

# Peer Power

AN EVALUATION OF THE PERSONALISATION FORUM  
GROUP - A USER-LED ORGANISATION (ULO)  
FOR PEOPLE IN DONCASTER

by **Simon Duffy**





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# Publishing Information

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# Summary

**The Personalisation Forum Group (PFG) is a dynamic User-Led Organisation (ULO) which has developed quickly since its beginnings in 2010.**

At the heart of the group's effectiveness is passion and self-belief - fostered by mutual support and respect. As lone individuals with mental illness it is easy to feel isolated and dependent on the judgement of professionals. As a member of a peer support group it is much easier to see your own strengths and to feel positive change is really possible.

The catalyst for the development of the PFG was the on-going difficulty faced by many people with mental health problems to access flexible budgets that can be used to organise positive support. The group feels that, with the right support, they could achieve faster rates of recovery, stay well, and use hospital services less frequently. However, the institutional nature of mental health services, has been hard to change. Self-determination and personalisation are rarely achieved.

However the group have turned their anger at the poor standards within the current system into a force for positive change. In particular they have created a system of mutual support called Support Buddies - a flexible system for making sure members of the group can get support from each other - building on their experiential expertise.

The group's success has been underpinned by careful and thoughtful facilitation by an independent social worker and by the development of a robust system of governance.



### **Key outcomes already achieved include:**

- 13,104 hours of practical support, per year, with an approximate value of £250,000
- Support for a wide range of community initiatives and partnerships
- Publication of several films and two important papers
- Savings for statutory partners from reduced rates of hospitalisation
- Some acceptance of the need for change in the local mental health services

The group's success is also reflected in the national awards they have won: Great British Care Award 2011 (Putting People First) and Adult Social Worker of the Year 2011 for their facilitator.

The group is positive and ambitious - not just for itself but also for the whole system. It has produced a comprehensive model for Personalised Mental Health that puts community-based solutions and peer support at the heart of the system. It continues to work to reform and improve local and national systems.

Despite all of this local statutory organisations have struggled to welcome and support the group's work. This is surprising and shocking. Despite their power and money, local statutory organisations have failed to respond positively to a local organisation that has much to offer.

In order to stay well and productive the group must continue to maintain its positive and supportive focus. However the difficulties experienced in getting respect and support from statutory services raise serious issues about the current organisation of mental health services in England, and the current systems for working with peer support and other community groups.



# Introduction

AN EVALUATION OF THE PERSONALISATION  
FORUM GROUP - A USER-LED ORGANISATION (ULO)  
FOR PEOPLE IN DONCASTER



# Introduction

**User-Led Organisations (ULOs) should be at the heart of changing society's negative approach to disabled people, people with mental health problems and many others. However the welfare system struggles to listen to people's voices.**

ULOs have been at the forefront of positive change in the lives of disabled people and people with mental health problems for decades. However there have been significant difficulties in building a relationship of trust and equality between ULOs and the powerful public bodies that shape and control services and funding.

ULOs can have passion, intelligence and a vision for positive change; statutory organisations do have power, money and a responsibility to meet local needs. At their best these organisations can work together to transform their local communities; but too often this is not achieved. Statutory bodies resist new ideas and ULOs can become stuck in a damaging relationship of dependency or conflict.

This report focuses on one ULO, the Personalisation Forum Group (PFG). This group has developed quickly and effectively. It has already had a tremendous positive impact. However the group has also been trying to develop a good relationship with its statutory partners - Doncaster Metropolitan Borough Council (DMBC) and Rotherham Doncaster and South Humber NHS Foundation Trust (RDASH).

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**By exploring the work of the group and its progress in working with others we will try to answer six questions:**

1. How should professionals best engage with ULOs?
2. What makes a ULO passionate and motivated?
3. What are the barriers facing ULOs and how do you get round them?
4. What can a ULO achieve?
5. How can a ULO develop and evolve?
6. What's the best partnership for a ULO and statutory agencies?

Given that this report focuses only on the work of the PFG our answers will be provisional. We are drawing from one set of experiences, in one local area. However there is much that the PFG can teach us and already their achievements are impressive.

The report begins at the beginning. People come together, not just to do something new and positive but also from anger, dissatisfaction and a desire for justice.

One of the things that make the PFG interesting is that from the beginning they saw their own needs and demands as a reflection of larger problems in society and in public services. However their response was not just to complain, but to build something powerful.

The outcomes and achievements of the group - in a very short period of time - are staggering. People's lives have improved, new solutions have been developed and real

progress has been made. All of this early work has been undertaken with no financial support from the NHS or from local government.

If we explore what lies at the heart of PFG, how it stays motivated, productive and focused, we find a critical balancing act. People need to be able to look outward for changes, while looking inward for solutions. People need to challenge themselves and others, whilst also seeking support and building bridges. People need to see problems, but also imagine solutions. All of this requires a combination of flexibility, good governance and effective facilitation.

The PFG continues to think big. It has developed a powerful model of what a reformed mental health system would look like. It is not only offering to help local services achieve this model, it is actually beginning to create practical solutions that bring this model to life.

The group is constantly developing. It has refused to define itself by its difficult relationship with statutory organisations; instead it has looked for ways in which it can develop and express itself. The PFG is dynamic - and things are changing all the time. This report aims to be true to the spirit of the PFG while offering some practical advice and suggestions.

We conclude with some reflections on the general lessons that can be drawn from the experiences of the PFG. We try to provide some answers to the six questions we outlined above. As a society we have only just begun to recognise the potential impact of peer support and self-help. Current models of top-down control and institutional provision continue to dominate welfare state thinking. But the opportunities for change are unfathomed.

# 1. Beginnings



# 1. Beginnings

The Personalisation Forum Group (PFG) is a good example of a dynamic User-Led Organisation (ULO) that initially came together out of frustration with the current mental health system; but which has now worked together to bring about positive change in its local community.

Like many good things the PFG began with dissatisfaction. For, all innovations only begin when you feel something is wrong, and you sense that things could be better. When these two feelings are combined with an inner sense that you have it within you to be part of changing things then the seeds of a positive innovation are planted.

In the case of the PFG, the very formation of the group owes a great deal to the commitment of an independent social worker, Kelly Hicks. A former local authority employee, Kelly based herself in the building of a local organisation and began to offer free support and advice to anyone who wanted it.

Doing this she was approached by several people who wanted advice and support in order to apply for an individual budget:

*Between July and August 2010 over 30 people all with mental health needs, came to see me for information on individual budgets. Supporting the individuals to request an NHS & Community Care Act Assessment highlighted that neither the local authority nor the NHS mental health service accepted responsibility for undertaking these assessments. Both services also could not advise how an individual would gain an assessment of need, a budget for any eligible needs or how they could manage a direct payment if they wanted to.*

*I asked people to come to a meeting so that we could discuss these difficulties. At the first meeting there were 10 people who agreed to meet the following week to decide how they would support each other to ask for an assessment and learn more about personalisation. Each week the number of people attending the meetings grew until there were approximately 30 people. The group had written to the Local Authority several times and never received a response; they accessed legal advice to gain clarity on their position; wrote to the Monitoring Officer - no response; individual complaints - no response.*

*Faced by this silence the group decided to become formally constituted in November 2010. The group felt that they would need each other's support to challenge the policy in Doncaster.*

One of the interesting features of the group's development was that, despite the difficulties it faced it began to **think big**. This is reflected in the group's name and its use of the word 'personalisation'. From early on the group understood that personalisation was not just about budgets; it was also about giving people choice, control and the opportunity for greater contribution.



Figure 1. Cover of the PFG Manifesto

This led to the publication of their own Manifesto which set out their vision for improvement in Doncaster (see Figure 1):

*We hope that this will be the start of a journey that will help people with mental health difficulties in Doncaster to regain control of their own lives, be recognised as the experts in their own problems and facilitate the creation of solutions that benefit both the individual and his or her community.*

The Manifesto also demonstrated a powerful awareness that just waiting for solutions from the system was not enough. And so the group began to identify practical solutions, that they could control. Holding and using the tension

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between the negative problems that need challenging and the positive solutions that need building still seems central to the group's effectiveness (see Figure 2).

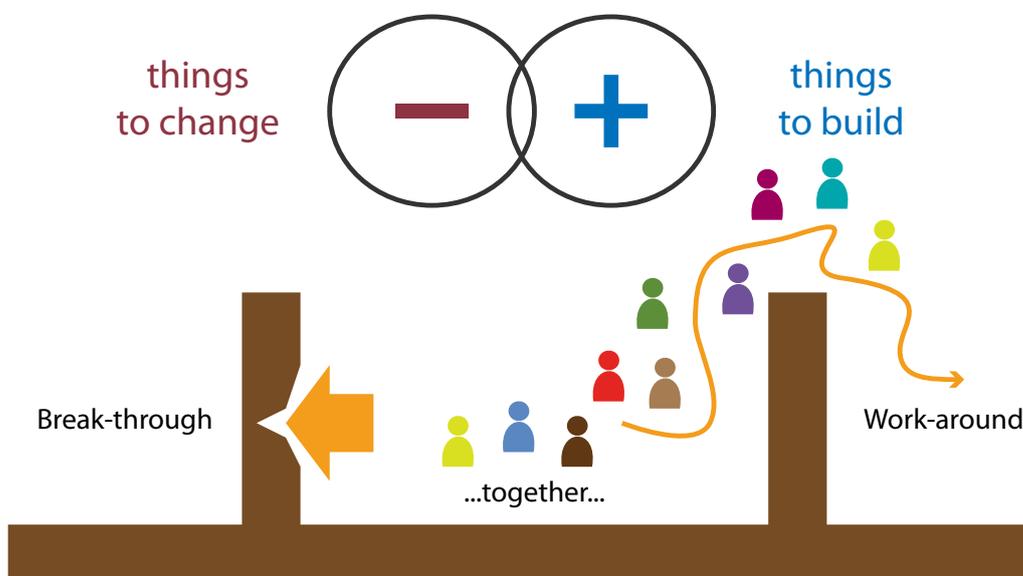


Figure 2. Challenging problems and working round them

Although the group received no funding they did not think of themselves as lacking assets, instead they shared their time, skill and networks. Central to this effort became the idea of *Support Buddies*, a system of peer support which was flexible, responsive and practical - and where hours of support provided were recorded by the group.

The group also developed its own system of governance, but one which reflected the strengths and needs of its members. The group was particularly fortunate that Kelly Hicks continued to provide support - completely for free. It was clear to everyone that Kelly's quiet, thoughtful but determined facilitation was an essential element in helping people channel their anger and frustration into something more positive.

Progress in achieving some of the changes in local services that the group seeks has been slow. While there have been some changes, Doncaster has yet to fully embrace the idea of personalisation in mental health services. However recognition from outside Doncaster has been very positive. The group has won the support of local MP and leader of the Labour Party, Ed Milliband and from the minister responsible for social care, Paul Burstow. In addition the group and Kelly have won important awards - a Great British Care Award 2011 and Adult Social Worker of the Year 2011 respectively.

Date	Key Event
August 2010	First meeting - a group got together because there were no direct payments available for people with mental health needs in Doncaster
September 2010	Meeting with The Centre for Welfare Reform to explore possibilities
November 2010	PFG was set up as an Independent Constituted Association. PFG won the Regional Great British Care Award - Putting People First category
	On-going lobbying of NHS and local authority together with the pursuit of legal advocacy
December 2010	PFG Manifesto published
February 2011	First public event - run at CVS Lisa goes into hospital - <i>Support Buddies</i> begins - visiting rota established for the group
March 2011	First website established
April 2011	Lots of fund-raising locally in order to help fund a trip to the national awards in London
May 2011	PFG wins National Great British Care Award - Putting People First category
Summer 2011	Rebound, local organisation that had given PFG an office, closed down - stressful period of reorganisation
Autumn 2011	New office and meeting space found - first funding identified New website developed
February 2012	Publication of <i>Support Buddies</i>

**Table 1.** Key events for the Personalisation Forum Group

## Mrs J - Recovering together

Scared to leave home, frightened to answer a knock at the door or the ring of the telephone - not the state of mind that you would associate with a successful, professional women in her mid-forties. This is the situation I found myself in. I was employed as a town planner and part way through a Masters Degree. Although I have never been the most outgoing of people, in 2009 I now found myself a virtual recluse. I resigned from work rather than wait for the inevitable 'push' due to non-attendance.

My head was full of 'noise' and voices, urging me to become a loner, to avoid social situations; even the simple act of grocery shopping was to be avoided. Over time I found myself unable to watch TV due to 'voices' speaking directly to me, encouraging me to harm myself. Even reading became almost impossible as I found myself unable to assimilate the information from the page.

In 2010 I came to the attention of the Crisis Resolution Team, and as a result of this I was hospitalised for 10 weeks, during which time I received a diagnosis of Schizophrenia with secondary depression. I was immediately placed on a regime of anti-psychotics and anti-depressants; but was offered no 'talking therapy' at that time.

The passage of time saw an improvement in my state of mind, and a reduction in the 'voices' and their urge to self-harm; however I was still housebound and actively avoiding any social situations. In July 2010 I came across Kelly and the PFG. Since that first tentative step out of the house I have attended PFG meetings on a weekly basis, I have been one of a small team representing the PFG at the Great British Care Awards. I am very proud to say that we were successful at both regional and national level.

I continue to make progress, with the support of fellow members of the group. I recently attended training sessions from independent suppliers; I needed to leave my home, attend unknown venues and walk into a place where I know no one. The training I am receiving will help the group as a whole, and may also enable us to offer help and support to a wider spectrum of society.

I still have severe, on-going mental health issues, but with the support I receive from fellow members of the PFG, I am slowly improving. I still do not go out to social events, I still do all my shopping online and I still have my 'voices'. I know that if I need company or help, my colleagues within PFG will be there for me. The initial raison d'être for the PFG was to assist people with mental health issues to apply for budgets, and this work is still on-going. However the unforeseen benefits of the group - the mutual understanding and practical support - has been of immeasurable help to me.

Despite on-going problems, I am now in a much better place with regard to my mental health. I know that, if I need support, my peers will be happy to offer help. I have also been able to feel useful and valued as a member of the group and I have been able to offer emotional and practical support to group members. I am hopeful that with continued support that I will soon be well enough to complete my second degree.

## 2. Achievements



## 2. Achievements

In a very short period the Personalisation Forum Group (PFG) has achieved wonders. It has saved lives, speeded recovery and won awards. All of this has been achieved with minimal support from outside.

The outcomes achieved by the group can be seen in a number of different ways. Individuals all have their own stories to tell and each describes the transformational impact of being part of the group. Individuals can also describe directly how the group has helped them (see the box below). The group has also been awarded a Great British Care Award and their facilitator, Kelly Hicks, was named Adult Social Worker of the Year 2011. Nobody who meets the group can miss its power and effectiveness.

### Testimony from members of the group

*The group gave me both the strength and reason to leave my home - something I'd not done for two years.*

*I don't miss meetings - now I'm not lonely - I can be with people like me, people who understand.*

*It's re-ignited my political and educational aspiration.*

*Yes - we have mental illness - but we are useful members of society.*

*The group is passionate - it's one big voice - it gives us strength in numbers.*

*Mental illness affects lots of people - so we need to break into new areas, where people are not currently listening.*

*We're passionate about getting people an individual budget.*

*It's a supportive environment, where we share the same aims.*

*It's fantastic to be around people who are not judgmental - it gives me the 'get up and go' - the confidence to get back into life, as an individual - not an NHS*

*number. It gives me the extended family I lack.*

*'User-led groups' were just words until I met this group. I am daily amazed by what the group achieves - things a statutory body can never do.*

*It's given me back hope, life and the will to live.*

*I suffered too many deaths, too many changes - now I've got a home and people who can help.*

*I was just walking alone - the group has given me purpose - I am more motivated.*

*A budget would help me make things more personal, get things fitted around my life - with no waiting - I'm sick of waiting.*

*I have lived in this country for 14 years. I had to learn English myself and I've had jobs all over (supermarkets, care homes, dinner lady, health centre, cleaner). I was being bullied and I was very scared - this group has been very powerful in supporting me to go for it.*

However it is also possible to identify outcomes that we might call ‘service outcomes’ - for the group is effectively providing a free mental health service to itself and to the wider community in and around Doncaster. This is not to suggest that the notion of a ‘service outcome’ is the most important outcome - but it does show that existing services need to take seriously the impact and effectiveness of the group.

## Support Buddies

The PFG sees each of its members as a valuable individual, with skills and assets to share within the group. *Support Buddies* involves a mutual and reciprocal agreement between members to both give and receive time and support.

*Support Buddies* is a deceptively simple approach to providing mutual support and the group have already published their own paper describing how the model works (see Figure 3):

*Citizens are encouraged to register as a Support Buddy. This simply means giving some basic details to the Support Buddy Co-ordinator: like contact details and the skills that they have to offer. If you register as a Support Buddy this means you both give and receive help. Everyone has something to offer in this model and the more people who register the greater the support we can both receive and provide.*

*Support Buddies also complete a short satisfaction questionnaire after support has been provided. This helps make sure that people are happy with the support they have got, helps us improve things and demonstrates the positive achievements of peer support. We use this information to support other peer support groups to become established. We hope that we will help to create successful Support Buddies in many other places.*

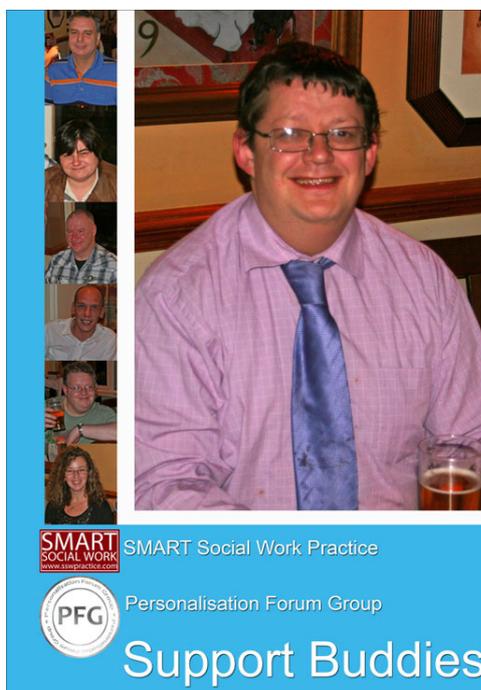


Figure 3. Cover of Support Buddies

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### Sam's Story - peer support comes natural

I developed the concept of *Support Buddies* because I wanted to help people to connect in a meaningful way. Lots of people tell me how brilliant they think our peer support is but I just think that it is what comes natural. When I think back to my childhood I remember that in our community everyone knew each other and helped each other out. There wasn't a name for it – it's just what people did. Experiencing mental illness does isolate you from other people and I can see that our project helps people to use their skills and feel part of something again.



By providing each other with practical help the group have discovered that it is full of talent, capacity and strength.

**Here are some important facts and figures about the Personalisation Forum Group:**

- ❖ The group currently has 64 members
- ❖ 42 members are also active in the *Support Buddies* system
- ❖ Each person contributes approximately 6 hours of support per week
- ❖ *Support Buddies* provides 252 hours per week, or 13,104 hours per year of support
- ❖ If this support had been commissioned from a professional mental health service provider it would have cost more than £20 per hour; this means that the current service value of *Support Buddies* would be more than £250,000 per year
- ❖ Support is flexible, some people provide much more than average - others much less
- ❖ Support will increase radically when members are in crisis - the maximum has been 500 hours in one week (that is over £10,000 in value)

To date *Support Buddies* has not been supported in any way by local statutory organisations. Instead, significant energy has been spent by the group trying to get statutory organisations to meet with them and to meet their demand for individual budgets and direct payments.

One of the great strengths of the group is its ability to focus on exactly what someone needs in ways that are flexible and practical.

The group is not restricted by rotas or by tight definitions of role. Instead the group can react flexibly and quickly to provide a whole range of practical supports, including:

**Attending appointments** - e.g. medical appointments, benefits etc.

**Social activities** - people who have been unable to leave their home for a long time are now able to attend mainstream community activities e.g. swimming, gym, sports events, cafes etc.

**Homes** - 3 members have been supported to move house. This included boxing all items and unpacking in the new home. On each of these house moves 7 *Support Buddies* were present.

**Transport** - 6 members transport people to important appointments etc.

**Hospital visits** - 3 group members who have experienced a period of hospitalisation. Each of these people have had daily visits from their peers throughout their hospital stay. Each was supported to return home with the help of their peers e.g. purchasing shopping and emotional support. Visits continued when the person returned home.

**Telephone network** - *Support Buddies* gives people someone to talk to – this is often during evenings and weekends. Often members ring each other as an alternative to phoning the crisis team. The group estimates that in 90% of cases they no longer contact the crisis team, for they can now talk to their peers.

**Help with bureaucracy** - support to complete forms, write letters etc.

**Craft group** - 10 people meet in a local café, twice per week, to share in arts and crafts. Involvement in this group is growing with members of the community without mental illness now joining.

**Daily living** - people receive help with shopping and budgeting.

**Crisis intervention** - *Support Buddies* sometimes stay at each other's home in times of crisis to support each other. *Support Buddies* have also provided homes to people in the group who have experienced episodes of homelessness.

**Talk For Health** – 10 members are trained and are providing peer-to-peer therapy.

**Planning** - 2 members are trained to facilitate and support to complete the WRAP process - Wellness and Recovery Action Planning.

The groups's passion is inspiring and has led to national recognition of the value of its work.



## Lisa's Story - life-saving support

I am a 53 year old woman with multiple severe and enduring mental health diagnoses. From my teenage years I have experienced repeated hospital admissions - some lasting for a several months. I am part of the PFG because I believe passionately that people with mental health problems need to have some control of an otherwise out of control existence.

My last hospital admission was triggered by the sudden and unexpected death of my father. I am still grieving and find it difficult to deal with this loss. For over four weeks after his death I repeatedly asked the mental health service for more help. I could see the signs from my previous experiences: the voices, the visions, the lack of energy and losing touch with reality. Help was not forthcoming and I reached a point where I no longer knew that I was ill. I ended up driving to Filey where I had every intention of ending my life.

I spoke on my mobile to a member of the PFG who stayed on the phone and gave me instructions and directions to walk into a police station. I have no real memory of this time I just know that at this point someone had to take control for me. The following days are a haze but I spent a frightening night in a hospital at Scarborough and then was transported back to the hospital in Doncaster.

The PFG Model of mental health services has been developed by people like me. Intelligent individuals who have a lot to offer and a great deal of insight into the system and how it works, more importantly how it should work. I know that I could have avoided this, and many other hospital admissions, if I had been given the opportunity to access help somewhere other than hospital when I first recognised my signs. If people had listened at this stage and understood that I did know what was happening to me and how to help I do not think that I would have ended up in hospital.

The power of peer support is evident from my story. Without which I don't know where I would have been. My peer supporters visited me every day in hospital, which gave me the hope that I had something to get better for, people that understood. Without this support I would have been looking at many more months in the hospital. Since being part of the group I have only had this one hospital admission. I believe that there would have been many more if I didn't have the support of my peers.

## Community developments

The group has also been very active in joining in, supporting or creating new community developments. These are just a few examples:

### YORKSHIRE WILDLIFE PARK

The group agreed with the owners of the Yorkshire Wildlife Park to get involved with planting the new outdoor eating area at the park. The group were hands on, in all weathers, planting the area. They were supported by the staff and garden consultant who shared knowledge about plants. The group took the opportunity to talk with staff about mental illness and this led to some excellent discussions.

**Cheryl Williams, from the Yorkshire Wildlife Park, said:**

We were delighted that the group were able to help us with the planting at our new South American village. Visitors have been commenting on the excellent planting and it was amazing to see the commitment and the enthusiasm that these guys brought to the job – even in the torrential rain on some occasions! Yorkshire Wildlife Park is a resource for the local community to visit and enjoy, but on this occasion it was a community project that helped to build something new for the park. It was very rewarding to see how much the individuals got out of working on this and creating something wonderful. The Park will be putting a plaque on the site to show that the group contributed to its development and an information board will share information about the group and its partnership with the Park. The Park have also offered more opportunities for the group, including work on other projects and maintenance within the park. The group found the project really rewarding and enjoyed doing something meaningful in their community.

The garden consultant will also be making a financial donation to the group to support their on-going work. The garden consultant has also begun to establish a social enterprise called *Planting Projects* and has pledged to work in partnership with the group. The aim is to support people with mental illness back into employment through the venture.

The group have also found some land that has been secured to plant and grow Christmas Trees. It has now been planted with corn to raise the fertility of land. In 12 months time the group will begin planting the trees. The group has also found a greenhouse space and will be looking to find funding to begin a real business.

### PREGOS

Pregos is a cafe in Doncaster's town centre. The cafe provides an upstairs room twice a week so that people can do arts and crafts sessions together. In return everyone who attends must buy a drink from the cafe. This works well and the group is growing to include people without an illness or disability, but who are cafe regulars and who like the idea of getting involved and doing something creative. The group provides all of their own materials to knit, sew, draw and craft.

## LORD HURST TEA ROOMS

The Lord Hurst Tea Rooms is a Doncaster florist and tea room that provides some space on Thursday each week. Some women group members meet there to have a more women-focused chat. This has also led to some women supporting each other to go out to events like Slimming World.

## RAMADA ENCORE ROBIN HOOD

The Ramada Encore Robin Hood Hotel has offered to help support the development of Wellness groups. The hotel is letting the group use its conference facilities once a week, so that the group can run WRAP training - this is an intensive 8 week course for up to 12 people.

## SANDTOFT AUCTIONS

Several members of the group chose to get involved in a local auction business. Members come and get involved with auction day and use the time as an opportunity to practice being in busy environments and talking to people.

This last opportunity is interesting. The auction business is a modest enterprise set up by Kelly Hicks and her husband. Kelly lets people get involved if they want to and many people do so because it is fun and interesting, they also want to give something back to Kelly. However, Kelly, who continues to provide all of her time to the group without payment and without the support of the statutory system, worries that this may be seen as 'exploiting' the group. This is a worrying symptom of how incoherent the current statutory system is. **When citizens worry that they cannot do simple things to include people in their own communities - without appearing to 'exploit' people - then opportunities for inclusion will go to waste.**

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## Learning new skills

One of the other powerful dimensions of the group's work is its growing effort to help its members to develop new skills - and then pass those skills on to others.

**22 members of the group have undertaken training in one or more of the following:**

- ❖ WRAP facilitation
- ❖ Secretary Skills
- ❖ Equality & Diversity
- ❖ Support Planning
- ❖ Assertiveness & Confidence Building
- ❖ Safeguarding
- ❖ Talk For Health
- ❖ Treasurer Skills
- ❖ Protective Behaviours
- ❖ Writing Better Funding Applications
- ❖ Chairing Meetings

## Benefits and savings

A wide range of benefits have been achieved, each of which should represent a significant saving to statutory partners:

- ❖ 16 people reported that without the support of the group they believe that they would have had an episode in the crisis house or have been **hospitalised** over the past two years.
- ❖ 3 members experienced a week's stay in the crisis house. Each report that they believe that their **recovery** would not have been possible without the support of their peers.
- ❖ Only 2 members of the group have been detained in hospital over the past two years. One lady reported having yearly episodes of detention over the past nineteen years. Her last stay was over a year ago and lasted only three weeks which she reports was significantly **reduced** because of support from her peers (her previous stays have been for months).
- ❖ 2 members report that they would not be able to continue with their **caring** role without the support of the group – in these two cases the group offer support by shopping for an older person and visiting socially to reduce pressure on group members. In exchange the older people provide someone to talk to and teach skills that they have.
- ❖ 1 member has now found full time **employment**.
- ❖ 2 members have now started full time **education**.

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The support the group provides to its members means that people now need less support from statutory services. If the statutory system were organised correctly then this would mean **reduced expenditure** in:

- ❖ medication
- ❖ domiciliary services
- ❖ social work time or support from psychiatric nurses
- ❖ family breakdown, increased care costs for children and adults from families
- ❖ hospital beds and crisis facilities
- ❖ day services

The critical question for statutory partners, community organisations and, in particular, ULOs is whether these potential efficiencies and improvements can be the foundation for a more effective and thoughtful form of partnership.

One officer from a statutory organisation observed that these positive changes would not lead to savings because the statutory system was not set up to reduce funding to the services that people no longer wanted. Moreover he also noted that the new system for funding with the NHS, so called Payment by Results, was likely to worsen the situation because statutory agencies would only be funded once someone had achieved a crisis that was sufficiently critical for funding to kick in. There is no incentive for NHS Mental Health Trusts to fund prevention because they are paid only for people with significant needs.

If either of these things are true then it is a damning indictment of the current mental health system. It implies funding is unavoidably linked to failure and that positive change is impossible without new funding. There seems to be no responsibility to make better use of existing funding. We will consider some of these issues again in Chapter 4.

# 3. At the heart of things



# 3. At the heart of things

Achieving positive change does not just happen. Instead a User-Led Organisation (ULO) must find a way of channeling its energy, dissatisfaction and intelligence. The Personalisation Forum Group (PFG) provides a good example of how this can be achieved.

The group has been highly effective, but it is necessary to go deeper to understand why it has managed to find the strength to work together and to achieve all that it has.

## Five principles

It does not take long in the company of the group to be impressed by its passion, dynamism and the spirit of mutual support that pervades everything it does. This does not stop people arguing, debating and expressing themselves strongly. But the way in which this happens seems to be a part of the group's strength.

From discussion with the group it is apparent that there are at least five principles at work within the group.

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### 1. TELL STORIES - RECLAIM YOUR LIFE

The group tell their own stories, both positive and negative. In fact they often, in the early stages of the group's development, found themselves engaged in 'Monty Python' one-upmanship: "if you think you've been unwell, well here's my story ..." But instead of bringing people down these stories build empathy and mutual strength. Perhaps telling the story to someone who has really suffered too, to someone who also wants to get better, makes all the difference: it is not an admission of weakness, it is a first step in reclaiming one's life. As the group has developed they have recognised this, and they give time and encouragement to new members to tell their stories too.

### 2. LEARN THE LESSONS - GROW IN CONFIDENCE

This story-sharing then begins to focus on success: how did you overcome that problem? The diverse group contains many stories of recovery, success, improved lives and problems solved - or better managed. Again these stories are stories from peers - they are not filtered by professionals - they are not delivered as 'advice' from above. This makes a big difference.

### 3. TAKE ACTION - MAKE A DIFFERENCE

*Support Buddies* - the system of mutual support - is just one side of the intensely practical nature of the group. People want real change - they want to be well and they want to stay

well - they invest their energy in the group because people really want to do something for real. Talk is not enough.

#### 4. STAY FLEXIBLE - LET THINGS DEVELOP

The enormous number of challenges faced by the group could not have been met without enormous flexibility and the ability to respond quickly to new challenges as they arose. This sometimes means letting different overlapping groups develop - not trying to plan everything to the last degree - instead focusing on the challenge ahead. The group seems to be excellent at seizing opportunities.

#### 5. DARE TO HOPE - KEEP ON FIGHTING

The group's success has involved a powerful balance between its role in battling the system and its role in creating practical solutions for its members - now. Although this second task is more acceptable to the official mental health system it is important to remember that part of the group's spirit comes from its sense that the current system is unfair. Changing the big things is difficult. But the group does not just look inward - it knows that the bigger battles are vital to them and to all who come later. Having hope that things can really change - personally and for others - is necessary but difficult - but it becomes much easier when you are with others.

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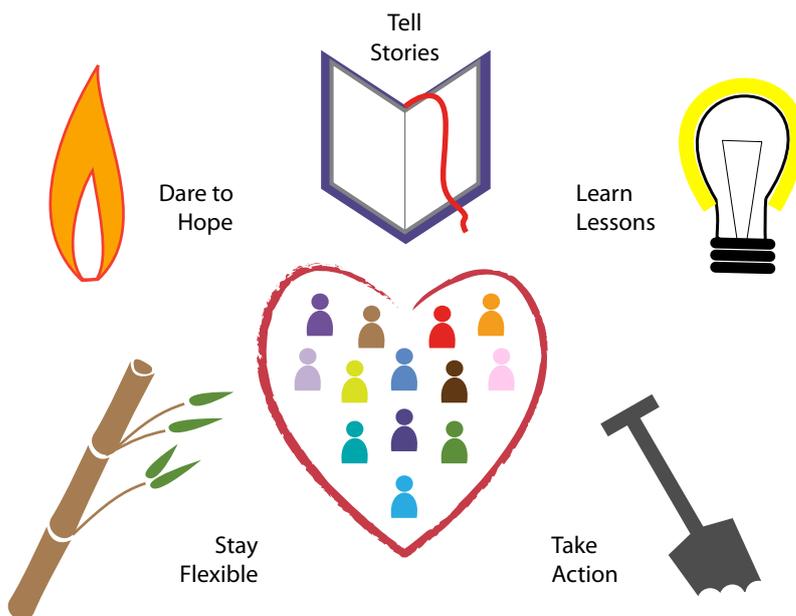


Figure 4. Five principles for Peer Support

### Claire's Story - friendship and fun

I have Asperger's Syndrome which makes the world a very noisy, confusing place. I have sensitive hearing and I take people literally. I also have fibromyalgia which makes me extremely tired and I have a lot of pain. Having friendship and support from the PFG is very beneficial to my mental health and I am very grateful to everyone for all the laughs we have shared together. People in the group understand the difficulties I have and I am able to just be me.

Being part of the group has enabled me to both give and receive support. This is really important for me and has helped me to grow in confidence and realise that I have many skills to share. I have attended lots of training and really feel part of my community. I am now able to go to many places with my peers instead of needing a personal assistant. We work very hard together to show that, as a true ULO, we make a real difference.

## Five actions

As the group follows these five principles and seeks to find ways to actually make a real difference we can see a pattern of 5 different kinds of actions emerging (see Figure 5):

### 1. SUPPORT BUDDIES - HELP EACH OTHER

The development of *Support Buddies*, may not have been the first thing the group did, but it now seems the most important. By helping each other - by not waiting for help from the system - the group has a real and immediate value to its members. It is this activity which seems to be closest to the heart of what the group is.

### 2. CHAMPION - IMAGINE BETTER

Part of the group's role is also to imagine a better system and a better society for people with mental health problems. They each know how often things get in the way of recovery and how easy it is to slip into sadness, anger or confusion when life throws up problems. But when these problems seem to be created by the mental health system itself then it is natural that the group will want to draw attention to how crazy things can get. However, as the group's Manifesto makes clear, it is the group's ability to offer a positive alternative to this craziness that is so useful. It holds up a picture of how things could and should be and in this way it begins to help society to imagine a better alternative. It certainly seems to help the group's own members to picture themselves as agents of change.

### 3. ADVOCATE - CHALLENGE SYSTEMS

The group continues to put pressure on the system to reform, using the law, lobbying, using traditional media and new forms of social media (Twitter, YouTube and Facebook). It has also had some limited success, for Doncaster has now recognised that Direct Payments must be made available to people with mental health needs and a system has now been put in place to make this possible - although this seems much more limited than the system the group would like to see. The wider use of individual budgets for mental health across the system has been very slow and many people, with very significant needs, do not seem eligible for even modest levels of support. This kind of group and individual advocacy also seems to be a natural result of the group's powerful and positive vision - injustice becomes the spur for action.

### 4. SOCIAL ENTERPRISE - DEVELOP LOCAL SOLUTIONS

It is astonishing to see how productive the group has been in such a short period. Not only does the group provide *Support Buddies* but it is also working to develop a range of other opportunities and solutions. The PFG is a real social enterprise, working within its

local community to find ways in which the group can add value to the local community, but also to benefit its members. Working with cafe owners, hotels and local businesses is opening up new possibilities - but also building bridges within the local community.

## 5. NETWORK - BUILD PARTNERSHIPS

From its very beginning the group has reached out to build partnerships both within and beyond Doncaster. It wants to encourage other groups, such as an emerging cooperative in Sheffield, to be as bold and as positive. It has also built an alliance with the other user-led organisations in the area to work together on common issues.

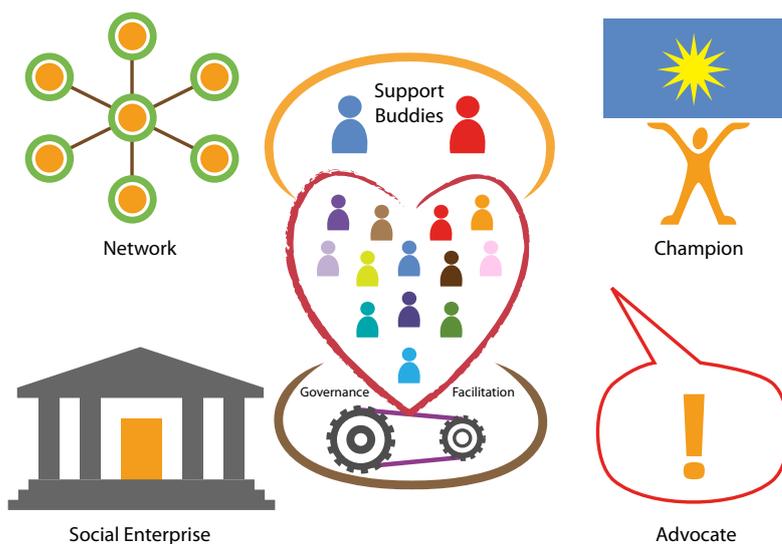


Figure 5. The PFG's five actions

## Structure and organisation

As a self-organised group the PFG has developed as a true ULO defining its own aims, values and objectives and it is free from any external control. This has led to the natural development of a powerful movement based on shared experiences and the vision of being active citizens in shaping future service development.

**From the very beginning the group identified the need for a governing committee and the wider group elected people to key roles:**

- ❖ Chair and Vice Chair
- ❖ Treasurer and Vice Treasurer
- ❖ Secretary and Vice Secretary

The use of this vice role - or deputy - is very important. Not only does it make the group more robust when people's needs change, it also means that there are more opportunities for sharing and working together.

There is an AGM for all the members, and the full group elects the committee. Every Tuesday there is an open house meeting - which everyone can attend. Special meetings are organised as the group sees fit.

The group has a bank account and its own memorandum of articles that describe how it works. Legally it is an incorporated association. There is also an important agreement with Kelly, which defines her role as the group's advisor.

The group clearly benefits from being large in size - but a size that is not so large that it becomes bureaucratic or faceless. It is also able to divide and join up organically - around different themes or interests. If the group did decide to grow much larger and seek many more members it may come to a point where it needs a more formally sub-divided structure - however the group has shown every sign of being able to manage these developments well and at its own pace.

## The role of the facilitator

One of the happy accidents that has helped the PFG to achieve so much was the connection with Kelly Hicks, an independent social worker, who volunteered to help facilitate and support the group's development.

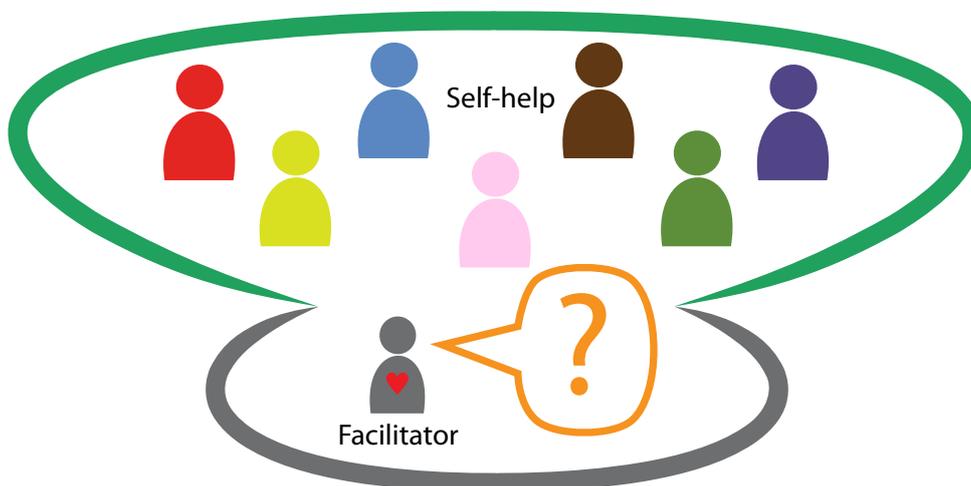


Figure 6. Facilitation and peer support

The group describes Kelly as “their rock” and as the “key link in the chain” and a “brilliant facilitator”.

### When we explored what that means these were some of the key issues:

- ❖ She is encouraging
- ❖ She is free from professional bias
- ❖ She helps the group use their experiences to develop
- ❖ She uses positive questioning
- ❖ She is not judgemental

### Kelly and the group were also able to reflect on some of the challenges for the facilitator:

- ❖ There is a lot of pressure from the group that can build up on Kelly - she needs to be able to ensure that problems are shared and she does not become burdened.
- ❖ There is a lot of suspicion from outside that focuses on Kelly - she needs the groups support to demonstrate the group's independence and integrity.



Reclaiming your own identity can quickly lead to a desire to make a positive difference in your own community.

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Fortunately Kelly and the group work together well and Kelly gets many benefits from the group - although she still earns no money for all her hard work. She subsidises her work by working outside Doncaster and running her own small garden centre.

The pressure on Kelly may be all the greater because she used to work for Doncaster Council, but did not feel it gave her the opportunity for creativity and independence that her social work training required. Kelly was keen to support people to benefit from personalisation and to advocate for themselves. But leaving the Council may also have led to some unduly defensive behaviour from the Council. They may fear that someone who was once an 'insider' is now in a position which leaves them too free to be critical of the Council.

This is an issue that many facilitators will experience. As groups become effective at advocating for themselves the system is likely to become fearful and resist this advocacy. As some groups have, in the past, been poor at speaking up for themselves, there is also a tendency to suspect that the facilitator is 'behind' any new voice. In some sense this true. A good facilitator does help a new and stronger voice to arise. However this is entirely appropriate and it was clear from all our work with the group that Kelly was serving - not directing - the group. So local agencies must ensure that they have the self-discipline necessary to avoid scapegoating facilitators when this happens.

It may also be important to further strengthen the facilitator by helping facilitators to come together, to learn together and by ensuring that there is a formal agreement between the group and the facilitator. As the group develops it will be important that there can be honest conversations about what is working and what is not working in the role. This will be doubly necessary should the group ever seek to commission the support of Kelly or any other facilitator.

# 4. Imagining better



# 4. Imagining better

The Personalisation Forum Group (PFG) has found that change does not come quickly; however the group has created a powerful picture of a reformed mental health system. This vision seems to help the group maintain its momentum and its focus.

## The failure of services

As the group met and talked it was clear to them that the current system of mental health services - while it had some positive features - was often woefully inadequate.

**The group identified several problems:**

- ❖ There is a long history of institutional practices that leave people feeling powerless, isolated and cut-off from ordinary life.
- ❖ Power and money is locked within inflexible acute services and professionalised structures that do not respond to individual need.
- ❖ Systems and responsibilities are confusing, complex and divided between the NHS providers, local government and GPs in ways are confused and confusing.
- ❖ Nobody seems willing to address the underlying causes of mental distress e.g. poverty, abuse, isolation, unemployment etc.

The mental health system feels like it has been designed wrong. There are good people working in it, often trying very hard to help people to recover and achieve better lives - but the system as a whole seems to work against them.

**For instance, one member of the group noted:**

*I don't want the kind of day-centre-style of mental health service that is available. They put people in dirty buildings with little opportunity to do much other than play scrabble. I am intimidated and frightened and it does not offer any real support. I want to be supported in the real world and in real life; I don't want these services from the past.*

This problem is rarely acknowledged by politicians, civil servants or professionals. The system seems to continue unchanged and to pretend that its only problem is lack of resources. The truth may well be the reverse.

**For instance, Professor Alan Rosen found that countries without significant mental health services are better at helping people recover from schizophrenia:**

*These findings [better long-term outcomes for schizophrenia in developing countries] still generate some professional contention and disbelief, as they*

*challenge outdated assumptions that generally people do not recover from schizophrenia and that outcomes for western treatments and rehabilitation must be superior. However, these results have proven to be remarkably robust, on the basis of international replications and 15-25 year follow-up studies. Explanations for this phenomenon are still at the hypothesis level, but include (1) greater inclusion or retained social integration in the community in developing countries, so that the person retains a role or status in the society; (2) involvement in traditional healing rituals, reaffirming community inclusion and solidarity; (3) availability of a valued work role that can be adapted to a lower level of functioning; (4) availability of an extended kinship or communal network, so that family tension and burden are diffused, and there is often lower level of negatively 'expressed emotion' in the family.*

[Destigmatising day-to-day practices: What Can Developed Countries learn from Developing Countries? World Psychiatry 2006, 5: 21-24]

As the PFG has developed its own thinking it seems that they share the same perspective. The problem is not lack of mental health services - the problem is much deeper.

#### People said things like:

- ❖ We are not medical conditions - but we are people
- ❖ We are told what we can't do - but we can achieve
- ❖ We get 'professional only' support - but we want peer support
- ❖ We are lost in the systems and paperwork - but we want normal things in normal places
- ❖ We are given services - but we want a life

It is important to see that this is not just a negative critique of existing services, it is also an assertion of fundamental human rights and of personal capacity. The group is **not** complaining that something is 'missing' - they are not demanding 'new services' - they are saying that **they** are missing from the community. They want to give and contribute and too often the community is missing out on this contribution.

**Identifying the problem in this way makes for a radical difference in the way that the ULO operates. Instead of simply 'lobbying' for change or thinking that the only power is out 'in the service system', the group began to look at their own resources - their own Real Wealth (Murray, 2011) (see Figure 7):**

1. Gifts - our own strengths, preferences, skills and even needs
2. People - family, friends, neighbours, colleagues, peers
3. Community - opportunities for creation, exchange and development
4. Assets - money, time, resources
5. Spirit - our faith, optimism, hope and creativity

This does not mean people don't sometimes need help - quite the opposite - mutual help and support is an essential feature of any decent society. But people do not want any help they receive to then undermine their dignity, personal control and participation in society. This is why systems like direct payments and individual budgets were developed - to ensure that people could get help - but help that people could control for themselves.



Figure 7. Real Wealth

Perhaps one lesson for any ULO is to ensure that this positive approach dominates. Change is hard to achieve if you only focus on deficits and barriers. **A positive focus on strengths and opportunities creates a better foundation for positive change.**

This is certainly the approach that the PFG took. Not only in their practical efforts - but also in how they thought about reform for everyone.

## The PFG Model

Almost from the very beginning, in 2010, the PFG began to develop its own model for reform in the mental health system. This model has been developed by people who are experts in how the mental health services work - from the inside. They know what works and what doesn't.

The model is thoughtful and respectful. There is a clear recognition of the valuable role played by GPs, social workers and mental health professionals at every level. There is a recognition that, in extreme circumstances, people may also need somewhere safe to go - even hospitals.

**However the PFG Model makes 5 radical suggestions for reform:**

1. Put peer support and community organisations at the heart of the mental health system - this should be the foundation for everything else.
2. Give people more control at every level of the service delivery system - even when people need support and guidance there are many things they can still decide for themselves.

3. Create a simple funding system that uses a set of low cost grants and individual budgets so people can pay for flexible support when they need it.
4. When needs become more acute make sure that there are professionals available who can act as a clear link to help people get the right support and speed up recovery.
5. Create a hospital avoidance scheme with a tariff set below the current acute hospital rates - but free up the resources necessary to fund positive respite.

The PFG Model is based on the recognition that, primarily, mental health is not improved by mental health services. Instead mental health is mainly achieved by citizens themselves, in partnership with their communities.

#### There are 6 levels to the PFG Model:

1. Peer Support - individuals and families working together to solve their own problems
2. Primary Care - individuals and families working the GPs and primary health care teams
3. Specialists - individuals and families working with specialist mental health services
4. Hospitals - individuals and families working to leave hospital provision
5. Commissioning - government, not just funding services, but working with communities
6. Community - an inclusive community creating opportunities for individuals and families

It is critical to achieve changes both in the whole system and the wider society - so that people with mental health problems can be in control of their own lives and play a much greater part in community life. Emergency services, like hospitals, play an important role - but they must not be allowed to continue in their predominant role within the mental health system. It is people themselves, their families and their peer support, that must be central to any reformed system.

#### It is particularly important that funding for mental health services is organised in a thoughtful way:

- ❖ Some services should be **free to anyone in the community** in order that people can get information, prevent problems and get the best advice possible. Many of these support can be provided by self-help groups or volunteers. However, as this is the most important and efficient form of support, it is also important that commissioners invest in their communities and help clear away any problems that obstruct good local solutions.
- ❖ People need choice of gender and the chance to get support in environments that bring with them no stigma and which feel safe. Solutions must be sensitive to the important differences between people; **gender and ethnicity** seem to be important factors that significantly shape the experience of mental illness.
- ❖ Sometimes people need control of money or access to therapies, medication and other treatments. Ideally funding should follow the person and enable as much **control** as possible. Individual budgets, vouchers, prescriptions and small grants will all be useful.
- ❖ Some services are very expensive, it is important that they are funded at the proper level - but also important that there is **no incentive to overuse** these services. The group is highly concerned that current plans for 'Payment by Results' may worsen the current situation if it encourages specialist service providers to wait for people to go into crisis.

The PFG Model proposes a system that is much easier to understand than the current funding system for mental health - and one which could transform ‘Payment by Results’ into a much more effective approach. It is also affordable and efficient. It is consistent with the thrust of government policy and offers a way in which GPs could reduce the pressure that mental illness creates in the primary care system.

How this new system would work in detail is described below, and Figure 8 offers a visual representation of the proposed system.

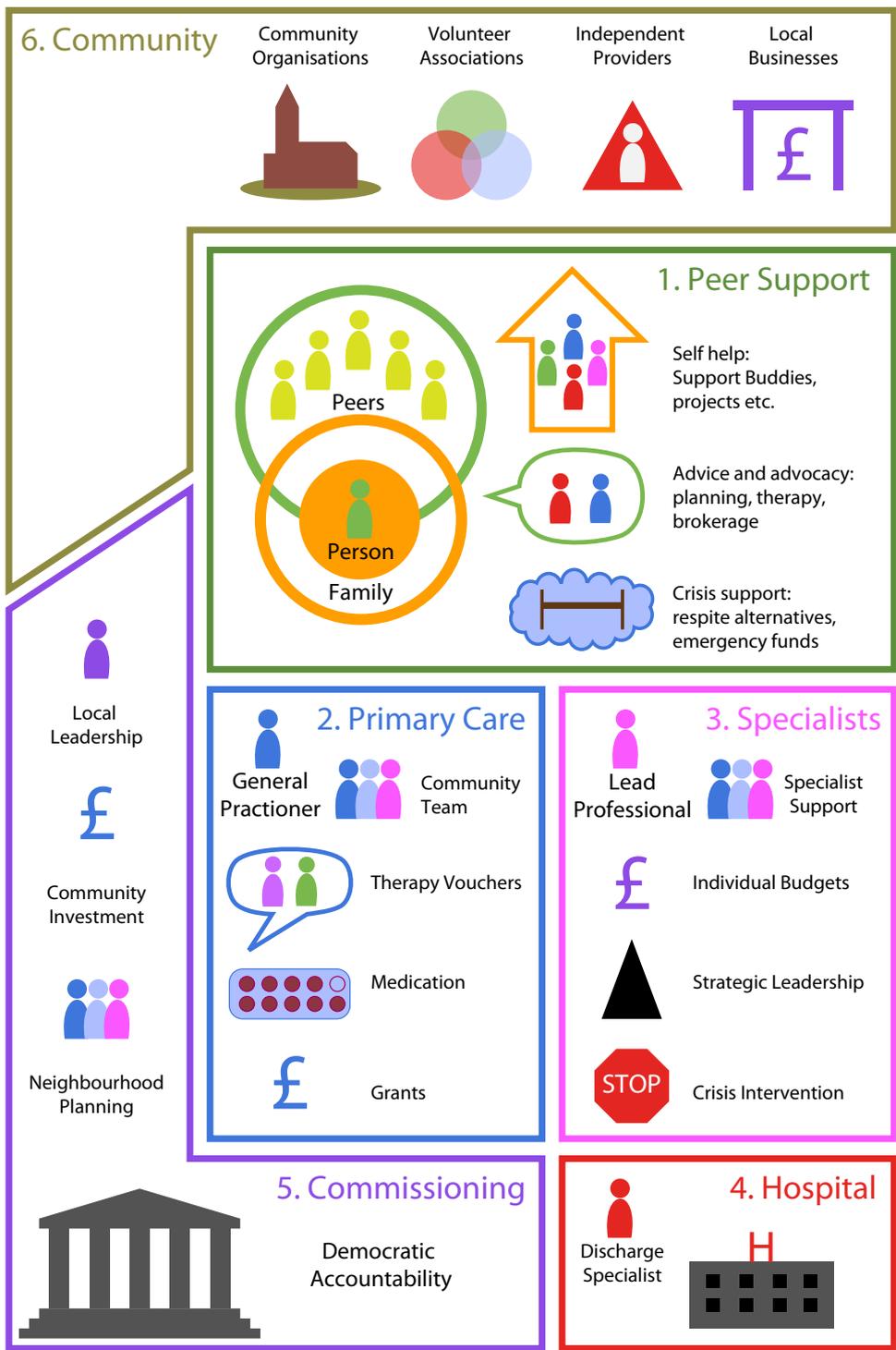


Figure 8. The PFG Model for Mental Health Reform

## LEVEL 1 - PEER SUPPORT

Peer support is the most powerful and natural form of support for people with mental health problems. Unlike other forms of support it generates power through the equality of its members. There is no professional paternalism, so people start from the empowering position of equality - even if they feel hurt, broken or sad. They are with others who feel the same - as equals.

Peer relationships can be complex, subtle and catalytic and as trust builds, people are able to respectfully challenge each other when they find themselves re-enacting old roles. This enables members of the peer community to try out new behaviours with one another and move beyond previously held self-concepts built on disability, diagnosis, and even a victim's worldview.

**Peer support seems to lead naturally to self-help and this kind of help seems powerful because it is:**

- ❖ **Natural** - we just do it, knowing we won't confuse it with friendship
- ❖ Rooted in **understanding** - we've been there
- ❖ **Honest** - less need for disguise or undue politeness
- ❖ **Spontaneous** - can be switched on in an instant
- ❖ **Flexible** - doesn't get restricted to professionally defined interventions

**In many areas there may be groups like the PFG already, because people want to help each other or volunteer. However local authorities (working with their health colleagues) should seek to ensure that there are:**

- ❖ **Places and people** you can see to talk things through
- ❖ Opportunities for people to organise **self-help** groups
- ❖ Good, readily accessible **information**
- ❖ **Facilitation** for peer support
- ❖ **Referrals** to peer support as a non-negotiable part of all clinical practice

There is no obvious limit to the scope of peer support. For instance, states in the USA have used peer supports to provide brokerage - advice and assistance in planning and managing individual budgets (Alakeson, 2011).

**The PFG is currently aiming to develop a brokerage hub which would help people:**

- ❖ Identify local resources that are positive
- ❖ Help people plan and organise their own support
- ❖ Provide practical support to manage money, purchase support or employ staff
- ❖ Monitor the effectiveness of local services, including therapists
- ❖ Share ideas and good practice

**A strong foundation of peer support should reduce the reliance on services and reduce crisis-driven institutional responses:**

*The current system is like a yo-yo. We go down and will maybe get some help, but when things go better support is suddenly withdrawn and there is no focus on maintaining well-being. Peer support helps us prevent crisis and maintain real well-being.*

One further radical proposal would be for a peer support group to act as the commissioner of additional services. For instance the group would be very helpful at developing alternative respite services to keep people out of hospital when they are in crisis.

## LEVEL 2 - PRIMARY CARE

Primary Health Care is led by the General Practitioner who acts as the primary gate-keeper to specialist mental health services. However, before referring anyone to specialist services it is the role of the GP to help people prevent or overcome mental health problems, by giving them access to a range of rationed resources, some of these are currently established, others could be helpfully developed.

One of the first responsibilities of the GP should be to refer people to sources of support in the community, especially to peer supporters. There could be a powerful partnership between peer supporters and GPs. This is even more important today given the growing importance of GPs as commissioners of services. If GPs begin to realise that peer support can reduce the demand for more expensive specialist services and hospitals, then they are in a good position to help reform the current system.

GPs also play an important role in prescribing medicine. Peer supporters recognise that medication can be useful - but it can also be damaging: undermining motivation, energy and often causing other health problems. It would be particularly useful to start making the cost of medication more transparent, as people often feel there may be more cost-effective alternatives - and without the worrying side-effects of medication. A greater dialogue with peer supporters about the use of medication in mental health could be very useful for everyone.

GPs also refer people to therapists - and there is now a particular programme called - *Talking Therapy* to fund such therapy. This is an area where more choice and control for the individual would make sense. It is probably not necessary to provide cash for therapists - instead a voucher system could be used - where therapists are able to go back and claim for any service they provided. However any voucher should be in control of the individual.

Vouchers would be a much more efficient approach for funding the support of therapists - growing community capacity, market responsiveness and increasing personal choice from within an accredited system. In order to make this voucher system work it would be useful to enable people to get a half hour of free counselling, before deciding to commit to any therapist. Moreover peer support groups or others could develop an accreditation system by which the local community could monitor the effectiveness of different approaches.

One more radical innovation would be to enable GPs to provide people with small grants to overcome immediate problems or to encourage people to engage in their community. Unlike a system of individual budgets these grants would not be provided after complex assessments, they would be small and time-limited.

A particularly useful model is provided by the *Small Sparks* system that was first developed in Seattle. Grants were provided in return for social contribution and community development. Individuals would match the grant with some time, or other money and promise to do something for the community and to share what they've learned. A grant level of £250 proved to be quite sufficient to create powerful and positive opportunities for the local community. Alternatively such a programme could be run and controlled by the peer support system itself.

## Vinny's Story - The power of small grants

I have multiple mental health diagnoses including ADHD. I find it impossible to travel on public transport and I go everywhere by bicycle. I cycle for miles every day. A while ago my bicycle became unsafe and I had to spend my time in the house. I self-harmed became depressed and felt suicidal. I lost my relationship and spiralled into mental health crisis. At this time if I could have accessed a small budget I would have bought a bike and saved myself from a lot of hurt. After three months I managed to get some money to purchase a second hand bike and my life began to fall back into place.

The PFG model would have been ideal because for £200 I could have a safe roadworthy bike with safety equipment. This would have saved several visits from the mental health team, countless requests from the crisis team and the medical treatment I needed because of my self-harming. I can't imagine how much I actually cost the system simply because I didn't have a bike. No amount of tablets worked for me during the period of being without a bike. It didn't matter how many doctors I saw. What I needed was to be able to get out. I needed a bike.

## LEVEL 3 - SPECIALISTS

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There are a range of specialist mental health experts, many of whom are paid and organised by the NHS. Their role is to provide expert advice and support to those people who need the on-going support of a mental health lead professional. Their involvement often starts when there are clear risks either to the person or those around them.

For some people, where there is expected to be a long-term relationship with specialist care, then that care and support is organised through a system called the Care Programme Approach (CPA) - which aims to clarify responsibilities and ensure people get the help they need, from the right person at the right time. About 1.25 million people use specialist services in a year - about 2% of the population, about 200,000 people are on the CPA (about 0.3% of the population). For Doncaster this means that something like 5,000 people will be using these services and about 750 people will be on the Care Programme Approach.

However the current organisation of mental health services means that the services that people access are often rigid, inflexible and commissioned in ways that do not allow support to be personalised. So, in order to improve the clarity and flexibility of this service, it is proposed that the lead professional should have access to funding which they can manage in partnership with the person (see Figure 9).

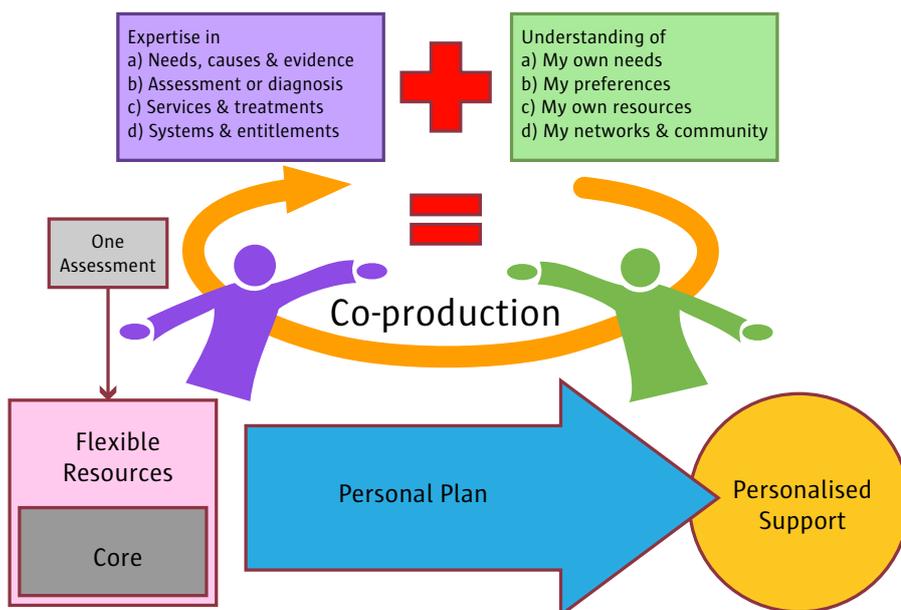


Figure 9. Co-production

It may be useful to design a system of individualised funding that is much simpler than some of the systems used in adult social care. It is important that time is not wasted in overly complex assessments or negotiations.

There could be a simple array of funding options, like this:

1. A flexible pot of funding to be used at the discretion of the professional, especially useful for one-off costs and grants.
2. A medium level individual budget set at a rate of £5,000 for a year, some of this could be used to pay for a buddy, peer supporter or other person. There would be no automatic renewal; people would work to become less reliant on this support.
3. A high level individual budget at a rate of £10,000 per year, which could pay for on-going support plus other help and access to professional community services. This package of support would be reviewed more regularly, say every 3 months.
4. For some individuals these options will not be sufficient and an individual package will need to be defined on an individual basis and the lead professional will review progress with the person as is most appropriate to their condition.

Although all the changes described above will lead to some reduction in the level of crises and mental health breakdowns there will also be some people who will need emergency help and support. So some crisis intervention team may also be necessary.

Specialists do not just provide services, perhaps more importantly they have knowledge and can train people about mental health and its treatments. They can provide some of the strategic leadership necessary to help the whole community improve its approach to mental health. However specialist experts in mental health should seek to work in partnership with peer supporters - with the experts by experience - and together these two groups could lead practical thinking and policy-making for the whole community.



A vision of powerful and positive change is not enough to make that change happen - but it's a good start.

## LEVEL 4 - HOSPITALS

A stay in a mental health hospital is likely to cost about £150,000 per year (about £410 per day). About 110,000 people went into mental health hospitals in England and on average people stayed in hospital for about 70 days (ten weeks). That is a cost per admission of about £28,700. The cost of the mental health hospital system in England will be about £3.2 billion. For an area like Doncaster with a population of over 250,000 this represents approximately £13 million per year (and this is for hospital services alone, it excludes consultant costs and additional community services).

It is recognised that this money will be paid according to tariffs agreed nationally or locally and that acute hospital care should not be funded from an individual budget. However it does seem, given the high cost of these packages and the fact that it is “tough to recover in hospital”, that the system should also develop an alternative method for funding emergency respite care at a rate of, say £750 per week (c. £39,000 pa). This could offer radical savings to current mental health expenditure and increase the overall rate of recovery.

In addition, whilst in-patient stays may not be directly funded from an individual budget it should be possible to make funding for in-patient care transparent. This would mean that people can be fully involved in deciding what type of in-patient treatment is best for them and where it should be. Therapeutic communities should also become a viable choice.

## LEVEL 5 - COMMISSIONING

At the heart of the PFG Model is a different approach to commissioning. Currently the process of funding services is driven by an over-commitment to a narrow range of professionalised services. However there is no evidence that this current pattern of service delivery is good, and there is much to suggest that there is a need for radical change. In the past any positive change has always relied on ‘new money’ and there is little history of the system making radical changes to invest more effectively in solutions that work.

This means that there is every reason to suggest that the current mental health system is stuck in the past - and unable to move forward. What is required is an approach that is both more innovative, empirical and focused on all the possible options that are being developed by the wider community. Figure 10 offers a different model of commissioning that could be used to support positive change.

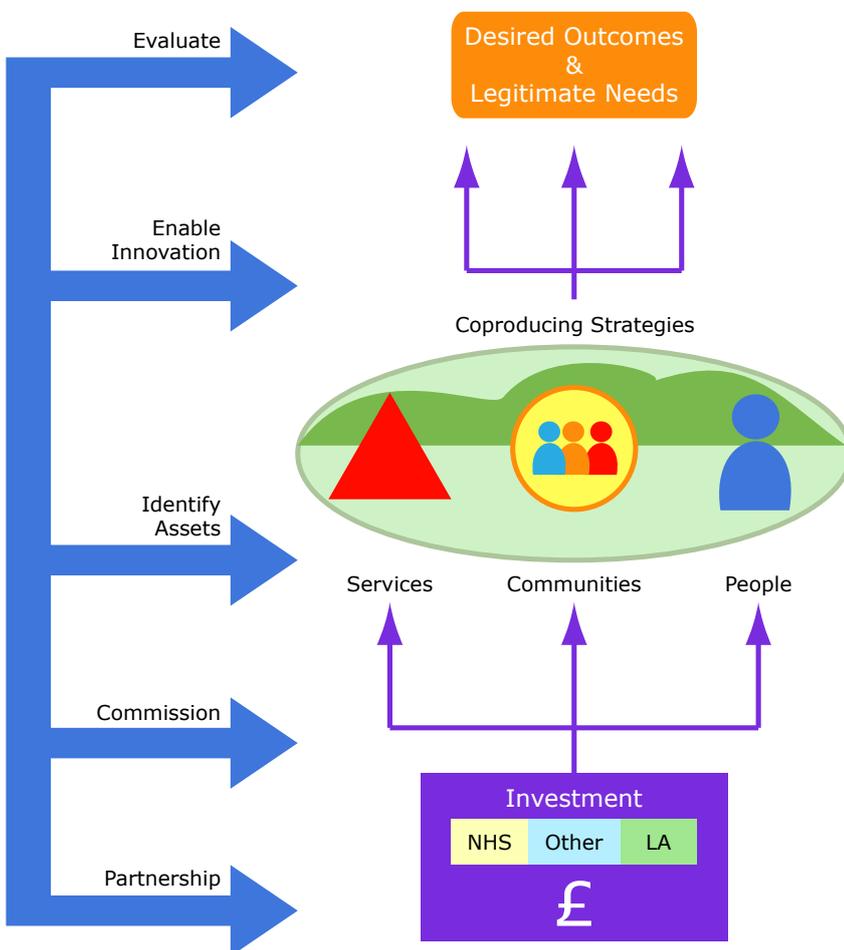


Figure 10. Commissioning for innovation

Commissioners should stop focusing only on services and instead also focus on the impact of services, communities and individuals together. We must recognise that positive change mean making big changes to the current pattern of investment - not just new investment, but also disinvestment - cuts to services that are not working.

In order to achieve this new way of working it will be necessary to:

1. **Evaluate** - funding decisions should be determined by real evidence of success, or relative effectiveness - informed by local citizens and peer supporters
2. **Innovate** - individuals, communities and services should be enabled to use resources flexibly, to innovate and to develop and share new models of good practice
3. **Inclusive** - it is by welcoming and building on the network of local assets that local change will happen
4. **Commission** - thinking behind investment decisions should be transparent and information should be public - contribution, scrutiny and challenge should be welcomed
5. **Partner** - where there are multiple and over-lapping responsibilities then local leaders need to come together, build partnerships and clarify responsibilities

In mental health it is clear that, not only are there important overlaps between the roles of the NHS and local government, but also that other aspects of community life are vital to improved mental health: housing, education, care and support. Although local government often has only limited control of local resources it has a critical role as the organisation with a real democratic mandate to lead change. **It is to be hoped that the new leadership role for local government in health and well-being will lead to more progress.**

If this model of commissioning were developed then it would have a radical impact on the relationship between peer support and the current system. At the moment - despite some rhetorical support - statutory bodies tend to treat peer support and ULOs as if they were 'merely a challenging group of service users, who at best only provide marginal, non-statutory services for people who may not even be eligible for support.'



Nobody knows better than people with mental health problems how current services could be improved.

**Instead commissioners should recognise that peer support offers:**

- ❖ **Leadership** - an essential partner in commissioning
- ❖ **Value** - a vital source of support in the community
- ❖ **Agency** - a source of creativity and service development
- ❖ **Expertise** - providing direct intelligence on service effectiveness

In other words recognition of and support for peer support should be central to all commissioning strategies.

## LEVEL 6 - COMMUNITY

Good mental health is not the result of services on their own, it is the result of the interaction between individuals and their communities. This does not mean that services are redundant or that communities are just 'good things'. In fact communities can be helpful or harmful - they can welcome and support people or they can exclude and damage people.

**This is clear when we recognise that the external factors that influence mental health are all aspects of community life:**

- ❖ **Welcoming community** resources, clubs, churches or other opportunities of membership
- ❖ **Opportunities** for work, paid employment or volunteering
- ❖ **Strong families** that can adapt and offer support
- ❖ **Mutual support** from peers, solving problems together

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This, the fabric of community life, is not the toy of government or commissioners. It existed before government and is more important than services. If there are problems within communities then these need to be resolved. Replacing communities with services does not improve anything.

A minimum level of community support must be commissioned by the local authority and the NHS together. And organisations, groups or individuals who want to offer community support should be welcomed to make their contribution to the community - with clear and public rules. As individual budgets are developed people themselves will commission their own support from community organisations.

Working with communities will be central to a reformed system. However statutory services often have little knowledge of what is available in communities and have no system to keep any information updated. One of the important roles of good peer support is to ensure that there is better awareness of community options. This includes self-help, support providers and community organisations that offer advice and guidance to help with issues such as debt, domestic abuse, housing, employment, relationships.

**Peer support is the most natural bridge into community life.**

## Sharing the vision

This model of a reformed mental health system may seem like a dream. But it is an important dream - a vision of a better system.

**This vision is important because it helps the Personalisation Forum Group:**

- 1. Inspire creativity** - the group's vision actually inspires the kind of positive and practical developments that the group have made, even while statutory services remain on the sidelines.
- 2. Create positive challenges** - rather than simply reacting negatively to the problems within the existing system the group are able to make positive suggestions, informed by their vision.
- 3. Maintain hope** - having a positive vision can help people live and act from hope, this is good for personal mental health and helps the group to be more effective.
- 4. Build bridges** - the vision also helps the group to build stronger connections with others, both locally and nationally - for the vision is based on important values that others can recognise and share.

To date the group has retained an intelligent balance between developing and sharing its vision whilst focusing most of its energy on positive, practical solutions. The balance between vision and action is always an important one to find and keep, and it is a sign of the group's strengths that they have managed this so well.

**As the internationally respected mental health researcher Dr Lynne Friedli said:**

*One of the most inspiring features of the PFG story is how the group both supports its members, like a traditional self-help group, but also advocates passionately for political and systems change and has itself become a force for change in the local community.*

# 5. Future direction



# 5. Future direction

Today the Personalisation Forum Group (PFG) is primarily focused on creating practical solutions to enable it to have a positive impact on its local community. Inspired by its visions and building on the strengths of its membership, it has identified a series of practical next steps and these are its current priorities.

## What is getting in the way

There have been three major challenges that the group has had to face:

- 1. Finding a home** - the group was originally based in a new organisation, called Rebound, which was set up to provide services for people with mental health services in Doncaster. However this organisation was unable to attract the funding it needed to survive and it closed in 2011. This led to a series of practical problems for the PFG, including the need to find a suitable office and meeting space.
- 2. Providing support** - the group has already developed a range of supports and services that it provides to its own members and to others. Within the group there is already a range of skills, energy and enthusiasm. The group needs to identify the most practical and positive structures for providing support.
- 3. Challenging the system** - the group began its life by supporting people to advocate for individual budgets or direct payments. The system in Doncaster did not enable this and there are still many problems with the current system. Challenging the system is difficult and takes a lot of time and energy. The group would prefer a positive and respectful relationship with statutory services.

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## What the group will do next

Even as this report is published there is ongoing work in all these areas. The section below describes some of the main proposals that the group is working on at the moment.

### 1. FIND AN OFFICE SPACE

The group is looking for an office that they can use for about 10 hours per week. They are exploring a number of options and they have made an offer to Doncaster Metropolitan Borough Council (DMBC) and Rotherham Doncaster and South Humber NHS Foundation Trust (RDASH). In return for free office space the group could provide free support and advice on policy developments in Doncaster.

The current system misses out on the skills and talents that people bring to the world and can share with each other.



## 2. FIND AN ACTIVITY SPACE

The group are seeking a community space as a hub where people could do the office based work needed and run meaningful classes, offering a meeting place but not 'day centre' provision. If they could access a free activity space for community activities the group could coordinate free self-resourced activities, clubs and other opportunities for peer supporters.

### For example:

- ❖ Fitness and exercise
- ❖ Cooking, eating and sharing food together
- ❖ Drama, creative arts
- ❖ WRAP - planning and supporting each other
- ❖ Marketing and promoting wellness in the community

## 3. CREATE A HUB FOR THERAPY AND COUNSELLING

If the group can access around £50,000 per year it would be able to set up a space and service providing mutual support and counselling for the whole population of Doncaster. This would be a highly efficient, low-cost service and could reduce costs elsewhere in the system.

### This would include:

- ❖ Support to use WRAP, Acceptance Commitment Therapy (ACT), Talk for Health and other person-centred therapies

- ❖ Drop-in peer support for local people with mental illness
- ❖ Group therapy and other collective supports, e.g. 'knit and natter group'
- ❖ Training for local people, professionals and services

RDASH have agreed to share training opportunities with the group and to support the group to deliver WRAP facilitation.

#### 4. CREATE A HUB FOR BROKERAGE

Currently people do not get the chance to use peer support to get advice and support about how to plan support, find the right services or manage budgets.

**The group intends to develop a community brokerage hub for Doncaster where it can use its expertise to:**

- ❖ Help people to develop their own plans, as individuals or in groups
- ❖ Give people access to information about community services, and use systems like Shop4Support
- ❖ Maintain a database of local resources
- ❖ Share good examples and innovative thinking
- ❖ Provide practical assistance or referrals with employment and finance issues.
- ❖ Manage budgets for people who can't have direct control
- ❖ Customer feedback to commissioners on local innovations and quality issues

So far DMBC and RDASH have agreed to look at opportunities for their employees to spend time with the group to learn about different ways of working. The group is currently seeking funding of £75,000 per year in order to deliver the community brokerage hub for local services in and around Doncaster. This is a small fraction of the cost of the current care management systems in health and social care.



It is easier to believe in the possibility of recovery from the experience of someone who has been as low as you.

## 5. PREVENTION WORK

The group aims to provide a community prevention service and they are seeking £40,000 per year, in return for:

- ❖ Extending and strengthening *Support Buddies* across the whole community
- ❖ Providing peer support to stay out of hospital and to leave hospital earlier
- ❖ Connecting to community services and organisation across Doncaster to help teach people about mental illness, wellness and prevention support - wellness not illness

This work could be funded from savings from reduced hospitalisation. It is to be noted also that hospitalisation rates are increasing nationally and that unless preventative action is taken there is a severe danger of more funding being driven into crisis solutions.

## 6. ADVOCACY

The group is naturally a source of individual and system advocacy. Ideally this should be recognised and supported by DMBC and RDASH as each should be seeking feedback on the current system in order to improve the system. Currently the group feel their voice is not welcomed and that statutory services are behaving in an unduly defensive way. Grown-up conversations should be taking place and there should be a real willingness from paid professionals to make themselves accountable to peer supporters and to see this as an essential and positive part of their role.

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## Investment

One of the most interesting questions that will arise if any positive relationship between the group and statutory services develops is how any investment in the PFG would actually work. Officers of the statutory services have described the possible relationship as that between “commissioner and provider” however it is not clear that this makes sense.

The language of procurement, tendering and purchasing that is used by statutory services seems to suggest that local community organisations are products that can be purchased off a shelf. However the reality is that these organisations already exist in their own right, they already bring value to their communities. They do not want to replace what they do for free with funding from statutory services - instead they want to “coproduce” new and better solutions - combining their own considerable resources with the powers and resources of the system.

The difficulty that statutory bodies face is that they are locked into a model of purchaser-provider service delivery that was invented in the early 1990s but which has had only limited success. This has become one of the reasons why statutory bodies across the UK have struggled to integrate citizen-led initiatives, like the PFG, into the top-down approach to commissioning that has become prevalent.

However, positive change is possible and there are real possibilities for making progress. Instead of treating the PFG as if it were just another commissioned service it will be

necessary to treat it as a community enterprise, part of civil society; one where modest investments from statutory partners can reap rewards that are much greater than those that can be purchased by a system of ‘tendering’ (see Figure 11).

**The key paradigm shift is to:**

## STOP PURCHASING SERVICES – INSTEAD INVEST IN YOUR COMMUNITY

Investment in the PFG, which may be as simple as working together to make better use of under-used buildings, would be a powerful and efficient way of improving outcomes in Doncaster. Treating ULOs as independent community enterprises - not as commissioned services - is vital in order to ensure ULOs can provide an independent voice, with creativity and flexibility.

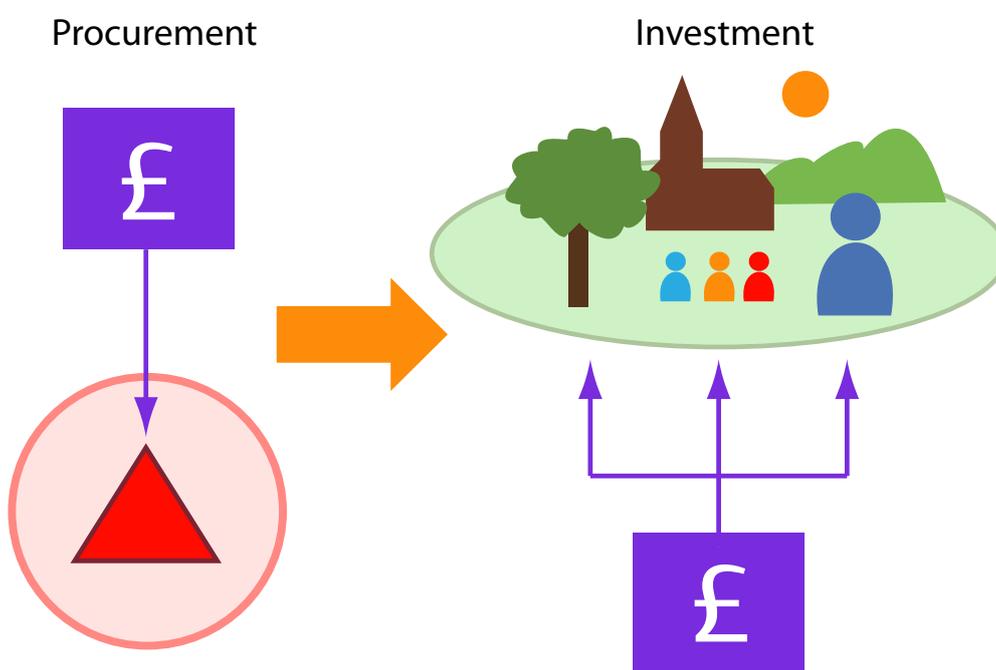


Figure 11. From procurement to investment

## Chris' Story - daring to dream of a future

I have had difficulties with my mental health for a long time. I hit rock bottom and ended up losing my employment and any hope of ever being able to return to work. For a long time I have felt worthless and struggled to see any kind of a future for me.

I have been a member of the PFG since the very beginning. As a group we have faced many challenges and it hasn't always been easy. I have given lots of my time to support my peers. I provide transport, have helped people to move house, supported people to attend appointments and much more. I have been getting involved in community projects and have really enjoyed supporting the planting

project at the Wildlife Park. Without the support of my peers I would not have been able to do this but I am now finding that I dare to think about a future; a future where I can see my own value.

I have been to a lot of mental health projects and as well meaning as many are I never felt that they really understood me or could provide the practical support I needed. Developing our own organisation has meant that we have been able to shape the support we need and be hands on in providing support. I feel like I have something to give and now I am not just dependent on others.

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# Conclusion



# Conclusion

Today the Personalisation Forum Group (PFG) is a good example of a User-Led Organisation (ULO). It is at an early stage of development, but has already achieved much. It has developed significant levels of self-help and made a difference in its community. It has challenged the existing mental health system, but it is seeking a positive relationship. It has clear plans for the future, but knows how to respond to opportunities as they arise.

It is also possible, to some degree, to draw out some more general lessons about ULOs from the groups experiences. So, we have tried to answer some more of the questions we posed at the beginning of this report about how to foster and work with ULOs.

## 1. HOW SHOULD PROFESSIONALS BEST ENGAGE WITH ULOS?

**The short answer is - with respect.**

Professional and public bodies are funded by the tax-payer in order to provide appropriate support to people with significant needs. But when those people get together, organise their own support or try to make the system accountable to them then they are faced with incomprehension or suspicion. This is unacceptable.

It is challenging for professionals, who are often used to power and control, to make themselves accountable - to work as equals - but it is the only successful way forward. The work of Kelly Hicks in supporting the PFG demonstrates that real change and meaningful and respectful work is possible. It is time that it becomes the norm.

## 2. WHAT MAKES A ULO PASSIONATE AND MOTIVATED?

The primary lesson of the PFG is that if the group starts to believe in its own strength, in its own capacity to provide help and assistance to its members then the possibilities are limitless. This shift from a merely political 'talking-shop' to a practical form of self-help is vital. This does not mean the other roles are irrelevant.

**The productivity of the groups commitment to self-help seems to flow naturally into:**

- ❖ Championing positive change
- ❖ Advocating for people's rights
- ❖ Developing business opportunities
- ❖ Building wider networks

However, without the kind of practical and self-reinforcing energy created by *Support Buddies* it is unlikely that the PFG could have sustained its energy.

### 3. WHAT ARE THE BARRIERS FACING ULOS AND HOW DO YOU GET ROUND THEM?

The primary barrier may be internal - it may lie in the tendency of oppressed groups not to believe that they, themselves can bring about positive change. Once the group was able to redefine its goals in a way that it could control then progress became possible.

There may have been several ingredients to why this happened in the case of the PFG - but it is hard not to think that the role of Kelly Hicks was vital. In this case a facilitator who understood what that really meant and how her role had to be empowering - redirecting anger towards achievable goals - helping the group listen to each other and gain strength from each other.

### 4. WHAT CAN A ULO ACHIEVE?

National and international experience suggests that there are no known limits to what a ULO can achieve. The birth of Independent Living and the radical transformation of the lives of millions of disabled people began when disabled activists came together in California at the end of 1960s.

The PFG is just beginning to stretch its wings. What makes the PFG unusual is the way in which it thinks big - but acts practical. If it can continue to keep alive this powerful combination of qualities it may be able to help bring about a similar revolution in mental health services as disabled people are now bringing about in their support.

### 5. HOW CAN A ULO DEVELOP AND EVOLVE?

**The PFG offers several patterns of development for a ULO, and arguably it is important to maintain some balance between each:**

1. **Self-help** - this can become stronger - although as it grows it may need to change shape and develop a more cellular structure.
2. **System advocacy** - helping society and public bodies to imagine a better system for everyone.
3. **Direct advocacy** - ensuring people get what they are entitled to, challenging bad practice and helping people stick up for themselves.
4. **Business development** - reaching out to community, looking for opportunities to people to produce solutions together, bringing together people with the same needs.
5. **Network building** - creating broader alliances for change, both within and beyond any initial community.

Success in any or all of these areas will always bring new challenges. It is still early days for the PFG. It may have to find new forms of discipline, organisation or different shapes for how things are organised. But the process of honest reflection at the heart of its work seems like a good basis for future progress.

## 6. WHAT'S THE BEST PARTNERSHIP FOR A ULO AND STATUTORY AGENCIES?

This is the hardest question to answer for the PFG. There has been so little partnership and so little progress that it is impossible to do anything but imagine a better future where statutory partners begin to treat local communities with respect.

**If statutory agencies are going to move away from their current patronising, wasteful and institutional approaches then they will need to really respect their own communities:**

- ❖ Stop talking about tendering and procurement - start building real partnerships
- ❖ Stop undermining local citizens - start respecting and celebrating local achievements
- ❖ Stop wasting money - start reforming their own services in partnership with local people
- ❖ Stop consulting people - start shifting real power and control to people

**Organisations like the PFG set new standards in what is possible. It is time the system, and all those paid handsomely to work within it, begin to step up to their challenge.**



Professionals and statutory organisations must not just respect peer support they must understand that enabling peer support is an essential part of their role - it is the heart of social work.

# Useful Resources

WRITINGS, FILMS, WEBSITES, RECENT PUBLICATIONS



# Useful Resources

The Personalisation Forum Group will also prepare an accompanying DVD to support the dissemination of information from the case study.

## WRITINGS

- Alakeson V (2011) *Active Patient*. Sheffield, The Centre for Welfare Reform.
- Campaign for a Fair Society (2012) *Manifesto for a Fair Society*. Sheffield, The Centre for Welfare Reform.
- Crisp N (2010) *Turning the World Upside Down*. London, RSM Books.
- Duffy S (2010) *Personalisation in Mental Health*. Sheffield, The Centre for Welfare Reform.
- Fulton K & Woodley K (2011) *Help and Connect*. Sheffield, The Centre for Welfare Reform.
- Friedli L (2009) *Mental health, resilience and inequalities*. Copenhagen, World Health Organisation.
- Glasby J & Lester H (2010) *Mental Health Policy and Practice*. London, Palgrave Macmillan.
- Hicks K (2012) *Support Buddies*. Doncaster, Personalisation Forum Group & SMART Social Work Practice.
- Murray P (2010) *A Fair Start*. Sheffield, The Centre for Welfare Reform.
- NHS Information Centre (2010) *Mental Health Bulletin*. London, The Health and Social Care Information Centre.
- Personalisation Forum Group & Hicks K (2010) *Manifesto*. Doncaster, Personalisation Forum Group.
- Vidarthi V & Wilson P A (2008) *Development from Within*. USA, Xlibris.

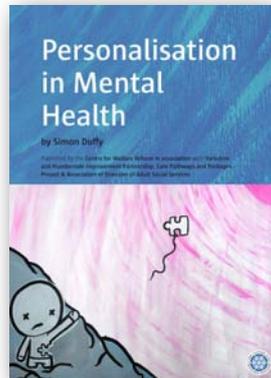
## WEBSITES

- Personalisation Forum Group [www.pfgdoncaster.co.uk](http://www.pfgdoncaster.co.uk)
- The Foundation for Families [www.foundationforfamilies.org.uk](http://www.foundationforfamilies.org.uk)
- The Centre for Welfare Reform [www.centreforwelfarereform.org](http://www.centreforwelfarereform.org)
- Campaign for a Fair Society [www.campaignforafairsociety.com](http://www.campaignforafairsociety.com)
- Small Sparks [www.seattle.gov/neighborhoods/nmf/smallsparks.htm](http://www.seattle.gov/neighborhoods/nmf/smallsparks.htm)
- SMART Social Work Practice [www.sswpractice.com](http://www.sswpractice.com)

## FILMS

- Taking part in the ULO study: <http://youtu.be/eehx3FFSstY>
- Getting involved in peer support: <http://youtu.be/sgkgs0qpDGo>
- What service users get from peer support: <http://youtu.be/nl3zmJlhbE>
- User-Led activity: <http://youtu.be/bwH4tTsrIFl>

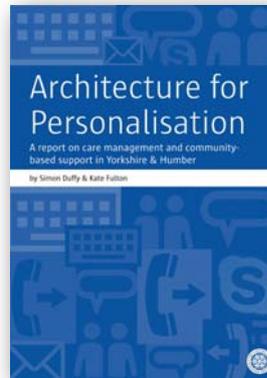
# Recent Publications



## PERSONALISATION IN MENTAL HEALTH

Despite the evidence that personalisation's impact in mental health is more positive than in any other field progress has been too slow. This guide offers practical ways forward.

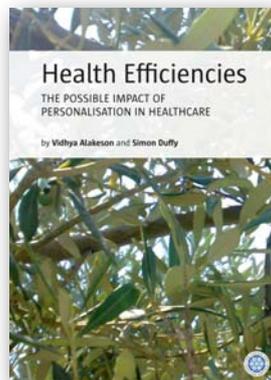
[www.bit.ly/p-mentalhealth](http://www.bit.ly/p-mentalhealth)



## ARCHITECTURE FOR PERSONALISATION

Underpinning personalisation must respect for communities, peer support and all the capacities of people themselves. It is not a new field for professionals, but an opportunity for community development.

[www.bit.ly/architect-pers](http://www.bit.ly/architect-pers)



## HEALTH EFFICIENCIES

Personalisation could not just transform our experience of mental health services it could improve support to people with chronic health conditions and bring real dignity at the end of life.

[www.bit.ly/health-efficiencies](http://www.bit.ly/health-efficiencies)



## PEER SUPPORT

Peer support comes in many different forms and this publication describes a range of different models that are currently helping people stay in control and to get high quality support beyond the professional system.

[www.bit.ly/peer-support](http://www.bit.ly/peer-support)





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