

Shaping Our Lives

Improving Understanding of Service User Involvement and Identity

A Guide for Disabled People who are Interested in being a Service User Representative

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Introduction

Shaping Our Lives is a national organisation and network of user-led groups, service users and disabled people. It is a user-led organisation committed to inclusive involvement. It specialises in the research and practice of involving diverse communities in policy, planning and delivery of services.

Listening to and respecting service users' voices and perspectives is increasingly known to be an essential part of developing quality services. Shaping Our Lives has gathered the experiences of Disabled people who have taken part as service user representatives in the policy, planning and delivery of health, social care and local government services.

From these experiences we have produced this guide for Disabled people who are thinking about becoming a service user representative. You may have been asked by someone who works for your local council or local health authority to become a service user representative or may be just starting out in this role having been invited. If you are reading this guide you are probably thinking ahead to what the task might involve and how to get the best out of it. When you have finished reading the guide you will have picked up some top tips about how to improve the experience.

There is an explanation of the following terms on page 20:

- Disability Equality Training
- Involvement activity
- Organisation
- Professional(s)
- Service user
- Service user representative (Representative)
- The medical model of disability
- The social model of disability



Things to consider before you become a service user representative

1a) Why do you want to be a service user representative?

When we asked someone "Why did you become a service user representative?" They said ...

"Partly it is me wanting to give something back, to thank the people who helped and supported me and to help make changes, and help with their professional development."

There are many reasons why Disabled people become service user representatives. It is important to consider if the service user representative opportunity will have the right outcomes for you.

Consider the reasons given below for taking part in involvement and ask yourself these questions:

I want to give something back

What would make you feel that you had given something back and will the involvement activity provide this?

I want to help services to improve

How will the involvement activity change services?

I want to stay professionally active

Does the involvement activity match your skills and are there opportunities for personal development?

I want to help other people like me

Do you feel ready to speak on behalf of others with similar and/or different impairments or health conditions?

Do you need any support or training to do this?

To speak and effect change on behalf of others may require skills to advocate, critically assess the impact of changes, make clear references in presenting an objection and be able to think on your feet.



1b) How will taking part as a service user representative make you feel?

It might make you feel good ...

Service user representatives have both positive and negative feelings about their experiences. When the involvement activities are inclusive, well planned and effective in bringing about changes, you can have these good experiences:

- Being listened to.
- Making a difference.
- Representing people who cannot represent themselves.
- Providing information to improve policies.
- Having a purpose to help people and not just Disabled people.
- Being empowered to talk about issues that affect people with similar impairments and health conditions.

It might make you feel bad ...

You need to be aware that there can be involvement experiences that may be stressful or can make you feel unhappy. These feelings may relate to you personally, or be because of poor involvement processes.

Personal difficulties include:

- Stress, distress and tiredness from sharing personal experiences and listening to the experiences of others.
- Apprehension about the knowledge required to take part and the interaction with professionals.
- Frustration from communication and access barriers that exclude people.

Many service user representatives feel that any negative personal outcomes are generally offset by the positive feelings of contributing to improving services, however, this is different for everyone and should be considered before taking a role as a service user representative.

Negative feelings that can be caused by poor processes for involving people are:

- Getting annoyed as it takes a long time to make a difference and sometimes there is no positive change to services.
- Frustration because a process needs to be followed that is not flexible to new ideas or accessible to non-professionals.
- Feeling patronised if you are not listened to, the professionals are not committed or some people are listened to more than others.
- Feeling demoralised if the service user representatives are not treated as equal partners and their views given equal priority.

The involvement activity that gives rise to these poor experiences will probably have no meaningful outcome as the process of involving service user representatives is inflexible, too long and/or tokenistic.



When we asked someone "What are your feelings about being a service user representative?" They said ...

"Quite complex really, it was difficult but rewarding at the same time."

1c) What are the good things about being a service user representative?

When we asked someone "What were the good things about being a service user representative?" They said ...

"This was a good time, full of optimism and enthusiasm and it felt like we were pushing on an open door."

Here are some of the good things about being a service user representative:

- Good to be part of a team.
- Gives a sense of purpose.
- Feelings of being wanted and needed.
- Valuable personal knowledge and experience.
- Motivating and exciting when the contribution is acknowledged.
- Good when it makes a difference, feeling of being stronger through effecting social change.

The key factors that service user representatives identify for good experiences are:

- Equality
- Mutual respect
- Ownership
- Structure
- Commitment
- Feedback
- Personal development

Personal development may include: training, acquiring new skills, gaining knowledge, opportunities for paid or voluntary work, increased confidence, opportunities to network/make new friends, increased self-worth and finding out about services and organisations in the area.

1d) What can be not so good about being a service user representative?

Service user representatives give many different reasons why involvement experiences may not be so good. Some of these are things that are personal to an individual and others are issues that arise from the organisation's approach to involving people – their processes.



Personal factors include:

- Difficulties from not knowing how to work with and support other Disabled people with different impairments and health conditions.
- Distress and tiredness from drawing on personal experiences.
- Not having the right knowledge to contribute fully.

Process problems that service user representatives experience can be put into three groups:

Practical barriers to having a good involvement experience:

- Not being sufficiently supported through accessible practices.
- Practicalities such as travel arrangements and parking not being arranged.

Communication barriers to having a good involvement experience:

- Not being listened to.
- Feeling inadequate because information is not equally shared between staff/professionals and the Disabled people participating as service user representatives.
- Professionals not acting on service user suggestions.
- Agenda is set before the first meeting and there is no opportunity to influence the process so it is not genuinely collaborative.
- Service user agenda items not given equal priority.
- No feedback on what happens as a consequence of a consultation or involvement process.

Attitudinal barriers to having a good involvement experience:

- Not having equal power and respect.
- Feeling intimidated.
- Involvement becoming less important because of financial/service pressures.
- A shift back to a medical model approach as a result of negative rhetoric about Disabled people and the impact of austerity policies.

1e) What should I look out for to help me decide if I want to get involved in this organisation?

There are several factors which identify if an organisation has put a lot of thought into involving service users in a meaningful way. Ideally they should have a planning process that has considered the following:

- Have service user representatives been involved from the start?
- Are the right people involved to achieve the objectives?
- Is there a clear aim and objectives for the process you will be part of and have these been approved by senior management?
- Do the professionals managing the involvement activity have the appropriate training, knowledge and skills to make the process inclusive?
- Have the service user representatives been given the necessary information to make informed decisions?



• Is there enough time to complete the process and has a budget for involvement been set aside?

When we asked someone to tell us the most important thing that had helped them to become a representative. They said ...

"It comes down to motivation. Work out what drives you to want to do this. Usually this is about trying to make a change for oneself, however, you won't get it right until you want to make a change for others too."

Top tip!

To decide if being a service user representative is the right role for you, talk to one of the professionals asking you to get involved. Ask them:

- What are you trying to achieve?
- How are you planning to do it?
- What will my time be spent doing?

Can you now decide if it is a role that you can undertake?

In the next section we give you lots of ideas for questions to ask to help make the service user representation a positive and meaningful experience.



Getting the most out of involvement activities

Now you have decided you want to be a service user representative you need to find out some things from the organisation or professional that has invited you. Check to see if they have taken some practical steps to involve you well.

Without this information you might find it harder to decide if an activity is suitable for you.

Have you been given:

- An overview of the activity, what it aims to achieve and what the outcomes will be.
- Terms of reference for service user representatives taking part.
- Clear guidance to the amount of time you will need to commit and for how long.
- Payment policy for reimbursing expenses with details of how to claim and how long it takes for a claim to be processed.
- Involvement payment policy with details of how to claim and how long it takes for a claim to be processed.
- A skills audit to see if you have the appropriate skills for the involvement project.
- An access audit for your requirements before any activity starts.
- An opportunity to discuss meeting venues, meeting times and other practical arrangements so meetings are set to suit service representatives as much as the organisation or professionals.
- Confirmation of practical arrangements, such as times and places for meetings.

The following things may be helpful to you.

Ask if you will be given:

- An induction for the service(s) you have been asked to advise on.
- Training or information on the range of impairments and health conditions that people taking part may have and how this impacts on their participation.
- Relevant professional training if required to take part effectively.
- A mentor from the service or a 'buddy' who is an experienced service user representative.

There is often an assumption that any Disabled person can be an effective service user representative and generally this is true if they have the appropriate skills and knowledge. However, service providers organising involvement activities should do a skills audit or similar to establish any training and support needed for service users to take part successfully.

Some opportunities may not be right for you and it is fine if you decide not to take one up. Service user representation roles vary greatly and some may not be for you.



Top tip!

Take this guide with you to a meeting with the organisation. Use the two lists in this section as a checklist; discuss each item with a member of staff and tick off the ones that the organisation can do. Agree with them how they are going to go about addressing the gaps.

Have they met enough of the checklist items for you to decide to go ahead with the involvement activity?



Relationships and conflicts

Will being a service user representative change or affect my relationships with service providers and other service users?

Sometimes professionals may behave differently when you are using services compared to when you are a service user representative in an involvement activity. You may want to think about the following ways that your relationship with a service practitioner could change if you meet the same professional while doing involvement activities.

- A professional may treat you as an expert when you are a service user representative, but not when you are using services (or the other way round).
- A professional may treat you the same in both situations.
- You may need to use a service while you are a service user representative for that service and this may be uncomfortable for you.
- Professionals may be more friendly because you are a service user representative.
- Professionals may fear that you are going to be more critical of their service if you are a service user representative.

However, in both situations service users and professionals should be in a good relationship in which they can work things out together. If you and they can do this then this will lead to an effective and positive involvement activity.

Possible disadvantages of being a service user representative relating to other service users:

- Perceived favourable treatment from professionals by other service users.
- Isolation and hostility if you have an opposing view.
- Difficult relationships with other service users.

Possible disadvantages of being a service user representative with professionals and services:

- Professionals can assume you understand what is happening in service provision.
- Professionals may ask you for advice.
- Potential conflict if also using the service, this can lead to feeling vulnerable.

Some people may not experience any of these disadvantages, this list is intended to make you aware of things that some people experience when working as a service user representative.

Think about any disadvantages alongside the very positive outcomes of being a service user representative. There are pros and cons of getting involved in most activities.



Top tip!

At the beginning of any involvement activity ask who can be your single point of contact in the organisation. Make sure you have their contact details and get in touch with them if you have any concerns you want them to look at.

They may not be able to address all concerns but it is important you are listened to.



Benefits and personal development

When we asked someone to describe what being a service user representative means for them. They said ...

"I love to speak for people who don't know what to say and making their lives a bit better... I've learned how to talk up for other people and changing my ways, doing things I never used to do, I have a better life, I help other people, it's a good thing."

4a) What are the benefits of being a service user representative?

The benefits of being a service user representative can be personal and/or things that increase your knowledge and skills. They include:

- Access to training and educational courses.
- Learning about rights and legislation.
- Finding out about other organisations and services in the area.
- Learning work relevant skills such as chairing meetings, preparing reports etc.
- Influencing policy and service development positively.
- Social opportunities and meeting other service users.
- Builds confidence, self-esteem and dignity.
- Stimulates mind and gives a purpose.
- Promotes self-care and self-advocacy.
- Provides an opportunity to take part.
- · Receipt of financial incentives.
- Altruistic benefits from speaking up for other service users.

Potential advantages of being a service user representative:

- Adds to knowledge and skills.
- Builds confidence and self-esteem.
- Feelings of making a worthwhile contribution.

Possible disadvantages of being a service user representative:

- Demands on your time and this may impact on health.
- Becoming frustrated, demoralised and dispirited. (Reasons may be slow processes, inaccessible processes, nothing happening, not being given time to talk, not listened to).
- Requires comprehensive knowledge and this could lead to more work.
- Stress and distress caused by the negative experiences.

4b) What new opportunities might come my way?

Getting paid or voluntary work is the most common new opportunity that people experience. In some cases involvement work may lead to a more permanent



voluntary or paid position. Some people are also offered the chance to do a qualification or higher academic study.

Being a service user representative may also lead to involvements with other voluntary organisations or to other involvement activities that can expand your knowledge and skills.

Becoming a service user representative may provide new activities and opportunities because you have more confidence. For example, people said they had gained enough confidence to write articles, challenge decisions, attend regional/national conferences, do radio interviews - a whole new world can open up once you have the confidence.

Many people find that through doing involvement activities they are invited to join user-led groups or voluntary sector organisations. It often also leads to invitations to aspirational events, other consultations and involvement events.

Finally, some people find that being a service user representative benefits their health and wellbeing; helping them to get well and to manage their impairments and health conditions.

When we asked someone "How did it help you?" They said ...

"For me it was a start to getting back out into the world and a step on the journey to being well again."

4c) What might I get for being a service user representative?

There is no national standard for recognising the contribution of service user representatives. Here are some of the things that may be offered and/or you may want to ask about:

- Payment of expenses to attend meetings and events.
- Payment for lived experience expertise.
- Provision of refreshments for meetings.
- Opportunities for professional development, studying for qualifications and training.
- Routes into voluntary or paid employment.
- Recognition and acknowledgement of the contribution service users make.
 This can be through many different ways but, for example, could be an annual event for service user representatives, acknowledgement in the annual reports or an award for service user contributions.
- Accreditation on published reports and papers.
- Opportunity to talk to other people about your experiences of being a service user representative.
- A personal reference for involvement activities you complete.



Top tip!

Be honest with yourself about why you are getting involved. What benefit do you want to achieve? You will have a better chance of your expectations being met if you know what they are in the first place.

What makes it a good involvement experience?

The most important factor for a good service user representation experience is that the activity is accessible to you. Having a fully inclusive process is essential for equal participation by service user representatives and professionals, allowing service users to share their knowledge and expertise.

You can use this list below as a checklist before starting any involvement activity and raise any concerns you have before the first event or meeting.

Have you been given?

- Plenty of notice for activities.
- Communications in your preferred format.
- Accessible meeting times.
- Meetings that are not too long (but long enough to do the work thoroughly).
- Accessible meeting venues including travel to the venue and parking if needed.
- Papers for the meetings that are in an accessible format.
- Using plain English rather than professional jargon in all communications.
- Provision of refreshments that meet your dietary requirements.
- Clear aims of the involvement activity.
- A process for feeding-back to service user representatives about the outcomes of the activity.

When we asked someone "What makes it a good experience for you?" They said ...

"It's about developing inclusive practice. It's about making them aware that service user representatives are integral to the meeting and they shouldn't treat us as an add-on. If they were able to do that they would be able to make much more valuable use of the service users and develop much better services as a result of that."

Do you know what your access requirements are? Are you able to say what they are to someone else so that they can try to meet them? Do you feel comfortable and confident asking for what you need in order to make a meeting accessible to you?

Top tip!

Take responsibility for clearly stating your access requirements. Don't wait to be asked.

Write down your access requirements and get used to sharing them with the person in charge of the meeting. Give them plenty of time to put your requirements in place.



Working with other service users in an involvement activity

It won't just be you who is asked to be a service user representative in a process. There will be people who have the same lived experiences as you, and people who have different ones. People will have different experiences of working in teams, of participating well and of how to make good decisions. They might have professional backgrounds and training which mean they have different expectations than you about how meetings should be run. Be prepared to be challenged and learn how to challenge other people well.

How can I work most effectively with other service users?

- 1. Understand other people's access needs.
- 2. Be clear about your own access needs and take responsibility for explaining to others.
- 3. See the person not the impairment.
- 4. Treat each service user as an individual, people manage their conditions differently.
- 5. Have an open mind and open agenda.

How should I take part in meetings and groups?

The point of being a service user representative is not to just represent yourself and the good and bad things that have happened to you as a disabled person. You need to think about the bigger picture. What can you bring from your lived experience which will help other people? How can you be effective in meetings?

- 1. Ask for materials in advance so you have time to read them.
- 2. Listen carefully and think before you speak, be polite and respect others views.
- 3. Be prepared to ask questions and don't be afraid to speak up.
- 4. Have confidence in your knowledge.
- 5. Think strategically for all service users.
- 6. Be prepared to be wrong.
- 7. Keep confidential issues to yourself.
- 8. Understand it's not an easy thing to do.
- 9. Don't be afraid to say you're not well enough to take part, be kind to yourself.
- 10. Don't be afraid to say no, do what you can, not necessarily what is expected of you.
- 11. Take it slowly, take your time to get to know the group and its dynamics, don't be afraid to say nothing until you are confident.



Summing up

What a service user representative said...

"Are you passionate about what you want to do, are you completely committed, do you have knowledge, experience and skills for what is required? If the answer is no to anything, then don't do it."

Being offered the chance to be a service user representative is a great opportunity. You need to work out if this is the right opportunity for you. To do this you need to think about:

- How prepared the organisation is to work with service user representatives.
- How well thought through the involvement activity is.
- How you will feel if you get involved in a process that is not good and how you will manage possible negative feelings.
- The benefits and advantages for you from being involved.
- The possible disadvantages to being involved and how this might impact on you as a service user.
- If you have the right skills, experience and attitude to contribute well to the involvement activity.

And finally...

Be realistic, change doesn't happen overnight.

Final top tips!

- 1. Ask for a brief job description of the role, what it entails, and what you are expected to do e.g. add an agenda item or prepare a short report.
 - Think what do I...
 - need to know?
 - need to understand?
 - need to ask?
- 2. Ensure that your own barriers to equal involvement have been removed by inclusive processes.
- 3. Be honest with yourself that you are interested in the area, passionate and committed.
- 4. Work out what you want to achieve and plan what you are going to do/say.
- 5. Separate your role as a service user and a service user representative.
- 6. Don't take on too many roles.



Supporting information

This best practice guide for service user representatives is one of three documents in this series. The other documents are the report of the research findings and a best practice guide for professionals.

You can find these under the heading 'Improving Understanding of Service User Involvement and Identity' in the Resources section of our website - www.shapingourlives.org.uk/resources.

Other resources on our website that may also be of interest are:

- Guide to accessible meetings and events (also included on page 21 of this document)
- Inclusive ground rules
- Definition of a service user written by people who use services
- A series of publications including electronic resources in the 'Beyond the Usual Suspects Towards inclusive user involvement'.

Or contact Shaping Our Lives about our inclusive involvement service:

Email: information@shapingourlives.org.uk

Telephone: 0845 241 0383



Glossary of terms

Disability Equality Training

Training developed within the Disabled People's Movement which outlines the distinctions between the medical and social models of disability and the implications for professional practice and service delivery of these different ways of understanding.

Involvement activity

An activity, series of activities or group set up by an organisation to engage and involve service users in designing, overseeing and/or evaluating one of the organisations services or processes.

Organisation

A body providing a service. Can be a public body (like a local council or GP, a University), a charity (e.g. drug and alcohol services) or a private company (e.g. a residential home).

Professional(s)

This term is used interchangeably with service provider(s) and practitioner(s) in this document. It is taken to mean someone who is paid to work for an organisation in a particular role, like a social worker, nurse, or commissioning officer. It is used as a noun and not as a descriptive term suggesting particular behaviours.

Service user

A person who uses a service provided by an organisation, often in a social care or health care setting. A service user is not always a Disabled person. However, in this document we have used 'service user' to mean a Disabled person who is a service user. Anyone can self-define as a service user.

Service user representative (Representative)

An individual service user who joins in with an activity to share their lived experiences and sometimes speak on behalf of other service users.

The medical model of disability

Disability is any restriction or lack of ability (resulting from an impairment) to perform an activity in the manner or within the range considered normal for a human being, for example the ability to climb the stairs or walk to the shops (WHO, 1981) (In other words, disability is an individual problem, a 'condition' caused by physical, sensory, cognitive emotional impairment).

The social model of disability

Disability is the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers (Disabled People's International, 1981)

(In other words, disability originates in the built and social environments, and is a matter of how society responds or fails to respond to physical, sensory, cognitive or emotional differences of people with impairments).



Guidelines for making events accessible

Access is about providing people with equal opportunity to participate fully in whatever is being offered. Meeting people's access needs should be done in a positive and affirmative way, which should be reflected in the language we use when discussing access requirements. All disabled people are individual and will therefore have different needs at different times. People with the same impairment/condition may manage it very differently and also have different access needs. However, here are some guidelines that Shaping Our Lives National User Network suggests are good practice.

Before a meeting/event

As a matter of good practice participants should be asked prior to a meeting/event if they have any access requirements.

It is absolutely essential that anything people ask for is available at the meeting/event. This means that events/meetings need to be planned well in advance as, for example, palantypists, lip speakers and BSL interpreters cannot be booked at short notice. Hearing loops in venues are notoriously unreliable and thus venues must be made aware of the importance of them working and be reminded of this closer to the event, with testing carried out prior to the event.

An agenda should be sent out in advance of each meeting/event. The agenda should include a paragraph under each heading explaining what will be discussed/covered etc. in this item. This will allow people to think about it or discuss it with a support worker if necessary before the meeting. (Funding must be made available to support this).

Getting to the meeting/event

Disabled people who drive, or who are being driven, need reserved, well signposted car parking nearby. People who take enquiries about public transport to the event need to be able to advise on accessible travel arrangements.

Getting in

Entrances to venues should be level or ramped, and if there are steps as well, these need to have a handrail and preferably step edges clearly marked. Some people with walking difficulties prefer steps to a ramp. Revolving doors are not suitable for wheelchair users or for many other people with different impairments. The position of the entry door needs to be clear, with glass doors well identified. It is a good idea if someone can meet and greet people at the entry into the building.

The place

Venues should have natural lighting and be well ventilated without air conditioning, which can be noisy and thus be a barrier for many impairment groups.

A 'quiet room' should be available so that if any participants want to take 'time out' there is a space set aside for this. Make sure all participants know where it is.



Water should be available throughout the event and a supply of plastic drinking straws is useful.

Food should be clearly labelled and not mixed.

During the meeting/event

House keeping: At the start of meetings it should be explained to people where the toilets are (accessible and non), and where the fire exits are. This should be done in an inclusive manner avoiding pointing, for example 'over there', and should take into account different people's access needs. For example, if the meeting is taking place in an upstairs venue how will wheelchair users evacuate in the case of fire, are the lifts operational in fire and so on.

Agendas must be stuck to so people can follow where they are in the day's proceedings.

Timing is an access issue. At the beginning of meetings, (even if they start late due to unreliable public transport) times of breaks, lunch and ending need to be agreed and stuck to.

During meetings 'ground rules' should be agreed (see next page).

If it is intended to include people with Learning Difficulties in a truly inclusive way then it is important that this is taken into account when the agenda is planned, as well in the practice that is adopted in running the meeting/event.

Before the meeting starts it might be a good idea to discuss the need for break times. Some people need regular breaks for a variety of reasons. For example, a break every ten minutes in order for people with learning difficulties to take 'time out', talk with their support worker, talk to each other or whatever they wish, might be necessary. This can be positive and have benefits for the entire group and for some specific impairment groups, for example hearing impaired people who are lip reading or following a sign language interpreter, people with pain who need to move frequently, or those with continence problems. The interpreter themselves may need a break.

It is important that the venue is checked in terms of access. Staff attitudes are a major factor in determining whether a venue is suitable or not. If possible it is advisable to seek personal recommendation from user groups. It is important to remember that a solution for one group of service users might become a barrier to another impairment group. It is good practice to have more than one option available.

Access is about providing people with equal opportunity to participate fully in whatever is being offered.



Acknowledgements

This report has been produced by Shaping Our Lives in honour and memory of our great friend Patricia Chambers.

Patricia, a prominent member of the black and minority ethnic mental health user/survivor movement and a dear friend and colleague passed away in May 2016. For over 25 years, Patricia worked tirelessly to address issues at the intersections of race/culture and madness, within services, within the wider user/survivor movement and within research and policy.

In 2009 Patricia took over as the Network Manager of Catch-a-Fiya, the only (and now defunct) national network for people from black communities. It is impossible to list all the places and platforms she contributed to/through: BUGS, the Afiya Trust, Shaping Our Lives, Black Women's Mental Health Project, The Forward Project, the DRE Ambassadors programme, NIMHE's Making a Real Difference programme, the Count Me In census, Dancing to Our Own Tunes.... and the many local/informal user groups where she acted as an advocate and friend to people who needed that.

We developed this project from an interest Patricia had in the conflicts for people who use services and who also work to improve them. The project has been funded by the National Lottery through the Big Lottery Fund. All of us at Shaping Our Lives hope it will go some way to keeping the very fond memories we have of Patricia alive as well as bringing about the kind of positive change she worked so hard and wisely to achieve.



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There are many other Disabled people who have given their time and expertise to the research findings and guides in this series. Shaping Our Lives is very grateful for their invaluable contributions.

Authors: Becki Meakin and Joanna Matthews.



Shaping Our Lives

www.shapingourlives.org.uk

Email: information@shapingourlives.org.uk

Telephone: 0845 241 0383

Facebook: @shapingourlives

Twitter: @Solnetwork1

YouTube: shapingourlives1