West Dunbartonshire

Survey of people using mental health services 2012

West Dunbartonshire Mental Health Forum

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About the survey

This survey was carried out by West Dunbartonshire Mental Health Forum in autumn 2012. The Forum gathered information from members who are people who use mental health services. We sent 85 forms and received responses from 30 people.

Some people commented that is was good to be asked for their experiences.

“Good to see someone is interested. Thank you for the questionnaire.”

Anne Connor from Outside the Box analysed the information and write this report on behalf of the Forum.

West Dunbartonshire Mental Health Forum wants to thank everyone who took part in the survey.

The people who responded

More of the people who responded were women – 18 people which is 60%.

Their ages ranges from people in their 30s to people aged over 60, with more people who are older:

- 4 (13%) aged 30 – 39
- 7 (23%) aged 40 – 49
- 8 (27%) aged 50 – 50
- 11 (37%) aged 60 or older

How people describe themselves

There is a lot of discussion about the best way to describe people who have expertise of using mental health services. The words that are commonly used have connotations and some people feel strongly about how they perceive and describe themselves and how they want to be described by other people.

We asked people what words they felt best described them, with a list of possible answers and space for people to list another word or phrase.

Service user and survivor were the 2 descriptions that were marked most often.

- Service User – 11 people
- Survivor – 9 people
- Client – 6 people
- Patient – 3 people
- Customer – 1 person
- 4 people marked ‘other’ and their descriptions were: carer, someone with a brain injury and mental health problems, alien and ‘don’t exactly know’.
People’s experience of stigma

We asked if people had ever felt stigmatised or discriminated against. Almost everyone said yes. Only 4 people (13%) said no.

People had experienced stigma and/or discrimination from a range of people and most people who responded listed more than one source. The public and care professionals were the most frequent, but stigma from family and friends is also a frequent experience.

Public – 16 (53%)

Any person in a professional health or care role – 17 (57 %)
  - Service Employees – 6 (20%)
  - Care professionals – 13 (43%)
  - Counsellors – 1 person
  - Doctor – 1 person

Any stigma from their family or friends – 10 people (33%)
  - Family – 9 (30%)
  - Friends – 5 (17%)

Other - 2
  - Through their employment – 1 person
  - Contractors – 1 person

Who people see as their carer

We asked people who they thought of as their carer. For a third of the people taking part, there is no-one taking on that role. 10 people marked no recognised carer and 1 person listed ‘myself’ under the ‘other’ box on the survey form.

Most other people listed a family member – 13 people (43% of all people responding, 68% of those with a carer).

For 7 people a friend is the person they think of as their carer: this is 23% of all people responding and 37% of those with a carer.

A few people noted people who are in professional roles under ‘other’: a doctor, a home carer or a CPN. These were not always frequent contacts – one person noted it was someone they saw once a month.

One person said that they were also the carer for someone else. We had not asked if people also saw themselves as carers, so this could apply to other people too. This may be an area that we can look at in a future survey.

For those people who did have someone who was their carer, we asked if the carer was aware of West Dunbartonshire Carers’ Centre and the services they offer. It
seems that about half the carers know of the Centre: 10 people said yes, 9 said no and 4 people said they didn’t know.

Support to keep people well

We asked about the friendships and activities people had to keep them well, and who they had contact with other than family and friends.

Most people – 27, which is 90% - said they are in touch with some sort of activity. The type of activity most people are in touch with is mental health services or a related organisation. From the few additional comments we received, it may be that some people are including services that deliver therapeutic care in this. This is an area we could explore in more detail if we do a similar survey again.

About half the people responding are in touch with a community group or are doing something else such as community groups or voluntary work.

For some people there were overlaps and links between the types of activities.

- Mental Health Organisations – 20 people (67%)
- Community Groups – 13 people (43%)
- Voluntary work – 8 people plus another person who was starting voluntary work the following week (30% in all)
- Employment – 2 people
- None of the above – 3 people

“Help run a football group for mental health and disability”

“Just starting to find my feet again - starting voluntary work next week”

“More Housebound than I used to be”

A third of people have ever been involved in planning a Recovery-focussed individual care plan.

- Yes – 11 people (37%)
- No – 13 people
- Don’t know – 5 people

This pattern ties in with the people who say their main or only activity is mental health services. It was the people who had been involved in a recovery plan who were more often doing voluntary work and in touch with community groups.

People's health and wellbeing

We asked people about their physical health and whether they had any illnesses. Over half of people (17 – 57%) noted at least one physical illness. Most people listed one or sometimes 2 illnesses, but 4 people listed 3 or more health conditions.
The illnesses covered a wide range – 18 different conditions were listed. Those listed by 3 or more people were: hearing loss, heart problems, diabetes, asthma, Fibromyalgia or ME, and arthritis.

The conditions people listed are mostly what would be described as long-term conditions – illnesses that people have often lived with for many years and where they are looking at ways to manage the condition and its symptoms. They are also conditions which make people less able to take part in everyday activities.

We looked to see if there was a pattern in the ages or other circumstances of the people who had other health problems. It seems that this is something that affects Forum members of all ages, men and women, and people who have various patterns of using other services.

The links between people’s mental and physical health and wellbeing is an issue which the Forum could follow up over the next year or so.

Most people said they do not smoke cigarettes – only 9 people (30%) said they smoked. This is above the rate for the population of Scotland as a whole, where 23% of people aged over 16 smokes (Scottish Health Survey, 2011). But the numbers of people smoking are higher among people in social groups who are less well-off, so the members of the Forum may be smoking at a similar rate to their neighbours.

Those who do smoke would be described as light-moderate smokers:
- 1 -10 cigarettes a day: 4 people
- 11 - 20 a day: 5 people
- More than 20 cigarettes a day: 1 person

Just under half the people - 13, or 45% - responding said they never drink alcohol, and the remaining 55% said they drink occasionally. No-one marked that they drink alcohol frequently. A few people commented that they had drank more heavily before, and some people said how many years they had now been free from alcohol.

**Use of other services**

Just over 60% of people (19 – 62%) had used psychological therapies and another person said they are in touch with Counselling. 7 people said they had not received psychological therapies while 4 people said they didn’t know if this had happened.

“I was prioritised for this years ago. Still waiting.”

Almost half the people taking part are in touch with one of the Resource Centres in West Dunbartonshire – 7 at Goldenhill and 6 at Riverview.

60% (18 people) are in touch with their GP. One person noted they don’t go to their GP because they feel discriminated against.
10 people – 33% - are in touch with voluntary organisations.

3 people marked None of the list of services in the survey form.

**Welfare benefits**

We asked people about the transition from Incapacity Benefit to Employment & Support Allowance (ESA). Most people said no, this had not happened at the time of the survey – 19 which is 63%. 7 people had made the transition, and 4 people said they didn’t know.

**Comparisons with results from earlier surveys**

Some of the issues that are covered here and the questions that were asked are the same as those featured in an earlier survey of people receiving care from the Goldenhill Resource Centre in 2011. The circumstances of the people who were asked are not exactly the same, as the Forum’s members include people who are no longer receiving this level or type of care and may have more people who have lived with a mental health problems for many years.

On some points the results for the 2 surveys were very similar. These included the proportion of people with a carer and who the carers were.

On other points there were marked differences in the results. These could be due to the different circumstances of the 2 groups or to differences in how the information was gathered

- More Forum members said they had experienced stigma – 90% compared to 75%.
- The proportions of people reporting stigma were higher among the Forum members: from the public (53% compared to 18%) and from professionals (20% compared to 6% for service employees, 43% compared to 22% for care professionals).
- For those people who have carers, more of the Goldenhill group said their carer knew of the Carers’ Centre.
- Many more people responding to the Forum survey are in touch with other activities that can help keep them well: 67% compared to 26% for mental health organisations, 43% compared to 16% for community groups and 30% compared to 9% for volunteering.
- More people at Goldenhill were in employment (16% compared to 7%)
- Fewer people at Goldenhill said they had been involved in a Recovery-focused individual plan: this could be down to the timing of the survey and the shorter length of time people had been in touch with services.