

# Muscular Dystrophy Ireland

## Survey on Adult Camp and Holiday Programme

### About MDI

Muscular Dystrophy Ireland (MDI) is a voluntary organisation that provides support to people with neuromuscular conditions and their families. Muscular Dystrophy Ireland envisages an Ireland that enables people with neuromuscular conditions to fully participate in society and reach their full potential.

**Our Mission:** Our mission is to support people with muscular dystrophy. We do this, using a member-centred approach, by:

- Providing information and support to people with neuromuscular conditions and their families through a range of support services.
- Advocating for services and entitlements for members, educating and informing society about the conditions.
- Supporting researchers and clinicians to carry out quality research into neuromuscular conditions.

**About Muscular Dystrophy:** Muscular Dystrophy is a collective name for a range of neuromuscular conditions. It is characterised as a progressive weakening, wasting and loss of muscle mass over time. It can present at birth, childhood or manifest later in life.

### Introduction and Aim of Survey

MDI invited members to take part in a survey between the 20<sup>th</sup> of November and 8<sup>th</sup> of December 2020 and received 104 responses.

This survey was aimed at adult members of MDI. The aim of the survey was to find out members opinions on MDI's Adult Camp and Holiday Programme (accessible and supported breaks in Ireland organised by MDI for Adult Members with Muscular Dystrophy). MDI will use the information gathered to help plan and develop programmes in these areas that best meet the needs expressed by members as a whole.

We want to thank members for taking the time to fill out this survey. It is also MDI's main priority to support you and your family during this challenging time ahead.

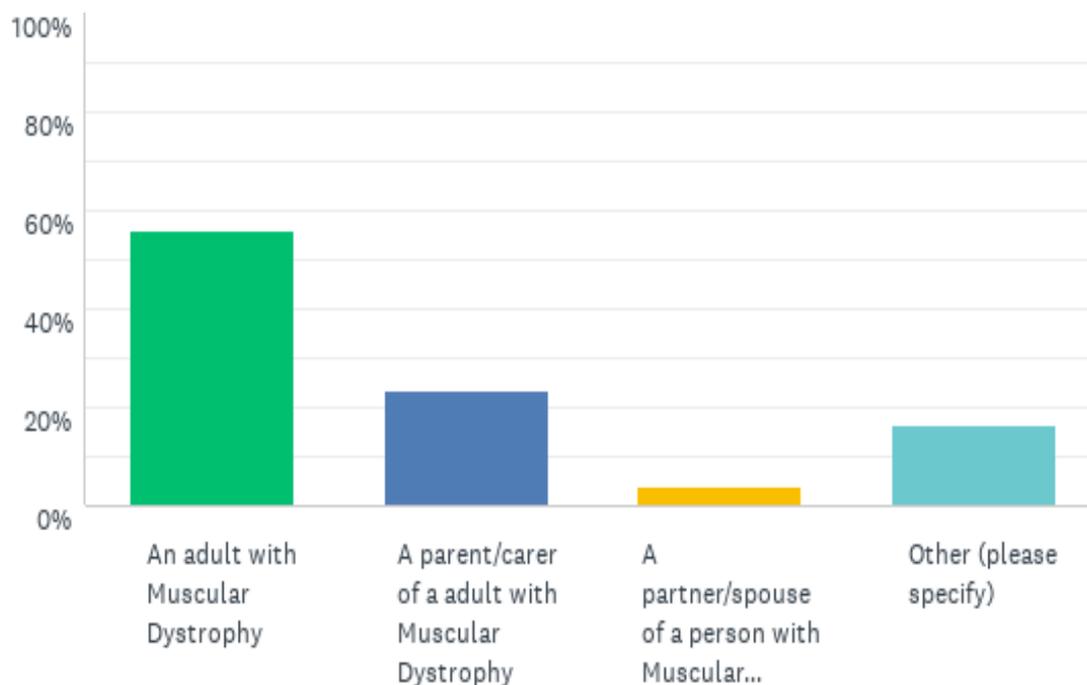
## Methodology, Insights and Data Trends

- 104 MDI members completed the survey.
- 40% completion rate
- Typical time spent completing 03m:54s
- We used the tool, Survey Monkey, to gather the data. There was a total of 12 questions.

## Feedback Received

### Q1: Which membership description fits you best?

Answered: 102 Skipped: 2

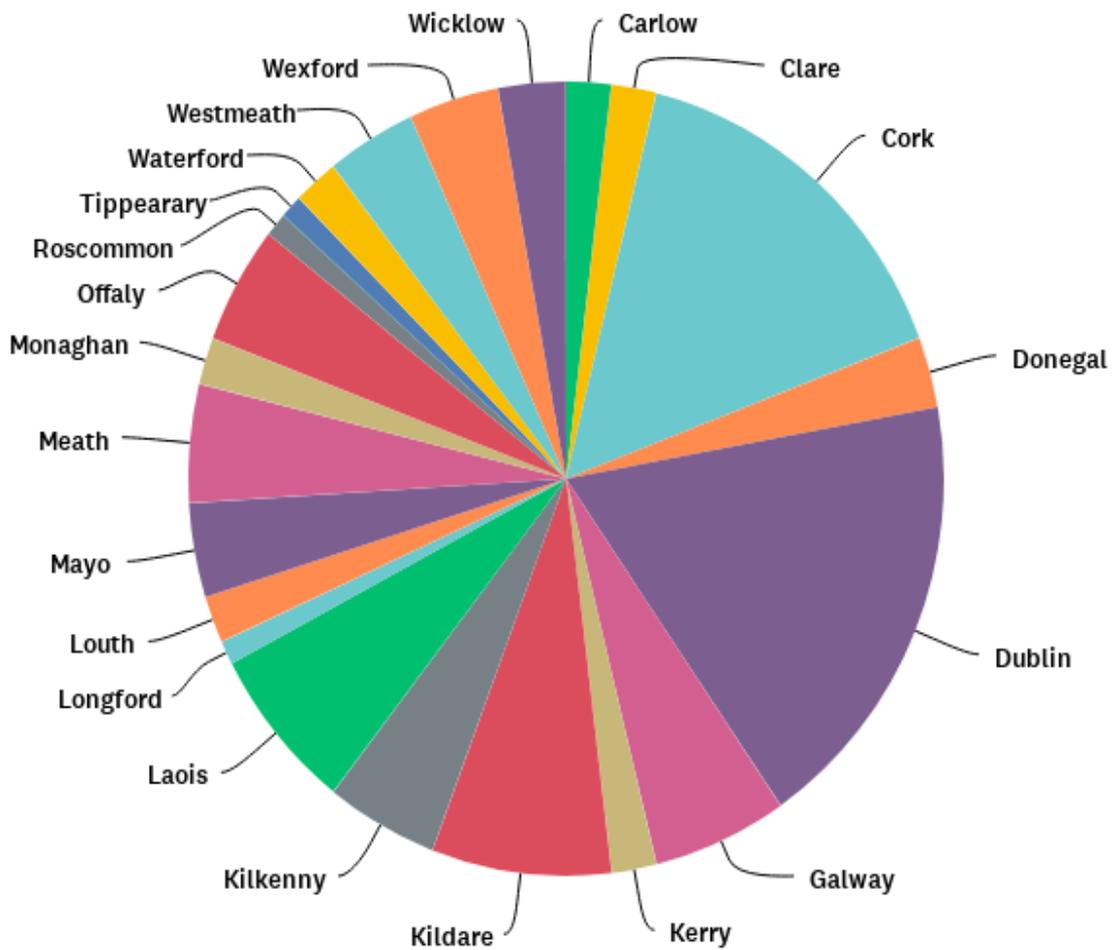


ANSWER CHOICES	RESPONSES	
An adult with Muscular Dystrophy	55.88%	57
A parent/carer of a adult with Muscular Dystrophy	23.53%	24
A partner/spouse of a person with Muscular Dystrophy	3.92%	4
Other (please specify)	16.67%	17
<b>TOTAL</b>		<b>102</b>

**16.67% Other:** The 'Other' category was mainly made up of parents of a child with Muscular Dystrophy and adults with long term illnesses that are not classified under the umbrella of Muscular Dystrophy.

**Q2: Select the county that you live in from the list below.**

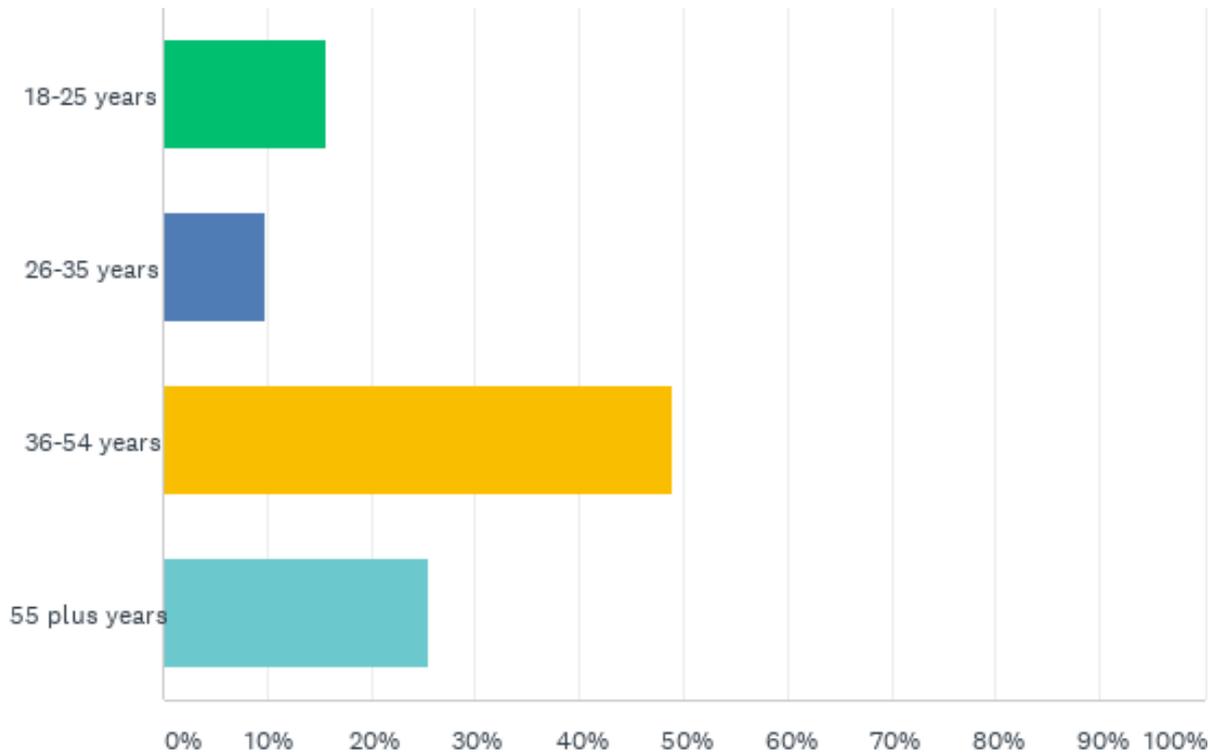
Answered: 104 Skipped: 0



ANSWER CHOICES	RESPONSES	
Dublin	18.27%	19
Cork	15.38%	16
Kildare	7.69%	8
Laois	6.73%	7
Galway	5.77%	6
Kilkenny	4.81%	5
Meath	4.81%	5
Offaly	4.81%	5
Mayo	3.85%	4
Westmeath	3.85%	4
Wexford	3.85%	4
Donegal	2.88%	3
Wicklow	2.88%	3
Carlow	1.92%	2
Clare	1.92%	2
Kerry	1.92%	2
Louth	1.92%	2
Monaghan	1.92%	2
Waterford	1.92%	2
Longford	0.96%	1
Roscommon	0.96%	1
Tipperary	0.96%	1
Cavan	0.00%	0
Leitrim	0.00%	0
Limerick	0.00%	0
Sligo	0.00%	0
<b>TOTAL</b>		<b>104</b>

### Q3: Which age group do you belong to from the list below?

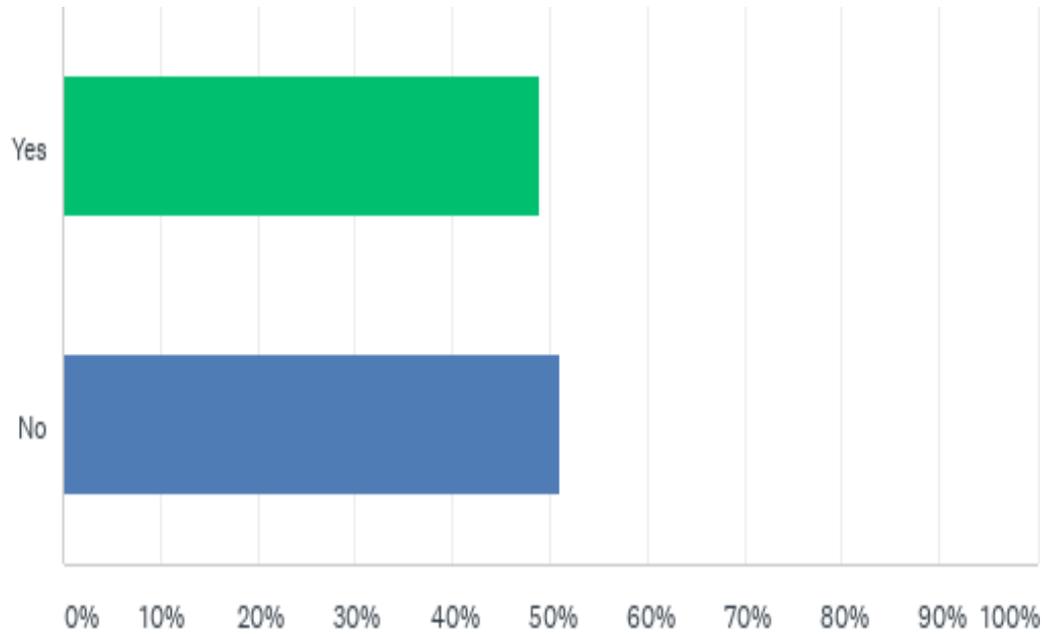
Answered: 102 Skipped: 2



ANSWER CHOICES	RESPONSES	
18-25 years	15.69%	16
26-35 years	9.80%	10
36-54 years	49.02%	50
55 plus years	25.49%	26
TOTAL		102

### Q4: Have you or your family member ever participated in an MDI Adult Camp or Holiday Programme?

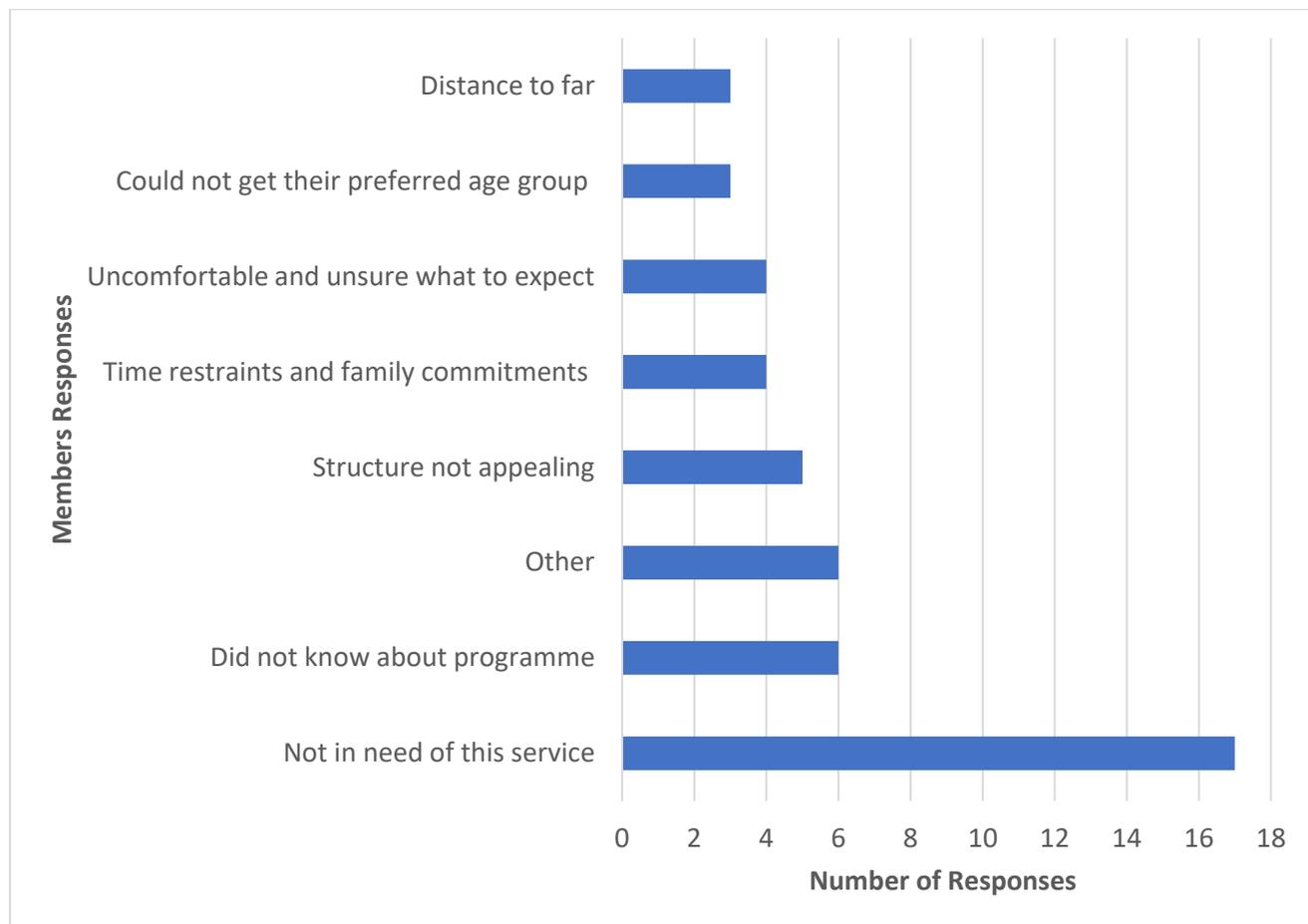
Answered: 104 Skipped: 0



ANSWER CHOICES	RESPONSES
Yes	49.04% 51
No	50.96% 53
TOTAL	104

**Q5: If no to question 4, could you tell us why you or a family member have never participated in an MDI Adult Camp and Holiday Programme?**

Answered: 47 Skipped: 57

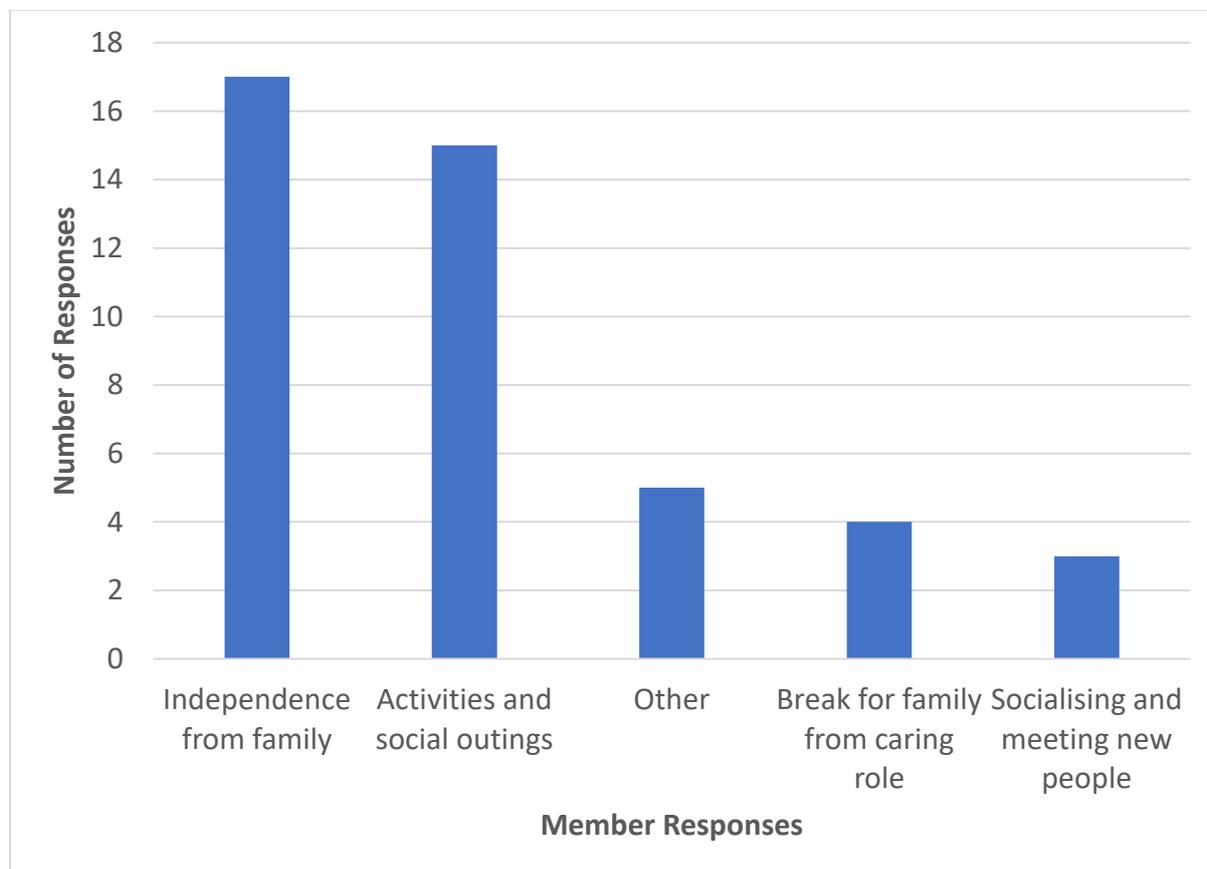


Answer Choices	Responses Number	Responses Percentage
Not in need of this service	17	35%
Did not know about programme	6	13%
Other	6	13%
Structure not appealing	5	11%
Time restraints and family commitments	4	8%
Uncomfortable and unsure what to expect	4	8%
Could not get their preferred age group	3	6%
Distance to far	3	6%

**13% Other:** The 'Other' category was mainly made up of parents of a child with Muscular Dystrophy and the child being too young to attend an Adult Camp and Holiday.

**Q6: If yes to question 4, what did you or a family member enjoy most about a past MDI Adult Camp and Holiday?**

Answered: 43 Skipped: 61

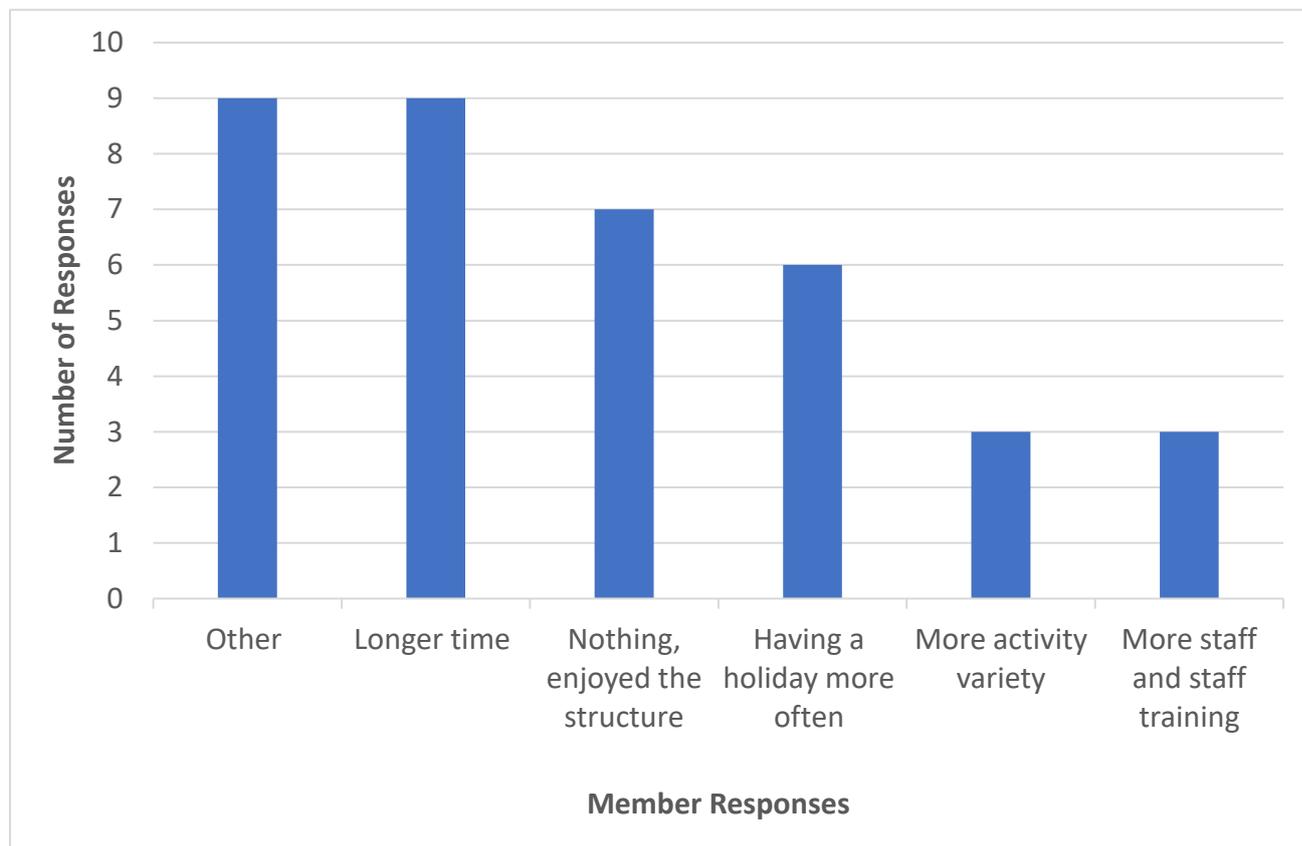


Answer Choices	Responses Number	Responses Percentage
Independence from family	17	39%
Activities and social outings	15	34%
Other	5	11%
Break for family from caring role	4	9%
Socialising and meeting new people	3	7%

**11% Other:** The 'Other' category included a variety of opinions about what members enjoyed most such as improvement in confidence, trying new things, and staff and general support provided.

**Q7: If yes to question 4, what aspects of MDI Adult Camp and Holiday Programme could be improved to make your or a family member's experience more enjoyable?**

Answered: 40 Skipped: 64

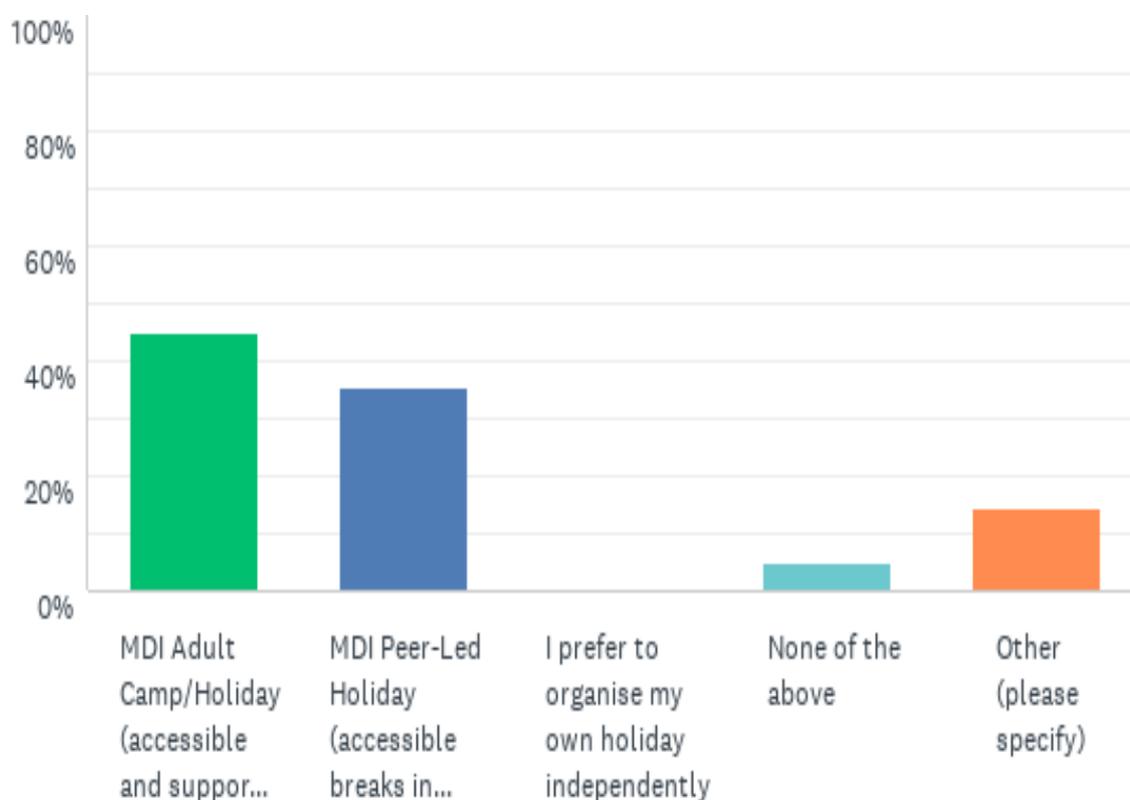


Answer Choices	Responses Number	Responses Percentage
Other	9	25%
Longer time	9	24%
Nothing, enjoyed the structure	7	19%
Having a holiday more often	6	16%
More activity variety	3	8%
More staff and staff training	3	8%

**25% Other:** The 'Other' category included a variety of opinions about what members felt could be improved such as having a family friendly holiday where friends and family can come too, less activities in evenings, choice of room sharing, location variety, venue safety adjustments and less rigid age brackets.

### Q8: Which from the options below would you or a family member prefer most in the future?

Answered: 42 Skipped: 62

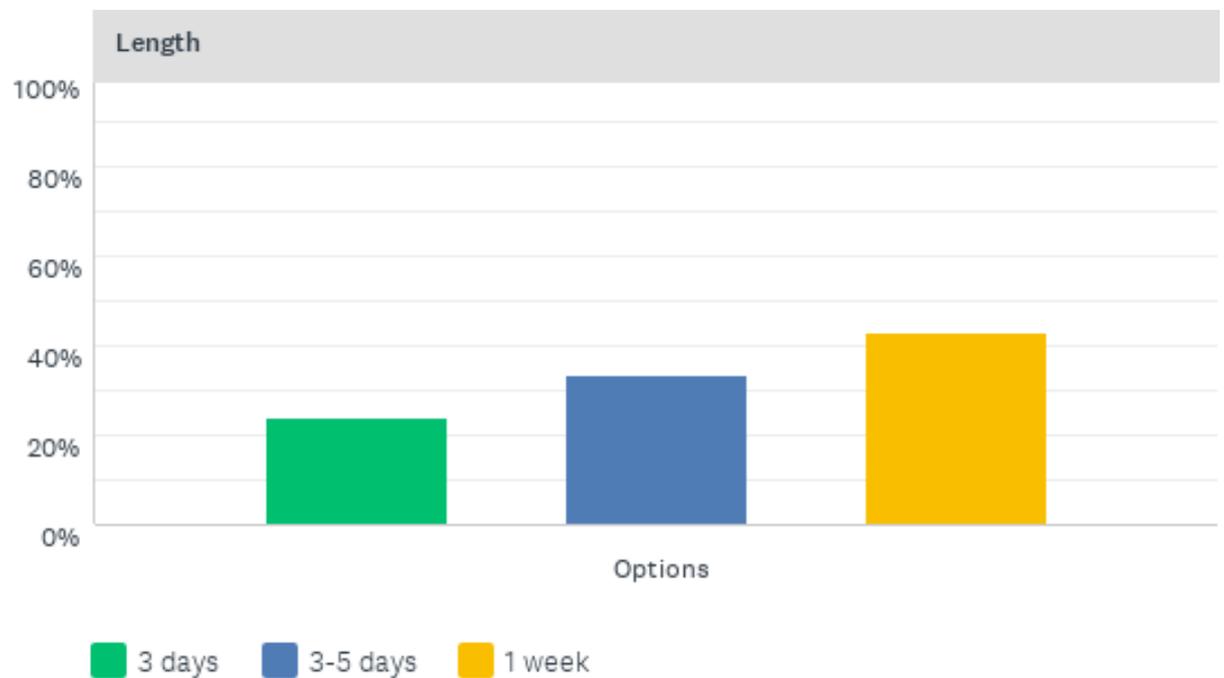
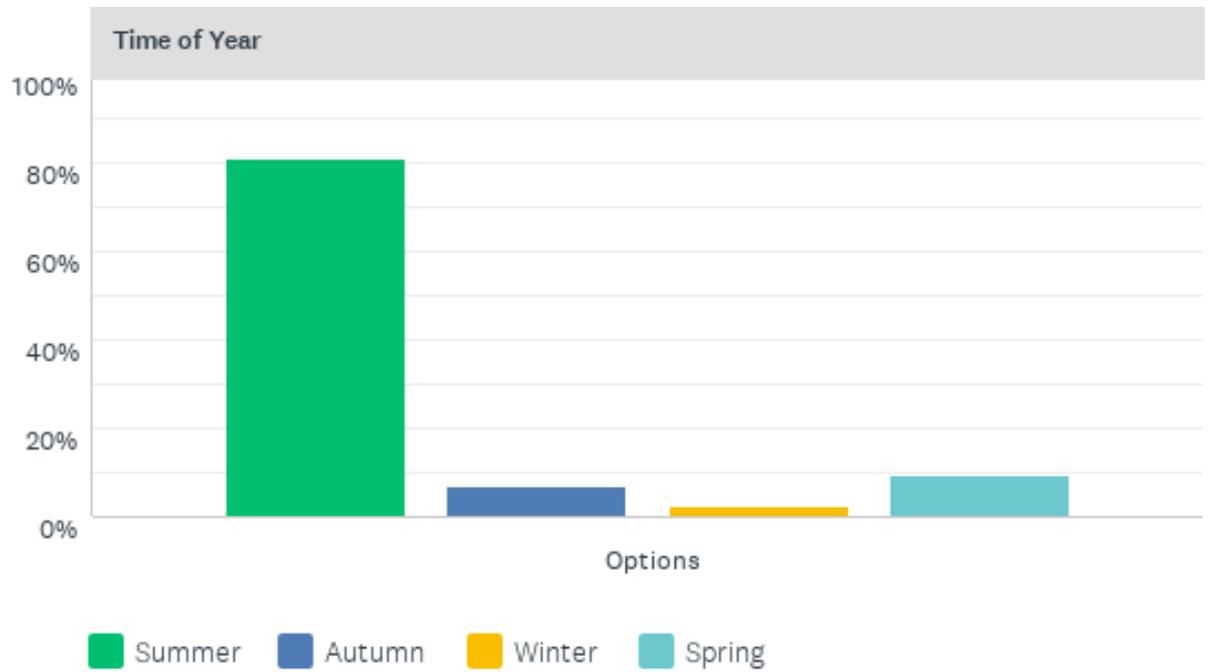


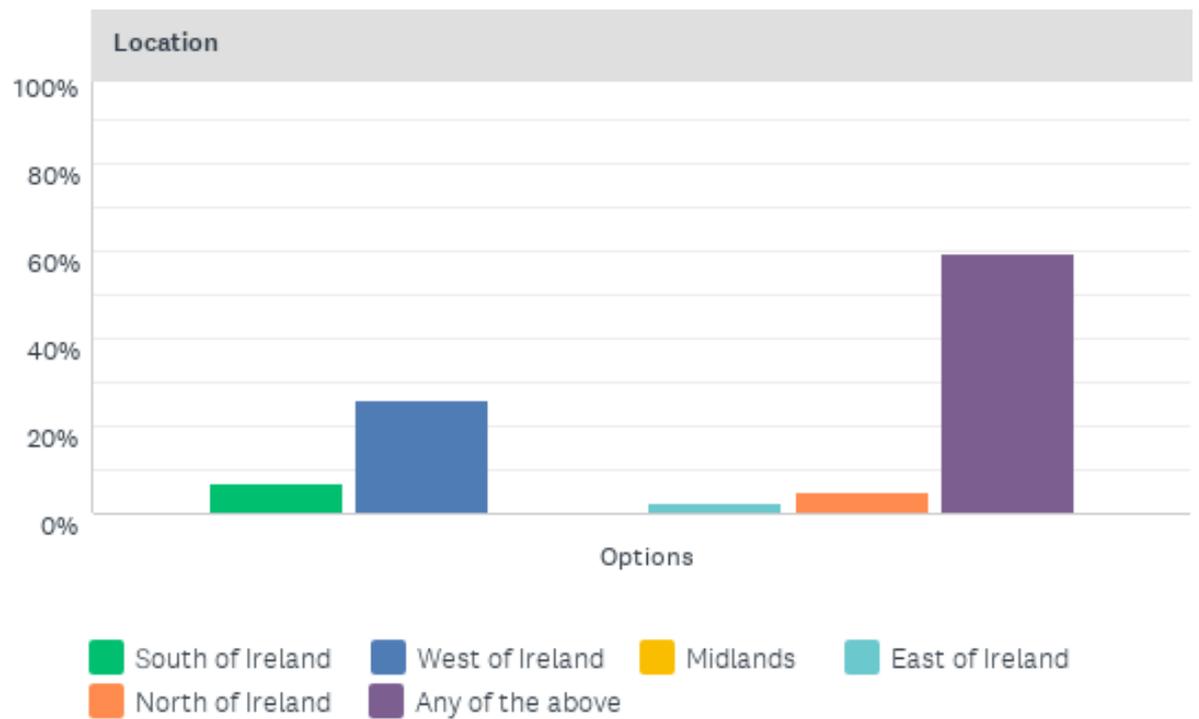
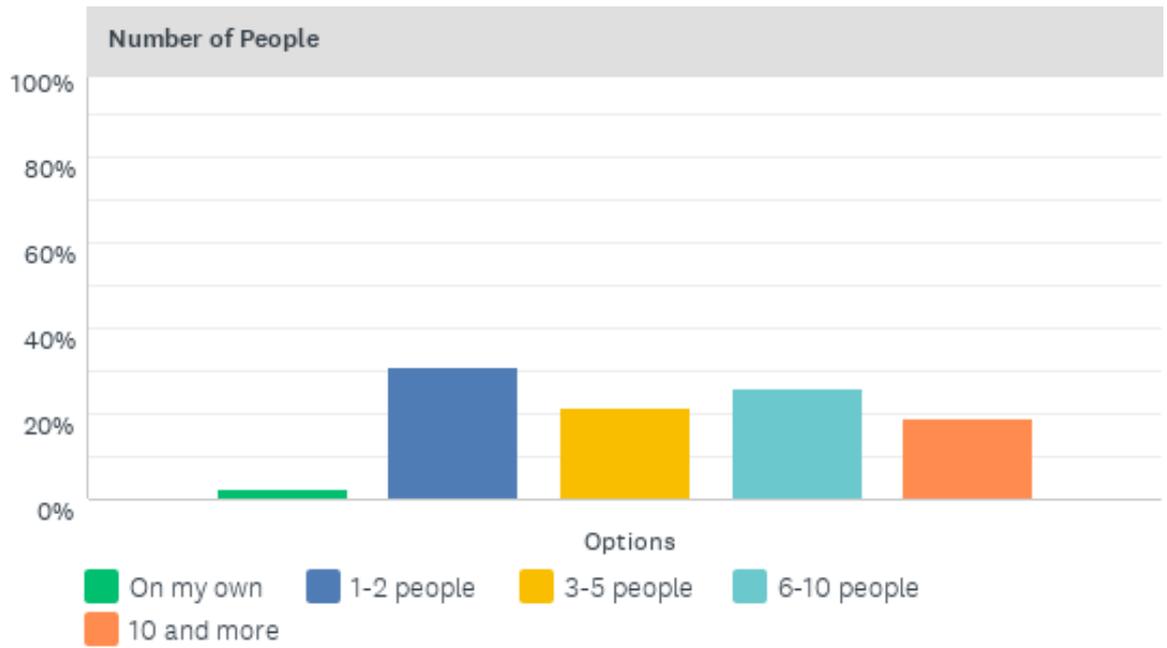
ANSWER CHOICES	RESPONSES	
MDI Adult Camp/Holiday (accessible and supported breaks in Ireland organised by MDI for adult members with Muscular Dystrophy)	45.24%	19
MDI Peer-Led Holiday (accessible breaks in Ireland organised by you with financial help towards personal assistants, equipment and transport)	35.71%	15
I prefer to organise my own holiday independently	0.00%	0
None of the above	4.76%	2
Other (please specify)	14.29%	6
<b>TOTAL</b>		<b>42</b>

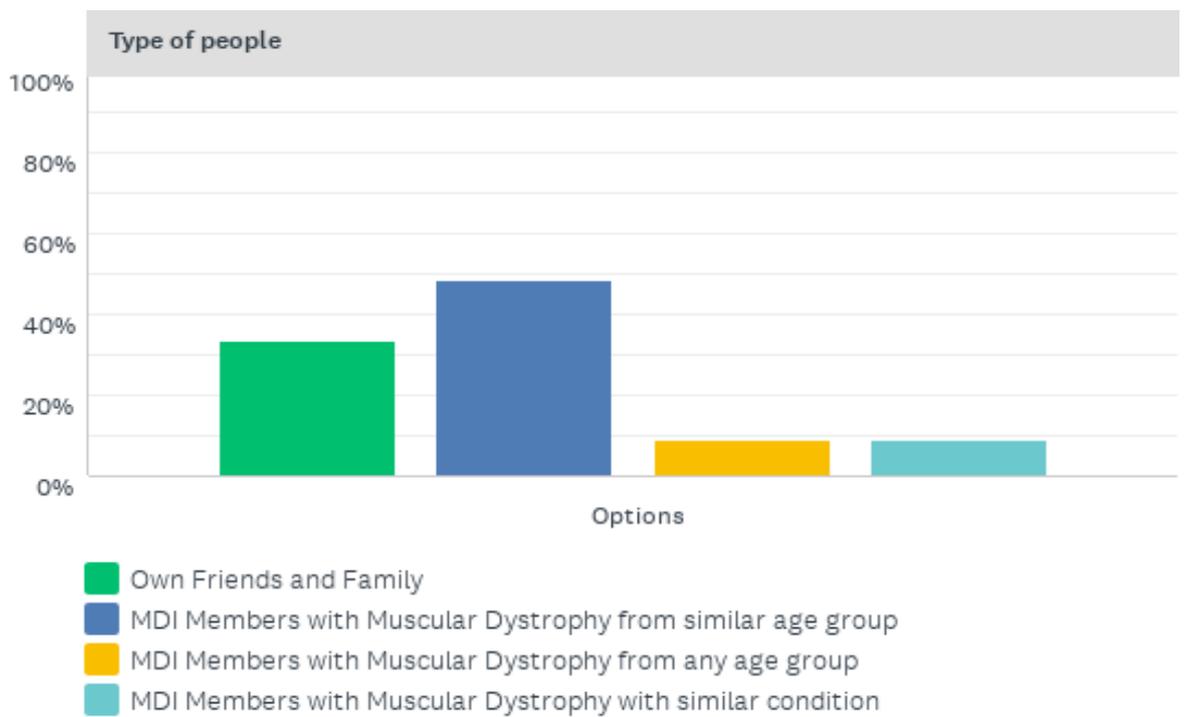
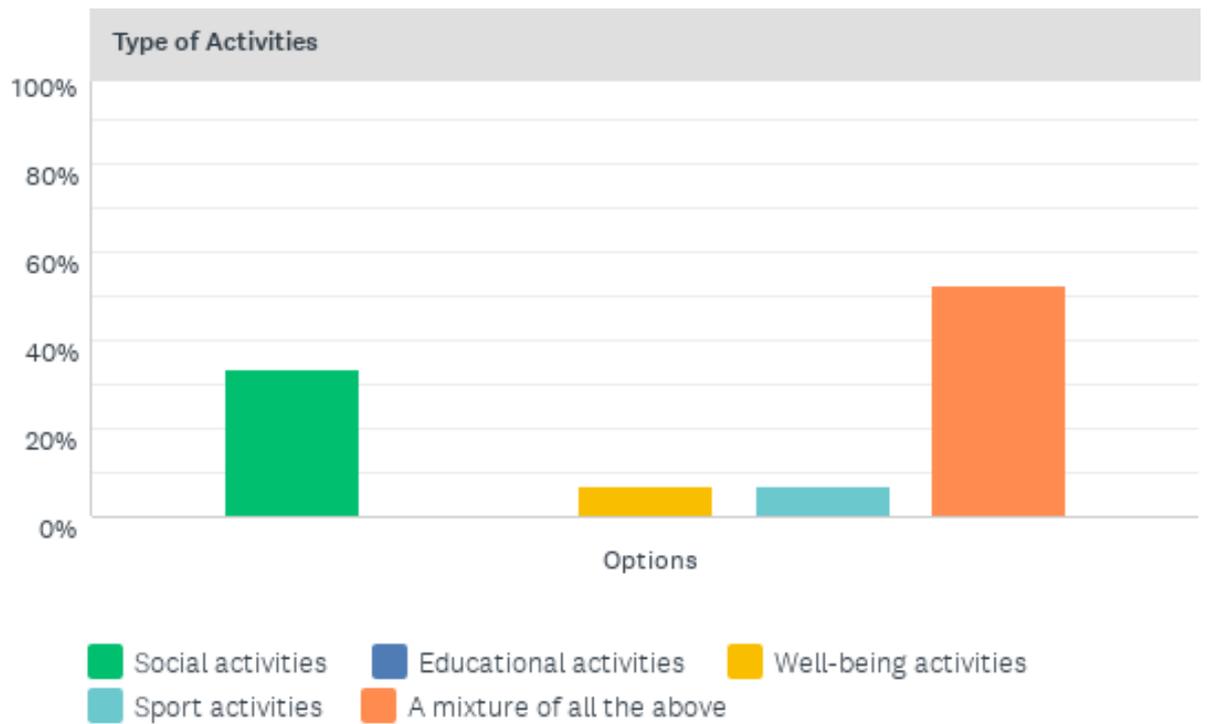
**14.29% Other:** The ‘Other’ category included a variety of opinions from members about what they would prefer such as having a peer-lead holiday abroad, family- centred and sibling holidays and having a mixture of attending a peer-led holiday and adult camp and holiday throughout the year.

Q9 & Q10: Please give us a sense of what you or your family member would like best in a holiday by selecting from the other options below?

Answered: 42 Skipped: 62







Time of Year						
	SUMMER	AUTUMN	WINTER	SPRING	TOTAL	
Options	80.95% 34	7.14% 3	2.38% 1	9.52% 4	42	

Length				
	3 DAYS	3-5 DAYS	1 WEEK	TOTAL
Options	23.81% 10	33.33% 14	42.86% 18	42

Number of People						
	ON MY OWN	1-2 PEOPLE	3-5 PEOPLE	6-10 PEOPLE	10 AND MORE	TOTAL
Options	2.38% 1	30.95% 13	21.43% 9	26.19% 11	19.05% 8	42

Location							
	SOUTH OF IRELAND	WEST OF IRELAND	MIDLANDS	EAST OF IRELAND	NORTH OF IRELAND	ANY OF THE ABOVE	TOTAL
Options	7.14% 3	26.19% 11	0.00% 0	2.38% 1	4.76% 2	59.52% 25	42

Type of Activities						
	SOCIAL ACTIVITIES	EDUCATIONAL ACTIVITIES	WELL-BEING ACTIVITIES	SPORT ACTIVITIES	A MIXTURE OF ALL THE ABOVE	TOTAL
Options	33.33% 14	0.00% 0	7.14% 3	7.14% 3	52.38% 22	42

Type of people					
	OWN FRIENDS AND FAMILY	MDI MEMBERS WITH MUSCULAR DYSTROPHY FROM SIMILAR AGE GROUP	MDI MEMBERS WITH MUSCULAR DYSTROPHY FROM ANY AGE GROUP	MDI MEMBERS WITH MUSCULAR DYSTROPHY WITH SIMILAR CONDITION	TOTAL
Options	33.33% 11	48.48% 16	9.09% 3	9.09% 3	33

**Q11: Have you any suggestions for accessible accommodation venues in Ireland for Holidays?**

Answered: 35 Skipped: 69

Thirty-five members answered this question and the majority of suggestions where venues such as Central Pars, Barretstown, variety of accessible hotels around the country for small group holidays, newly build student campus accommodation and Hoist Away in Donegal.

**Q12: Do you have any further information you would like to share with us about MDI Camp and Holiday Programme not mentioned above or about your support needs in general for 2021?**

Answered: 31 Skipped: 73

Thirty-one members answered this question and the majority of members where thankful of support they have received to date during Covid. Some respondents mentioned organising small regular safe day trips or weekend trips, providing financial support to organise their own family holiday in Ireland, types of activities they would prefer to participate in in the future, trips aboard and online physiotherapy sessions for 2021.

**Thank you for reading.**

**END**