



Highland Joint Community Care Plan SUMMARY OF CONSULTATION



Plana Co-Chùram Coimhearsnachd Na Gàidhealtachd GEÀRR-CHUNNTAS DEN CHO-CHOMHAIRLE

Highland Community Care Partnership

Com-pàirteachas Cùram Coimhearsnachd na Gàidhealtachd

Introduction

Ro-ràdh

The Highland Community Care Partnership has been keen to listen to the views of a range of stakeholders and in particular those of people who use community care services and their carers and ensure that these views shaped the final version of the Joint Community Care Plan. Following a successful initial consultation exercise undertaken summer 2009¹, the Highland Council and NHS Highland commissioned Highland Community Care Forum (HCCF) to carry out a second, more comprehensive community consultation with stakeholders, service users and their carers. The consultation exercise took place from April - June 2010 and was based around four specially-developed booklets. In addition to a general booklet, there were booklets tailored specifically for older people in need (aged 65+), younger people in need (aged 16 to 64) and people who have mental health and/or substance misuse issues. They set out the outcomes that the new Plan seeks; summarised what people who use services had told us in the first stage consultation; and set out the proposed approach to delivering improved services. An easy read version was used as an aid to discussion.

HCCF worked with others to raise the profile of the consultation and to ensure that as many people as possible across the Highlands were able to contribute. In particular, they targeted “harder to reach” individuals and groups², who may not have ordinarily responded to the survey and ensured that they were able to voice their needs and opinions. People also had the opportunity to fully discuss the proposed plans, thus providing the Partners with a deeper understanding of opinions and feelings. For many people, this was the first time they had taken part in a consultation. It was encouraging that many new voices were heard, as well as voices that would not have been expressed without the help and support of someone to work through the booklets with the person involved. The diversity of groups also meant that we heard about many new and different experiences and opinions.

¹ Almost 400 people from a wide range of adults in need and their carers contributed to the first stage of the consultation, which then helped to shape the development of the draft Joint Community Care Plan. Full and summary reports are available at: www.hccf.org.uk

² This enabled people to voice their opinions with confidence. A full list of the organisations who were consulted is available in the full report.

The Partners firmly believe that people's views are important and this wide-reaching approach was taken to enable the new Plan to reflect what matters most to people. 600 people across the Highlands took part in the process and included the views of:

- older people;
- carers;
- people with a learning disability;
- people with a sensory impairment;
- people with mental health issues;
- people who misuse drugs, alcohol and other substances;
- people who are homeless;
- gypsy/travellers;
- people from ethnic minority communities; and
- people who are LGBT (Lesbian, Gay, Bisexual and Transgender).

Key Findings

Prìomh Thoraidhean

The majority of people who participated in the consultation process were positive about the proposed outcomes and areas for improvement that were highlighted. However, many felt that the information provided was in the form of very broad statements and in order to comment and provide feedback, more detail would be required about how issues would be addressed, particularly in a time of severe economic pressure. Some people wanted to know more detail around what was being proposed for particular interest groups or geographic areas.

The four key questions that HCCF discussed with people during the interviews and workshops were:

- Are the outcomes identified in the booklets the important ones?
- Are the issues identified the important ones?
- Are there other issues the Plan should consider?
- Are the improvements identified in the booklet the ones that need to be made?

Question 1:

Are the outcomes identified in the booklets the important ones?

Nearly all respondents believed that the identified outcomes were important ones. Many people felt that the document was aspirational and would have liked to be given more detail about how the outcomes would be achieved in order to understand what they will actually deliver in terms of Community Care services. Some people had concerns about how the ambitious outcomes could be delivered during a time of budget cutbacks.

"They are important, but it is the quality of life we need to focus on. There are clear needs that people with disabilities and carers have and we are very concerned that these broad statements are not focussing on how these needs in outlying areas may be met. They are not in their present form relevant to people with care needs."

LIVING LONG AND HEALTHY LIVES

Nearly everyone agreed this was important but many felt that quality of life was also very important:

"Yes, if I had both."

"Service providers are disinterested in quality of life because not 'obvious'."

A carer felt: "Life should not be prolonged unnecessarily in cases of severe dementia."

"This is an unrealistic aim. It has been promised before but not delivered."

FEELING SAFE

Feeling safe was a priority, particularly for people who are more vulnerable or felt different due to their situation or condition:

"Some people can feel unsafe due to their condition. There is a difference between 'perceptions' of being safe and reality."

A young man living with addictions said: "A lot of people feel intimidated too. Friends come and ask 'do you want this...do you want that?' It can lead you back to drugs."

One person with dementia said: "It is important that I feel safe when out on my own. The dementia can make you more vulnerable. But because I feel safe in my community I can go to the shops or walk into town on my own."

"There are two issues. To be safe from crime and safe from harm or risk in the home, and the need to have the confidence that someone will be there if things go wrong."

"Sometimes it is not safe to leave a person in his or her own home."

"Financial stress can make you feel unsafe, e.g. fear of not being able to pay the mortgage and losing your home."

"Lack of services lead to people feeling unsafe - hospital and police services feel patchy. I don't feel there is anyone taking care of me."

"My confidence is returning as a result of feeling safer."

STAYING IN A HOME OF YOUR OWN WHEREVER SENSIBLE

Nearly everyone expressed a strong preference to stay in their own home, although this did not necessarily mean living on their own. Some people questioned what the term 'sensible' meant:

"Who decides when it is sensible?"

"Sensible to friends and family may not be the same to the individual who may feel they can cope for longer than they can."

"Yes - this is the most important thing."

"Yes - even though this is not always what your parents think is best."

"Yes - with the right help."

"Yes, but only while we can cope and are not at risk and while people are still enjoying life."

"I fear being moved to residential care."

"Beware the dangers of isolation."

"Dementia sufferers can go wandering, where they live may not always be suitable."

"Most crucial of the outcomes, as people with mental ill health prefer to be kept at home rather than in hospital."

BEING FREE FROM STIGMA AND DISCRIMINATION

This was a priority for many people and many felt that anti-discrimination education, particularly beginning with schools, is required:

"It should be a given."

"Not sure what they are going to do about it?"

"Most difficult one to achieve as resources need to be put into anti-stigma campaigns. Educating the young within school is vital."

"People can cause that for themselves."

"You can put a suit on but people still see an alcoholic."

"Being labelled by people as autistic or whatever does not help. See me – I am a person not a label."

"More awareness is needed desperately of conditions such as Aspergers, especially by Social Services. They need to take on that there is a wide spectrum of Autism and Aspergers."

KEEPING UP IMPORTANT RELATIONSHIPS

Most people said that this was really important to prevent isolation and deterioration of health. Some people stressed that not everyone has important relationships:

"It is very important, a priority. It is easy to get isolated with mental ill-health."

"How can it be their goal to keep up relationships?"

"Transport is going to be a big issue."

"When we're getting ill we stop relationships as we stop communicating. Being part of social groups is really important as it's an informal network between peers. Not comfortable with folk who have no experience of mental health as they judge you."

"I don't want to go away to work like my brother. My brother has more severe learning difficulties and there is nothing for him locally. He is working on a special farm outside Edinburgh and was previously at school in Aberdeen. It was very difficult to keep in touch as he is not a good talker and can't write."

DEVELOPING THROUGH HAVING INTERESTING THINGS TO DO

Nearly everyone felt that this was very important in order for people to develop and that achievement gives people a sense of being valued and helps build self-esteem. Many people stressed the need for the right support and transport to enable this:

“How is this going to be possible if they are closing facilities – swimming pools, libraries, parks and that's if we can get there.”

“Not just interesting things, have to have a purpose, feeling valued is important.”

“The highlight of my week is the outing to the Day Care at Tigh na Drochaid.”

Question 2:

Are the issues identified the important ones?

There was wide agreement that the issues identified were prominent issues that the Plan should address.

Question 3:

Are there other issues the Plan should consider?

Many people, when discussing other issues, said that the plan should consider expanding on the issues already identified. Other issues raised were directly relevant to the needs and experiences of a particular interest group but some common themes emerged. Paying greater attention to prevention rather than intervening in a crisis was something that people raised as being important:

- there is a need to be more proactive by, for example, finding better ways of monitoring people's changing needs and reviewing their support appropriately;
- investment in quick access to low level support, including home adaptations, physiotherapy and talking therapies to prevent people losing their independence, capabilities or having a crisis;
- having somewhere to go was a key issue for some vulnerable people, including homeless people and those who misuse substances, which meant they might be out and vulnerable at night or bored and at risk of addiction during the day;
- improving current practice around communication between service providers, people using services, communities, the voluntary sector and other potential stakeholders was something that was frequently mentioned. Many people felt that service providers needed to improve listening skills, relationship building and empathy and that better training could play a key part. Treating people in a caring and respectful way is important in enabling people to maintain their dignity. It was also highlighted that some people with community care needs should be shown how to go about asking for help. Pride, or not knowing the routes for accessing help, were mentioned as barriers to communication. Some people felt that services should be focused on needs and not targets, and on relationships and empathy. Some people felt that targets and quality don't always sit side by side.

“People assumed what my needs were but didn't listen to ME.”

- Some people felt that in modern society, people were increasingly isolated and that Community Care had the potential to reintegrate isolated people including people who are homeless, people with addictions and people with a learning disability back into society. Developing more opportunities, particularly

those that allow mixing with a wider range of people in everyday situations, was sometimes described as key to reducing stigma and achieving reintegration into communities.

- A holistic approach to mental and physical wellbeing, particularly in older people and people with mental ill-health. Sometimes older people felt that their mental wellbeing could be neglected whilst people with mental ill-health felt their physical wellbeing could be neglected.

Question 4:

Are the identified improvements in the booklet the ones that need to be made?

People were positive about the changes proposed, but they also highlighted other important areas of change to consider:

TRANSPORT was often seen as a key underpinning factor in addressing isolation and enabling access to services. Hence there needs to be accessible and flexible provision of transport across Highland.

"It's what makes everything else possible."

INCREASED EQUITY and recognition of the diversity, vast geography and differences in communities and need across Highland must be taken account of when planning services. Some people felt that there is still an inequity in provision across communities. People don't appreciate the distances involved and many services and decisions tend to be centred in Inverness.

"South West Ross-shire is often unrecognised as being a separate one, being lumped with the rest of Wester Ross (Ullapool and Gairloch) or with Dingwall (where many of the support services are based) and suffers as a result."

"There is far too much going on in Inverness. Their way of doing things don't necessarily work in Fort William."

CHALLENGING STIGMA through campaigns to raise public awareness is essential in enabling people to 'feel safe'.

"We should educate people so that they do not bully people who are different. It needs to start at primary school. Sometimes the way to educate people is to be 'THERE' in society-being part of things."

IMPROVED SKILLS AND COMPETENCY through better training for service providers, schools, family and carers. People believed that the care workforce needs to be appropriately trained in communication, equalities and working with specific conditions such as dementia and the autistic spectrum.

"Any training needs to be compulsory/built in to agreed training programmes for professionals to actually happen."

"One of the main reasons services don't work well is because people don't have the right or needed skills."

"We need appropriately trained therapists – people with Autism don't like a 'touchy-feely' approach."

ACCESSIBLE INFORMATION in different formats, including different languages and easy read versions. Some people felt that one point of contact would enable them to get the right information at the right time. New creative partnerships, not just between Social Work and NHS Highland, but with the voluntary sector, Job Centre Plus etc. are also needed to ensure that information is co-ordinated.

Investment in **PREVENTION AND LOW LEVEL SUPPORT** is essential to ensure sufficient numbers of key staff including physiotherapists, psychiatrists, prompt assessments and faster home adaptations.

A MORE PROACTIVE APPROACH by service providers would be better able to monitor people's changing circumstances and need, thus preventing a crisis and people needing more intensive help.

"People providing support and services should check on people and carers to make sure they are coping or if they have any particular problem."

Care packages need to be **FLEXIBLE** in order to meet the social as well as care needs of the individual, maximise an individual's independence and enable key relationships to be maintained.

"How can I take part in social events if I have to be home for 8pm so that my home help can put me to bed?"

CONTINUITY of services, especially home care, is important so that people do not experience stop/start services which can have negative consequences to personal confidence and independence. The importance of being able to develop a relationship and understanding with the paid carer rather than having to adjust to a variety of carers was something that was raised by a number of people and particularly highlighted by those people living with dementia.

"Continuity of care is essential. My father had Alzheimer's and had different people coming to care for him. It was embarrassing to him to have to explain the situation every single time."

CARERS need to be supported with appropriate information, equipment, training, respite and regular communication to make sure they are continuing to cope with the caring task.

A **WIDER CHOICE OF HOUSING OPTIONS** with flexible support is important in supporting people to stay in their communities.

IMPROVED WORKING RELATIONSHIPS between the Highland Council, NHS Highland and their partners are important to ensure better co-ordination of information, services and opportunities.

INCREASED ACCESS AND AVAILABILITY OF SOCIAL OPPORTUNITIES, WORK OR TRAINING to enable people to contribute to their community or acquire skills that will enable them to gain employment.

When an older person with learning disabilities was asked if she had ever worked or volunteered she replied: "No". When asked if she would like to, she said after a pause, "Yes, I would like to help old people."

A young blind lady said: *“Because I don't do anything, I have nothing to say, because I have nothing to say I am not confident to socialise with other people.”*

RISK ASSESSMENT AND MANAGEMENT was currently experienced by some as having a negative impact on encouraging independence. Some people felt that they were capable of more than they were being given credit for and wanted to become more independent. Individuals' views also need to be routinely taken into account when assessing risk and how it impacts on how people are cared for and supported;

“Safety and developing independence do not go hand in hand.”

Some older people wanted to stay in their own homes but did not feel safe; for some, being social isolated increased their concerns about living safely at home.

COMMUNITIES gave mixed responses to the suggestion that individuals and communities should do more to help themselves and each other. Some people have been positive whilst others were reluctant and wanted to know what they would be expected to do for themselves. Some people were open to the idea but were concerned that they might not get sufficient support from the Council or NHS.

“This is a regressive step which poses the prospect of care being thrown back on family members who may be unable to cope.”

It was generally agreed that there is a lot more to do in some communities than others, and that some communities have much higher levels of social capital to draw on than others. Some people felt that communities did not exist, just individuals and that it was always the same individuals who 'did everything'. The need to make sure that whatever services or support the individuals were developing really met the wider needs of the community was also highlighted.

Some people felt that there needs to be much more communication and discussion about how people and communities could help themselves and that communities should have more of a say over the future of services.

ACKNOWLEDGEMENTS

The Highland Community Care Partnership and HCCF would like to thank all the individuals and groups who gave their time and contributed to the consultation. We would also like to acknowledge and thank the valuable contribution made by all the local community care forums and the wide range of organisations across Highland³ who assisted in the organisation and facilitation of the focus groups.

To request this information in an alternative format
e.g., large print, Braille, computer disk, audio tape,
or suitable language, please contact:

info@fhcommunities.org

³ The full report on the consultation includes a full list of these organisations. This can be found at: www.hccf.org.uk