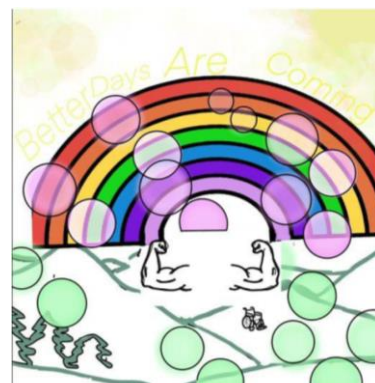
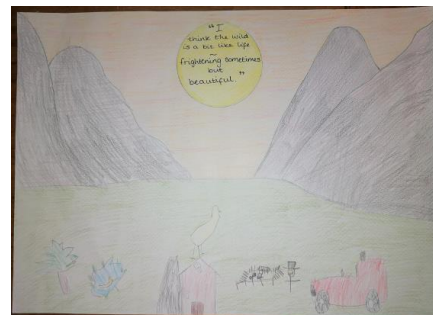
2.2.3. Supported good mental well-being & hope for the future

The indicators of signs of change from Virtual Muscle Dreams were:

- spirit and/or confidence being uplifted (reported by young person/family)
- using the Charlie Mackesy book to create their own drawings and messages of hope for others in the Muscle Warrior community

Families shared drawings and messages from beneficiaries inspired by the Charlie Mackesy book with others in the Muscle Help Foundation community; see examples of drawings below. The Community Engagement Lead received messages from families outlining the impact that taking part had on their child.

Here are a sample from the nine entries to the Mackesy competition:



There were many messages of hope received by the Muscle Help Foundation from beneficiaries who took part in the project; a sample are provided here.

"We are new to the [Muscle Help Foundation] and it was a great first experience and it did lift our spirits. Look forward to seeing what else is coming up, now we are part of the Muscle Warriors!"

"[Our child] felt loved, appreciated, noticed, nurtured and part of the tribe. [Our child] is feeling so much more positive and his confidence has definitely been uplifted. We definitely feel part of the Muscle Warrior tribe now."

"The whole thing has really given him the boost that he needed and to be part of something. His mood has been lifted and he has been playing his guitar and singing much more since the session. He loves his music."

Case Study

Child I is 15-years-old and has a muscular degenerative disease and pompe disease, type 2 GSD. Lockdown and shielding for the past year has had a hugely negative impact on Child I's physical and mental wellbeing. Due to Child I being extremely clinically vulnerable, the family have had to move from their shared hostel accommodation to new premises, which has unfortunately not been fully adapted for Child I's needs.

Child I has been experiencing low moods, is increasingly isolated and very anxious about the future. As a single parent family, his mother has found it difficult to support her three children, especially Child I, due to the struggles he faces on a daily basis exacerbated by the ongoing pandemic. Child I finds it difficult to make friends and has felt increasingly lonely this past year.

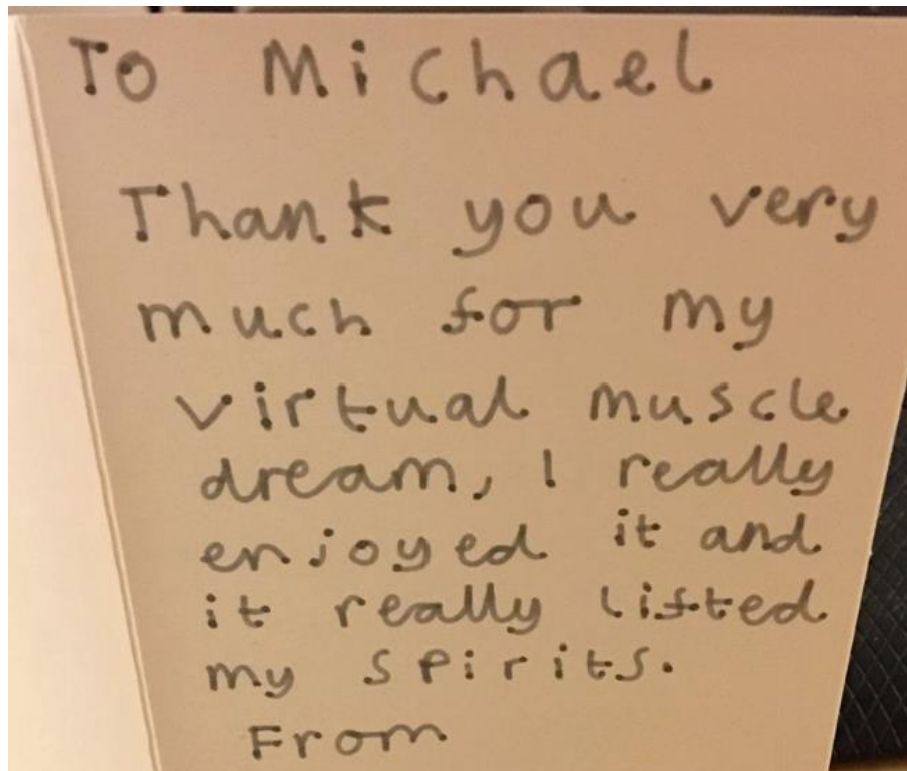
The family were connected to the MHF by a Specialist Care Advisor (Pompe) who had been called by the Community Engagement Lead. The programme of Virtual Muscle Dreams and activities were recommended to the family.

The family applied to all of the activities that the MHF has been able to offer thanks to the support from Children in Need. These include the Virtual Muscle Dream Laughter 2.0 programme, Virtual Muscle Dream Music 1.0, Virtual Muscle Dream Art 1.0 and the Virtual Cuppa & Catch-up. The family also entered MHF's creative competition, with two entries from Child I's siblings. This competition was inspired by Charlie Mackesy's book, 'The Boy, the mole, the fox and the Horse' which was sent to all the families as a gift. Through these virtual activities and the ongoing support from MHF, there has been an increased confidence noticed in Child I.

From observations from the charity, there has been a marked difference from the first Virtual Muscle Dream engagement to the last. From the first, where Child I's camera was off and there was no interaction with the session, to the third where Child I's camera was on and he was actively participating, making jokes and fully engaged in the session. The family also noticed a difference with Child I engaging more, feeling proud of himself for attending the sessions and his confidence growing.

As a result of the programme Child I is now looking forward to joining future activities and has also made suggestions of activities for the charity to organise. The online activities and engagement have helped to reduce isolation not only for Child I, but for the whole family who have all been able to take part in the different

activities on offer. Through these sessions they have been able to connect with other families who are also shielding and have consistent support from MHF. Child 1's mother says: *"We don't lose hope and these Muscle Dreams really help us with that. This is just what we all needed to boost our spirits. I would love this to happen more regularly"*



To Michael
Thank you very
much for my
virtual muscle
dream, I really
enjoyed it and
it really lifted
my spirits.
From

3. Conclusions & recommendations

3.1. Conclusions

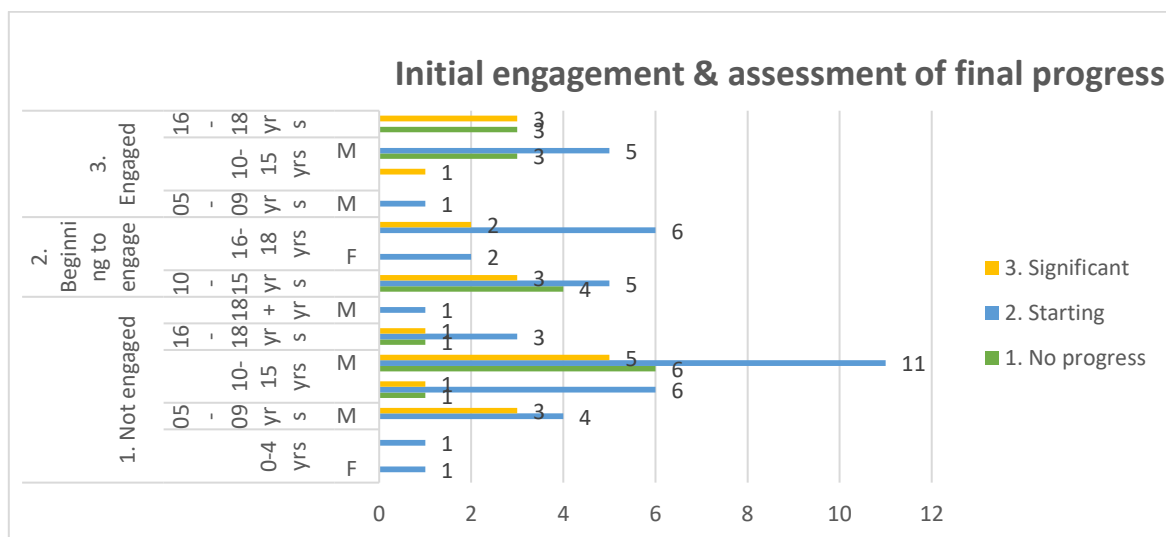
This project has demonstrated that community engagement and Virtual Muscle Dreams have a positive impact on reducing social isolation, staying connected and supporting good mental well-being.

“The power of a phone call, an opportunity to chat, listen and give a young person a voice to, for example, share they’re feeling about the pandemic is something that the Muscle Help Foundation is looking to explore further through additional community engagement initiatives.” (Chief Muscle Warrior)

This project had a clear short-term impact on the lives of beneficiaries and their families. More beneficiaries would have been likely to make progress with a longer project time frame.

The key findings from the project with regards to progress measures across the indicators by age and gender, were that:

- just under 80% (78.3%) of beneficiaries were assessed as having started to make progress (55%) or make significant progress (23%)
- 82% of previously not engaged beneficiaries were assessed as having started to make progress or make significant progress, of which 76% were in the 10-15 age group
- the largest group starting to show progress or significant progress were boys aged 10-15 (third of total)
- the largest group showing no progress were boys aged 10-15 & 16-18 years (21.7%) (of which 16% 10-15 & 5% 16-18)
- of the Virtual Muscle Dreams, the Art experience was assessed as having the best progress outcomes



3.2. Recommendations

The project duration, which was less than 3 months, has meant that it will be difficult to identify the longevity of its impact. It would be useful to revisit the beneficiaries who took part in this pilot project to undertake follow up activities from the community engagement and Virtual Muscle Dreams.

Recommendations from this pilot project are:

- Using a validated tool to identify the well-being of beneficiaries, when gathering baseline and post-activity data. This would need to be carefully identified for suitability and be subject to ethics approval and parental/beneficiary consent. Examples are the Warwick Edinburgh Mental Wellbeing Scale (WEMWBS) (validated for children aged 13 and over), the Huebner's Students Life Satisfaction Scale (considered suitable for children aged 8 to 15 years), and the Good Childhood Index (validated for children aged 8 and over)
- Deliver future Muscle Dreams experiences to distinct age categories of children and young people (8-12 years, 13-18 years and 19-28 years) so that beneficiaries take part in experiences that are bespoke to their requirements and maximise opportunities for engagement
- Longer project duration, ideally a minimum of 12 months, to enable deeper and more sustainable engagement with beneficiaries and their families
- Deliver connected and mutually reinforcing activities to inspire beneficiaries and achieve the best progress outcomes; in this project this was a visually engaging book, the Art Virtual Muscle Dream and a drawing competition.

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