Independent evaluation of the Transforming Access to Therapies project: a final report from Cloud Chamber

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Author: Matthew Terry

Muscular Dystrophy
Support Centre
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1 Introduction

1.1 Background

In 2021, the Muscular Dystrophy Support Centre (MDSC) commissioned Cloud Chamber to evaluate its Transforming Access to Therapies (TATT) project. With a grant from the National Lottery Community Fund (the Lottery), the project sought to expand and support MDSC's offer through additional capacity and an expansion of the service into satellite sites across the Midlands. The project ran for five years to April 2025.

1.2 Evaluation objectives

The following objectives, framed as questions, were agreed for the final evaluation report:

- How well has the project met its planned objectives, outcomes and the needs of its target beneficiaries?
- What lessons have been learnt from the project's challenges, achievements and failures? In particular, what lessons have been learnt in the development of the new satellites that other groups of people with MD could apply in the future to develop their own therapy centres?
- How effective have the approaches been around: management of a remotely dispersed team; partnership working; sustainability; increase in clinical effectiveness; and monitoring and evaluation?
- To what extent were people with MD and their families meaningfully involved with the project at an operational and strategic level? How could this have been improved?
- How have service users' needs changed since the project was planned in 2019?
- What are the recommendations for the next phase of MDSC's development to support people with MD?

1.3 Evaluation activities

The evaluation has run alongside the project since March 2021 (approximately one year after the project began). In addition to this final report, an interim report was produced for MDSC in November 2022.

In March 2022 we produced a systems review and evaluation plan for the project which included:

- A theory of change for the project, and a logic model for MDSC's outcomes and impacts (Annex A and B)
- A review of current data collection and recommendations about changes to data collection mechanisms
- A focus group with service users to understand the difference MDSC makes to them

For this final evaluation report, we carried out the following fieldwork and research:

- Semi-structured interviews with 18 people: staff (4), volunteers (7), trustees (2) and other external stakeholders (5)
- Analysis of the service user survey 2024 (the most up to date)
- Analysis of other secondary data including reporting to funder, management reports, etc.

1.4 Notes on the evaluation

It should be noted that TATT was more a strategic programme for charity growth rather than a ring-fenced, standalone project. In this evaluation, therefore, we are assessing change and impact across the whole of MDSC's operation during the funding period as it is not sensible nor feasible to isolate that element funded by the Lottery grant alone.

The project began in 2020/21 at the time of the Covid-19 pandemic. This had an understandably negative impact on the growth plans anticipated by the TATT project and wider challenges for the charity, as was the case in so many parts of life at that time. We mention Covid during the report where there is a specific significance (e.g. the development of online classes), but more generally the impact of Covid should be borne in mind when considering the success and impact of the project.

The views contained in this report are those of the independent evaluators. We would like to thank all those people who gave up their time to speak to us about the project.

2 Delivering the project objectives

2.1 Introduction

In this section, we reflect on how well MDSC has delivered on the project's objectives, namely:

- Improve the ability of people with MD to live well with their condition as a result of expanding partnerships, growing service capacity, scope, reach, accessibility as well as its relevance to younger people
- Improved organisational sustainability via improving mechanisms for putting pwMD in the lead, and improving systems for governance, sustainability and clinical effectiveness
- Improve organisational sustainability by diversifying income streams and improving communications / marketing

A detailed exploration of service user outcomes – which form an important part of these key objectives – follows in Section 3.

2.2 Improving support for people with MD

A cornerstone of the TATT project has been the expansion of services for people with MD. Broadly this has involved three aspects: more staff, new satellite centres, and additional services.

2.2.1 Staffing

Lottery funding allowed investment in staffing including the following new posts:

- Chief Executive Officer
- Clinical Services Manager
- Engagement and Fundraising Officer
- Administration support

In addition, the grant enabled the part-funding of other roles to help maintain and grow charity capacity.

Staff, volunteers and stakeholders described this support as having been pivotal to the growth and development of the charity in many areas including:

- Strategic leadership: previously, the charity relied on the Chair of Trustees, the Fundraising Manager and lead physiotherapists, but the recruitment of a CEO (who was with MDSC for the duration of the TATT project) formalised a management leadership role, enabling a clearer separation between management, governance (trustees) and service delivery (therapists); and providing valuable resource for driving service growth and establishing new partnerships
- Service capacity: investment in additional physiotherapists directly led to an increase in the availability of treatment hours for service users, despite challenges with recruitment due to a tight labour market.

- Service quality: the charity developed a new clinical management system and a better system for service user annual reviews (see later in this section). The Clinical Services Manager role was intended to drive this long term, but the potential was never realised. Clinical management now lies with the two co-leads of the physiotherapist team.
- Communication with the NHS: staff and NHS stakeholders reported that communication between MDSC and related NHS services (including those referring in people with MD) had significantly improved over time, including NHS partners recognising the value of MDSC services more. This was put down in part to the increase in staff and therefore greater capacity to engage with external stakeholders and build better working partnerships

Overall impact of staff growth

"TATT is so significant, it can't be underestimated. Prior to lottery funding, the passion and delivery of services was never in question but it was such a small team" (Trustee)

"It's just expanded dramatically…We've expanded in terms of with our space, and with that we've been able to employ more staff. And we can offer more therapies and that increase in space has allowed us to invest in better equipment, more equipment. And I feel that what we offer now is a tenfold improvement on what we were offering [before TATT]. And it's been managed in such a way that we've been able to do this." (MDSC staff member)

Relations with the NHS

"The relationship has much improved. That's a recognition that the NHS really can't provide much ongoing support…and all the evidence and the research shows us that [people with MD] need ongoing support…and I think there's more acknowledgement about how valuable that is. So we have many more NHS people coming nowadays, wanting to have a look at the centre and making contact" (MDSC staff member)

2.2.2 New satellite centres

The growth of the charity's geographical footprint during the project has focused on the development and launch of new satellite centres. MDSC already had two satellite centres in Birmingham and Leicester; two more were added during the project in the Black Country (Tipton, 2021) and Northampton (Daventry, 2024).

MDSC's argument for additional satellite centres was clear at the time of their Lottery bid: according to the charity's own research, many people in the Midlands needed access to specialist support and therapies but were not always able to get to the MDSC Centre in Coventry or its existing satellites. This has subsequently been borne out by the conversations we have had with stakeholders, and the growth in user numbers more generally (see below).

The satellite centres cannot deliver the same range of services at the headquarters in Coventry, but this was always expected given the availability of locations and the resources required to run them. What MDSC has been developing over time is the relationship between the satellites and the HQ to ensure that it works for service users in a coherent manner. Satellites focus on core therapies like physiotherapy, while the HQ has a wider variety of services and a greater sense of community spirit. All service users are encouraged to visit the HQ at least once and usually attend for their initial assessment. Service users visiting the satellites are happy trading off a less comprehensive range of services for a reduced travel burden, according to service users and MDSC staff; but it is recognised that this is not a trade-off that all service users are willing to make, especially if they are able to travel to the HQ in Coventry.

The development and ongoing operation of the new satellites has required MDSC to establish new partnerships with host organisations:

- In the Black Country, the satellite is located on the premises of the Murray Hall Community Trust, a charitable community organisation providing a range of support services to the local population. MDSC rents space in the Trust's premises and has equipment located there.
- In Daventry, MDSC services are delivered within the Reach for Health Centre. Reach for Health is a charity in its own right, focusing on not-for-profit health, wellness and rehabilitation; and especially in the areas of active ageing and specialised rehabilitation support. There was a clear fit with MDSC's needs and the premises was already accessible.

Our conversations with stakeholders confirm that the relationships between MDSC and their satellite hosts are good. To an extent, the two satellites offer different approaches to partnership delivery: in the Black Country we felt that the relationship was more transactional (room hire), while in Daventry the relationship was stronger and seems more integrated.

It's important to note that the two satellites were not the only 'physical' changes during the lifetime of the project:

- MDSC's HQ itself moved to larger premises in 2023 which has helped to expand capacity and the range of services on offer.
- The pre-existing Leicester satellite moved from Loughborough to Leicester (LOROS Hospice) as a result of Covid restrictions in 2021
- The pre-existing Birmingham satellite is currently in the process of transitioning to new premises, having had to move twice since the pandemic
- A planned fifth centre in Worcestershire was not established (as originally planned) during the project, which was mainly due to the knock-on effects of Covid on MDSC's strategic growth ambitions. The original target of three new satellites was reduced to two and achieved.

2.2.3 Additional services

Physiotherapy has been the predominant service since before the TATT project, and more sessions are now available due to the increase in staffing and physical capacity brought about by the project (see reach below). Another aspect of growth that the project focused on was increasing the diversity of the services and support provided to people with MD, drawing heavily on what people with MD said they wanted and/or needed. This has included:

- The development of an online offer: begun during the pandemic, an online support offer has become part of business as usual for the charity. This includes four physiotherapist-led classes a week: yoga, seated exercise, seated/standing exercise and breathwork. Some service users engage in a regular programme, others drop in. Classes are livestreamed and available pre-recorded on our website.

- Wellness Hub: a series of quarterly online information sessions on topics relevant to living well with MD. External speakers are engaged to share knowledge and learning about MD with service users. Past topics have included nutrition, worry management, respiratory health and nutrition.
- Social support: an expanded range of social opportunities are provided for service users to enjoy contact in person. This now includes coffee mornings at satellites, dinners, and a Knit and Natter group.
- Peer-led groups: Adapting to Change is a peer support group focusing on the transitions that people with MD go through as their condition progresses. The theme was one suggested by service users themselves and aims to provide mutual support through the experiences that some service users have already gone through, for example coming to terms with the need for mobility aids.

Adapting to Change

"You hear the stories of people making changes in their lives, particularly psychological changes and their acceptance of many of the conditions that are progressive. There is at times quite a healthy resistance to change, trying to hang on to what we've got. But in some ways, we have massive expertise about adapting to major life changes. For us to be able to tell our stories is to some extent a little bit therapeutic. And also you think, oh yeah, actually maybe if I just give in on this, it's going to be easier for me and it'll be easier for my family." (service user)

"We've [all] got experience of bashing up against complex systems and being rejected and then problem solving around it. And so hearing stories of how people have done that is both inspiring and helpful…Given it's a complex world that we're dealing with, hearing some of how that's happening I think is a very nice way of maximising learning and validating people and their experience. And when then you hear [someone has been successful] …it opens your eyes to exploring things in a different way." (service user)

The sum of all these new services is a more holistic offer to service users who have a range of choice, not only in which services they choose to use, but the frequency and manner with which they interact. Attendance just for physical therapies is still very much an option, but as we will show in Section 3 the evidence suggests that the holistic approach is helping to maximise outcomes for service users.

2.2.4 Impact on reach and accessibility

The combined impact of these changes has been to broaden the reach and accessibility of MDSC's services considerably over the five years of the TATT project:

- Geographical reach within the Midlands area has expanded through the two new satellite centres: in the final project report to the Lottery, MDSC states that service users live in 31 counties, not all of which are in the Midlands.
- Registered service user numbers rose 62%, from 379 in 2019/20 to 613 in 2024/25, slightly exceeding the revised project target (101% achieved). The original target had been 1,100 users, but this was judged overoptimistic earlier in the project and revised down.
- The number of monthly therapy sessions has more than doubled, from 201 pre-project to 468 at project end, which represents 92% of the project target. At the end of the project, MDSC was employing 16 therapists: 13 physiotherapists, two osteopaths and a complementary therapist.

The scale of the charity's growth has been impressive over a relatively short period of time and further bears out MDSC's original belief that there was unmet demand in the Midlands for high quality, effective support for people with MD.

2.3 Organisational sustainability - mechanisms

2.3.1 Involving service users

The TATT project has succeeded in increasing engagement between MDSC and its service users and involving them more in decision making and delivery. There are now a number of mechanisms that support this including the following:

- More user-driven initiatives, such as the peer-led Adapting to Change group mentioned earlier. This was inspired by an Open Day session involving the co-lead physios and service users, focusing on the challenges people with MD commonly face in adapting to the loss of function due to progressive muscle weakness.
- out of an idea from service users, and which involves service users drawing on their own experiences to support one another.
- Quarterly service user focus groups held online provide structured sessions that enable service users to provide feedback and make suggestions about the work and services of the charity. This evolved from the project steering group (see below). More generally, service users noted that their own ideas were given serious consideration by the charity and often acted upon, even if they weren't always successful.
- The Project Board, which includes service users and which has provided some strategic oversight of the TATT project, directly reporting to the CEO

To these can be added other mechanisms to engage service users, including the annual service user survey (Section 3) and the active presence of people with MD on the board of trustees. There are also many volunteering opportunities open to service users/people with MD and our conversations with volunteers identified a range of benefits to them including:

  - Satisfaction - contributing to something they have benefited from, knowing that they are helping others
  - Skills development – some volunteers described learning a lot from their work with MDSC, helping skills development in a number of ways
  - Sense of purpose – some volunteers described the strong sense of purpose volunteering provided for them in dealing with their own situation
  - Opportunity to influence the direction of the charity: volunteers valued the trust placed in them to help shape the development of the charity

Volunteers are treated as de-facto staff members, with one volunteer benefiting from 1:1 sessions with a line manager; many attend staff meetings, and some having a written role description (which wasn't always the case before the TATT project).

> *"There's a really nice community that they've cultivated there. I've taken part in steering group discussions. I think it's great. Rather than just sitting there saying, 'we're doing a great job', they [MDSC] actually come to us and say, look, what can we do differently? What can we do more? It feels like a collaborative organisation. They know they're doing great things; they absolutely are. But they also want to know how they can do things differently all the time. So they're always communicating with us." (service user)*
>
> *"They are looking at all different ways of engaging with service users and improving the services, and I think that that really has developed very well and effectively over recent years…It keeps improving year on year." (service user)*

This has been a deliberate and incremental shift by the charity towards a culture that is more involving of service users than it was previously, and there has been learning along the way. For example, the original intention was to have a service user steering group with a great deal of independence from the charity that would take the initiative and ownership of collectively agreed upon ideas and strategies. In practice, it did not have the intended effect of galvanising service user leadership within the group. There was good engagement in ideas generation but less willingness to act on behalf of the charity to implement change. Volunteers also reported a lack of clarity about the terms of reference for the steering group. The steering group subsequently turned into the regular service user focus group which involves greater facilitation by the charity, while some members of the steering group took on more active individual roles as volunteers.

2.3.2 Governance

The TATT project has operated with a Project Board providing oversight of the project and reporting via the CEO to the trustees. It is made up of service users and other key stakeholders (including external partners). Its role has been to understand progress, challenge and make suggestions for improvement; ensure that the project meets its Lottery milestones; report upwards to assist the charity's overall governance of the project.

Project Board members felt on the whole that the Board worked well and maintained a focus on the effective delivery of the project, although it was not always clear to them how their reporting was received by trustees. Overall, members considered that the project had been successful in achieving its objectives, particularly in growing the capacity and scope of service delivery. Their biggest concern for future sustainability at the end of the project was about finance and funding, which they considered (almost universally) to have been the most challenging area to address.

As the TATT project ended, it was intended that a modified form of the Board would be established to continue to support the charity's ongoing work to develop a new five year strategy.

2.3.3 Clinical effectiveness

Clinical effectiveness has been improved through the project. The development of an annual review system for service users this tracks service user progress against a set of outcome measures which draw on existing clinical good practice. The reviews are delivered separately to normal therapy sessions and provide an opportunity for reflection and planning for both therapists and service users. Our interviews suggest that the review process is appreciated by service users, as the quote below illustrates.

> *"My sense is that's really helpful - having an annual review with a physiotherapist where there's a bit of reviewing and planning…somehow it's a different conversation than you have during a treatment session…I think that's something that is of real value…on an annual basis to give over one session to thinking about what might happen and what has happened and what support you can get at home. We did little videos of things so that my carer can actually do some of the stretches at home [with me]." (service user)*

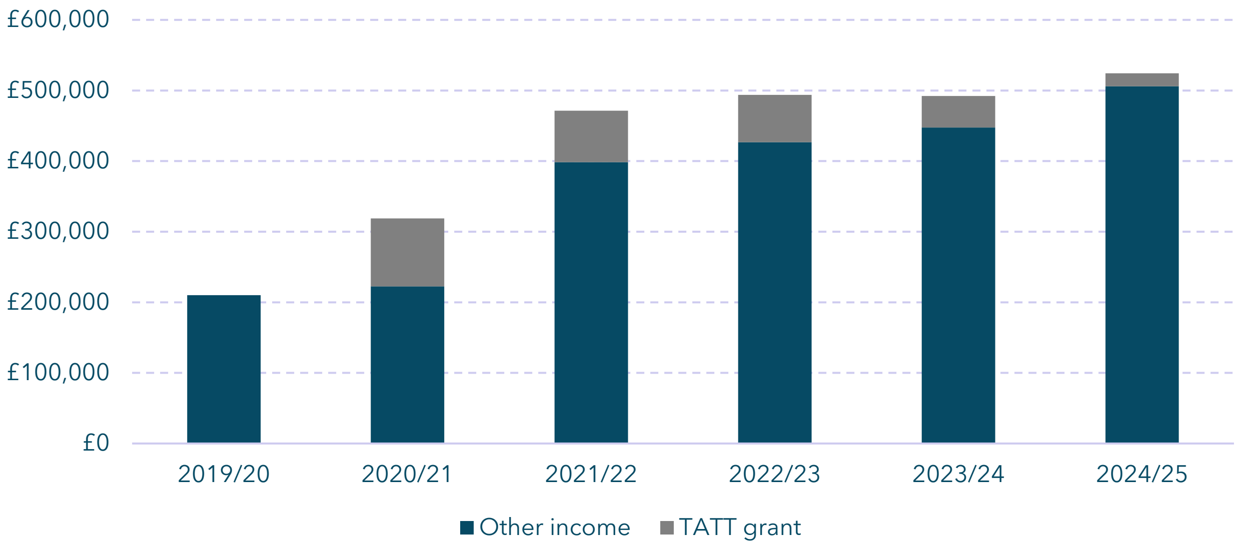
2.4 Organisational sustainability

2.4.1 Diversification of income streams

Diversifying income streams was an important goal for the TATT project and the Lottery grant was deliberately tapered so that MDSC would have time to replace the funding from other sources in a gradual manner.

Figure 1 shows how MDSC income has grown over the course of the TATT project – from £210k in the year before the project started to £524k in 2024/25 – reflecting the increase in activity over the same period. Non-Lottery funding has more than doubled from £210k to £506k. At the same time, the proportion of income represented by the Lottery grant has reduced from 30% (in the first year of the project) to 4%. The 2025 outturn of £524k total income represents 87% of the final year target of £599k.

Figure 1: MDSC income over the course of the TATT project (source: MDSC)



While MDSC has succeeded in diversifying away from Lottery funding – and has grown its non-Lottery income by 65% - the charity acknowledges that income diversification is still very much a work in progress. Many of the findings from a review of the first three years of the project still hold true in 2025:

- Income from charitable activities is dominated by MDSC services that are paid for by various NHS organisations on behalf of their patients. This now accounts for about half of income and its growth reflects the overall rise in the charity's activities.
- Grants from trusts and others (including the Lottery) are also a substantial source of income.
- Community fundraising generates a very small amount of income – and likely makes a loss if in-kind support (such as staff time) is included. Its benefits are more likely to be non-financial through the social benefits of those service users who take part
- Individual and corporate giving have also generated limited income and the scope for expansion here seems limited (see conclusions section)

> *"I think that we have a way to go on that [income diversification] …I think we've done our best with the resources that we've had in order to try to diversify those streams. But I think certain types of streams such as individual giving and corporate, those two in particular really require a lot of resource that we don't yet have the capacity for." (trustee)*

The funding picture is complex and is similar in our experience to other charities in this sector. NHS funding is understandably significant, and we reflect on this in the final section of the report. It also comes with a substantial administrative burden: the funding comes from upwards of 20 different NHS organisations, some of which only have a very small number of service users. Diversifying away from the NHS helps to manage risk – much of the service is not delivered under contracts – but it will inevitably remain an important source of income.

MDSC recognises that there is more to do in terms of growing and diversifying income streams. This remains a priority for them post-project.

2.4.2 Communications and marketing

Communications and marketing activity has increased as the capacity of the charity has grown. This has been helped by the appointment of a Communications Officer. Developments include the following:

- Increased output generally, with a faster and more coordinated approach to updating communications messaging and the website
- The involvement of volunteers who assist with communications including a regular newsletter, website blog and bi-annual magazine
- Internal communications for staff including a weekly round-up email for staff, Trustees and contractors
- An improved website with a greater focus on long form service user stories and more timely updates on events and activities.
- Communication and engagement with external partners has also increased, as noted elsewhere in this report.

3 Making an impact

3.1 Introduction

In this section, we consider the impact of the project on service users – people with MD. The first three section headings are taken from the project Logic Model (Annex A).

Evidence comes primarily from the 2024 service user survey, supplemented by qualitative information from our evaluation interviews.

We also present evidence from service users and others about how the needs of people with MD have changed since the TATT project started. This was a specific evaluation objective.

3.2 Physical

Physical therapies are the most significant area of support provided by MDSC. These come predominantly in the form of physiotherapy, osteotherapy, some complementary therapies, and the use of specially adapted exercise equipment.

Given the importance of physical therapies to people with MD, it is understandable that the bulk of the service user survey focuses on physical outcomes for service users. Overleaf, we provide four tables representing some of the responses to relevant survey questions which help to demonstrate the significant value of the different physical therapies according to service users.

In the table below, we further summarise the results across all nine physical domains in the survey (and four treatment types) by focusing only on the proportion of respondents agreeing or strongly agreeing with the relevant questionnaire statement. This shows that, with only two exceptions, the proportion agreeing or strongly agreeing that they felt an impact was above 60%. The most positive responses were for improved flexibility of joints, while osteotherapy among all the therapies tended to generate the most positive impact across the different outcomes.

Figure 2: Proportion agreeing or strongly agreeing they felt an impact (n varies)

Outcome	**Physio therapy**	**Osteo therapy**	**Comp. therapies**	**Adapted exercise equipment**
Improved flexibility of joints	94%	94%	89%	89%
Improved core stability	81%	78%	71%	83%
Improved muscle strength	73%	79%	61%	82%
Reduced chance of falling over	71%	65%	65%	73%
Improved mobility	81%	90%	61%	80%
Improved balance	69%	70%	50%	63%
Improved posture	83%	86%	62%	76%
Ability to do things around house	77%	89%	62%	79%
Improved pain control	75%	88%	78%	49%

Figure 3: Reported improvements in **joint flexibility**

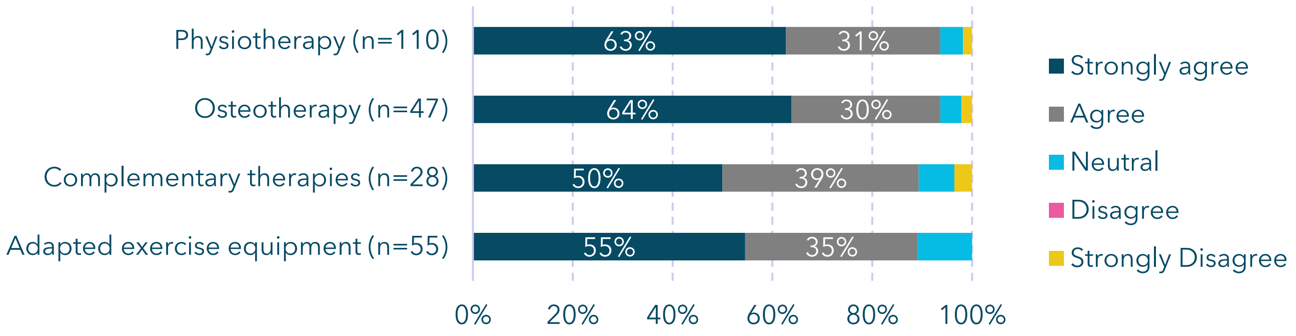


Figure 4: Reported improvements in **core stability**

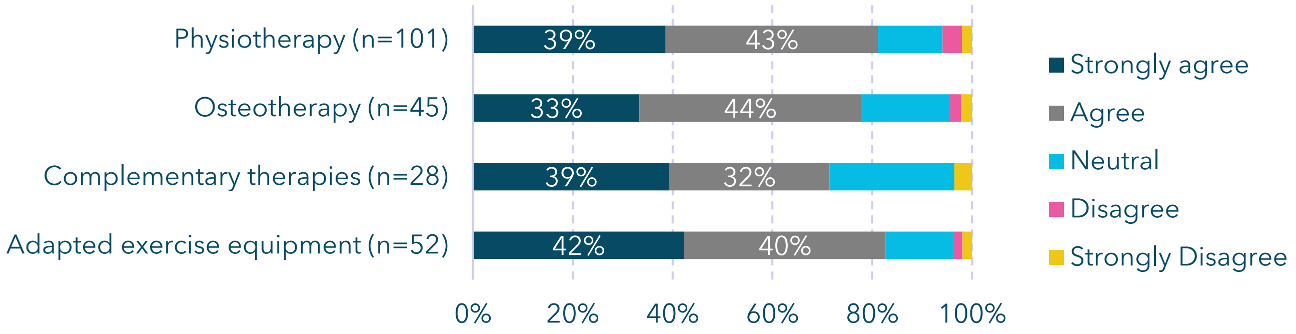


Figure 5: Reported reduction in the **chance of a fall**

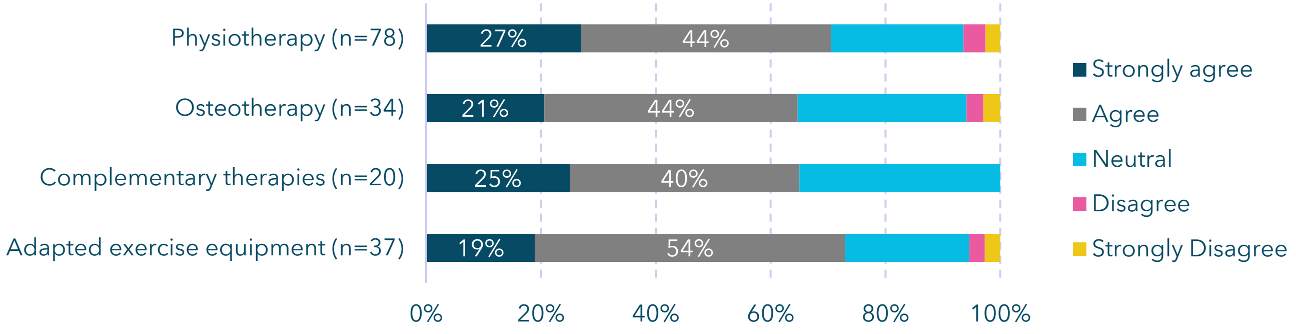
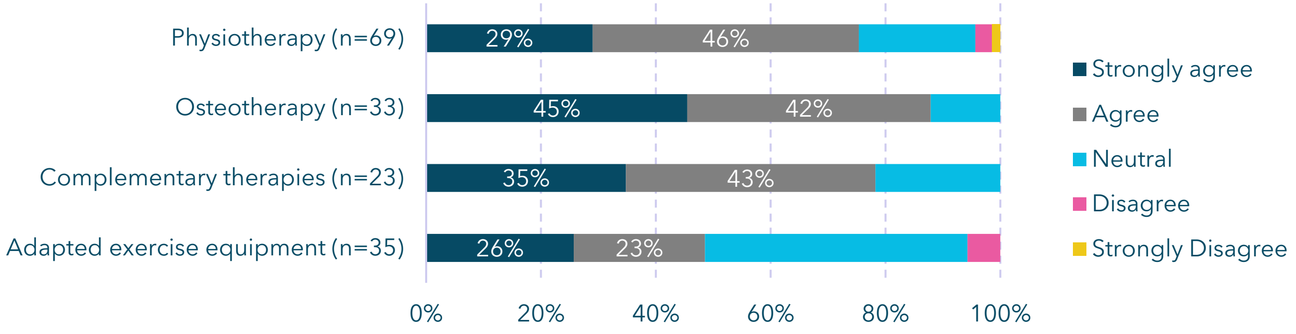


Figure 6: Reported improvements in **pain control**



Quotes from service users drawn from the survey reinforce the positive picture from the quantitative elements (text box below). In particular, service users tended to mention reduced pain/better pain management and improved range of movement as outcomes from physical therapies.

Service user quotes: physical outcomes

"Therapy I receive helps to maintain upper body movement."

"Improvements to energy levels when regularly using the equipment and reduced pain."

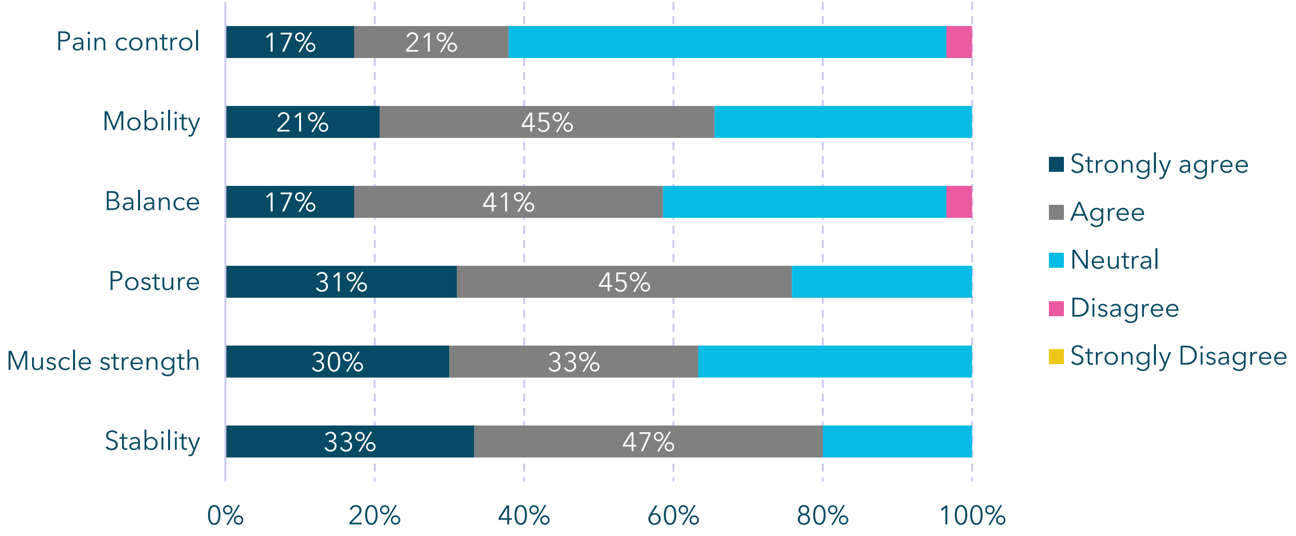
"I've increased my range of movements and learnt how to exercise effectively. The difference has been remarkable."

"Understand how to control the pain associated with my condition especially muscle groups after suffering an injury. The use of a massage gun, the use of stretching exercises etc. to bring back pain free mobility."

"Before being referred I was struggling through with pain management, and coming here has really helped me to move away from entirely relying on pain killers (which aren't always effective) and therapies have actually tackled the issue rather than covering it up"

The survey also covers physical outcomes for people attending online classes. Figure 7 shows the relevant responses (but note the low response rate). It is understandable that for some aspects of therapy, an online offer will not generate the same level of benefit as a physical therapy session, but it is clear from the survey that those who attend still get positive outcomes, for example in terms of improved posture and stability.

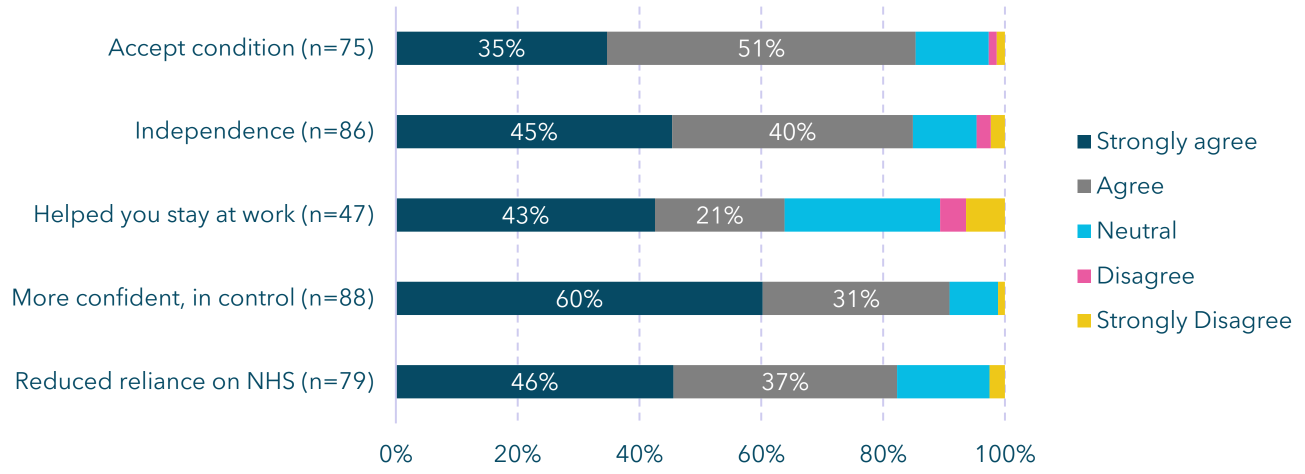
Figure 7: Physical outcomes related to online classes (n=30)



3.3 Mindsets

A range of questions in the service user survey related to 'mindset' issues but were not directly associated with particular activities or therapies as was the case with the physical outcomes above. Figure 8 shows how engagement with MDSC services improved various elements of mental wellbeing, most notably service users' sense of being more confident and in control of their lives; and less reliant on healthcare services. With one exception, those agreeing or strongly agreeing to the statements exceeded 80%. The outlier was about support helping people to stay at work, but this is of relevance to a smaller cohort of service users.

Figure 8: Extent to which survey respondents agreed with mindset outcome statements



Verbatim comments by service users further support the view that support from and engagement with MDSC has a very positive impact psychologically and emotionally (text box below). Several service users explicitly linked mental wellness with their physical wellbeing.

Service user quotes: mindset outcomes

"It has improved my confidence and general mental health"

"It gives me a sense of control and agency in the face of a progressive condition"

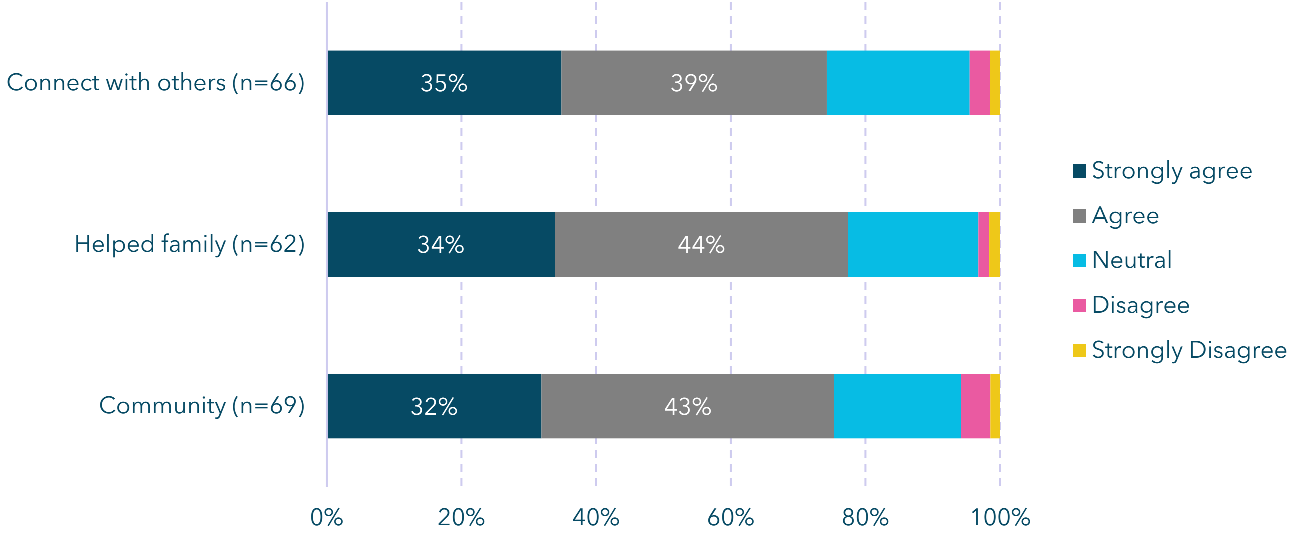
"Just great advice on how to manage my condition and especially fatigue. What to do and what not to do and this has given me confidence to make good decisions. It has also helped me express some of the struggles I was experiencing to my employer which has brought about changes to my role to help me manage."

"I feel that seeing [MDSC physiotherapist] has improved my ability to live with my condition. The point of contact and understanding is priceless. I really feel my mental health is supported as much as my condition."

3.4 Support

Figure 9 provides survey responses related to other aspects of support received by MDSC service users, specifically focusing on elements of community and connectivity. In all cases, the proportion of those agreeing or strongly agreeing with the statements was at least 74%

Figure 9: Extent to which survey respondents agreed with support outcome statements



Qualitative responses from service users further support this positive picture, with many comments noting the positive, friendly and communal atmosphere at MDSC, and especially its Coventry headquarters.

Service user quotes: support outcomes

"I find attending my physiotherapist sessions helps me to re-engage with the world especially when I'm able to chat with other [people] who have MD"

"The support centre make me feel like I'm part of the family and have always made me feel welcomed and appreciated"

"MDSC has provided me with an opportunity to have various therapies and a place where I can go which understands my difficulties and provides a central body that I can rely on for support, therapy, social gatherings and general peace of mind with my condition."

"Just so grateful that you are there, the support has been all round not just physical support."

3.5 The impact of multiple sources of support

In addition to the 'sectoral' outcomes mentioned already, it is worth noting that the combined impact of different and multiple sources of support is likely to be greater than any single intervention, although it is more difficult to attribute.

In the survey, there were two questions that sought to demonstrate this wider impact and these are set out in Figures 7 and 8 below. In terms of the overall impact of MDSC support on their MD, a majority (62%) reported that it had 'very much', 'much', or moderately. More specifically on the impact of support on their physical deterioration, 18% said that it had prevented deterioration and 63% said that it had slowed down the progression of the disease.

Figure 10: Overall impact of MDSC support on MD (n=90)

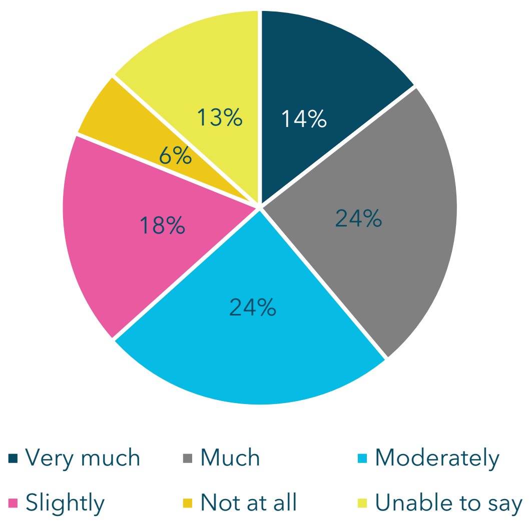
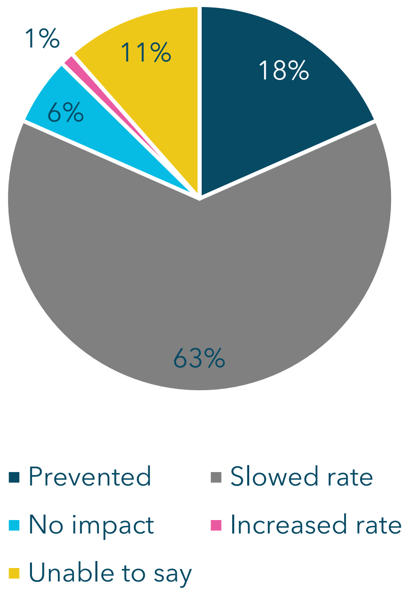


Figure 11: Impact of MDSC support on physical deterioration (n=87)



3.6 Changing service user needs over time

We spoke to a range of different stakeholders about this, including service users themselves. In the main, there was agreement that the most important needs for people with MD had remained the same, especially in terms of wanting better and more regular access to physical therapies.

Nevertheless, there was a sense among some people we spoke to that the pandemic specifically had brought about some changes in thinking, most notably:

- A realisation that physical activity/movement was important for general health and wellbeing
- The value of social connection and a sense of belonging.

From the project’s perspective there this has fit well with the development of MDSC services, in particular the increased profile that has been given to social support.

MDSC was also seen by service users as being good at helping people with MD to keep pace with changes in equipment and mobility aids.

4 Lessons, conclusions and recommendations

4.1 Introduction

In this concluding section, we reflect on the remaining, more reflective evaluation objectives:

- What lessons have been learnt from the project's challenges, achievements and failures? In particular, what lessons have been learnt in the development of the new satellites that other groups of people with MD could apply in the future to develop their own therapy centres?
- What are the recommendations for the next phase of MDSC's development to support people with MD?

4.2 Overall performance

MDSC is a larger and better run organisation than it was when the TATT project started. This isn't to denigrate what came before. Previously it was what we would describe as a 'micro' charity where its scale did not allow for a clear delineation of roles and it lacked capacity to plan for the long term and deliver service growth. The TATT project helped MDSC to deliver a step change in activity by providing the resources to grow the team and, in turn, its geographical presence, user numbers and service portfolio. It has facilitated a greater professionalisation of roles, space for strategic thinking, and a critical mass of therapists who work well as a team, while maintaining a very close relationship with its service users.

- **Recommendation**: the end of the TATT project, and the recent departure of MDSC's CEO, provide an opportune moment for the charity to reflect on the successes and lessons learned over the past five years. We know that this is already the Trustees' intention. MDSC is now a larger organisation in all senses than it was pre-TATT, and this offers the charity many more options for where it goes and what it does in the next five years.
- **Recommendation:** the future direction and ambition of MDSC will inevitably be linked to its ability to generate income. The charity needs to be realistic about the extent to which non-grant and non-NHS sources of income (e.g. community fundraising and individual and corporate donations) will grow to balance out these two sources which currently predominate. MDSC is a small charity working with a small group of service users, and this will limit opportunities for non grant /non NHS income. At its heart, the charity is a service delivery organisation, and it would be useful for MDSC to look at similar organisations (charitable and non-charitable) for income generation ideas.

4.3 Learning from Covid

The pandemic hit very early on in the TATT project. Understandably, this slowed user growth and delayed satellite expansion; but the response of MDSC in continuing to provide a level of support during the pandemic is still (in 2025) viewed very positively by service users. It demonstrated that the charity could adapt quickly to a changing environment and support its service users who were more vulnerable than most during that period (both in terms of the risks of Covid and the likelihood of isolation).

Online support was welcomed during the pandemic, and online services continue to offer support and positive outcomes for those who engage with it.

- **Recommendation**: online services deserve to remain part of the charity's service portfolio because they help to support those who cannot travel and/or have lifestyles that do not easily permit an organised schedule of sessions. Online physiotherapy in particular has made rapid progress in recent years and, while not a complete substitute for hands-on therapy, has the potential to broaden the service user base.[1]

4.4 The satellite model of service delivery

MDSC doubled its number of satellites during the project to four while also managing the move of its headquarters to larger premises. The launch of a fifth satellite has been postponed while the charity takes a moment post-TATT to pause growth and plan for the future.

The new satellites work well and point to a number of positive lessons:

- This has proved to be an effective way for the charity to extend its support to service users across a wider geography, and significantly to those who struggle to travel to Coventry and the MDSC HQ; the growth in service user numbers demonstrates that the charity well understood the nature and extent of unmet demand among people in the Midlands (and beyond) living with MD.
- The charity has shown its ability to establish new partnerships and make them work at an operational level. It opens the door for potentially more centres and partnerships in future.
- MDSC has maintained a high standard of service at the satellites despite them being remote from the centre. Although there are some differences in what is on offer (e.g. in terms of equipment), the evidence shows that the therapies provided are no different in quality to those at the centre. This is due to a great extent to the recruitment of high calibre, specialist therapists and strong communication between those who work in the satellites and the team at the centre.

The following are our observations about the potential risks of this model, although they are outweighed by the benefits we have observed during the evaluation:

- Permanence means a lot to service users who rely on charities like MDSC for support. There is a risk with renting rooms and small spaces in that they may not be available for the long term. In 2021, for example, the charity's Loughborough centre had to close due to issues relating to the pandemic; it later re-opened in Leicester. This can bring uncertainty for service users plus extra work for the charity.

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[1] See for example, A Systematic Review on the Application of Virtual Reality for Muscular Dystrophy Rehabilitation: Motor Learning Benefits; Life (Basel) June 2024

- It is clear from our conversations with staff and service users alike that the satellite model does not suit everyone's needs or wants. Satellites cannot offer the same breadth of service offer that is delivered at the Coventry HQ, nor do they have the same atmosphere. That was never the intention, but it means that the charity has to manage service user expectations carefully and be clear about the trade-offs. It does that well, but it will be an ongoing task. Encouraging service users to visit Coventry at least annually for a review helps to maintain that link with the charity more generally and the other services and support it can provide.
- Satellite centres will never fully solve the challenge of transport. Travel is a significant issue for people with MD and not just in terms of accessing therapy and other support. Shortening travel times certainly makes a difference, but it will remain a limiting factor for some even with a growing number of satellite centres. This is likely beyond MDSC's ability to change, but it was raised by some service users we spoke to, so it is important to acknowledge.
- **Recommendation**: MDSC has undergone a period of carefully managed growth. How many satellites it might eventually run is an open question. The charity now has a very good understanding of what a satellite model looks like, but there is likely to be a point where further expansion is not worth the additional administrative and logistical burden. If and when it reaches this point, MDSC will need to consider more strategically what it means for them as a charity. Expanding the model beyond the Midlands, for example, may require transition to something like a franchise model, and/or acting as a centre of expertise for others who want to run similar therapeutic services. We have not investigated this as part of the evaluation but expanding or sharing the model with charities who support people with similar neurological and support needs might provide a wider base of operation in future. A lot will depend on the risk and growth appetite of MDSC, and how expansion sits with its charitable objectives.

4.5 Impact, quality and the NHS

Stakeholders we interviewed – staff, service users and people working in the NHS – commonly said that the service provided by MDSC should be available to everyone in the country, not just people with MD in the Midlands. This was a commentary both on the quality and impact of MDSC's work, and the general lack of similar support elsewhere.

It was made clear by the same stakeholders that the NHS is not able to provide a physiotherapy service that meets the needs of people with MD: sessions tend to be strictly limited and rehabilitation-focused; and there is a lack of experience or understanding of neuromuscular conditions due to their rarity in the NHS. At the same time, the health and wellbeing benefits from the MDSC service will undoubtedly help to save the NHS resources. All of these are borne out by our interviews as the quotes overleaf demonstrate.

The challenge for MDSC is how to evidence this in order to make a convincing business case to the NHS and thereby generate more – and sustained – income for the charity (assuming that the NHS remains potentially the most significant source of charity funding in the medium to long term).

“Patients really like it because, unlike in the NHS, they will be seen long term whereas in the NHS they are discharged after six sessions [of physio] or we might only see them once a year.” (NHS stakeholder)

“There are very few patients I’ve met who don’t enjoy going to [MDSC] because of the exercise that they get…they might have been to NHS physios before who might not be neuromuscular specific, so they realise that actually they’ve got the specialist knowledge they need. They’re not asking them to do exercises which are not appropriate for them and that may actually hurt them, which unfortunately we get a lot of comments about at times” (NHS stakeholder)

“Our NHS physios here have actually said, can you send us some patients? Because you don't send us any patients anymore…I've never had complaints from the NHS that they're not getting enough patients…Patients sort of tend to stay with [MDSC] and don't tend to need NHS care, which is wonderful. And it does free the NHS up.” (NHS stakeholder)

This is a significant challenge, and one that faces many organisations operating charity-delivered healthcare services in the community alongside the NHS. Specifically, the challenges include:

- An NHS currently going through a significant structural review, where the outcome for commissioned services may be unclear for months, if not longer
- The need to work with a multiplicity of commissioners/NHS organisations across different geographies and with different healthcare priorities, often without formalised contractual agreements
- High expectations among healthcare providers and commissioners for evidence-based proof of value for money/cost-effectiveness
- The specific difficulties of demonstrating value for money for services that focus on slowing the progression of a disease (like MD) where the counterfactual tends to be more difficult to prove
- The absence of a single validated outcomes measure for people with MD (confirmed to us by stakeholders), reflecting the disease’s progressive nature and the multiplicity of different disorders and morbidities covered by the term ‘muscular dystrophy’

Against that background, we feel that MDSC is already doing much of what is feasible to demonstrate cost effectiveness, in particular:

- The introduction of annual reviews provides a regular, systematised way of assessing service user progress, although they tend to be very personalised (depending on a service user’s condition) and therefore not easy to aggregate across the whole service user population
- A good annual survey of service users with a high response rate (very important) and a range of questions that address issues relevant to NHS commissioners and others (e.g. other government bodies). These include questions on falls, the ability to stay in work, and reliance on NHS services
- **Recommendation**: we recommend that MDSC continues with these approaches and explores adding another element to help its ability to tell a good value for money story:

costed case studies. A costed case study is an individual story of how a person has benefited from an intervention that also include costs to demonstrate economic impact. It works in the context of MDSC because of the following:

- Individual trajectories of MD progression and therapeutic benefit are so varied across the service user base, collecting consistent outcome data for the whole population is likely not feasible
- The annual review provides a sensible point where more economic-related questions could be included in a conversation with service users
- Placed alongside the quantitative, broader picture of impact from the service user survey, it would deliver a strong blend of quantitative and qualitative evidence of cost effectiveness

We would be happy to help draft a pro forma for therapists to use at the annual review to help generate the relevant cost elements.

A comparison of MDSC's cost per therapy session and a private alternative may also help to demonstrated to commissioners/funders that it is providing good value for money. Our very brief research suggests that this could be in the order of £80 for a specialist neuro physiotherapy session, although costs vary considerably.

4.6 Balancing supply and demand

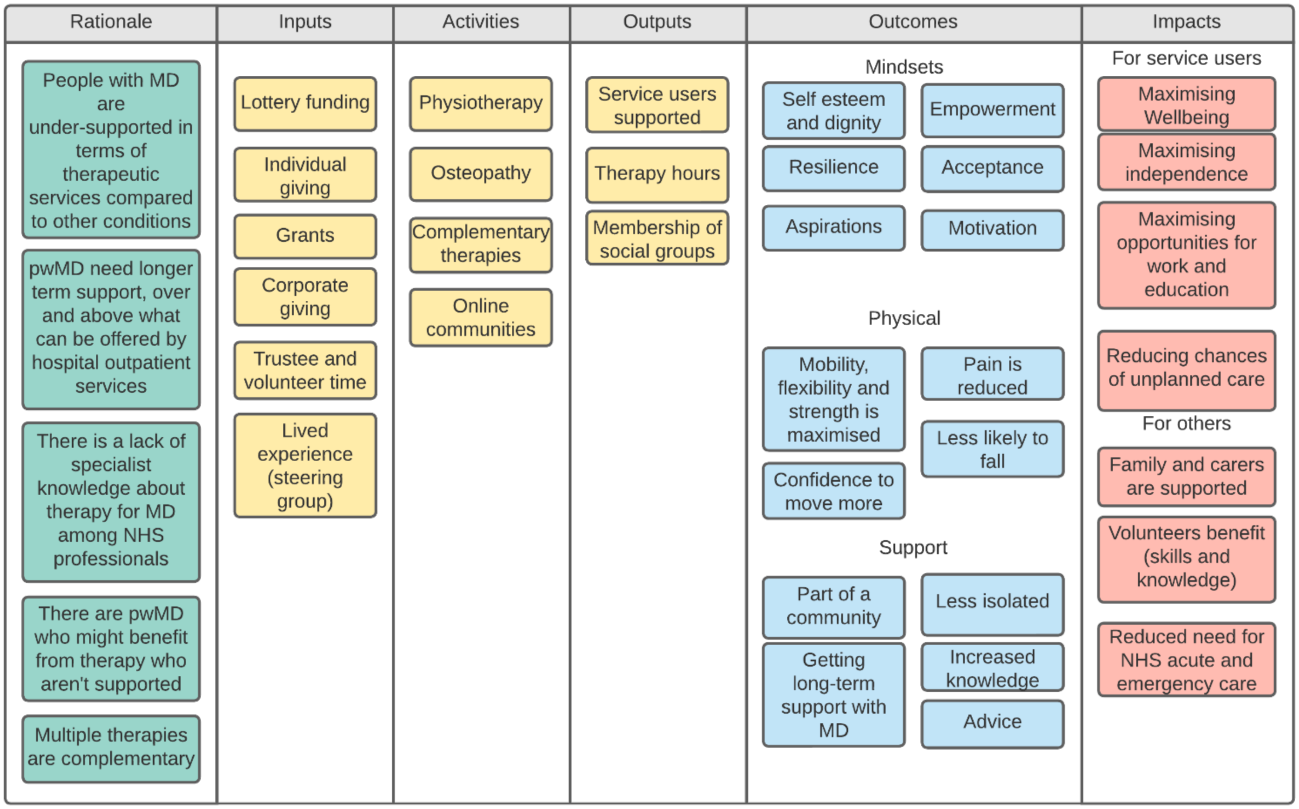
One issue that was raised in our interviews with stakeholders was that of payment for therapy services. The context in which it was raised with us included the following observations:

- The understandable reluctance of MDSC (in line with many other charities) to charge for its services
- Some bottlenecks in service delivery (experienced by service users) as demand sometimes outstripped therapist supply
- Challenges (but not major issues) with session cancellations
- Some service users expressing a willingness to pay, in principle rather than in terms of any specific cost/fee

MDSC already encourages service users to make donations towards their therapies, but this has perhaps not had the same visibility as was the case pre-pandemic.

- **Recommendation**: we are not recommending payment for services outright, but we do think that it deserves a serious and open discussion, if only to rule it out. There are many options to consider including asking for a suggested donation, a partial fee, or a full cost fee; and payment for missed appointments. Service users and supporters of the charity are likely to have strong views on both sides, and varying ability to pay for therapy, so we recognise its sensitivity.

5 Annex A – Project logic model



Rationale

- People with MD are under-supported in terms of therapeutic services compared to other conditions
- pwMD need longer term support, over and above what can be offered by hospital outpatient services
- There is a lack of specialist knowledge about therapy for MD among NHS professionals
- There are pwMD who might benefit from therapy who aren't supported
- Multiple therapies are complementary

Inputs

- Lottery funding
- Individual giving
- Grants
- Corporate giving
- Trustee and volunteer time
- Lived experience (steering group)

Activities

- Physiotherapy
- Osteopathy
- Complementary therapies
- Online communities

Outputs

- Service users supported
- Therapy hours
- Membership of social groups

Outcomes

Mindsets

- Self esteem and dignity
- Empowerment
- Resilience
- Acceptance
- Aspirations
- Motivation

Physical

- Mobility, flexibility and strength is maximised
- Pain is reduced
- Less likely to fall
- Confidence to move more

Support

- Part of a community
- Less isolated
- Getting long-term support with MD
- Increased knowledge
- Advice

Impacts

For service users

- Maximising Wellbeing
- Maximising independence
- Maximising opportunities for work and education
- Reducing chances of unplanned care

For others

- Family and carers are supported
- Volunteers benefit (skills and knowledge)
- Reduced need for NHS acute and emergency care

6 Annex B – Theory of Change