

Upmo

Survey Dec 2018



Upmo
support and
opportunity

About this work

Just Enterprise is a Scottish Government funded programme to support the growth and sustainability of an Enterprising Third Sector in Scotland. Upmo applied to the programme through its Business Support strand and was awarded some consultancy support to gauge customer satisfaction and generate ideas and improvements to be made in relation to services.

Community Enterprise Ltd was commissioned to carry out this work in Autumn 2018.



Background

Upmo is an Edinburgh-based charity providing support and opportunity for adults with learning difficulties and autism. It has experienced significant growth in terms of user numbers and scope in recent years and demand is now higher than ever. As a result, Upmo now lacks space to deliver its work. In addition, the property landlord announced the building is to be sold, prompting Upmo to seek alternative premises. Upmo views this as a good opportunity to take stock, understand what its students and partners value about the organisation and suggest enhancements to future delivery. This feedback will be considered in the context of developing a new space.

What we did

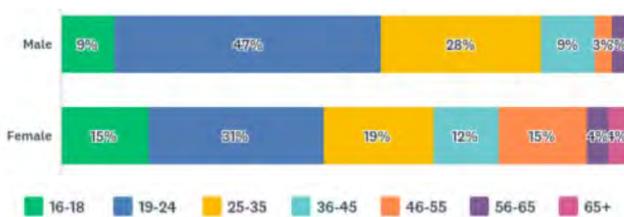
We carried out an online survey targeted at existing students, their parents and carers, referrers and partner organisations. This gained 110 responses. In addition, we held 2 focus groups with 10 Upmo students on site. This was designed to tease out further detail on people's experience and gain a more personal understanding of the difference the organisation is making to their lives.

Survey Feedback

Profile of Respondents

Of the 110 responses to the online survey, 22% were students, 44% parents and carers, 26% referrers and 9% people who have never used Upmo but are interested in it.

Roughly half of those asked opted to tell us their age and gender:



In terms of level of support needs, there was a fairly broad spread: around 13% reported that 'day to day life was extremely challenging', 33% said 'day to day life can be difficult', 48% said 'mostly fine but there can be challenges' and 7% reported 'no challenges at all'. Difficulties reported included:

- Being overwhelmed by situations is a daily occurrence for my daughter, she needs a lot of structure and routine in her life which is not always possible in a household like ours.
- I am in a chair and nonverbal. I need assistance with the toilet and eating.
- As a carer, you always have the background need to be there for your young person. But there are other challenges in life too. So, you are always a bit close to the edge, even at the best of times.
- Behavioural issues, no peer friendships, family issues, learning difficulties, health conditions

- Trying to find something productive for my daughter to do, that she is able to cope with, can be a nightmare.
- He can become very anxious. At home he can be very repetitive and demanding which can spill over into aggression and sometimes violence.
- Not enough social events especially accessible venues/pubs for him to go to and meet new people
- Managing money, being reminded to respect other people's personal space.

Of those that had used Upmo services, the majority had attended workshops (94%), followed by one to one support (53%) and social events (50%).



Impact of Learning Disability/ Autism

We asked respondents to tell us what impact the learning disability or ASD has on their lives or those of their carers. This was an open question (ie no predetermined responses) which received 36 comments. These included:



- My sons can be socially isolated. Their youth club is 22 miles away. Services are limited and far away. They spend most of their time otherwise with mum and dad. This can be very frustrating for them. Our life revolves around caring and we still
- need "babysitters" for an 18 and 21-year-old so we can go to a meeting. Forget about a night out.
- Massive. It has been incredibly difficult and will be for the rest of our lives.
- The way we live is very different from friends' families and can be quite constricting.
- A lifelong impact on skills and abilities. Loneliness, lack of independence and "othering" - where a young person is seen as disabled first and a person second. Shunned or ignored by society and all treated as though they are "the same" e.g. considering an 18-year-old with complex needs is suitable for a placement in a day centre filled with elderly people.
- Employment - not enough is done to support young people with disabilities with suitable work placements.
- I think you can be happy and have a wonderful life, but you live in a parallel universe. There is a lifelong impact of caring.
- It can be very limiting on our daughter and on us as a family. You can feel on edge most of the time, particularly when out and about.
- From having no safety awareness to being unable to express her feelings properly to needing constant supervision to needing help with most parts of her life. Her autism and learning disabilities impact every single party of her life.

Access to Support

We asked students, parents, carers and referrers if there was anything they found particularly difficult to get support for. Again, this was an open question. 29 responses were recorded. Breaks for carers was mentioned by several people, help with challenging behaviours and finding out about support that is available were also cited. Transition for school leavers was also raised as an issue, as one referrer reported:

'Families I work with find 16+ transition very stressful and obtaining information challenging. Support is given usually to those who shout loudest, which means many families miss out.'

The range of services in Edinburgh is limited and decreasing every year due to spaces being filled. This dilutes the service for young people leaving school and means more people are clamouring for limited spaces. In turn, people are being fitted in anywhere there's space and this means more destinations are less individualised... than they were 10-20 years ago.'



Overall rating for Upmo

Asked how they would rate Upmo, a very positive 88% rated it as either 'excellent' or 'good'. Only 12% rated it as 'ok' and no-one rated it as 'poor.'

'The staff are all great and the workshops are really good with plenty of variety. Our daughter has been going to Upmo for over 5 years and loves it.'



'Everyone I have ever had contact with in Upmo is so kind, attentive as well as professional.'

'My daughter has a safe, happy environment to come to where she meets new people, builds her confidence and learns new things.'

I think it's a good place to be, all of the staff don't treat you with a disability or see you in a wheelchair.'

'It provides a variety of creative opportunities and adapts well around individual students needs.'

'It is an amazing service...I would encourage anyone to go to Upmo.'



'There is a great youthful "college" feel to the main building at St Margaret's House. My son loves it and has made lots of friends. He has grown in confidence and I see him doing things his siblings take for granted.'

'Upmo is, in my opinion, the best adult service in Edinburgh right now. It is designed with young adults with learning disabilities in mind and is highly inclusive. The atmosphere is young and fun and filled with hope.'

It's excellent. The atmosphere at Upmo is magical. The staff are respectful, friendly and full of enthusiasm. There is a real buzz.'



The Benefits of the Service

We asked what benefits involved with Upmo has brought to the students. 65 people answered this question. In order of rating ('helped a lot', 'helped a bit'), making friends and meeting new people came out on top. Improving job skills and helping people to find work scored the lowest.

<i>Benefit</i>	<i>Helped a lot</i>	<i>Helped a bit</i>
<i>Making friends and meeting new people</i>	<i>84%</i>	<i>16%</i>
<i>Increasing confidence and self esteem</i>	<i>81%</i>	<i>19%</i>
<i>Improving social skills</i>	<i>81%</i>	<i>19%</i>
<i>Helping cope with challenges</i>	<i>80%</i>	<i>20%</i>
<i>Improving independence and life skills</i>	<i>78%</i>	<i>22%</i>
<i>Reducing loneliness</i>	<i>76%</i>	<i>24%</i>
<i>Being more positive about the future</i>	<i>73%</i>	<i>27%</i>
<i>Improving health and wellbeing</i>	<i>71%</i>	<i>29%</i>
<i>Getting good advice and information</i>	<i>65%</i>	<i>35%</i>
<i>Breaks from caring</i>	<i>64%</i>	<i>36%</i>
<i>Continued learning (literacy and numeracy)</i>	<i>51%</i>	<i>49%</i>
<i>Improving job skills</i>	<i>38%</i>	<i>63%</i>
<i>Helping people find work</i>	<i>5%</i>	<i>95%</i>



The difference this is making

Students, carers and referrers were asked to put in their own words the difference Upmo has made:



'It was very depressing before as I had fears about my son's future. Now I don't worry about his future because he lives such a happy life in the present!'

'Her being back into a routine has settled her down again which means we have less "kick offs" or meltdowns. Now that she has somewhere to go on a daily basis we get a chance to recharge our batteries.'



'It's lovely to see my daughter blossoming into a confident, happy and outgoing young lady again, Upmo has been helping her to learn new skills (cooking and cleaning up) which has rolled over into her home life and she'll now help tidy up more at home.'

'It means that I can go out to work and not worry. I know that my son will be having a great time and will also be safe. It also isn't like any other day facility - It is like a college for adults with support needs.'



'Immense relief that he is happy and enjoying his time at Upmo. He would like to attend 7 days a week!!'

'After my daughter left school her confidence dropped, going to Upmo and meeting new (and old) friends brought her confidence back up. She's become a lot more independent around the house since she started at Upmo and a lot more willing to help out with household chores.'

'Without Upmo I would not be able to continue working and supporting my family. It gives me reassurance to know my son is somewhere he enjoys being safe and supported during the day.'



'It means the world to me, to see my son so happy and confident, and learning new skills and improving on his existing ones.'



Strengths & improvements

We asked people to tell us what they think Upmo is particularly good at and where it could improve. Below is a sample of the feedback:

What Upmo is good at

The themes that emerged were:

Inclusion / Good communication / Consistent support / Person centred / Being creative / Vibrant, fun atmosphere / Holistic approach / Professional, caring staff team / Welcoming/ "Making me feel happy"

Comments included:

'Giving the young people space to find their own way without allowing them to struggle. Recognising our young people have hopes, dreams and aspirations like everyone else.'

'Not treating young people like they have a disability.'

'Keeping me informed of what activities my daughter does at Upmo via a daily diary.'

'Providing a sociable and vibrant setting for young people.'

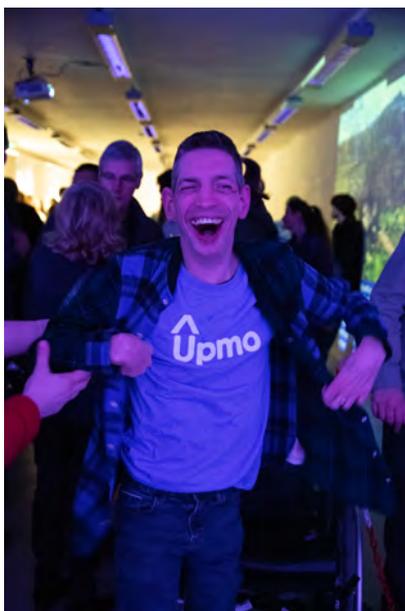
'Very approachable and excellent at getting to know the young people who attend.'



'Making the students and families feel involved and welcome.'

'Variation and creativity in the different workshops.'

'Developing a person-centred programme, based on existing interests but still offering a challenge and scope for development.'



'Teaching new skills, improving confidence and encouraging new friendships.'

'Treating people with respect and having a holistic, happy approach.'

Where Upmo could improve

The themes that emerged were:
More opportunities / more capacity / travel arrangements / better communication / outcomes focussed workshops / helping students move on / space improvements



'I think as a parent we would like more understanding of where progress is seen in different workshops, life skills etc. Reviews are good and we get more staff reports but are of necessity at quite long intervals.'

'It seems as though there are lots of creative opportunities people can access via Upmo, and that people enjoy taking part in these. However, young people don't seem to move beyond Upmo as a service - I'd be interested to hear about plans for young people gaining skills or qualifications that lead to their developing and moving beyond the service into other opportunities.'

'Have more Upmo services and tell others about what you are doing.'

'Better means of communication. This is common among support services but it can still be improved.'



'It would be nice to have a social event that included parents/carers so we could all get to know each other and possibly arrange to socialise away from Upmo.'

'Cafe-needs to be bigger / Breakfast club could have a bigger selection of food.'

'Managing the quiet room as it is too loud.'

'Having a concrete plan for how young people can gain skills and experience to move on from and beyond the service.'



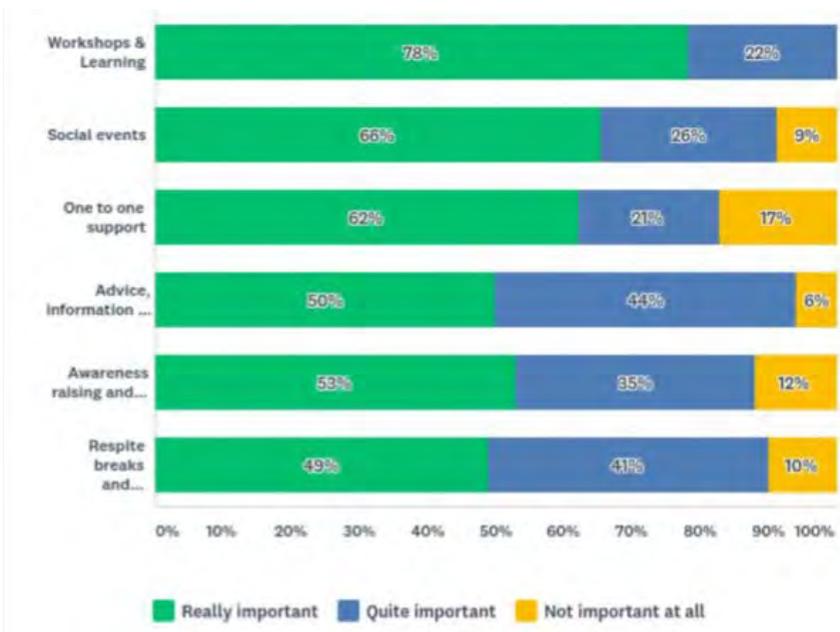
'Make information more accessible to people with more significant communication needs. Getting all service users opinions in a person-centred way.'

'I feel that there is disparity between the two services. St Margaret's house is excellent but in my opinion the service at Prestonpans is not as good and does not offer the same opportunities as those at St Margaret's House.'



Prioritising services

We asked people to rate the importance of services to them, the people they care for or refer. The highest rated was 'workshops and learning', followed by 'social events'. This correlates with the benefits people reported through engaging with Upmo ('making friends and meeting new people' and 'increasing confidence and self-esteem') and are clearly key areas for support going forwards.



Services in a New Space

Respondents were asked what kinds of activities and services they would like to see in new, expanded premises. 60 people responded to this question, choosing from a list of options. All options were very positively supported, but in order of importance:

The most popular were more workshops spaces and quiet / sensory space

IT facilities, performance spaces and social areas also scored highly

'Space to enable students with walkers to be able to have physiotherapy as part of their day at Upmo. Space for students to have their own lockers to reduce the amount of items that need to travel daily with students.'

'Large kitchen area for cooking and baking.'

'Drop off zone.'



'Perhaps interacting with outside workshops? I.e. there is a sewing workshop that opened up near me that would be willing to lease their services, or there is an 'upcycling' place in Leith that your service users could gain skills from.'

'A space to go to when they need time out that they can get to themselves.'

'Bigger sensory room-bean bags in social spaces.'



'Take consideration of sensory needs of clients re: lighting, noise etc as current building can be very noisy in the social spaces particularly. Lighting is also quite harsh in areas. Considering the mobility needs of clients to perhaps have easier access to getting outside including a garden perhaps?'

'I would like it to look the same as I get nervous.'

'One of the areas that gave Upmo the advantage over other care providers was that the building was open, flat throughout and easily accessible - hopefully this will be similar at the new premises.'

'As young and upbeat as you can make it with a calm, welcoming environment.'

'Would like it to be all on one level. More hoists, wheelchair accessible toilets. Would be great for wheelchair users to be able to get out of their chairs and maybe do stretching, exercises, relaxation etc on mats.'

'Sensory area would be good. Spaces to help people relax. Workshops using sensory spaces.'

'Not clinical a lot of these guys have spent a lot of time in hospitals.'

'Fancy wallpaper (student led design).'

'Less crowded in at least some areas, more spacious/relaxed areas. Gallery area in or outside café.'

Focus Groups

Students who participated in the workshops have attended Upmo for a range of 1 to 6 years and came to Upmo from different backgrounds including:

- Living at Home
- Supported by foster carers
- Straight from School
- Attended College
- Supported accommodation



A number of students commented on how positive their experience at Upmo was in contrast to other more institutional structures such as Day Care Centres. Students talked about negative college experiences and how important it was to feel safe and welcome at Upmo.

Good things about Upmo/Things students like to do:

Key themes:
Variety, Personalisation, Socialisation

'S loves cooking, music workshops and Art activities, he lives at home and likes to get out of the house and meet new friends he feels he is becoming more confident and independent.'

'D has attended for 6 years and loves his 1/1 music sessions where he is developing his song writing talents. He feels these sessions are "a very important part of his life."





'L loves his DJ role, meeting new people and cooking and dancing. He has "some great moves.'

F who lives in supported accommodation loves the community feeling and the fact that Upmo does not feel like a day care setting or an institution.

'K loves her Edinburgh Tales Workshop which involves photography and learning about the history of places as well as performing and being involved in making a movie.'

'R loves day trips and visiting other places. He has been to North Berwick and museums.'



Students talked about outdoor activities such as the walking group.

The social club at night was felt to be such an important time to meet new friends and get to know people better. Throughout this discussion, it was clear students had their own individual programme of activities based on their own needs: the diversity of opportunities and range of workshops was important to the students, enabling each of them to develop their interests.

What difference has being at Upmo made to students?

Key themes:

Friendship, Being Active, Learning, Belonging, Challenged

'R talked about having her own group of friends and the fact that she can make new friends. She felt it was important to step outside of her comfort zone in a place where she feels secure and safe.'

'K loves visiting new places and finding out more about local history.'

'J is making new friends.'

L talked about the importance of getting out of the house and having activities that he can look forward to.

'F is clear that if there was no Upmo she would not know what to do.'

'J is becoming more confident.'



'S is learning new skills like cooking and song writing he also loves karaoke and Neil Diamond songs. S talked about the importance of being able to support fundraising activities, S and his mum raised over £1000 at his mum's work from sales of baking.'

Friendship, meeting people and developing mutual interests were important to the students, as was being active and learning new skills rather than being bored at home. The social and educational aspects taken together appeared to have a significant impact of the students' confidence and self worth in general terms. Observationally, throughout both sessions students were very respectful towards each other and sensitive to the needs of fellow students who may have more complex support needs.

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Key themes:

Sad, Lonely, Unconfident, Bored,
Stressed

There was a huge sense of how devastating this would be for everyone and the profound, negative effect it would have on their lives:

'K would not be as confident.'

'J would be much lonelier.'

'L would feel very sad.'

'D would be very bored and not know what to do with himself.'

'J would be bored, tired, fed up and stressed.'

'R who attends 4 days would be very depressed if there was no Upmo.'

'F would feel very isolated.'

'S would be very bored as he does so many different things when he is at Upmo.'



Things that Upmo could do better and improvements that could be made in a new space:

Key themes:

More time at Upmo, Better equipment, Bigger spaces

All who participated in the workshops wanted more time at Upmo and there was a real sense that the students loved being there and were keen for even more activity and that more funding was needed to make this happen. The students get really fed up when everyone talks about social work budgets.

'Better changing facilities would help.'

'The current venue was not built for purpose and everyone has made what they can of a building that has considerable limitations.'

'Bigger rooms for workshops and meetings.'

'Improved hoists built into room design.'

'A bigger café area with a juke box.'

'More toilets with better facilities.'

'Would be great to have a sound recording studio.'

'More trips -R mentioned her trip to Paris 2 years ago.'



'More opportunities to go on holiday with friends.'

'New IT Suite is fab / more funding for improvement in technical equipment.'

'Staff are great but sometimes people with more complex needs need a bit more support.'

'Better minibus as the one that Upmo has keeps breaking down.'

'More Outward Mobility ie more trips in the evenings and during the day.'

'Swimming pool, Jacuzzi and steam room.'

'Space to relax and get out of your wheelchair during the day as you can get quite sore and stiff.'



If someone asked you about Upmo what would you say to them?

Key Themes:

Amazing, Safe & Supportive, Responsive, Self-determining

D lit up with a smile and said “it is an amazing place. Upmo is my life.”

F feels that Upmo is an important safety net for her as she can get support if she is hurt or upset.

L thinks Upmo is “superb.”

'S thinks “it’s amazing and the staff are great.”

J feels his voice is heard.

R was clear that if Upmo wasn't here she would be at home stuck in the house and watching TV all day.



Finally, everyone who participated felt the very best thing about Upmo was that you get to pick the things you want to do and that “everyone has a choice.”



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