

THE personalisation forum group



manifesto

Date: 10th November 2010

Everybody's Mental Health Matters





*“for far too long, mental health has been seen as a Cinderella service, when in fact it is critical to helping people achieve good quality, well balanced lives... I do hope that the **Personalisation Forum Group** go from strength to strength”*

Ed Miliband MP, Leader of the Parliamentary Labour Party



“It is always heartening to hear of groups such as this who have taken it upon themselves to support each other, represent their shared needs and bring their depth of experience to the local debate. I particularly endorse your approach, which highlights the crucial importance of personalisation, choice and control. I wish you well”

Paul Burstow MP, Minister of State for the Department of Health



P.F.G

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We would like to thank Simon Duffy from The Centre for Welfare Reform who has supported us, provided encouragement and helped us to view the bigger picture.

We would also like to thank the many individual group members who have contributed not only to this manifesto but to the ongoing work. We are proud of this group effort, but special thanks go to:

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A full list of members involved in this manifesto who wished to be identified is included at the back of this document.



Introduction

This is the Personalisation Forum Group's **Manifesto**. We agreed that this would be our document and it sets out the values, goals and intentions of the group.

This paper is written to explain what the group is all about and why we believe in the group's objectives.

We have aimed to provide a clear, plain English language document, so that everyone can understand it.

We hope that anyone who reads our manifesto will seek out more information on our work and be encouraged to join or support the group.

This is a citizen manifesto that we intend to be a powerful document. We hope that it will help to stimulate greater public discussion.

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.

Quote from Simon Duffy from The Centre for Welfare Reform

Personalisation means a radical rethink about power and control in public services. This is difficult and challenging at the best of times. What is so exciting about this Manifesto is the way in which the group are confidently demanding their rights; but what is even more impressive is the spirit of mutual cooperation and social contribution that the group demonstrates. This is not about people asking for more for themselves - its about people working to ensure that they can each give something back to the whole community.



Who are we?

The Personalisation Forum Group aims to work together to promote more personalised services and support options for people with mental health difficulties. We are a service user group run by people with mental health difficulties for people with mental health difficulties. As a group we commit to continue working together to reduce stigma and to promote recovery, independence and social inclusion.

Why did the group come together?

The Personalisation Forum Group evolved from a number of individuals who were seeking to access more control over the support they received to live with their mental illness. The individuals highlighted the fact that people with mental illness in Doncaster were not afforded the same rights available to all other vulnerable groups to self direct their own support. The individuals felt that their experience of traditional services was inefficient and ineffective. It is believed by the group that a greater emphasis should be placed on a social model of mental illness.

It was identified that gaining access to mental health support in Doncaster is complex and confusing with a number of barriers adding to inequality. The individuals felt that as lone citizens they were powerless to affect any positive change. Most people described already feeling over burdened and challenged by the daily management of their illness and had little energy left to ask for their rights to

be upheld. The individuals agreed that by working together as a group of citizens that they could find strength in each other and share the responsibility of making a positive contribution for all people in Doncaster who suffer from ill mental health.

What is Personalisation?

Personalisation is about giving people much more choice and control over their lives and goes well beyond simply giving personal budgets to people eligible for council funding. Personalisation means addressing the needs and aspirations of whole communities to ensure everyone has access to the right information, advice and advocacy to make good decisions about the support they need. Personalisation means ensuring that people have wider choice in how their needs are met (SCIE, at a glance 29, October 2010).





Why is mental ill-health important to people in Doncaster?

One in four people experience mental distress at some time in their lives and a third of all GP visits relate to mental health (A Review of the Evidence, MIND, 2008).

Doncaster has a current population of around 291,000 individuals of which 147,600 are female and 143,400 are male (Office for National Statistics, 2007). Using previous age range estimates (census 2001) we can assume that 79.1% of the population are over 16 years of age.

The incidence of the most common mental disorders (anxiety and depression) has been shown to be consistently associated with unemployment and measures of poverty. Poverty and deprivation are most frequently associated with lack of employment. Poverty and unemployment increase the duration and frequency of episodes of common mental disorders. The decline of the coal mining industry in Doncaster has significantly increased levels of unemployment throughout certain areas of the Borough. The DETR Indices of Deprivation provides key information on the most deprived areas in England. There were 354 Local Authority districts used in this measurement. Doncaster is ranked 39 (1 is the most deprived ranking).

The number of lone parents in Doncaster is currently 3900 (source Doncaster Council, 2008). There is much research (Cooper et al, 2000, Crosier et al, 2007) to suggest lone mothers experience higher rates of psychiatric morbidity. 'Lone mothers are twice as likely to have a common mental health disorder or to be depressed as other women, and this seems

particularly linked to greater financial strain.' (Cooper et al, 2000).

Rotherham, Doncaster and South Humber Mental Health Trust (RDaSH) report that it works with approximately 4,500 people in Doncaster. Through understanding national research and the individual stories within the group we estimate that this is only a small percentage of the actual people in Doncaster suffering from mental ill-health.

A national pilot of Personal Budgets took place in 2007-2008 across all groups of disabled people. 14% of service users in the pilot were people with mental health support needs. This group had the most positive outcomes in terms of their overall well-being, and a tendency to work towards better psychological health. Research demonstrates that given the opportunity and sufficient support, people with mental health needs use Direct Payments imaginatively and effectively, on the whole.

People with mental illness in Doncaster have not been able to access a Direct Payment despite the law stating that they have an entitlement to be considered for one. Doncaster Metropolitan Borough Council asserts that it transferred its statutory functions to RDaSH for the mental health client group under partnership arrangements. RDaSH do not provide Direct Payments to people with mental ill-health in Doncaster. The group has worked together to challenge this position and has sought out appropriate legal representation to help it address this discrimination and disregard of statutory obligations.



The group also challenges the information presented by RDaSH which states that it is the intention to provide Personal Budgets in March 2011 but restricted to the most complex of needs only. The advice to the group is that this is unlawful and not consistent with the statutory provisions governing direct payments and eligibility. The group's view is that such a policy makes little practical or economical sense in any event. The group believes that personalised support, focused on early intervention and prevention, will ultimately provide the most positive individual and community outcomes, as well as demonstrating more cost-effective use of public funds.

The group has also identified that the process for obtaining an assessment of their full needs is complex and confusing in Doncaster. Individuals' accounts demonstrate that there appears to be no clear and consistent route to assessment for people who have mental health needs, particularly where there are accompanying physical needs and other 'social'

care needs. The group challenges the logic behind what is viewed as a 'health' need and what is viewed as a 'social' care need since this appears to be the root of the confusion. The group supports an assessment of need that views the person as a whole without an arbitrary division of which need should be met by which agency – as that must surely be the point of the Care Programme Approach and Joint Working.

The group recognises that the medicalised model for treating mental illness offers valuable support but believes it should operate alongside recognition of the social impact of mental distress. The group believes in promoting personalisation as a positive model because it supports a social model for understanding mental ill-health – a model which recognises the importance of social factors in contributing to mental well-being. Personalisation supports a user-centred concept of 'recovery', in which recovery is a personal journey of learning to live well, despite the continuing presence of mental health support needs.

The group believes that public resources could be channelled more effectively into promoting the overall well-being of individuals and the local community. The group aims to demonstrate how this can be achieved practically.





The group's aims, principles and values

- * We will remain open to anyone who has an interest in supporting the personalisation of mental health services. The group will always recognise that everyone has individual talents and skills to bring to the group. We will always respect diversity and support everyone's involvement.
- * We will always be supportive of working with health and social services but will always retain our independent identity and value base.
- * We will demonstrate a clear value base and commitment to improving and developing our local community. We will provide practical, creative and effective application of personalised support options to improve individual and community growth.
- * We will work with others, including local businesses, existing support providers and individuals, to raise awareness of personalisation.
- * We will work to develop peer support initiatives and assist other community groups to develop greater peer support networks.
- * We will provide clear and accessible information and advice.
- * We will maintain a political profile at a local and national level with the aim of providing a positive, influential voice for people with mental illness.
- * We will continue to be a group that shares its work to distribute our learning, experiences and knowledge.

- * We will commit to continuing our learning through shared, lived experience, local and national developments, research and case law.
- * We will remain focused on our core value of promoting greater service user involvement to make individual decisions regarding the use of public money in people's lives.
- * We aim to continue to make a positive contribution to effecting real change.
- * We aim to identify barriers to self-direction and social inclusion for people with a mental illness and create responses which tackle these barriers.
- * Group responsibility will be shared. Any 'leadership' will be supportive and facilitative. All decisions will be shared, with members retaining control.





How will the group achieve their aims?



* The group will challenge negative discrimination on whatever grounds and recognise diversity, whether it be individual, family or community based. The group will challenge unjust policies and work in solidarity by challenging the conditions that contribute to social exclusion and by working towards an inclusive community.

* The group will demonstrate practical cost-effective alternatives to traditional support options, maintaining its value of respect for the use of public funding and demonstrating a 'whole community' approach to development and measurement.

* The group will work to reduce the stigma attached to mental illness by promoting the

positive achievements and the contribution we can make to our community.

* The group will speak out as a collective voice and for those who are unable to speak for themselves.

* The group will create a comprehensive and up-to-date service user-rated directory of information, identifying local services and support options. The group will provide service user feedback on the services, to support others in making decisions. The group will provide a clear example of the criteria used to inform feedback on services, and offer opportunities for services to obtain a personalisation 'check-up' from the group.

* We will collect and maintain examples of good, creative or inspirational support examples to help others think about their needs, and how they could be met.





* We will continue to fund-raise to support our aims and goals.

* We will continue to keep our information up-to-date on line and provide further opportunities for people to be involved through web-based access.

* We will publish the story of the group's journey and developments to provide good practice examples to others thinking about becoming more active citizens and building community

* We will hold regular events, incorporating opportunities for others to share their learning and experience. initiatives.

* We will develop peer support initiatives with regard to support planning, gaining advice and aftercare support.

* We will press for clarity in the application of eligibility criteria and the assessment process in our community for people who suffer with mental ill-health.

* We will work towards developing strategies to reach out to people who are less likely to be able to access personalised services.

* We will create crisis planning guidelines to be used if an individual becomes unwell, with the aim of reducing the likelihood of repeated hospital admissions.





A Peer Support Example:



Within our meetings we look at a range of support needs for people with mental health difficulties and try to find practical solutions to meeting some of these.

Lots of people tell us that having the motivation to cook a nutritional meal is a big daily struggle. It's common for people to go without food, regularly, or survive on unhealthy options. We know that we must look after our physical health and being without energy from lack of nutrition does not help our mental health.

People tell us

that they find it difficult to budget within their income to be able to afford healthy meals.

People have told us that they often turn to comfort-eating which increases weight and reduces feelings of self-worth as well as exacerbating physical conditions.

Lots of people told us that the anxiety and panic attached to having to go out to purchase food often prevents them from being able to shop sensibly.

The Personalisation Group has developed a community-based option to meet some of these needs. The new kitchen at Rebound has been designed and built by service users. As a group we are lucky enough to have a qualified chef as part of our group. Vinny has given his time and skills to leading this project.





The kitchen will offer hot meals to people, offer basic cookery classes within a group setting and on a 1:1 basis too, as well as providing weekly menus and examples of planned and budgeted for shopping. The kitchen will be entirely staffed by service users who will gain qualifications to support them back into the employment market and increase their confidence within the work place. All the food used will be sourced and purchased from our local community. The group has also established a gardening project and intend to grow all of its own organic vegetables to be used in the kitchen. The cafe will support people to learn the skills required to use the internet to purchase food shopping on-line.

The group will be looking to expand this idea to providing a catering option within the community by preparing good quality food for businesses and events.

The group will measure the success of this initiative by:

1. Collecting personal accounts of involvement to determine how individuals have felt that the opportunity has contributed to their well-being.
2. Evidencing the number of people gaining qualifications and new skills.
3. Evidencing the number of people this supports to gain paid employment.
4. Making the cafe sustainable enough to enable re-investment of any profits into other community initiatives.
5. Demonstrating that fewer people will be requiring ongoing public funding to meet needs arising from poor nutrition.
6. Demonstrating that a greater number of people gaining skills to be able to shop for themselves on-line, empowering themselves

as individuals.

7. Increasing our links with the local community by encouraging members of our community to use our cafe.

8. Increasing our business links within the community and developing schemes where we can exchange our fresh home-grown produce for other items essential to the cafe.



Thank you to all the people who were involved and contributed to this MANIFESTO:

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Tony Robinson
Patrick Mcandrew
Vicky Edgley
Tanya Benjer
Chris Pow
Martin Mcguire
Wayne Hancock



Winners of the Great Yorkshire & Humberside Care Awards 2010 in the category of Putting People First.





The group will be invited to the National Care awards that will be held in London early 2011.



This award seeks to recognise a team who have embraced the 'Putting People First' Personalisation Agenda and can demonstrate an innovative approach to empowering people to have more control over the support they need in their lives.





How to contact the group

The group meets at

**Rebound Doncaster
Pillar House
19-21 South Parade
Doncaster
South Yorkshire
DN1 2DJ**

We meet every Wednesday at 2.00pm

We are always welcoming of new people and you don't have to book a place in advance.

**You can contact us by telephone: 01302 349300
By email: andrew@notbonkers.co.uk**

Information about us and all our minutes are available at

www.notbonkers.co.uk