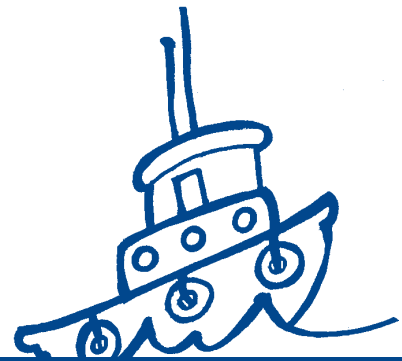


Tugs helping Supertankers

Working
Towards User-
led Services:
What happened
and the difference
it made

Report from the Outside the Box project



Background

About this report

Over the past 5 years Outside the Box has been working with community groups and other people to develop user-led services. In 2008 we received a 4-year grant from the Big Lottery Fund which part-funded Working Towards. Development support for user-led services is now a major part of the work which Outside the Box does.

The impact of Working Towards is

- **Support to 80 projects.**
- **Working with 681 people, who gained skills and confidence to run projects and influence other organisations and local policies.**
- **Developing 43 user-led services.**
- **Helping projects bring in over £680,000 for their services.**
- **Bringing benefits for over 12,000 people.**
- **Publishing 33 reports – plus postcards, posters, leaflets and a DVD.**
- **Using what we have learned to show what is possible for user-led services, develop more programmes to support user-led services, and to feed in to national initiatives.**

This report is the story so far. It shows what happened and the achievements that we have been able to track to early 2013. It also shows how user-led services can contribute to wider policies around support for people who need extra help and to ideas around different ways to provide services used by the public.

We hope it will give ideas and tips for other people who are developing this type of service.

About Outside the Box

Outside the Box is a voluntary organisation which is based in Glasgow. We provide development support to new and existing projects across Scotland. We also work with other partners on issues that affect people across the UK and in other places. You can find out more from our website: www.otbds.org

Our annual reports describe the work that is done by the organisation and show how the Working Towards project has complemented other work that we do. www.otbds.org/about/annual-reports

This is the definition of user-led services that we used for Working Towards

- 1 These are practical services that deliver care, advice, information, training, or some other practical activity. The services bring benefits to individual people.**
- 2 The services are led by the people who will be using those services, or by people who share very similar circumstances to the target service user group (or members, or consumers, or clients, or other term that the people in that situation prefer to use). Sometimes, this will mean that everyone leading the service – for example, on the board of a voluntary organisation – will be someone with experience of using the services that the organisation delivers. In other examples other people will also be involved but there will be a majority of people with relevant lived experience.**
- 3 Leadership comes from the people who will be using the services around the values and direction of the service, and around the practical day-to-day service delivery. Often there is a strong peer support element to the services. In other cases the service is delivered by other people who are working to the values and approach set by the people who use the service.**

The starting point: Our ideas and what we hoped would happen

In a community somewhere...

Something needs to change and nobody's doing anything about it!

There is an answer

We should do something about it then...

What? Could we really?

Seriously - we could do it better

But how?

Help is at hand

First of all find other people to help. And ask them what they think...

Then we can make a plan

We'll need some money

Let's DO IT!

You can get help too



When we were at the planning stage we thought about what we wanted to achieve and how this could be made to happen – which is what the initial stage is for all the people and groups who go on to develop their new activities.

The ideas and vision drew on several sources

- What we were hearing from people who used support and people who were looking for different types of support – what worked well and what could be better, the barriers they faced in getting the support and in making the contributions they wanted, and the gaps they described in the range of provision available to them and others in similar circumstances.
- The work that we and other people and organisations were doing to develop opportunities for people to participate in planning for services in their areas, and in the direction and delivery of specific services.
- Wider experiences and good practice from many community development settings.

We wanted to create positive impacts for people and for groups

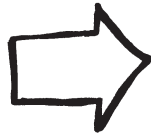
- A series of (probably quite small) user-led services.
- Capacity building for individual people, who contribute to the development of user-led services.
- More choices and options for people as a consequence of the user-led services. These in turn contribute to the capacity building benefits for more people.
- Capacity building outcomes for groups, which also contributes to more and stronger user-led services.
- Different types of services, as well as more of what was already there.
- Different types of contributions and roles for people in user-led groups, as well as more of what is already there.

Out of this we also hoped to see an impact for communities

- Influencing other services and policies, as people feel better able and more confident to feed in their ideas.
- Showing what is possible and giving other groups and organisations more ideas.
- More options for local communities, as small user-led services complement other services to provide a better overall range, and options that are financially feasible.

This is the range of policies we saw Working Towards linking in to

- Contributing to the Scottish Government's Strategic Objectives
- Achieving personalised care – which is now being taken forward through Personalisation and the work on Self-directed support.
- Development of Recovery-focussed services
- Encouraging participation by service users in services
- Increasing public participation in community planning and community capacity building
- Promoting equality and diversity
- Creating opportunities for people to contribute to service delivery – Co-production



Where to get more information

There is material on the Scottish Government's strategic objectives at www.scotland.gov.uk/About/Performance/scotPerforms/objectives

These are useful resources on Personalisation and Self-directed support:

www.selfdirectedsupportscotland.org.uk

www.ccpsscotland.org/providers-and-personalisation

www.scottishhumanrights.com/application/resources/documents/Finalpersonalisation2012.pdf

Recovery is reflected in policies and good practice for people who live with mental health problems and has been part of national policy in Scotland since 2004. The ideas are now also part of policies and services for people who are affected by addictions.

www.scottishrecovery.net

in 2012 the Scottish Government consulted on a Bill to develop Community Empowerment:

www.scotland.gov.uk/Topics/People/engage

This is the definition of co-production from New Economics Foundation: "Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours."

A useful publication is: http://www.nesta.org.uk/publications/reports/assets/features/co-production_right_here_right_now

The people who came to the first events in 2008 described what the impact of user-led services could be for them.

“Getting something new started can feel such a big, complicated task. Sometimes you just need someone fresh to help you break it into manageable chunks.”

“A place where you feel welcome and that people like you, not where they see you as someone who needs help.”

“So many ideas! I’m away to reflect and talk to the group about where we can start. The main thing is that now I know we can start.”

“Services that are designed by the users are more effective.”

“A service where the people remember what it is like to be a teenager and be a bit scared.”

Participants also described the types of support they wanted from Working Towards and the roles they saw themselves and people and groups like them taking.

“Being a tug, not a supertanker! Tugs can help supertankers to change course.”

“The support we want is someone to walk beside us.”



Where to get more information

Reports and discussion papers from the early stages are on the Outside the Box website:

www.otbds.org/workingtowards

The background note on the policy context shows how the project linked in to the policies, with links to policy documents and other resources.

The report on the ideas from the first events shows how user-led services bring together several well-established aspects of work by community groups, person-centred services and participation to create something that is more than the sum of its parts. It also describes the ways in which people hoped Working Towards would help them tackle issues that were important to them.

The report from an event we held in September 2011 shows how many of the ideas and policies came together through Working Towards:

www.otbds.org/assets/uploaded_files/project/peopleworkingtogethereventreport.pdf

Many of the reports from individual projects that got development support through Working Towards are also on the website. They describe the background issues for the people involved and the type of support they got through Working Towards.

What happened

We delivered Working Towards as a specific project within our overall work from August 2008 to July 2012.

The total cost of the project was £500,366. The Big Lottery Fund grant was £373,707. The other sources of income were smaller grants and payments through the local projects. We also had help in kind through the projects and partners such as local authorities and NHS Boards and other voluntary organisations.

There was an independent evaluation by Community Enterprise, plus on-going feedback from projects and partners and our own monitoring and evaluation. This report draws on all these sources.

The projects within Working Towards

The aim was to work with 60 projects over the 4 years and involve 250 people who were taking on leading roles, such as committee members, volunteers or staff who were actively involved in planning or starting up the new activities.

We knew that not every project would lead to a new or expanded service or other practical outcome. The aim was to support the development of a user-led service in half these projects, so the target was 30 projects producing some form of practical service that benefitted other people. We agreed with the Big Lottery Fund that we would stop taking on new projects as part of Working Towards early in the fourth year, to give enough time to let projects develop.

We worked with 80 projects. We also met with over 30 other groups where we gave initial advice and looked at options with the group. In these situations either the group was not yet ready to take things further, or the interest was in a model of service with little leadership from the people who would be using the service.

There were 68 projects which had a local focus and 12 bigger projects where the aim was to benefit many people throughout Scotland. Often these grew out of a local group wanting to tackle an issue and realising that it would be easier to work with more people and approach it in a different way.

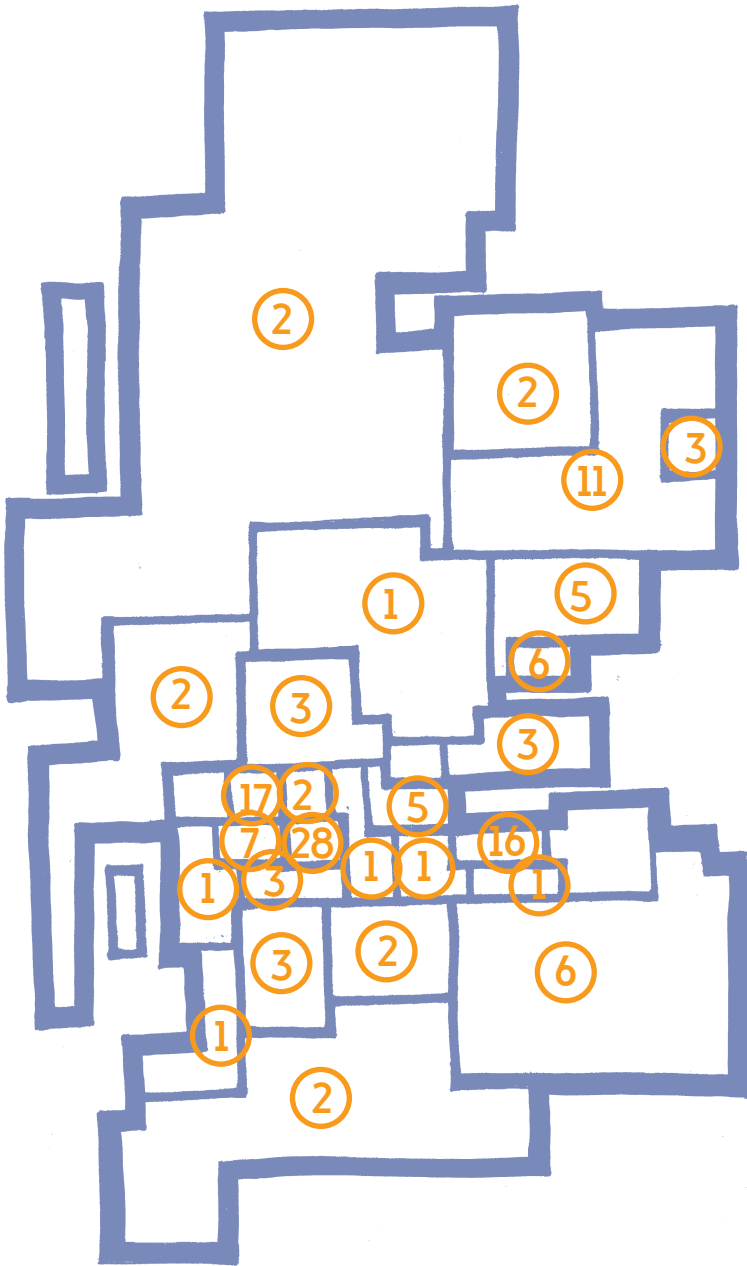
Overall, 681 people were involved in the 80 projects.

The projects involved a wide range of people:

- **People with mental health problems and/or carers 18 projects**
- **People affected by drug and /or alcohol addictions or their families 13 projects**
- **People with physical disabilities or other long-term health conditions 9 people**
- **People with learning disabilities 9 projects**
- **Older people 6 projects**
- **Young people, including young carers 3 projects**
- **Families of children and young people with disabilities or health needs 3 projects**
- **Other families 3 projects**
- **People who use self harm 3 projects**
- **People affected by domestic abuse 3 projects**
- **Homeless people 2 projects**
- **Community groups with a wider or mixed membership 8 projects**

These are the locations

(Some projects involved people in more than 1 local authority area)



Argyll and Bute:	2
Aberdeen	3
Aberdeenshire	11
Angus	5
Dumfries and Galloway	2
Dundee.....	6
East Ayrshire	3
East Dunbartonshire	2
East Renfrewshire.....	3
Edinburgh.....	16
Falkirk.....	5
Fife.....	3
Glasgow.....	28
Highland	2
Midlothian.....	1
Moray.....	2
North Ayrshire.....	1
North Lanarkshire.....	1
Perth and Kinross.....	1
Renfrewshire	7
South Ayrshire.....	1
South Lanarkshire.....	2
Scottish Borders	6
Stirling.....	3
West Dunbartonshire.....	17
West Lothian.....	1

Case examples

The Brain Injury Experience Network in West Dunbartonshire produced a DVD – Getting your head around brain injury. Members of the group explain what people with a brain injury can achieve, to encourage other people and their families. They are now giving presentations to staff in services across central Scotland, to help them develop better support for people with brain injuries.

You can find out more and see a short trailer for the DVD at: www.otbds.org/bien

Young people with physical disabilities started a peer support project to get better access to social and leisure activities. This included working with the managers in a few local pubs to help them improve access for disabled people, so other people could benefit too.

People First Fraserburgh developed an IT project, which enables people with learning difficulties to learn how to use computers and get safe access to the internet. This is creating more opportunities for people as well as giving them more confidence. The Computer Buddies project draws on both sessional trainers and people with learning difficulties who have some experience of using computers providing peer-based encouragement to people who are just starting.

A group of people with lived experience of drug and alcohol addictions started a peer-led drop-in, to give people somewhere safe to go.

Another group of people living with drug addictions developed the informal meetings into a more structured service, with regular sessions and publicity to enable more people to come along.

FAST is a group led by people who have alcohol or drug problems. They held an event – a Wee Day In – to highlight the services in the area and enable more people to say what sort of supports they wanted. You can see the report from the event at http://www.otbds.org/assets/uploaded_files/project/FAST_sWeeDayInReport1.pdf

A family support group had lost their venue and several active members had moved on. The group were considering winding things up. We helped them find another community group – which was not involved in that issue – who could help them with new premises. We put in grant applications and got some small-sale funding to cover volunteers' costs and the running costs of the support group. The group found more people to take on active volunteer roles and join the committee. They then extended the support group to hold peer support meetings in an outlying town.

Some NHS staff and women in community groups saw a gap in the range of services for women whose mental wellbeing was not great but who did not need support from specialist mental health services. We met with mums in 4 areas and produced a report which describes what women can do themselves and how services can give better support to mums and their families. Some of the groups expanded the services they delivered, including training more volunteers and helping spin-off groups in other areas get started.

You can find out more and see the report at: www.otbds.org/mumsmentalhealth

Stepping Stones is led by people with mental health problems and provides a range of support services to people in West Dunbartonshire. They realised that there was little support for people who were parents, as they tended to fall into the gap between mental health services and services for families. They looked at what people would find helpful and realised they could adapt existing services and provide more support at very little extra cost.

You can read the report that followed on from the work with Stepping Stones at: www.otbds.org/issuesfacingparents

Several groups wanted to develop handbooks or on-line resources to help people through difficult periods in their lives. They included people from minority ethnic communities who were facing harassment, men and people in same-sex relationships who were affected by domestic abuse, people who were dealing with a change in their health, and people who were worried about a friend. Eventually we all decided to produce a single resource – Making changes in our lives – as this showed how people can face several difficult situations, and raised awareness about the range of supports that can help people.

You can see the resource we produced at: www.otbds.org/makingchanges

Reports and other publications

There were 33 publications from Working Towards, plus leaflets and postcards about the project itself.

Half (17) the publications came out of the projects, when a group described what they had done. Here, the aim was to tell other people about the group, their achievements or their plans.

In 5 cases the publication effectively was the new activity, or a major part of it. These were where people shared their experience to give 'tips and hints' for people to use in making more opportunities in their lives.

Seven publications were about the craft of being a user-led group, influencing change or getting things started.

For most of the publications, the circulation and dissemination was aimed at both local and wider audiences:

- **Through the project and their contacts: this was another way of building relationships and influencing people.**
- **Through networks that are linked to that topic, such as the NHS Health Scotland Mental Health and Wellbeing bulletin.**
- **Wider networks reaching many community projects, such as the Community Health Exchange.**
- **Feeding back to people with a policy role, such as MSPs, MPs, civil servants and staff in local authority and NHS settings.**

Case examples

PAGES

PAGES is a voluntary organisation in Formartine, which is in the central part of Aberdeenshire. The group is led by parents of children and young people who have an Autistic Spectrum Disorder. PAGES was the first group we worked with through Working Towards. They wanted to look at options for developing more services for children and young people who have autism. Their starting point was to make the case for funding to develop additional separate play and leisure activities.

We worked with the group to find out about what parents and young people wanted, and find out what the range of possible solutions was. Together we identified ways of getting better access to existing services as well as ways to develop the services that PAGES provided. This could give the families more opportunities sooner and with less funding than people had expected at the outset.

The report was Field of Dreams. PAGES used the report to have discussions with staff in the local authority, schools and NHS as well as with other voluntary organisations. The public launch of the report was a joint event with the local Community Planning Partnership.

You can read the report at: www.otbds.org/assets/uploaded_files/project/fieldofdreamsweb.pdf


Recovery Happens event

Grampian Family Support Forum brings together families of people who are affected by a drug addiction. They are growing their links with families across Aberdeen, Aberdeenshire and Moray. The network gives families a voice and highlights issues that are important to them, as well as providing valuable peer support.

The Forum developed good links with local MSPs as part of a project under the Scottish Parliament's Community Partnerships Project. They organised an event at the Scottish Parliament – Recovery Happens – to help raise the profile of the issues facing many families and the role they can play in people's recovery from addictions.

We worked with Grampian Family Support Forum on several aspects of developing services for families that are led by families and increasing their influence. As part of this, we wrote the report from the event and helped the Forum disseminate it. The impact from the report contributed to the Forum becoming more established locally as well as reinforcing the role of groups doing similar work across Scotland.

You can read more at: www.otbds.org/grampianfamilies



“You have shown that families are an overlooked resource. They have a lot of experience and advice to offer.” MSP at the Recovery Happens event

Tugs Helping Supertankers

Winter shelters for homeless people


Bethany Christian Trust provides an overnight care shelter for homeless people between November and early April each year. A growing number of people who were using the service came from outside the United Kingdom and they did not all use English. We gathered feedback from the people who use the Edinburgh shelter and did an evaluation of the service. The following year we went back and worked with Bethany and the people using the service to see what had changed.

Bethany has used the reports to develop links with other organisations to provide more opportunities for people in Edinburgh who are homeless. After the first report more people volunteered to help the care shelter in Edinburgh over the following winter.

Bethany used the survey design to get feedback from people using a similar service they provide in Inverness. This led to more secure funding for that service and benefitted more people.

The feedback and ideas from people in Edinburgh also contributed to the plans for new services in Stirling and Dumfries, and the report helped make the case for funding and support from local partners.

You can read the reports at: www.otbds.org/havingoursay



“Thank you for listening to us. Please keep on providing services for us where we can help ourselves and each other.”

Perth and Kinross young carers

We carried out an evaluation of the Young Carers Perth and Kinross project. We then worked with young people to produce a report that everyone would want to read – children, young people and their families as well as teachers, social workers and people responsible for policies that affect young carers.

The publicity included an event planned and led by young carers.

The posters and postcards were distributed in every school across Perth and Kinross.

More children and young people have been in touch with the project – including some who had not had any support as a young carer before.

The project used the report to support funding applications, to let it continue and expand.


Perth and Kinross Council and NHS Tayside are listening to the voices of young carers as part of improving the services they provide.

The report and poster are increasing other people's understanding of what life is like for young carers, and how they can help.

You can see the report at: www.otbds.org/assets/uploaded_files/project/youngcarersreport.pdf

This is our poster: www.otbds.org/assets/uploaded_files/project/youngcarersposter.pdf

Our postcards are at: www.otbds.org/youngcarers



“Some schools are fantastic at supporting young carers. Others could do better. We want every school to be good at this.”

Publications that provide direct support for people with addictions

Supporting our Recovery and Enjoying Ourselves is the experience and suggestions from a group of people who are in recovery from alcohol and/or drug addictions, to enable other people to move on in their recovery at their own pace.

Surviving Christmas and New Year was a follow-up from the group, to help people over a difficult time of year.

We had 500 printed copies of each booklet, which mostly reached people living in the local area – who were the people the group wanted to benefit.

There was also a wide circulation through national networks in touch with people and services focussed on Recovery, Addictions and community health services, statutory and voluntary services for people affected by addictions, and participation and peer support groups. We know that each publication reached at least 2,000 people, and possibly many more.

People in several areas contacted Outside the Box and the local group for advice on how they could adapt the booklets to include services in their area.

We know that peer support groups and services giving support to people with addictions have repeated the publication to give a practical benefit to people in their areas. Some have also repeated the process we used for gathering the information, to also get the capacity building benefits for the volunteers taking on that role.

www.otbds.org/communityresource

www.otbds.org/survivingchristmas



“A fabulous resource. So practical and full of hope.”

“We’re doing our own version now. Thanks for the idea and the encouragement.”

Tugs Helping Supertankers

Learning the Craft

We talked to people who were involved in some of the projects we had worked with. We also found other people who had started user-led or community-led services and groups. We asked them what had got them started, what had helped and had made life more difficult, and what advice they would give to anyone else who was starting on that path.


The report brings together their experiences and suggestions on the craft of developing a user-led service – no matter what the topic or the focus is.

“Don’t rush it. The best advice I got was to remember it takes time to build good working relationships.”

“Recognise that everyone – including you – can have other things happening in their lives and might need some help with these. Don’t give yourself a hard time. Don’t try to do it all on your own.”

We used this as part of our learning and built the ideas into our practice for the rest of the Working Towards project and in other work we do. We also shared it with other people.

www.otbds.org/assets/uploaded_files/project/Learning_the_Craft1.pdf



“It helps to know that other people struggle with this sort of thing. It also helps to know that they managed to get a service going. We can do it too.”

How long it took

The length of time we worked with groups varied a lot, reflecting their different circumstances, what they were hoping to achieve, and factors such as ease of access to funding when this was needed. Overall there were 70 projects where there was a point at which we could identify an outcome – and there is more on this in the next section. These points included getting a new service underway, getting the report published and the initial dissemination well underway, making internal changes in how the group worked, or securing the funding they needed to develop a service.

- **This took between 4 and 6 months for 14 projects.**
- **We worked with 37 projects for between 6 and 12 months.**
- **We worked with 16 projects for between a year and 18 months.**
- **For 3 projects it took over 18 months to get things going – the longest was 23 months.**
- **The average period for a project within Working Towards was just over 10 months.**

In the projects which were completed more quickly, the group had already done some of the development work, and/or they had or found good support from someone such as a member of staff in the local authority or another voluntary organisation, and it was an activity that was specific and realistic in a short time.

One of the later sections in this report looks in more details about the factors that we found made a difference in whether projects got underway and whether this was an easy or longer process.

What difference it made

Overall the Working Towards project has brought the changes we hoped in the lives of individual people and for organisations and groups through which they work.

Benefits for people using the services that the groups developed

By the end of 2012, 43 projects had achieved a new user-led service. This is more than the target of 30 projects having a new user-led service.

The early estimates of the numbers of people benefitting tend to be under-estimates, because the numbers are often increasing over time. The services that the groups have developed are mostly small-scale. Typically, the projects each benefitted around 10-30 people in services such as the drop-ins and peer support networks, rising to a few hundred people in others such as the Tips and Hints guides. A few projects have gone on to benefit much larger numbers of people.

This is broadly the pattern we expected and it reflects a range of factors: the level of activity that these groups can manage at this stage, the practical aspects of managing grants or other income, and the time needed for groups to grow in their own skills and their credibility.

The overall benefits from user-led services can be considerable. From the information we had in early 2013, the projects were together already benefitting around 12,000 people and have the potential to benefit several thousand more people over the next year or two.

Influencing other organisations

49 projects achieved their outcomes in another way – for example by influencing the local authority or an established voluntary organisation to provide the type of service they wanted and working with them to develop and deliver it. Some of the biggest impacts came when a group developed their own services and used this experience to encourage other services to change what they provided.

Some of the ways this has happened are:

- **People having more confidence and skills to take part in meetings with staff from statutory bodies.**
- **Working on a more equal partnership between community groups and other bodies – public bodies or larger voluntary organisations.**
- **People using the resource materials that show people how to have more influence.**
- **Local projects using the reports about their own and other groups' achievements to raise awareness of issues and demonstrate what is possible.**
- **Some of the projects focussed mostly on influencing the services and policies that are provided by other organisations.**

Case example

Shared Strengths



Shared Strengths is a network of people who want to raise awareness about the way some people use self-harm as a way of coping. The network brings together adults with lived experience of using self-harm, families and carers, staff and volunteers from services that provide support – including peer support, and people who are trainers or taking on other roles.

People share information about things that are going well and get encouragement when raising issues around services or policies that affect people who use self-harm – especially adults, who often find that there are few services for people who use self-harm once they are in their mid-20s or are older.

We also use the Outside the Box website as a place to bring together resources that people have found are useful in helping people minimise harm or find their own safe coping strategies.

These are some of the ways Shared Strengths has enabled people to influence local policy and practice.

- **Members use the examples they learn about through the network to help them raise issues through local forums – for example, knowing that a service is established and working well in one area helps people suggest trying that in their area.**
- **We produced a summary of national policies and professional good practice standards. People have used this to help them raise issues. People can refer to the policy documents as authority on issues that may otherwise be taken as individual service users challenging a service.**
- **People have fed back that this less personal approach and drawing on borrowed authority has been an effective way of opening up a dialogue on issues that some people can find it difficult to discuss.**
- **The material we produce and the support people get from being part of the network has helped individuals feel more confident when raising matters and using the opportunities to have influence that are already there.**

You can read more about Shared Strengths at: www.otbds.org/sharedstrengths

You can download the summary of the national policy issues from that page.

The collection of useful resources is at: www.otbds.org/selfharmresources

Tugs Helping Supertankers

Sustainability of the groups

In 42 projects one impact from our support was a more sustainable group.

The people taking part identified benefits for the groups:

- **Stronger committees and no longer being dependent on a few people doing most of the work.**
- **Robust process for peer support, working with volunteers or paid staff, and for delivering support services to vulnerable people. These in turn made the service safer and more effective for everyone.**
- **Increasing the confidence other people had in the group's ability to deliver this project/service and future services.**

An important element of sustainability for many community groups is getting additional income. There are particular difficulties for smaller and new projects which have not yet established a track record.

- **By December 2012 we had helped 28 projects secure over £260,000 in short-term grants, ranging from just under £1,000 to £20,000.**
- **10 projects had secured on-going income of between £3,000 and £30,000 a year – totalling around £140,000 each year for at least 3 years.**

Projects where there was little or no impact for the group

In 10 projects there was no identifiable impact in terms of benefits for the group or a new service, although the process of getting to this point could still be useful for the people involved. The projects where there was no wider impact included:


- **Situations where the people who were most involved decided to focus on other things, often to concentrate on making changes in their own lives.**
- **Groups which were having internal difficulties or a period with a lot of change, such as a high turnover in the management committee, which they wanted to get stable before taking on anything new.**
- **External factors which led to the group deciding that the time was not right for them to press on with a project – for example, when they knew this topic was not a current priority for the local authority and/or NHS.**

Benefits for the people taking part

The people involved fed back the benefits they saw for themselves and for the other people they knew. These included

- Increased confidence and skills in running the group or in aspects of the new services such as supporting volunteers or people taking on peer support roles.
- Increased confidence and a sense of more control in people's own lives, which for some people contributed to them going on to college or looking for paid work, or making other changes in their lives.
- Knowing how to influence or having good working relationships with other people, such as staff in public bodies or people in other voluntary organisations.

What we learned



"It's a learning curve for everybody."

The main, overarching lesson is that this approach can work and can deliver good services that bring benefits to the people who go on to use them.

The experience of this project has also highlighted the difficulties facing many people who live with illness or disability when they are running voluntary organisations and when they are developing and delivering services to other people. We knew that they would face all the difficulties that anyone encounters in taking on these roles, and knew that there would also be additional challenges – such as looking after their own health and well-being and higher than average turnover among committee members or people leading the groups. In this, the project has confirmed our initial thinking and expectations.

There are factors that make it more likely that a project will take off and lead to a new activity, and factors that mean it is probably not the right time, or will only happen with extra measures to reduce the difficulties. The list/box below is a list of these factors we identified in the Working Towards projects that did go on to develop a new or extended service.

In contrast, the projects that were not able to get a new activity started were having difficulties on many of these factors. The factors included all the issues described in this section: what the groups do, features of the services they set out to develop, and the role of other people such as staff in local authorities and other voluntary organisations.



"I just felt that there were gaps...I saw a need for someone to get people to talk and share information and involve the community."

These points are based on our experience, the feedback from the people and groups we worked with, the external evaluation by Community Enterprise, and other research and experience from other people tackling similar issues in the United Kingdom and in other places.

Model of user-led services

What groups led by people who use services need to get started and sustain what they do

The starting point is the capacity and resilience of the group who want to develop a user-led service.

This is what we learned about their role

- Generally the groups led by people who will be using community care and similar services need advice and practical support that is similar to that needed by any community-led group. But there are also some additional circumstances which mean that the start-up support usually has to go a bit further, or be delivered in a different way.
- People need development support that understands and accommodates their circumstances, such as fluctuating health difficulties.
- It helps when people have examples to learn from. This gives them confidence and practical advice. It also often gives reassurance to other people.
- When groups are looking at what other groups and projects have done, it is useful to not only look at those working with people who share those circumstances, but also find out about experiences from user-led services that are led by people in other situations and in other places.

On funding, it is easier when there is enough funding for the development stage. This is usually small-scale – sometimes a few hundred pounds – but it can make a big difference.

It helps when the people leading the new project have practical support for the development stage and then for the start-up stage. Aspects have included a place to meet, access to a phone and the internet for people who would struggle to meet this cost themselves, advice on recruiting and working with volunteers and sessional staff, and help with publicising what the project is planning and then doing.

Individuals and groups need confidence to take the opportunities that come up.

Types of activities and services that this model produces

It appears that some types of activities are well-suited to being delivered by user-led groups. We want to put a note of caution here: this is based on our experience of a few dozen projects, and we only followed them to a few months after the Working Towards project ended. It is likely that some projects will go on to develop further and achieve a lot more. Others will probably wind down over the following year or so. This pattern may not be very different from that of other small-scale, community-led projects.

This is what we have learned from the experience so far

- Many of the projects that are developed can be thought of as pilots - trying out new ideas and evolving in the light of experience.
- The model is a good way of starting services that are small-scale and which have a strong peer-support element.
- It works when the services are easy to start up and also easy to change or wind down if circumstances change. For example, a group can be doing well but have most of the leading people move on over a few months as the result of changes in their own lives or well-being. There are types of service where this is not a major problem.
- If these small, user-led services are supporting people who have higher or more complex needs, it helps when the group have good links with other services which can provide more support when needed, or when the project has been planned from the outset as complementing and extending other services. This way, both the people running the project and those using it can be reassured that everyone's wellbeing has been thought about.
- The services that user-led groups develop are not necessarily based around or similar to traditional types of care services. This can confuse other people who expect them to fit neatly into conventional service forms such as day care or home support.
- The services are often good use of a small level of resources. This is not only because they are drawing on volunteer rather than paid staff's time. The models themselves are often based around getting more impact from a limited level of resources.

There are opportunities for increasing the numbers of people who benefit from the services. But this is more about scaling out to having more small-scale projects doing similar things, rather than scaling up and these projects becoming bigger.

What other organisations can do

We also learned what steps staff in local authorities, the NHS and other organisations can do to get the best impact from user-led services.

We saw how these smaller, user-led services could contribute to national and local policy and practice developments, such as new approaches to care for older people and for people with long-term health conditions. They also have a potential contribution when a public body wants to see a more diverse range of providers or of service types.

This is what we have learned

- It helps when the group has enough time and space to develop their ideas to the point where there is a user-led service.
- It also helps when there is access to some sources of funding for smaller-scale projects. In some areas local authorities and/or the NHS are building this into the way they use the Change Fund on Reshaping Care for Older People. In many places small groups are encouraged to apply for Community Chest grants and new grants schemes that use NHS endowment money.
- User-led services are unlikely to come forwards when the only way for new services to get funding from the public sector is through commissioning for services where the type of service is already set.
- There may be more scope when the focus is on commissioning for ways to achieve outcomes for the people receiving support.
- Other aspects of the commissioning process can make it difficult for smaller, user-led groups – such as the requirements on the providers that are very unlikely to be met by a smaller group. The advice that is available on helping the voluntary sector to take part in tendering may miss this type of group – for example when committee members cannot get to day-long training courses.
- Encouragement and advice from someone in a public body can play a big part in building the skills and the confidence of potential user-led providers.
- It helps when staff in the public body understand that user-led groups may see the world differently and not reflect the ways other people see roles and activities. For example, groups can be taking on activities that other people see as service delivery, campaigning, collective representation and participation, speaking up for individual people, influence public attitudes and tackling social inclusion. To the group, this is all just getting the best for their members and other people in similar circumstances.



“The opportunity to work in partnership with the local Community Education service was a good source of help.”

External factors

The experience of the project also showed the impact of external factors in the development of user-led services. One was access to funding, as over the course of the 4 years access to small grants became harder. The smaller voluntary organisations and informal community groups have also found it very hard to compete when local authorities and NHS boards are using tenders and other formal commissioning processes for services with a budget of a few thousand pounds. Groups sometimes were caught up in a local authority delaying making any decisions about any new activity in an area while a strategy or major service restructuring was being planned and agreed.

Another external factor has been restructuring within local authorities and the NHS. In practical terms, this has meant groups losing working relationships with staff who understood how the group worked and had helped groups be involved in wider developments and opportunities. It has also led to new developments, such as different types of services becoming priorities, being delayed.

Our learning was to be aware of these external factors and suggest to groups that they focus on the matters they could control and influence – such as their internal arrangements, or planning to have smaller-scale developments – rather than spend a lot of time and energy on other issues or get caught up in other people’s agendas. This also led to us changing the balance of work across the project, such as having the projects that developed tools and resources for wider use when it was difficult to get a local project that delivered a direct service to a small group of people underway.

This is what we learned about these situations

- **It helps to focus on what is possible in the circumstances, such as pilot projects that use smaller charitable grants such as the Awards for All and Investing in Ideas programmes at the Big Lottery Fund.**
- **Sometimes it is easier for groups to begin discussions with potential partners before getting into the plans for specific projects or meeting deadlines for tenders or grant applications.**
- **Talking to people who are members of user-led groups, or share their circumstances, is always useful. Often groups got the ideas for the service they later went on to develop during these periods of listening.**
- **Some groups also used these waiting periods to find out what was happening in other places and make contact with groups in other places.**


Factors in Working Towards projects that have gone on to develop a new service

Characteristics of the community activist/s – the person and group

- **The group or person keeps pushing for the solution to the gap or issue.**
- **It is led by a person or group that has enough drive and enthusiasm.**
- **It is led by a person who has enough skills - e.g. from other community roles and experience, or work related skills, or from their life experiences.**

- The person has the opportunity to learn other skills that they need and/or has other people around them to help them grow capacity – for the person and ideally also the group.
- There is a group of people who share the roles and/or support the lead person. It can be a formal group such as a committee or an informal group of friends.
- If it is a community group, the group itself is viable and is doing ok. For example, the committee is quorate, they agree on values and direction, etc.
- If the lead person/people have additional difficulties in their lives, such as health problems or other responsibilities, they are getting enough support for these and it is manageable over the period they are working on the new project. The result is that they are less likely to be away at key times, or the group has planned with them how to deal with this situation when it does arise.
- The person or group has encouragement from other people, such as other community groups, staff in other organisations and roles.

Characteristics of the host/bigger organisation - if the project is based in or linked to an existing organisation



“It was our own determination. The need was there.”

- The ethos and practical processes encourage innovation.
- There is good management support to the people taking on the leading role. This could be staff support for a service user involvement group, or someone else taking on a mentor role, for example.
- There are quick and flexible processes for making decisions, making changes to existing services, approving spend of small sums of money, handling publicity etc.
- The organisation understands and is good at partnership working.
- Smaller projects are able to get access to funding. For example, there are start-up costs from the host, and/or they are able to make applications for external funding.

Features of the task/project

- What the person or group is trying to achieve is feasible: what it is, size, timescales and costs.
- Planning for the project/task happens. Either the person or group is able to do this aspect themselves, or they get someone else to do it or help them do it.
- The practical aspects of getting the project/task done happen. Either the person/group has the skills, time and other resources, or they get someone else to do this. Often they get someone else to help them with it, which helps the people in the group learn how to take this on in the future.
- Any partnership aspects work well: they happen, and they feel fair.

- There are enough resources to at least get the task/project started.
- The planning and early development stages work well. The people involved at that point are not planning for ever, but getting started and past the start-up stage. They are also thinking about longer-term sustainability from the outset or soon after the project has got underway.

Context for the project

- There is support or encouragement from the local authority (and/or their partners such as NHS staff) to tackle the issue. This support is coming from someone in a relevant and senior enough role.
- There is support from/an ally in someone who is in the local authority or other body, even if they are not especially senior. An example is someone helping the group find the right process to use and useful people to contact.
- The local planning and policy context includes this gap or issue. For example, the issue is included in the Community Plan or the Single Outcome Agreement.
- The planning/policy context recognises the role of the voluntary sector, including smaller community groups etc., and/or has a strong and real focus on participation – so there is scope for user-led services even if not described in that way.

“Those contacts we built earlier on really helped as time went on.”

Lessons for Outside the Box and what we do

The experience of Working Towards has helped Outside the Box develop and refine the support we give to projects like the ones we met. We are building the learning into the plans for new areas of work as well as drawing on the experience in our day-to-day work.

- **The timing of work with user-led groups needs to be very flexible, to take account of changing circumstances. We knew that at the beginning, but the extent to which plans were revised and extended was greater than we had expected.**
- **We did learn that not meeting the initial plan, or the second or third version, did not always mean that a group would not in time achieve what they had set out to do. For example, in each of the projects that took over 18 months to achieve an outcome things had to pause to accommodate a big external change or changes within the group. But in the end the group picked up the project and made good progress once the time was right.**

“Learn how to listen to and engage with people. Everyone. It’s up to us to make sure that we don’t forget the people.”

- It helped when we could take off some of the pressures that are common in community-led groups at times when the lead people were unwell or having more than the usual level of pressure or excitement in their lives. We also had to make it easy for people to ask for a bit of extra help, or accept it when offered. In this, we were often drawing on the principles and language of approaches that people recognised, such as Recovery and managing long-term health conditions.
- We found it also helps groups when we stand back and take a wider, longer-term view. People providing external support can help with anticipating the next stage of project and group development. We found it helps to be explicit about this, as the underlying aim of what we are doing is building the capacity of people to do this for themselves.
- Helping people develop skills and experience around influencing other people and building partnerships was a factor in the success of many of the projects. Even when the initial aim of a user-led service did not work out as planned, the longer-term relationships that people had made were often important. We found it helped to be very explicit about this and build it in to projects, even if people think it does not matter that much for them at the start.
- The experience of many of the Working Towards projects was that publications were an important way of raising the profile of a group and the type of service they were developing. It also helped them influence other organisations such as local authorities and NHS boards. We are building in the time and (relatively small) resources to plans for future work with community-led projects.
- There are benefits in people being able to meet each other and find out what other people and groups do, but with no expectations or commitments. In practice, peer networks have developed and are an effective approach to giving people additional support around sustaining what they do. But we have also learned that this is difficult to achieve and sustain when people have other priorities and challenges in their lives.
- Another approach which brings benefits is giving people opportunities to network in other, less active ways, such as updates on the work of other projects and sharing the reports and material that other groups are producing, and events that encourage people to talk to and learn from each other.

The experience of Working Towards also confirmed that participation and developing services are connected but different. We found we were more likely to get strong user-led services when people were already engaged and involved. Also learned that the timescales sometimes need to slow down to enable people to get experience at and through participating in other aspect of service plans before going on to think about leading a service themselves.

“The most important thing at the start was having someone to talk to about ideas.... In particular, basic things like constitution and banking”.

What next

The ideas and approaches from Working Towards are now reflected in the support we give to many groups. Aspects include thinking about what supports people will need to help them make their work effective and sustainable, and helping them think about the partners or alliances that can help them achieve their aims. It has also helped us show groups led by people who have health problems or who live with other difficult circumstances what other groups have been able to achieve.

We are now working with several new over-arching projects that are based on aspects of the experience and achievements from Working Towards. These bring together a series of smaller projects and an over-arching element, to have more influence and impact on policies or other organisations and to spread the learning to other people and places.



- **Wisdom in Practice** brings together work with older people, including those in the equalities groups, to develop user-led services. This has a grant from the Scottish Government Equalities Fund and runs to 2015. We have taken a different definition of user-led services in this project, to reflect the wider range of ways people can lead the direction of services and reflect what older people told us made sense for them.
- **Getting There** develops the capacity of user-led voluntary organisations which provide support to older people, people with disabilities and other people who use social care services. The aim is to enable this type of organisation to make best use of the opportunities that are coming with the expansion of Self-directed support, and to minimise the potential difficulties for smaller service providers. This project has funding from the Scottish Government as part of the programme to build the capacity of service providers around Self-directed support, and runs to 2015.
- We have been working to develop **Mums Supporting Mums**, which is a project to improve the opportunities for peer support and other user-led activities for mums with young children who are living in rural areas. It is getting underway in parts of Dumfries and Galloway, South Lanarkshire and Scottish Borders. This pilot stage is supported by a range of funding sources, including LEADER in each of the 3 areas and charitable trusts.

Tugs Helping Supertankers

Where to get more information

There is more information about the range of work we do on our website:
www.otbds.org/service/thinking-out-the-initial-idea-and-getting-a-plan

Contact


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There are also updates about each of the bigger projects:
Wisdom in Practice: www.otbds.org/wisdom
Getting There: www.otbds.org/gettingthere
Mums Supporting Mums: www.otbds.org/mums



“Don’t rush it. The best advice I got was to remember that it takes time to build good working relationships - with other community groups and active individuals, with staff in the statutory organisations.”