

## Notes from Steering/ Focus Group meeting – 15<sup>th</sup> March 2023

### Winter Wellness Hub feedback, Events 2023 and MD Support Centre Website

#### Welcome

Attendees:

MDSC Staff: Sarah Ann Moore, Helen Hone and Nina Hanks

Service Users: Nick Randle, Emily Bonner and Naima Ali

#### Introductions and background to meeting

Sarah welcomed everyone to the meeting and acknowledged that the number service users in attendance was small, inviting feedback from the group on why that might be. **The consensus was that timing might be an issue and that for the next quarterly meeting we will try an evening timeslot to see if that increases interest/ participation.**

#### Discussion: MDSC Events calendar 2023

##### *Feedback on recent Wellness Hub – Respiratory Health*

Focus group members were asked for feedback on our first Wellness Hub around Respiratory Health that took place in February.

- Nick stated that he had participated without any expectations, and that he found the session went well. He enjoyed learning the medical content about respiratory function and found the polls functionality and results interesting. He noted that some of the discussion veered off topic on occasion and some of the service users discussed very personal situations.
- Emily agreed that the session went well, despite the initial technical issues. She found the session useful and educational.
- All agreed that it would be useful for some of the material (specifically the technical material and tips) to be posted on the MDSC website so that other service users can benefit from that, but that the **service users questions, comments and stories should be edited out from any video.**

##### *Other Events 2023*

Sarah shared and talked through the proposed events calendar for 2023 (see appendix 1). All were receptive to the timing and type of events being suggested in this first year of the Centre returning to more face-to-face social activity.

For key upcoming MDSC-led events, the group discussed the need for volunteers, in particular:

- Wellness Hub – Equipment Show and Tell (Online and in person) - Looking for volunteers to demonstrate some of the equipment they rely on or find useful in their day-to-day life
  - **Emily suggested she could make a video of her new WAV** for both the website and to use for the session
  - **Nick is happy to demonstrate his foldable scooter**
- MD Support Centre Open Day and 10th Anniversary Celebration
  - Volunteers for all areas including refreshments, car parking and set-up

Sarah raised that the Charity has the Centre and satellites where events can be held, but very limited staff capacity to organise and support service user peer/ social events. She asked how MDSC can

empower and engage more service users in volunteering and taking the lead in organizing such social events.

- The group acknowledged that getting people to take the lead is challenging and that everyone has their own unique circumstances.
  - Emily suggested that it is necessary to build up a group of interested people from the ground up. She acknowledged that it would take time to identify and encourage individuals to get involved.
  - Nick pointed out that there is often a lack of motivation stemming back from the pandemic and the feeling of being lonely that stops people from stepping forward.
  - Naima mentioned that both time and capacity can be an issue.
  - Sarah asked if more could be done within the MDSC social group on Facebook and in the current socials to ask people if they want to get more involved. All agreed that this is a start.
- Naima also shared her thoughts that events need to cater for all abilities and reconnaissance work undertaken around key aspects such as suitability of toilet facilities, as a lack of appropriate facilities can undermine people's confidence to take part. She suggested that initial events should be easy ones to organise (such as picnics in parks or bring your own events), where people can connect and then if there is an appetite for more exciting accessible events (such as skiing at the Snowdome) interest in co-ordinating those events might come out of participation in other smaller events. She emphasised that events planning should always focus on the summer months as many SUs will hunker down in the winter/ poorer weather months. And that **for any event, there needs to be some gauging in advance of the level of interest and the abilities of those interested so that places can be allocated accordingly.**

#### *Events – other thoughts and ideas*

- Nick suggested an **integration of a second-hand selling group for equipment open to Service users, their carers, family and friends only.** This could be integrated into the website or managed through the MDSC social group.
- Emily mentioned an interest in having a **monthly service user get together**, potentially running on a Saturday, starting off with Coffee morning but evolving into bigger outings including sporting events or nature events. Suggestions were sit-skiing at the Snowdome in Tamworth, cinema visits and sky diving in Milton Keynes.
- Nick agreed that more in-person events are welcome and particularly these sorts of day trips.

#### **MDSC Website**

Sarah explained that the Charity has recently been reviewing and updating content on its website. While more work is needed to improve the overall look and usability of the site, she asked group members about their feelings on the site's current content, look and user experience – enquiring in particular: *Do you use our website and if so, what for? If you don't look at it, why not? How user-friendly do you find our website site? What additional information would you like to see on it? What could be done to improve the site/ your experience of it?*

- The general consensus was that the website was not as visually appealing as some other sites but that it is very informative, and the content has improved. However, the group acknowledged that its main benefit is to new service users or people external to the organization - group members get most of their information from the E-Newsletters and only click through to the website if prompted to do so. It is therefore really important to get as many people as possible to sign up for the E-newsletters (and particularly the Fundraising

newsletters) if the Charity wants to get more SUs and carers involved. The group suggested In order to get more people to sign up to our E-Newsletters that the Charity do an annual update of information preferences and include a data capture exercise in the registration exercise for the upcoming Open Day.

- It was noted that the new service user resources section is a good idea but could be expanded to **include a section on tried and tested service user tools such as accessible travel apps.**

### **Any other topics or ideas!**

- Naima emphasised that any activity planned by MDSC for service users (or led by service users for other service users) needs to be relevant, inclusive and that in the run-up to the event the expectations of all service users, carers and families need to be managed e.g. what abilities are required to participate, how many places are available for people with each ability level, what accessible facilities are available.
- **Emily volunteered to promote the Steering/ Focus group in the MDSC Social Group and in the upcoming MDSC magazine to try to increase participation.**

### **Next Steps, Summary, and Close**

Sarah thanked the group for all their thoughts and ideas. The intention is to share notes from the meeting with attendees initially, and then with other service users on the MDSC website. All attendees consented for their attendance and comments to be recorded and the notes shared.

Sarah thanked all participants for their time and participation.

### **Appendix 1 -**

#### **MDSC Events Summary - 2023**

| <b>Date</b>                       | <b>Event</b>   |
|-----------------------------------|--|
| <i>Tuesday, February 21, 2023</i> | <i>Online Wellness Hub - Respiratory Health session</i>  |
| <i>Wednesday, March 15, 2023</i>  | <i>Quarterly Steering/ Focus Group</i>   |
| Tuesday, April 4, 2023            | Online Wellness Hub - Cooking and Nutrition with "the Mindful Chef"                              |
| Thursday, March 23, 2023          | Easter Raffle Draw   |
| Monday, March 27, 2023            | 10th Anniversary Celebration Dinner - Leicester Satellite - Chef and Spice restaurant, Leicester |
| Tuesday, April 18, 2023           | SU Social - In person coffee morning, Coventry   |
| Thursday, April 27, 2023          | Andy C Golf Day  |

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|----------------------------|---|
| Tuesday, May 2, 2023       | Online Wellness Hub - Equipment Show and Tell                         |
| Saturday, May 20, 2023     | Open Day and 10th Anniversary Celebration, venue Finham Park 2 School |
| Wednesday, May 31, 2023    | SU Social - In person coffee morning, Tipton                          |
| Wednesday, June 14, 2023   | Quarterly Steering/ Focus Group                                       |
| Monday, June 19, 2023      | 10th Anniversary Celebration Dinner - Tipton Satellite - location TBC |
| <i>TBC - Jul 2023?</i>     | <i>Clothes Show</i>   |
| Thursday, July 6, 2023     | David Golf Day  |
| Wednesday, July 12, 2023   | SU Social - In person coffee morning, Bournville                      |
| Wednesday, August 23, 2023 | SU Social - Boccia experience   |

|                              |   |
|------------------------------|---|
| Friday, September 8, 2023    | Andy C Barge Trip   |
| Monday, September 11, 2023   | Quarterly Steering/ Focus Group   |
| Sunday, September 17, 2023   | 10th Anniversary Celebration Dinner - Birmingham Satellite - location TBC |
| Sunday, October 1, 2023      | MDSC Christmas Cards go on sale   |
| Wednesday, October 4, 2023   | SU Social - In person coffee morning, Coventry                            |
| Tuesday, October 31, 2023    | Halloween Murder Mystery Social   |
| Tuesday, November 14, 2023   | Online Wellness Hub - TBC   |
| Wednesday, December 6, 2023  | Quarterly Steering/ Focus Group AND Christmas social                      |
| Wednesday, December 13, 2023 | Christmas Raffle Draw   |
| Friday, September 8, 2023    | Andy C Barge Trip   |
| Monday, September 11, 2023   | Quarterly Steering/<br>Focus Group  |
| Sunday, September 17, 2023   | 10th Anniversary Celebration Dinner - Birmingham Satellite - location TBC |
| Sunday, October 1, 2023      | MDSC Christmas Cards go on sale   |
| Wednesday, October 4, 2023   | SU Social - In person coffee morning, Coventry                            |

