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User networks

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**Social Geographies of Rural Mental Health
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User Networks

Introduction

In this paper we explore ‘user¹ networks’ in the Highlands: in other words, we explore the connections which exist between people who use mental health services. Using the words of our interviewees, we firstly document how users conceive of themselves as being bound into distinctive ‘mental health communities’; reciprocal support networks which are generated by the use of a variety of mental health care provision. Secondly, we document the development of ‘formal user networks’ in the Highlands, with a specific reference to the Highland Users Group. Thirdly, we consider in more depth the existence of ‘informal user networks’, the social connectivity that exist between users of services outside of the spaces of formal provision. We conclude by focusing on one study area where substantial user networks have not developed, offering evidence as to why this may be the case.

Mental health service sites and mental health communities

In this paper we explore the ways in which formal and informal services become important sites for the development of user networks:

But the majority of people that you know, you tend to know from the same sort of groups like this [TAG] or travelling day hospital and things like that. So I don't know, we've all got our own sort of groups. So like all the mental health people stay together 'cos they all know each other. They spend certain days or whatever together whereas the rest of the community up here wouldn't really be that bothered. [Larissa, ER, 12/12/01]

In other findings papers, we have illustrated the physical and social isolation experienced by users of mental health services, and the role of formal and informal services in combating this isolation (see findings papers **Formal services** and **Drop-ins**). Larissa's comment neatly summarises the argument put forward in this section, that services play a crucial role in the developing and sustaining user ‘communities’ in different localities throughout the Highlands. Interviewees detail the importance of services such as hospital, drop-ins, day centres and TAG units for the formation of dense social networks of other users from whom support, advice and friendship can be drawn. The development of informal users networks will be detailed later in the documents, but for now we highlight how service sites enable a symbolic identification with what users' call a ‘mental health community’.

Service users often feel themselves to be ‘outsiders’ in the wider rural communities in which they are located, partly because of exclusionary practices surrounding people with mental health problems. However, interviewees counter the notion that they are *always* ‘outsiders’, by relating how they feel bound into other communities, ones explicitly

¹ Throughout the document we refer to ‘users’, denoting users of mental health services.

associated with mental health services. The following quotes emphasise the symbolic and practical importance users attach to such communities:

Interviewer: *Do you feel supported by the community?*

Hazel: *Well, by the mental health community, yeah. I mean, the CPN, the staff at the Cabin, my GP and the practice nurse and whatever and [psychiatrist] I've got nothing to complain about. I think I've been looked after very well.* [Hazel, SL, 13/8/01]

Interviewer: *Do you think the community supports people with mental health problems?*

Meg: *Just the ones that are related to the mental health community. Like the day hospital*

Robin: *I would say we were in excellent contact with [charge nurse], that's our main stay. I wouldn't phone a psychiatrist or a doctor, I would phone [charge nurse]. He would come out and phone the psychiatrist and get us an appointment.* [Robin & Meg, ER, 7/11/01]

What is interesting about the above statements is that these users automatically assume that questions about 'community' relate to health services. We suggest that this reveals less about a mis-communication within the interview situation, and more about an important dimension to where users feel their sense of support and belonging is located. Clearly for the users above, their sense of 'community' is bound up with the practical support of service staff, but for others this relates to their association with other service users:

I suppose The Cabin is a community in itself because they go through a lot of things Yeah I mean, how can I put this, apart from the fact everybody knows everybody's business, people do rally round to help, there is a community spirit, it's not like you are alone. [Collete, SL, 19/9/01]

For most we're all in the same boat. We build lasting friendships in here, we're strong because we're together. For me it's the first time I've been part of a mental health community and I have found it so supportive. We accept people for what they are here. We don't care what their problems or addictions are, it's what we feel here that counts. We don't care what people outside say about anyone. You know what I mean, you accept people. Most people try and leave their problems outside it's a little oasis. First it's an oasis of sanity in a mad world, we're convinced we're more sane than what's walking around the streets so there you go! [Melissa, INV, 14/6/01]

Mental health service sites enable a collective gathering of people with mental health problems, and in this sense they facilitate links between people that may not have been possible otherwise, especially in places where mental health difficulties are routinely hidden as a result of a fear of cultural intolerance. The above quotations signal clearly some key dimensions to 'mental health communities' and these include a sense of 'sameness' (perhaps in opposition to feelings of 'difference' in wider rural communities), a sense of support, and a sense of collective strength. For people with mental health

problems being part of a mental health community might primarily relate to new feelings of ‘insiderness’, and as Melissa says above: ‘*We don’t care about what people on the outside say about anyone*’.

The extent to which a mental health community is present, or has the potential to develop, depends partly upon the availability of services. The study areas vary in the extent to which interviewees discuss the existence of mental health communities, mirroring the provision of uneven geography of service provision across the region (see the findings paper on **Formal services**). As one would expect, Inverness, with its concentration of services, offers the largest and most diverse ‘community’. Within Inverness, opportunities to meet others with mental health problems are opened up not only through the variety of services available but also the relatively close proximity of services, meaning that people can shift between various sites throughout the day:

I’ve got some, some of my friends are in Birchwood. You know it’s like supported accommodation for people that had mental health problems. I’m friendly with a couple of the people in there. [Jackie, INV, 22/6/01]

[I]head for the bus at 9.11 and I am heading generally toward Bruce Gardens and I go to Bruce Gardens and on a Thursday I go to their lunch club and after that I come down here [Cairdeas Cottage] and I spend quite a lot of time, the whole of the afternoon till it closes here. [Thomas, INV, 23/5/01]

Inverness users have more opportunity to connect with a variety of service staff, as well as to develop more informal links with other users. Even the routes between service sites exist as geographies of social opportunity, with users meeting other users on the street:

Just when you’ve been in a hospital, you tend to meet people you’ve been in hospital with, you tend to meet them in town and they say ‘oh come meet my friends’ and then they say, ‘oh I was in Craig Dunain’, you [don’t] only seem to meet the people who have been in hospital ... you meet other people. [Adrian, INV, 11/6/01]

Adrian’s comment highlights the importance of the psychiatric hospital (old and new) as a site for the development of user networks. As Maria comments ‘*most of my friends are ex-patients*’ [INV, 21/5/01]. This hospital based community ‘*stretches all over the Highlands*’ [Thomas, INV, 23/5/01] upon discharge. Thomas’s observation is supported by a number of people who have kept in touch with friends made during spells in hospital; ‘*now I have got a very good mate that I have met in Craig Dunain, we clicked together, we kept each other going and stayed good friends ever since. I phone him up and he phones me*’ [Daniel, SL, 15/8/01].

Interviewer: *When you came back [from hospital], did you keep in touch with those people from the village? Did they come back to the village as well?*

Katy: *Yes, aye.* [Katy, NWS, 9/7/01]

Other study areas do not have the same density of service sites and networks as Inverness. However, similar descriptions of ‘mental health communities’ do arise, albeit with reference to singular or few service sites. While the introduction above highlights

perceived benefits of such communities, there may also be disadvantages. Thinking critically about what being part of a ‘mental health community’ means for service users includes an appreciation of how users can become enmeshed in the routines, politics and personalities of particular service sites. While close connections with service providers and other users can provide much needed support and understanding, over time, these may also represent a rather closed social world in which users only ever socialise and interact with other people with mental health problems. Clearly, a balance must then exist between different experiences of community for users of services, with the ultimate goal surely being that feelings of ‘insiderness’, belonging, support and understanding can be evoked within other geographies, ones quite unrelated to mental health care provision.

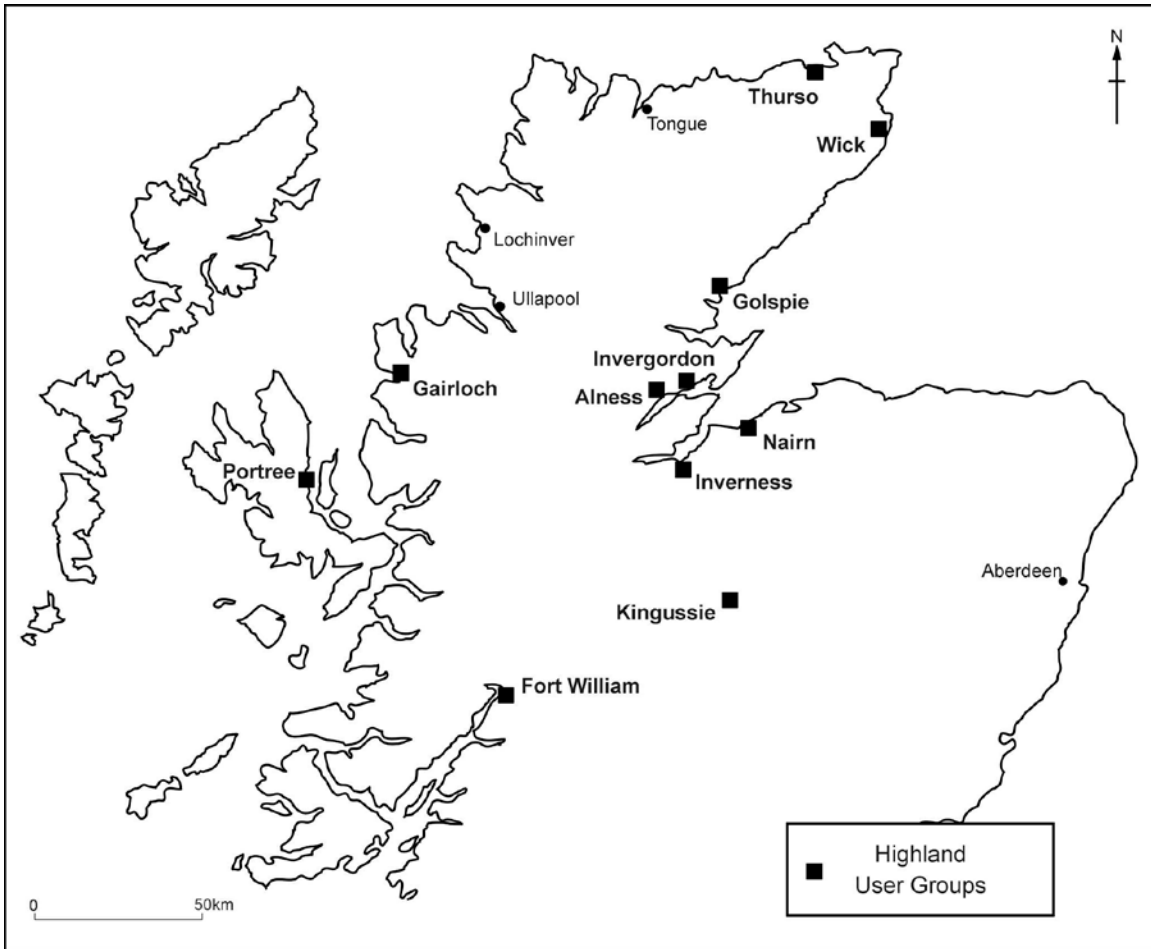
We have only provided a brief snapshot here of the ways service sites are significant in facilitating user networks. Through the following sections we elaborate the different ways in which Highland users are connected.

Formal User Networks

In this section we discuss how mental health service sites in the Highlands have facilitated the development of formal user networks in which people with mental health problems represent themselves and their interests in an organised fashion, usually with the goal of influencing and changing current service provision and policy decisions. Our comments here necessarily focus on few examples, with the most prominent being the Highland Users Group (HUG).

Highland Users Group: the aims and purpose of formal user organisations

HUG aims to ‘represent the interests of users of mental health services living in the Highlands’ (HUG, 1999). Established in June 1996, HUG aims to provide an opportunity for users of service to meet with each other and discuss their needs. HUG has a membership of around two hundred and fifty members, and operates with twelve groups located around the Highlands (see the map below). Two people are currently employed by the Community Care Forum in Inverness to manage and co-ordinate the activities of HUG. Each of the twelve groups holds at least one meeting every two months, often in specific mental health sites such as drop-ins or Training and Guidance Units (TAG). The key paid co-ordinator and/or his assistant attend each of main bi-monthly meetings, seeking opinion and giving feed-back on previous discussions around service provision both at the Highland and local level. These discussions are often represented in reports which focus on different aspects of everyday life for service users within the Highlands (previous reports have covered ‘places of safety’, ‘benefits’, ‘housing’, and ‘the closure of Craig Dunain’ to name but a few). Similar to many user-led organisations (see Beresford and Wallcraft, 1997) one of the main aims of HUG is focused around influencing the planning and management of service provision in the Highlands. HUG also has a commitment to informing users of services about their rights and aims to challenge discrimination against those with mental health problems.



Map 1: Location of Highland User Groups²

HUG feeds into debates about the planning of the Highland services landscape through a number of mechanisms, not least through its association with the Community Care Forum. In particular, it has been involved in discussions around the closure of Craig Dunain, and contributed to the consultation process relating to the Millan Report, and is currently involved in implementation meetings of the Highlands Mental Health Framework. HUG occupies an important position within the mental health scene in the Highlands, acting as a voice for users throughout the region and providing service providers with a recognisable and accessible organisation for the channelling of user ‘voices’.

User opinions are central to HUG and the organisation provides a forum in which people can feel comfortable to voice their opinions and thoughts as noted by Clara:

Having gone across the whole of Highlands and in informal situations got people to speak up, who normally wouldn't have said very much and gained a knowledge from folk that are suffering [Clara, ER, 27/11/01]

² Please note two groups are held in Alness.

HUG's commitment to listen to user opinion across the region is facilitated through the travelling of two paid employees over great distances. This is a point re-iterated by Peter: *'He [the HUG co-ordinator] will sit and listen to what you are saying ...'* [Peter, ER, 12/11/01]. Clara suggests that HUG taps into user experiences and opinions that are not usually available to service providers. Often those with mental health problems can have problems expressing opinions. HUG opens up an opportunity for users to express opinions in a supportive environment. For those who are active members of HUG, affiliation to the group has not only provided an awakening of a political consciousness, but a growing sense of confidence in themselves, as Clara continues:

For me it gave me a lot more confidence because I hadn't spoken out much ... [the co-ordinator] asked 'would you come along and maybe join in some of these and if you feel like speaking do it and if you don't it's not a problem'. So yes it has done a lot for me in that respect. It gave me back some of the stuff I had lost [Clara, ER, 27/11/01]

For some, affiliation to HUG offers access to opportunities to be heard by service providers in ways that would perhaps not be possible otherwise:

I want to see the services change and so far I've been trying to do it by banging on at individual nurses and doctors and they're not going to change. You can feel you're stretching yourself out that way, you [are] against everybody. Whereas through HUG it's an organisation and people give it time that they wouldn't give to me as an individual. I went and gave a talk to a GP's practice and they wouldn't have listened to me if I had just phoned up and said, 'Hey I have something to say'. [Maria, INV, 21/5/01]

I expect to join HUG and speak for those who can't speak for themselves. They can't exactly slap me in a corner if I've got a degree, they're going to have to listen. [Melissa, INV, 14/6/01]

Melissa and Maria's comments reflect their ideas about the opportunities and potential for change offered through HUG's legitimacy with service providers throughout the Highland area. Clearly HUG plays an important role in being a supportive medium through which user opinions on the provision of service in the Highlands can be fed back through to health care professionals. As noted by Michelle:

I think they have very strong support, a very good image, I'm not sure that's the right word. Very effective role, I think they are listened to [by health care] and do a very good job in managing who does what. [Michelle, INV, 11/05/01]

Apart from the effective role HUG plays in gathering legitimate voices for service change, the organisation can also be seen to facilitate the empowerment of individual users through the sharing of information:

Interviewer: *Would HUG have any relevancy for you - as an organisation which seeks to link users of services across the Highlands?*

Gareth: *well it's the sharing of information that's important - because you're isolated - and not much is known about what is available - then if there are*

groups that push people to relevant agencies - then the more likely they are to get the kind of help they need [Gareth, NWS, 2/7/01].

While there are many dimensions to the benefits of HUG as an organisation, we will now turn to some of the perceived problems as raised by interviewees.

Limitations and the further potential of HUG

While HUG facilitates the essential representation of users voices at key moments in the organisation of mental health services in Scotland (such as in Mental Health Framework implementation meetings), individual users can find the process of involvement difficult:

I think at some times it can be a wee bit too formalised, there are too many people there and they just feel a bit ... I haven't got something to give. There are far too many professionals there and not enough users. I don't know how you get round that to make them feel comfortable [enough] to make a contribution. I'm cynical about they have got their wee qualification and covered these courses and this is fine and there is a complacency amongst management, yes we are reaching out and getting feed back, I would question the validity of some of that. I really think they are just confirming what they think selves and what they have said ' we have consulted and we have asked'. I'm not sure it's as widespread as they would like to think. I'm maybe being a bit unfair but that is how I see it. [Clara, ER, 27/11/01]

While this quote is critically directed at service provider responses to user consultation processes, it does raise issues about the realities that lay behind the impact of collective, regional user voices. It may be that in responding to 'regional' user representation, local needs of users are sometimes over-looked. This is certainly not the intention of an organisation like HUG, whose very structure reflects the need for local, but co-ordinated user voices. However, it may be that when responding to HUG representation, service providers risk collapsing varied voices and needs in a generic 'Highland user' category and thus miss vital differences between user's experiences in different Highland places. An interviewee, below, muses on what impact this perception might be having on local HUG groups:

HUG in Alness doesn't seem to exist at the moment. Before I moved away it was down to about four or five people at [a] meeting, and since I've been gone, there's nobody. ... I don't know what it is about Alness, but I get this sort of feed back, because I've been saying to people how are you getting on ... but it doesn't actually achieve anything, you know, and that's the sort of feedback that I've been getting from people. Whereas most of the Highlands seem to have quite high groups, and I don't know why Alness in particular has just got so lethargic about doing anything. I think you know, in Inverness you actually see more changes, they've got the out-of-hour's service, they've got the new hospital and whatever. [Miriam, ER, 13/11/01]

Miriam's comment raises an important issue around the visible impact of HUG achieving change. The impact of HUG voices is more likely to be obvious in Inverness as it is here

where most services are located. The uneven geography of mental health service provision in the Highlands, then, may effectively call into question the possibility of a meaningful regional user identity and imagination, as progressive change may only visibly occur in particular places. The stated aims of the mental health framework policy for the Highlands includes a de-centralised strategy for services (which may help HUG in this regard), but how this is translating into real change for users in the rural Highlands has yet to be seen. As Miriam reiterates with regard to local HUG groups: *'I think it's [that] a lot of people are just lethargic, you know, can't be bothered. You know they don't see it as a direct influence, they don't see any affect on their lives improving, so why bother'* [Miriam, ER, 13/11/01]. For other interviewees, the different levels of involvement of users with HUG was related to their understanding of how their views contributed at a strategic level. Below, Danny argues that most users do not really understand how their views make a difference:

Well, non-activists are not aware of the framework, simply ... I would imagine people who use the mental services haven't heard of the framework ... they [HUG members] have a voice through HUG and they identify what is important for them. It would be nice if they knew about it feeding into the framework. [But] I don't think it matters particularly [to be] aware of things at a strategic planning level. [Danny, INV, 14/5/01]

Although for Danny this is not a great concern, it may be that for others this lack of awareness acts as a barrier to further participation and hence lead to disillusionment with HUG as an organisation. While there can be no doubt that HUG acts as a catalyst, helping to turn some users into 'activists', the fact remains that few of our interviewees have anything to say about HUG and this suggests that it still has to raise its profile and demonstrate its purpose within its own constituency. Although the lack of visible improvements in some places may be a reason for lack of active involvement and support of HUG, other factors can also be gleaned from interviews with users.

Despite the enthusiasm and active participation of a number of users around HUG, many interviewees have either never heard of it or have a vague understanding of what it is: *'I think so, yes, that's right, because it is for the whole of the Highlands isn't it?'* [Eleanor, SL, 20/8/01]; *'Yeah. I heard they'd done a lot of good work. They come here and they have meetings and discuss various things.'* [Hazel, SL, 13/8/1]; and: *'a lot of people talk about this meeting thing called about HUG but I don't know nothing about that'* [Keith, ER, 15/11/01]. Keith's statement raises issues over who, and how, HUG reaches those it claims to represent. Despite little or no knowledge of HUG, a number of users express the need for such an organisation:

Yeah, I think we are needing people who can stand up and say 'look this guy has a mental health problem, but it doesn't make him an idiot'. We need some to stand up and say to the powers that be, depression ... is an illness and we need as much help as a guy who has had his leg chopped off. [Alistair, SL, 17/9/01]

For some, however, their very illness experiences mean that they are unable to participate for some periods of time: *'I wasn't very aware of HUG when I came here at first. It*

wasn't high profile and I think I was too unwell to deal with anything out with this' [Clara, ER, 27/11/01]:

I heard when I was in the hospital and when I started going to The Cabin and that. They would have meetings and that. I went to one HUG meeting and they were talking about mental health problems, but I didn't really take part in it. I wasn't exactly well that much. [Rebecca, SL, 16/9/01]

I just ... I don't want to know ... about groups ... I think I went to one of the meetings ... but I was that sedated I didn't have a clue what they were talking about ... but then I went to one last year in the hospital and I think I must have scared him, I was ranting and raving. [Charlotte, NWS, 10/7/01]

Such descriptions suggest that illness experiences can mean a perceived isolation and non-participation even within HUG groups, and this highlights a question as to whether there is a need to facilitate very ill voices in such groups. Clearly, HUG does provide an inclusive forum in which users *are* supported, but the extent to which all people with different mental health problems can access this form of representation is an issue. Thomas suggests that HUG maybe of more relevance to those well enough to participate: *'Perhaps at their stage in their recovery if you like, they are not wanting to come to Bruce Gardens or Cairdeas, perhaps they want to go to HUG.'* [Thomas, INV, 23/5/01].

For those actively involved in HUG, it provides an opportunity to 'see the bigger picture' rather than focusing solely upon their own problems, as Miriam comments: *'I've always been one that tries to look at the bigger picture. I think a lot of people are very sort of, 'if it isn't going to change my life why should I give my time?'*' [Miriam, ER, 13/11/01]. However, for many, coping with their day to day life is enough of a struggle, while for others, involvement in the organisation focuses upon aspects of their identity that they would rather forget, conceal or move on from:

I suppose being involved in HUG you are prepared to stand up and say this is what it is like having a mental illness, this is my experience. Whereas there are lots of other people it is a part of their life they want to forget about or move on from. [Michelle, INV, 11/05/01]

I just want a life - where I take my medication, look after myself, hopefully just get a job or a course or go on to university and to be well ... and I feel quite selfish at the moment and don't really care about other people. [Charlotte, NWS, 10/07/01]

Justine concurs with this point of view when she discusses the Hospital Patients Council, based in Inverness:

There is a patients group in the hospital and [I] can get involved. But I haven't accepted that I, I do accept that I've been ill, but I suppose I'm not embracing mental illness, I want to move out of it. It's silly, it's daft really. It's just great to speak to people here [TAG], just have some commonality that sort of thing.

But I suppose I am a bit, finding it difficult to come to terms within myself. Hopefully that will change. [Justine, INV, 14/6/01]

In other words to become an active member of a group like HUG involves identifying yourself as a user of mental health services, something which many of those interviewed are reluctant to do (see findings paper **Visibility, gossip and intimate neighbourly knowledges**).

In concluding this section, we note that HUG faces a particular challenge of operating in an area as vast and diverse as the Highland region, it is difficult to ascertain and retain a sense of a common cause. The lack of service sites in rural and remote parts of the region also make it more difficult to bring people together and facilitate a sense of a political consciousness in ways that effect real material change in all Highland areas. Related to this point, people may know of meetings, but problems with transport and travel may rule out the opportunity to get involved. Fear of exclusionary practices within local communities may also stop some from being open about their mental health status and hence becoming involved in organisations such as HUG. Below, Josephine discusses the conditional possibilities of raising mental health awareness through HUG activities in her area:

Josephine: Well you would have to have a bigger group of people who would support each other to say that we use those services, it is difficult to break the barrier if you are on your own ... and to say - that we are not sort of 'ga ga' - we are normal people - you would not point us out in a crowd

Interviewer: If there were those kinds of activities going on here, would you participate?

Josephine: (pause) I think it takes a special breed of people to get involved in all that sort of thing ... [Josephine, NWS, 4/5/01]

The different social and environmental contexts that Highlanders find themselves in may mean that a lack of comparable service experiences across the region acts as a divisive force to collective use representation. It may be that for HUG to work more effectively on a local as well as regional level, service providers have to be more responsive to the differences between user voices as well as the similarities amongst them.

Other formal user networks

While HUG takes on the most overtly 'political' role in the Highlands through its placing of itself as representative of all users of mental health services, other groups do exist, albeit only in some areas.

Within Skye and Lochalsh, an organisation known as SLUG (the Skye and Lochalsh Users Group) exists. SLUG acts as a forum for users to come together and discuss a variety of mental health related issues. Focused around The Cabin drop-in and the Kyle outreach centre, SLUG has 200 members. It also takes part in Mental Health Framework implementation meetings, as explained by Cameron:

Well, the implementation group only started this year and we only had, as I say, the one big meeting in April which you were at and the smaller one in the resource centre. I think there was about 10 or 12 folk, which is to look at what is needed within the community and identify which is the most important. For instance, we were talking about within the HUG group and SLUG buddy system and we put that forward to the local implementation group and the mental health framework brought it forward ... I think it's a very good idea because we have spoke at it, about it, at length and we think it's a very good idea to have somebody in that you know and you can trust until such help arises. They come to your door and say, right, here is your medication. If you can trust them. So they put that back on the plans again, they were going to scrap it altogether, if it hadnae been for me. [Cameron, SL, 25/09/01]

Such examples show that HUG and SLUG can work in partnership and can feed into and inform the shape of present and future services in different areas of the Highlands. However, SLUG is dogged by many of the problems facing HUG, in that only a few users appear to be involved and active in the group:

Em well, I don't know if it's quite in the same league as HUG, but yes it's the same people left to run around and do jobs. For example when I was secretary, Hilary [staff member] was leaving and Matt and Luke and [a] handful of others were running around trying to organise a do for her, the others couldn't be bothered, you know? [Collete, SL, 19/9/01]

The low level of interest in SLUG is highlighted by Cameron's admission that: 'Well, we've no actually had a meeting within SLUG for five months because our chair person's busy doing other things, because the secretary has resigned and the vice chair which means it's all down to me which I'm acting chair, acting secretary and treasurer.' [Cameron, SL, 25/09/01]. Lack of attendance at meetings may not simply be due to little enthusiasm, but can be the result of difficulties of reaching such meetings in an area where public transport is costly and often inadequate. Ralph provides an example of how distances can divide users in the Skye and Lochalsh area:

Yeah, well The Cabin members is actually SLUG. It is quite active ... like the [outreach] centre they have got in Kyle it would be good if the two [The Cabin and the outreach centre] could get together because you don't know what they are doing. There is a lot of debates about that because they [SLUG] have meetings here [Portree] and the Kyle members can't get to them [SLUG meetings] and they are part of it. [Ralph, SL, 18/9/01]

Apart from SLUG, a number of diagnosis-specific groups also exist in the Highlands and are based in the drop-in 'Cairdeas Cottage' in Inverness. No other diagnosis-specific group meetings were held in the other study areas and this may be related to the sparse population away from the main centre, Inverness. This may be because Inverness is the only place where such groups can easily function, due to population levels, relative anonymity and a dense network of users of mental health services orbiting around the Highland capital due to the city's concentration of services. Such groups offer an opportunity for people to share specific illness experiences with others who have gone

through similar episodes, something highly valued by some interviewees: *'It's great that [the CPN] comes and the district nurse comes and the lady from The Cabin comes but I'm desperate to speak to another manic depressive to see how they cope'* [SL, 20/8/01]. It may be that for those in rural areas, the need for diagnosis-specific groups are even greater than in Inverness, although they are more difficult to establish. For those who can access such groups, being a part of a bigger network of users with the same illness can provide a source of inspiration, as Daryl's enthusiasm attests:

Daryl: *Then I went to this hearing voices conference in Dundee, since then I've been quite hyperactive!*

Interviewer: *Why is that?*

Daryl: *Oh it just inspired me. The fact that this guy who set up the conference he has seven voices and he was on no medication and I thought 'that's for me'. The more medication cuts the better I feel.* [Daryl, INV, 21/6/01]

He continues:

It's given me hope for the future. As you know we're setting up a hearing voices group and I'm really getting involved with that and it's my chance to do something for other people. It makes you feel quite useful. You're doing something that not only makes a difference to me, 'cos I feel better. [Daryl, INV, 21/6/01]

Daryl's statement highlights the real differences that can be made to an individual's life through association with particular user networks³. There are many possibilities for the development of specific diagnosis groups across the Highlands, and this is perhaps an area that could benefit from further exploration by existing generic user groups.

Informal user networks

As indicated earlier mental health sites enable the formation of friendship and support networks between users. In this section we examine the dynamics of user network formation and the meanings that people attribute to this process.

For many, the primary importance of service sites is the bringing together of people who accept each other:

'So it's very, I mean like come to a place like TAG I mean you don't have to talk about it, everybody knows you're here because you're having problems. You don't need to unless you want to, it's a common shared thing, that itself is quite a therapy, because you are not competing against anyone'. [Gerry, ER, 29/11/01]

Well, it's not, you feel you're part [of something] when you come down to The Cabin, you're mixing with people who are like yourself, but up the street you are not. [Ralph, SL, 18/9/01]

³ We should emphasise that cutting medication is not an automatic outcome of participation in user groups.

I just come to feel normal again. Some people come to this place have got problems, so this is why I feel normal, everybody has got problems same as me, so I feel normal, don't feel the odd one out. [Keith, ER, 15/11/01].

Acceptance also involves feelings of belonging and normality, emotions that may not be experienced in wider rural communities. These positive attributes of what we previously termed a 'mental health community' may facilitate supportive networks which operate only actually within service spaces. As Simon notes: '*[I] would say maybe not so much friendships [develop] but [there are] people you have a chat with when you come here*' [Simon, ER, 19/11/01]; *When we're here, we only take each other to a certain level, we don't go back to each other's houses we don't get involved in each other lives* [Eve, INV, 30/5/01]; and Thomas observes:

Well I feel very much part of the community in Bruce Gardens and in Cairdeas, they know me and I know them. Also just that very way I said it, there's no one leaning too heavily on each other, they don't lean on me and I don't lean on them. I think there is a definite community spirit alive and well between the mental health people, people suffering from mental health because they always acknowledge each other and from what I said at the beginning, you fall out with no one. [Thomas, INV, 23/5/01]

Some distancing strategies can be detected here between users, some of whom may find other users stressful if they demand too much support and attention. Nevertheless, for others, service sites can provide a meeting place where a higher level of companionship can be found. The ability to share experiences and to express emotions, without fear of lack of understanding or reproach is important for users: '*Other folk from the day hospital, you make friendships with them. It's people you can talk to*' [Karen, ER, 20/11/01], '*I had one girl three years ago and she was manic depressive as well and it was good we shared the bad things but we could have a giggle about things as well*' [Sally, SL, 20/8/01]:

I would talk to a friend that I've met in TAG that I know who have had similar feelings and that, so I suppose that has been useful to be in a centre ... I suppose that's the one thing about having a protected environment, is suppose that's what they are about really. [Justine, INV, 14/6/01]

[Y]ou meet people down in the doldrums when you go there [TAG and the Cabin] and somebody is unable to talk for the day and you may be in a foul mood and down and you know you can be yourself there. Nobody will point the finger at you and say whatever. What happens there and what you talk about stay within these walls. I've never been able to trust anybody and now I have people I can trust, it's good. [Chloe, SL, 21/8/01]

[S]ometimes because if people don't know you feel embarrassed. This is what I find about TAG. I broke down here a few times because I couldn't handle it and they will say 'oh come on we know what it is like' they understand. [May, ER, 12/11/01]

Meetings with other users provide many of the social interactions and feelings of belonging which are missing from users dealings with the wider community. User networks offer the potential to share experiences and speak frankly and in safety about issues that the rest of the community cannot or will not engage with (also see our findings papers on **Highland economy, culture and mental health**). For some, such encounters open up the possibility of friendships which may operate outside of services. However, the ability of users to fully develop friendships outside services is hindered by the logistics of everyday life especially in rural areas. Problems of distance, inadequate transport and limited finances all conspire against users in developing connections outside of the times and places of service provision. Nevertheless, networks do grow out from service sites in rural areas:

Several people down here [The Cabin] go up to the pub and have a drink sometimes, but I don't get into any conversations apart from amongst ourselves, which is more acceptable. [Hazel, SL, 13/8/01]

Maybe arrange to meet a friend in the Granary café, I like going in there, have a blether and coffee [Ken, SL, 19/9/01]

There's a couple two anyway that I could call, sometimes we do ... we have a chat. Maybe somebody has not been in we would maybe call and see if they are okay and phone and things like that. When I leave I will still keep in contact with a few of them which is nice. [Karen, ER, 20/11/01]

Karen's use of the phone as a means of contact with other users, highlights the difficulties of maintaining and meeting up with friends outside of formal service provision. Keith also from Easter Ross, points to the problems in developing friendships, but also the benefits which can be gained through sharing experiences:

If I'm in Dingwall and she [Charmaine] sees me, we always say we will meet up. We haven't done it yet because I haven't been in Dingwall in a long time apart from coming here ... I've got a friend who comes [to the TDH], should have been here today but he was still in bed when the taxi came. I can talk to him because he has exactly the same problem as me. So I think me and him can talk: 'I had that last night' and 'yeah I'm getting it today' you know? We always have a laugh and try to cheer us up about it. He's the only person I can talk to and I don't talk to him that much because I don't see him much. [Keith, ER, 15/11/01]

At a practical level, travelling around Inverness does not pose the same logistical problems as it would in some of the more remote sites studied. Transport is readily available, and there is a possibility of walking to meet other users as the distances are not so great as to be impracticable. As documented earlier, Inverness users are more likely to feel bound into a 'mental health community', and because of this they are arguably less in need of informal user networks outside of formal service provision spaces, due to the relative density of formal support opportunities and the more flexible opening hours of communal service spaces. While we would not want to argue that Inverness users do not

participate and benefit from informal user networks, it is in more rural and remote places where such connections arguably make a greater difference to the lives of service users.

User networks are undoubtedly formed predominantly in association with service spaces. However, although rare, networks do form independent of mental health services:

I have a very good friend that works in [a shop] and she suffered with depression for a long time as well ... well, as I say the only one I really discuss it with is the wee lassie from [the shop] because she knows about it, she understands how it is. [Peter, ER, 12/11/01]

Interviewer: *You were saying there are people in the village that have mental health problems; do you discuss that? would you perhaps say to someone 'how are you?, how's it going'?*

Greg: *Yes, there are three people I know. Yes I know certain people so if I saw them and they weren't, um, as normal, I would be apt to sort of say you know 'how are you getting on today' and they know that you're not referring to 'how are you getting on' but [points at me] 'how are you?' Aye. So its sort of like you can talk to someone and if they've been in the same boat as you, its not the same as someone who's not. [Greg, INV, 18/6/01]*

[T]here are four or five people on the park [caravan site], that's 10% have experienced mental health problems. They're very supportive, very welcoming and we chat amongst ourselves about our problems you know. It's good. It's quite a percentage. [Alex, INV, 11/5/01]

Charmaine, a user from Easter Ross, also provides us with a fascinating account of the user networks she has established outside the mental health services community:

Well, I've known her [other user] since she was a kid and like, she'd known that I'd been in the hospital and she actually came up to see me one time when I was in hospital a few years ago because she's got a little boy of 12 and I used to take him for the night for her when he was a baby, you know. I used to take him out a walk to give her a break for a while and things. And I think she probably knew 'well, it'll be alright to go and say it to Charmaine', you know, 'I'm no really feeling very well'. I get that with a few people, you know, like a few people have stopped me in the street and said, 'I don't feel well at all just now.' I'd say, 'what's wrong?' 'I've been on anti-depressants for 6 months but I can't really tell anybody about it, you know, cos folk don't understand'. [Charmaine, ER, 22/11/01]

Charmaine's labelling by the local community as a user of mental health services has opened up the possibility of a connection with others in the community who appear to be suffering in silence, due to fear of reprisals by the wider community. In a curious twist on notions of community social inclusion, those who find themselves in difficulty seek out Charmaine as a well known local user of mental health services. Charmaine continues:

Cos I knew her when she [other user] was younger and she'd approached me in the street one day and said, 'I've been in Newcraigs, you know. I haven't been very well'. So I've been meeting her and talking to her and going for a coffee with her and things ... Aye. She'll phone me usually, you know, and say, do you want to come for a coffee or I'll say to her, you come over to mine or we'll go down the street or whatever, you know. [Charmaine, ER, 22/11/01]

What is interesting about Charmaine's story is that approaches were made by people in public spaces [in a relatively crowded market town] and that people feel safe enough to disclose their own problems to Charmaine. As Charmaine herself explains, she is well known in the community, not only because of her health problems, but through family connections: *'like my family go back a long time in [the town], you know'* [Charmaine, ER, 22/11/01]. Clearly, from Charmaine's descriptions, she is discussing the networks of support that can exist between local people who have intimate and long standing knowledge of each other. Although we have argued that explicit discussion of mental health issues is rare amongst rural Highlanders, these examples show that change is taking place and that supportive networks between people with mental health problems can be established. However, as we show in the following section, the cultures of silence and 'visibility' that pervade every day life in more remote rural areas may facilitate against such developments.

Remote areas and potential for user networks: the case of North-West Sutherland

North-West Sutherland is the only area in this study which does not have a service point where users of mental health services can meet with each other, and as such this has profound implications for the development of user networks. For many people in North-West Sutherland, there is a knowledge that there are other users 'out there', but there exists little contact between them: *'Well you hear of people, you know, like, well no, you don't actually. I heard about a couple of people, but you know. But really you don't'* [Stephanie, NWS, 17/7/01]; *'as far as I know - there's no way of finding out ... if someone has had mental health problems - then they might be going to Thurso - or Craig Dunain in Inverness - but I wouldn't know about it'* [Rowland, NWS, 05/7/01]. The lack of services through which contacts with other users could be made is felt keenly by some users:

Interviewer: If people knew it was like, you know, Thursday night, 6 o'clock or if that depression group ...

Connor: ... And it's depression maybe they would, yes.

Interviewer: Really, right. You don't think that would carry any stigma? to be seen going into that meeting and coming out and ...

Connor: Well it's the same as if you're an alcoholic, the first step is that got to know that you've got a problem. So if they can't accept that they've got a problem, how can they help themselves basically? ... You actually see that in the local paper now [the] Northern Times, which is actually from Golspie on the east coast. Which is the main paper for this area, and you see adverts on the back of that for Alcoholics Anonymous and different things. And phone

numbers. That's in the paper you see. But these kind of support groups are all on the east coast. [Connor, NWS, 16/7/01]

Connor goes on to discuss the problems of accessing a group due to problems of visibility and ends by noting that: *'I thought I could handle it, but I didn't. You really need to talk to somebody, everyone needs help.'* [Connor, NWS, 16/7/01]. This need to talk to someone frankly about feelings and illness experience, where family and friends may not provide a medium for such discussions, is echoed by Lisa:

I mean I have sometimes thought, and I know when I was actually seeing [the CPN] I sometimes actually thought I wonder if I should suggest to her that it might be an idea to have a sort of group meeting. And to a degree by that time I was thinking would it help her any. You know, would it... Would it ease things a bit from her point of view, you know. Whereas if we had a problem, instead of having to get in touch with [the CPN] and say I need to see you now, the rest of the day sort of thing, we could say to each other. You know, not to the point obviously of excluding [the CPN], but just simply as an extra, if you like. But I never did suggest it. [Lisa, NWS, 11/7/01]

The lack of service points such as a TAG unit or a day centre or a drop-in means that the development of user networks depends upon individuals identifying and approaching others who are in contact with the local CPN [the only identifiable mental health service in the area]. Despite some knowledge of other users: *'Yeah, the chap next door there's a single chap living next door he's prone to depression. I mean, I see him about maybe once every three months, or something like that, if he's passing.'* [Katy, NWS, 9/7/01], this has rarely developed into a network of users. Jessica explains:

Jessica: *Well, Bob of course, because he's my husband's cousin, so I know him. Some of the other people I have visited myself, so I know that ... So they told me. So we're kind of bound together, the ones who see the CPN.*

Interviewer: *Really? Do you actually do that informally? Do you have a little network?*

Jessica: *No, but they know that I've been to her, and I know that they've been to her, so nobody actually says that to each other, but so they might ... If they're in terrible need, or whatever, or they're desperate, then they might say 'Oh, have you got [the CPN's] number?', or 'Can I come up?', or 'Can I do this?'. So in some measure we have got our own ... I know Bob sees her too, so we know who has been to see [the CPN].* [Jessica, NWS, 18/7/01]

Jessica's comments suggest a superficial connection to other users, as she points out the CPN is the only common link between people scattered throughout the remote north west of Scotland. Where connections do exist, they are with family members and their associates who have mental health problems, but who don't *'actually say that to each other'* [ibid]. This is not to suggest that discussions never take place between users, and that support is never offered in this area, but we are unsure about how 'deep' such connections go, as illustrated by the contradictory nature of Seamus's comment:

It's not a network as such. I know that they've had problems, and they know that I've had problems. We don't discuss those problems. I did with one person, who's had the same problem as me, and she was quite open to discuss it. I actually went to my appointment with another person from the village. They were in either before or after me with the psychiatrist. [Seamus, NWS, 9/7/01]

[A]nd a few of us will get together and have a chat, and it's almost like a mini self-help group. A cousin, Pamela, has problems as well, so occasionally [Darren, NWS, 18/7/01]

Darren's comment offers the possibility of a potential network, but he later qualifies his statement and Stephanie also raises the potential problems of such collectivity:

I wouldn't like to know exactly how Pamela is doing, have that kind of information. The responsibility of not letting it slip. So having that information from another patient could be a danger in case you let it slip. You know, some folk would absolutely love that information, you know, tittle-tattle everywhere. [Darren, NWS, 18/7/01]

The thing is it would have been nice to have had maybe once a week support, like somewhere for all of us to have met, people that felt like that, but ... In a small area like this, there is a lot of bitchiness going about and you soon learn that you cannot trust anyone. So it would be good for some people to go and speak about their experience, but they also know that we'll always get the one or two that will go about repeating what we say. I think that's why a lot of us wouldn't go. I mean I would love to go and meet other people and ... Because there's ... not much ... I don't know to explain it ... [Stephanie, NWS, 17/7/01]

As we have argued in our findings paper **Visibility, gossip and intimate neighbourly knowledges**, fears over the repercussions of being seen to be linked to mental health services or even others with mental health problems are very real throughout the Highlands, particularly in the north west. The level of surveillance in small places makes the notion of group support for people with mental health problems operative *in one site*, difficult to envisage:

Interviewer: I mean if there was any kind of group that did discuss these matters - like an evening a week or something - a discussion session for depression or something - do you think people would go?

Lorraine: it's hard to say I don't know ... it's maybe better one to one - I don't know if they would like a big group, I'm not sure that that would work. [Lorraine, NWS, 5/7/01]

I don't think it would work in a community like this, because we're such a small community. Even though you have various folk suffering from the same sort of illness, putting it in a group I don't think will help, because we don't really want to know anybody else's business at all. [Darren, NWS, 18/7/01]

I think if there was a centre where they could go to where nobody would know they'd been, yes. That is the thing up here of course, nothing up here is anonymous. ... I wonder if anybody would go. It would be ... because I said, folk are not very keen to admit they've got a need. They usually, as you say, I know a couple of women, one of them's now dead, and they turned to drink. [Deborah, NWS, 23/7/01]

But no, there's no getting together of us all. I don't think they would want to. I think everybody, as far as I can see, probably keeps it quiet Cos I've been sort of surprised when somebody said, "Oh yes, she's on anti-depressants". I didn't know, you know. So I think everybody keeps it to themselves. They're trying to hide it, they're ashamed obviously of the illness. [Deborah, NWS, 23/7/01]

Here cultural attitudes towards mental health are clearly drawn upon to explain the lack of a will to attend group meetings and to debate the possibility of the development of user networks. What is so frustrating about the situation in North-West Sutherland is that users cannot even *imagine* an alternative scenario where groups can meet to garner support and advice from each other. Fear of adverse community attitudes perpetuates the culture of silence around mental ill health, and so stifles the potential for alternative user and service futures. Until users and service providers can overcome this, individuals will be left wondering: 'Well, is it only me?' [Katy, NWS, 9/7/01].

Conclusion

We have found that services are key to the development of user networks. User networks can be operative within service sites and formal in nature (i.e. representation occurs and friendships are formed within the times and spaces of formal service provision). User networks can also be operative outside of service sites, support and friendship networks flowing out from this initial meeting place (i.e. users engage in telephone calling, meeting and visiting outside the time and spaces of formal provision). In remote places where collective care sites are few or non-existent there is a dearth of user networks and innovative thinking is needed to help build these.

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