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BUILDING A CARERS' COMMUNITY IN SOMERSET

A report by Denise Hodgson & Sam Roche of the No Limits pilot site in the Skills for Care New Types of Worker project.

1. Executive summary

This project is part of a wider set of initiatives in which Skills for Care seeks to remodel the social care workforce by developing 'new types of workers'.

This project is one of many established to support the 28 pilot sites for the New Type of Worker project that were orientated to considering the views, needs and aspirations of people who use services and carers. We sought to engage the carers of Somerset in an informed debate about current issues:

- recovery for carers
- how do we maintain carers' vital role?
- education for carers
- how to we enable carers for their role?
- employment for carers
- how do we enable carers to maintain a work / life / caring balance?

Although a significant infrastructure exists in Somerset it is controlled by workers – we sought to engage carers independently and to help them towards self-determination.

It is fundamental to this report that the word 'carer' is understood to mean unpaid family or friends who deliver social care, and explicitly excludes care workers delivering social care as part of their employment.

2. Introduction

The London Mental Health Carers' Charter has outlined six principles that would enable carers to undertake their role more fully:

1. Your role and expertise are recognised and respected.
2. You are given the information and advice that you need to help you care.

3. You are involved in the planning and agreeing the care plan for the person for whom you care.
4. Your individual needs are recognised, responded to, and reflected in the care plan.
5. You receive appropriate help and support when you need it.
6. You are actively involved in the planning, development and evaluation of services.

(*Valuing Carers*, LMHCC 2004)

During our consultation with Somerset Carers we discovered that for many carers these principles are not reflected in their everyday experience. In fact, many carers felt excluded from information, involvement and respect and believe that the levels of support offered are poor at best.

In the national strategy, *Caring About Carers* (www.carers.gov.uk, 2003), the government acknowledges this:

"Three-fifths of all carers receive no regular visitor support services at all. Carers' needs are currently only being met patchily."

And the Carers' Federation reports that:

"Carers are frequently isolated 'invisible' members of the community whose responsibilities go unrecognised because resources are generally aimed at the person that they care for."

(www.carersfederation.co.uk, 2005)

Although social care and health policy is "increasingly focusing on outcomes for those in receipt of services rather than on inputs and processes" (SCIE 2004), there is little evidence of this on the ground. In fact, listening to the stories of Somerset carers would suggest that the gap between policy

and practice is particularly wide in relation to carers.

Many carers have little or no knowledge of government thinking or social policy and do not realise that many of their concerns and fears are being heard at the most senior levels. In their national strategy for carers, *Caring About Carers*, the government offers:

“We want to enhance the quality of life for all carers. This means finding ways to give them the freedom to have a life of their own.”

This encapsulates the aspirations of No Limits in relation to carers in general and this project in particular.

Most statutory agencies have a vested interest in maintaining carers in their current position, i.e. as carers, rather than promoting self-determination. When society asks carers to pursue their own agendas for enhancement it risks them withdrawing from the caring role and leaving society to pick up the pieces.

We believe that carers need our support to attend to their own recovery and development as well as maintaining their caring roles. To ignore the former in pursuit of the latter is to take carers for granted—and to pursue short term gains at the cost of some of society’s most vulnerable people.

3. Background

There is no accessible database for carers in the county of Somerset. There is no infrastructure for carers in Somerset outside of those provided separately by:

- social services
- NHS Primary Care (Carer Support Workers)
- NHS Mental Health Service (Carer Assessment Workers)
- non-statutory bodies including Rethink, Age Concern, Mind and Carers UK.

These networks are controlled by workers and although some communication passes between these bodies there is no active plan

to develop an independent network for carers.

The electronic patient record systems in primary and secondary care record the next-of-kin but do not make separate distinction for carers.

The emphasis seems to be on informing carers about some statutory initiatives, providing basic level services to some carers (estimates vary: Rethink believe that dedicated services reach 5% of carers – this was confirmed by Carers Assessment Workers) and providing for social and supportive local networks through carer support groups, most of which are facilitated by workers. The workers are generally from health and social care backgrounds and do not seem to have experience of community building or participatory methods of involvement. Many have had no formal training in groupwork.

Carers’ groups seem to rely on general discussions and external speakers who are drawn from health and social care service providers. These speakers are often booked nine months in advance.

The statutory services also provide an annual conference for carers: “It’s a day out for them!” said a senior manager with responsibility for carers in Somerset.

This may well be so. The carers we have talked to have found this event to be very useful in terms of providing networking opportunities, information and new skills—particularly those that were designed to help carers to cope with the stresses of their role.

There seems to be no recognition of the need to develop an independent voice for carers within the county; indeed, there seems to be some suspicion about such an idea.

4. Aims

At the outset our project had two broad aims:

- To identify the various carer groups in the County of Somerset and bring them

together in order to promote a sense of identity that is informed, independent and inspired.

- To develop an independent voice for carers that addresses the challenges that lie ahead in relation to employment, education and training and recovery.

The purpose of consulting carers was to generate an agenda that they wished to pursue. We hoped that this project would enable the carers of Somerset to declare their own aims and our job would then be to service those aims and develop a community structure that was:

- robust and sustainable
- independent
- acceptable to carers.

Some of the carers at our November 2005 consultation event had expressed a desire to find employment in this sector when their caring role ceased or diminished.

We therefore held a further event in which we invited carers, carer agencies and local employers to explore the extent to which carers could be encouraged to pursue a career in social care, an issue under discussion at the Department for Communities and Local Government (DCLG). Our work on employment arose from the realisation that carers in Somerset or those who support them had no information on this subject whatever. Because the information they receive comes down through the statutory sector, carers only know that which professionals want them to know.

This employment event formed the backbone for a separate piece of work on the development of an Entry Level Skills Pathway for Carers into Social Care on behalf of the local government Employers' Organisation (due at www.nolimits.co.uk in summer 2006). The aims for the event and that work were:

- To explain the current workforce shortfall in social care.
- To explore the extent to which this problem could be solved by encouraging carers to enter the social care workforce.

- To consult with carers and the wider health and social care community over the steps that would need to be taken to enable carers to take up careers in social care.
- To produce an entry level pathway, which provides easy access to a career in social care, and which takes account of the difficulties and barriers that they have been raised in consultation.
- To enable Somerset carers and local providers to have a voice in national decision-making.
- To promote self-determination among carers.

It was intended that by the end of the conference participants should be able to:

- Explain the barriers that currently exist in a rural area that prevent carers from undertaking a career in social care.
- Outline the current arrangements for carers in employment including rights and entitlements in relation to any ongoing caring roles.
- Understand the steps that they should take to take up a career in social care – the pathway to entry level.
- Understand the learning opportunities that currently exist and could offer support, confidence-building and opportunities for growth and development.

5. Engaging with carers: methods and consultation

We decided that we wanted to model a way of working with carers that was different to the established norms. In Somerset, carer consultation is tokenistic at best: as a senior manager with responsibility for carers said, “On the carers’ forum the professionals outnumber the carers by four-to-one—the two carers who do attend aren’t even carers anymore.”

When we asked questions about how such representation was achieved, the systems for feeding back, etc., we were told that, “It is difficult to achieve this with carers.”

We were to discover the truth in this remark – it is indeed difficult, but as soon as we settle for tokenism we also accept ‘second best’ and

we deny carers a true voice. We do accept and understand that poor representation is better than no representation: we could not blame health and social care agencies who are “over-stretched and under-resourced,” but we decided to strive for something more meaningful.

Various committees across the social care and health communities of Somerset are served by one or two dedicated carers who struggle to be as representative as they can. They do not have access to the support and infrastructure of the professionals, nor are they as privileged in terms of their access to information. We decided to try and redress this imbalance.

We would not invite carers to sit on committees or steering groups, where they would be disadvantaged by virtue of their lack of experience of such mechanisms. It is interesting that so many carer agencies believe that the answer is to provide training for carers on how committees work, as if the traditional professional methodology is the only way forward. In keeping with the tradition of building communities and breaking down barriers, we decided it would be easier to ask the professionals to adapt to a new way of working that suited the carers.

We decided to engage carers in a process of consultation called Participatory Appraisal, where power differentials are equalised and participants are encouraged to be creative. This approach promotes creative expression using colour, symbols and personal opinions. We would use plain English, devoid of jargon and pejorative terms like ‘service user’ and we would faithfully record the views of carers—however trenchant.

Throughout the process we would publicly repeat our intention to serve as a catalyst—that is, an agent that speeds up the process without fundamentally changing it. Our aim was to inform carers about the three topics – employment, education and recovery – and to then gather their views on these issues and to feed those views into the Skills for Care carer

strategy and explore the potential for developing new types of workers in Somerset.

6. Building a carers’ community in Somerset

Our project had three stages:

1. Creating an informed debate.
2. Bringing carers together so that they can form a carers’ community in Somerset.
3. Bringing carers together so that they can express what they want.

We provided information and workshop material to carer groups so that they could engage in an informed debate about recovery, education and employment. We found many workers were very defensive about our project—as if the desire to provide carers with an independent voice and a structure detracts from the work already carried out on behalf of carers. Many workers did not co-operate with the project and could give no coherent reason for this. The most common reason was, “Not enough time.”

Very few groups took up our offer to attend their meetings and work through the materials with the groups.

Prior to the launch of the consultation process we informed those who work within the existing carers’ infrastructure of our intentions. This was done through informal discussions, through sending copies of all the learning and publicity materials to ‘key’ players, and through meetings.

In primary care the ‘take up’ was poor. Advance warning was given to carers’ assessment workers at their team-training day in July. Some of these workers made enquiries, but not to us—senior workers told them they knew nothing about the project, giving the impression that the ‘authorities’ did not sanction the work.

During meetings with senior managers it became clear that we had ‘failed to play their game.’ We decided to play our own game and put the ball into the carers’ court.

Accessing carers presented a real challenge; we put this challenge to the carers who came to our consultation workshops and to our November 2005 event.

6.1 Creating an informed debate

We identified 74 carers groups and contacts in Somerset and sent each one:

- a letter explaining the project
- a survey form to identify who was taking part in the project
- a workshop pack on recovery, education or employment, containing a plan, handout material, exercises for the group to complete and evaluation material
- an invitation to send delegates to a local workshop
- an invitation to a county-wide one-day event.

6.2 Bringing carers together so that they can form a carers' community in Somerset

We explained to carers that there was no simple way to contact them without first going through workers. We asked carers some questions about how they would like to relate to each other, access information and create new networks. Did they value the idea of an independent network? Their responses are summarised below.

6.3 Bringing carers together so that they can express what they want.

At our November event we asked carers, through the medium of 'participatory appraisal', what they wanted for themselves – their responses are summarised below.

The results of our participatory appraisal exercises are recorded below – as with many forms of action learning, the key device is the question. A question is posed and individuals are encouraged to provide their own answers. Discussion is encouraged but we do not expect participants to form a consensus—in fact, this is discouraged.

Editorial note: An example of a learning programme for carers can be found at City & Guilds' site www.learning-for-living.co.uk

7. Issue 1: recovery

Crisis support for carers – what do we need?

- In a crisis, to know exactly who to contact.
- Introduction information.
- A proper carers' research and development department—ask industry and private companies.
- How to communicate and reach customers.
- A new support system that can act immediately.
- A local drop-in.
- Counselling for carers and family at points of crisis, e.g. at admittance.
- A phone number for someone knowledgeable, who can offer practical and emotional support.
- Emergency response service for carers—properly funded and staffed.
- 24-hour crisis help line for carers in Somerset.
- Carers' phone network.
- Someone to come in deal with the situation and then leave giving a follow up call.
- Time for ourselves.

How can we foster/ promote independence?

- Use skills gained in caring, networking with systems, etc.
- Be flexible in time out (not 9–5).
- Recognising that you and your needs are as important as the cared-for's needs.
- Evening meeting with a sitting service where carer can discuss anything else than caring.
- Caring circles—like baby-sitting circles.
- Group of carers and cared-for people getting together to help each other like idea of playgroups in the first instance.
- Thorough education, i.e. learning how to care appropriately and to foster your own space.
- Being honest with your own and cared-for's feelings.
- Education.
- Financial assistance for support.

- Coping with distress techniques, e.g. drumming, relaxation, etc.
- Share the responsibilities, as a couple.
- Better systems for grabbing time when the cared-for is out.

In the discussions about carer recovery a number of themes emerged:

- Dealing with grief and loss.
- Dealing with guilt.
- ‘Juggling’ became the most repeated word of this session.
- Knowledge is extremely important – how it is given, when and where, and by whom.
- To have carers checked out in respect of their information.
- Having physical health needs checked by a GP – ‘passport to fitness’
- Using trained carers to help train others in caring role.

8. Issue 2: learning

We had a lively discussion on learning in which the following points were noted:

- Problems shared across diverse backgrounds.
- Learning requires *time*.
- Learning for carers – confidence to enable advocacy skills.
- Learning self confidence.
- Something has to give.
- Learning to de-stress.
- Learning-specific outcomes.
- Learning for pleasure.
- Learning to understand the cared-for person (family therapy).
- Learning to promote relationships – mutual respect.

Barriers to learning were listed as:

- Lack of encouragement.
- Fear.
- Lack of time.
- Need for mentoring.
- Being able to commit.
- Lack of confidence.

- Family commitments.
- Restricting circumstances.
- No flexibility in resources.
- Lack of opportunities for placements.

What is needed for carers to be able to learn?

- Support from family.
- Suitable courses at flexible times.
- Transport.
- Financial freedom to learn.
- Flexible time.
- Confidence.
- Flexible resources.
- Flexible employer/ benefit provider.
- No to feel guilty.
- Support and understanding from the course re home situation.
- Learning buddies.
- Help with cost.
- Mentors.
- Jargon-free discussion and reading material.

9. Issue 3: employment

Advantages of combining caring and work

- Paid work as a sanctuary from caring.
- Work can be a break from stressful caring.
- Stimulation of different environments.
- There is a life out there, and other subjects to talk about.
- Paid work would improve finances.
- A variety of human contacts – important contact with the outside world.
- Forget about the caring role – concentrate on something else.
- Having day-to-day conversations.
- Cared-for is not so reliant on one person.
- Glad that I can give back what I receive.

Disadvantages of combining caring & work

- Being pulled in different directions, especially if the carer is alone with the cared-for.
- Loss of income (had to give up full-time work).

- No spare time – need for ‘my time’ but concerns about ‘Am I being selfish?’
- Worrying about the person I care for whilst at work – poor concentration, worrying whether cover is appropriate.
- Becoming over-tired and stressed with two jobs.

Suggestions for combining caring & work

- Arranging flexible working hours.
- A calling service – phone call to see if all at home is OK.
- Government needs to recognise additional benefits needed for carers – financial and council tax.
- It would help if ‘work’ is close to home, in case one is needed at home.

What do carers need to be able to work?

- Time to re-assess what they want to do and which direction to go.
- Flexible hours and an understanding employer.
- Someone to call if a crisis arises.
- Time.
- Support in managing the balance.
- Reliable service for the person I care for.
- Transport and petrol money.

9. Themes and messages arising from the project

9.1 Messages participants wanted to send to government and employers

- What would you do if all the carers went on strike?!
- Give us money and resources.
- Systems in place to allow time off when needed.
- Acknowledge the cost to the country that are shared through carers’ input – give back a little to enable carers to carry on.
- Training courses are needed.
- Time / job share initiatives to encourage carers’ applications.
- Possible subsidy to employers to allow for necessary absences.

9.2 General carers’ messages ‘to the powers that be’

- Empower the voluntary sector.
- Think creatively within government guidelines.
- Do not promise what cannot be delivered.
- Actively listen to carers.
- Carers need a break too.
- Carers and people who use services are inextricably linked – *care for both*.
- Beware of raising expectations.
- Ring fence money for mental health purposes.
- Remember carers are experts.
- Work in partnership with others to deliver more.
- Don’t expect progress to continue on goodwill and commitment alone – keep the money flowing!

9.3 General themes emerging

- More courses for carers.
- Professionals and others *not* to assume they know how I feel.
- *Keep* checking out and asking the carer how things are going with involvement with mental health services.
- Carers’ crisis help line and response centre.
- Someone to give reassurance: “It is OK to have time to yourself.”
- Follow up visit to affirm carer has relevant information.
- Central response centre.
- Imaginative respite.
- Spontaneity.
- System to deal with new carers.
- Checking carers have up-to-date with information, even if they’ve received leaflets in the past.
- To be offered a package of alternatives to discuss.
- Using trained carers to help train others.
- Carers’ education programme.
- Practical help, e.g. someone professional or trained to reason with an ill person.

- Phone regularly – check out if carer is OK, inform others if necessary.
- Opportunity to work through emotional issues – therapy.
- Care plan for carers' information.

9.4 New services and new types of workers that carers envisage could help

- Carers information pack on first episode (admission).
- A new support system that can act immediately, including a crisis response worker – visit once in crisis, once as follow-up – a new kind of Support Time Recovery (STR) worker for carers.
- A local drop-in for carers.
- Counselling service for carers at the point of crisis.
- A phone number with a knowledgeable person who can offer practical support.
- 24 hour crisis help-line emergency response service for carers (properly funded and staffed).
- Database of all carers and carer phone network.
- Better respite.
- Befriending volunteers / buddies if required.
- More specialised services for carers.

9.5 Summary

Having engaged carers at different levels, in different ways and times, we identified that carers aspire to:

- being treated as equal partners in all of the relationships that are relevant to the caring role
- services to support them
- information
- link up with each other
- training for themselves
- training for the people that they care for
- control their own destiny
- understanding from employers and workers
- an independent voice that is heard and acted upon.

10. Recommendations

Carers at our events made the following recommendations. No Limits will pursue these in Somerset in 2006–09 subject to funding approval.

- Establish a carer centre that enables carers to access information, administrative support and networking opportunities.
- The development of a database of Somerset carers that is independent of workers.
- An independent website for carers run by carers.
- Establish a system whereby carers can offer training for others.
- More education for carers on recovery, learning and employment).
- A critical evaluation of education programmes for carers such as Learning for Living and Making Your Experience Count. (Evaluation is due to be undertaken by Somerset Social Services and Adult Learning & Leisure in 2006.)
- A conference for Somerset employers in which carer needs are discussed.
- Training events on confidence building, assertiveness and recovery for carers.
- Training events for the people they care for on recovery and well-being.
- Development of befriending service / crisis worker for carers.

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