Report from
Self-Carer Rapid Improvement Event
3rd September 2013

Update 2016

At the start of 2013, Edinburgh Community Voices became aware of the issues faced by self-carers - people who live alone in the community and do not have a carer at all, be it a relative, partner or friend.

There were concerns that the care provided to self-carers is often inadequate and does not take into account the fact that they do not have a carer to help and support them.

Edinburgh Community Voices discussed these issues with Linda Irvine, Strategic Programme Manager – Mental Health and Wellbeing at NHS Lothian. She supported us to hold a rapid improvement event to identify the issues self-carers face and explore solutions.

In 2015 - 2016, Edinburgh Community Voices reflected on the report and the issues faced by self-carers and agreed that the issues are still relevant and very little has changed since the report was first published.

What is Edinburgh Community Voices?

- Edinburgh Community Voices is a group of people who have lived experience of mental health issues. We meet to share our experiences and views and campaign for services to be improved and developed to meet the needs of people living in the community. We are supported by AdvoCard, Independent Advocacy.

- We believe in being constructive in approaching issues and their possible solutions. We aim to work together and have a dialogue with professionals.

- We meet every month. The meetings are friendly and safe. If you are interested in attending, please contact AdvoCard – 0131 554 5307, collectiveadvocacy@advocard.org.uk.

- AdvoCard support us to develop our campaigns, get the information we need and invite speakers who can help us find solutions and answers.

Rapid Improvement Event

33 people attended the event, including self-carers living in the community, voluntary sector workers, and NHS Lothian and City of Edinburgh Council staff.

The participants sat in random groups of 5 and discussed the following questions:

1. How do self-carers need to be recognised and supported so that they get the appropriate care and the same level of support as other service users?

2. What should be put in place to support self-carers going through a crisis (of any type)?

3. What should be considered when a self-carer has to stay in hospital (psychiatric or general) to make sure the right level of support is provided when away from home and when returning home?

These are the results of the discussion event and do not necessarily represent the views of Edinburgh Community Voices.

Discussion Groups

1. How do self-carers need to be recognised and supported so that they get the appropriate care and the same level of support as other service users?

What are the issues?

- Service providers often make the assumption that everyone has someone (e.g. a family member or friend) to look after them, to talk to, speak up for them and to ask for help when it's needed. This is often not the case.
- Self-carer status is not acknowledged in assessment.
- Self-carers often do not have the confidence to say what they need, to feel like they can have a dialogue and to ask for help.
- It is often hard for self-carers to admit that they can't do things. There is a fear that they might not be taken seriously.
- Self-carers often don't have social contact, they are living/existing but can have little quality of life.
- In case reviews, doctors tend to lead the review instead of listening to the person.
- Processes can be really complicated. Self-carers often do not know about all of the services and support they are able to access. Often the services themselves do not know what other services are available.

- Professionals do not take self-carers seriously and do not see their perspective as credible.

What’s needed?

- It should be identified on someone’s case notes if they are a self-carer.

- The assumption that everyone has someone needs to be addressed.

- There needs to be better awareness and understanding of what we mean by self-carer and what their issues are.

- Personal experience should be valued when assessing needs.

- Individuals need to be respected and listened to. Their views are important.

- There needs to be better assessment by GPs and other professionals. Whether or not someone is a self-carer should be established as early as possible.

- When needs are being assessed, face to face assessment is important.

- Professionals need to make sure that people understand what is being planned for in terms of care and treatment. Self-carers should be involved in the planning, if they wish.

- More discussion needs to be had regarding the roles and responsibilities of Occupational Therapists.

- It is particularly important that self-carers are told about and are able to access independent advocacy.

- Self-carers need safe places to drop in.

- Services should be longer-term, for continuity and to avoid upsetting changes.
- Self-carers should be told about all the different services that are available.
- Self-carers should have a care co-ordinator.
- More peer support.
- Professionals should ask about home circumstances routinely (this gets missed too often with self-carers).
- Greater access to social care.
- Services should not discharge you when you’ve had your quota but keep the door open.

2. What should be put into place to support self-carers going through a crisis (of any type)?

What are the issues?

- Self-carers often do not want to encroach on others when they are going through a crisis.
- Self-carers are often not aware of where they can get extra help when they are in crisis.
- Self-carers often are not aware of the support available to allow them to create a Wellness Recovery Action Plan which would help when they are in crisis.

- It can be extremely difficult for self-carers to recognise when they are unwell, and as a result it is harder for them to get help.

- Self-carers often cannot ask their neighbour for help because of their stigma induced fear.

What's needed?

- Self-carers should be supported to develop a wellness recovery action plan, if they wish.

- Befriending and buddying connections should be in place before a crisis happens.

- A way of informally "checking in" for people who fall off the radar.

- A toolkit or traffic light system so self-carers can silently communicate how they feel.

- It's important that someone (in the team looking after a self-carer) has their phone number.

- Self-carers need to know what support is available:

    - NHS 24
    - MHAS
    - Crisis centre
    - Community map with phone numbers/resources
    - Samaritans
    - Breathing Space

- There should be a greater variety of ways of asking for help.

- Self-carers should be supported to recognise the early signs of getting unwell and be able to contact someone for help ASAP

- Self-carers should have the option to self-refer or not.

3. What should be considered when a self-carer has to stay in hospital (psychiatric or general) to make sure the right level of support is provided when away from home and when returning home?

What are the issues?

- Leaving the acute ward can be un-planned and quick.
- No milk in fridge when self-carers return home.
- Self-carers often face problems when they return home (e.g. their benefits have been messed up or their gas has been turned off).

What's needed?

- The team in hospital should identify if someone is a self-carer.
- Baseline questions should be asked when someone goes into hospital, regarding housing, benefits, pets, bills, powercards etc.
- If the self-carer going into hospital is a worker or volunteer, the organisation they work for should be informed of what's happening (if the self-carer wishes).

- It would help if there was someone who could pick up a self-carer’s mail for them when they are in hospital.

- Access to a corporate appointee if someone cannot deal with finances.

- A financial assessment should routinely be offered when self-carers are discharged.

- A Welcome Home pack should be provided (e.g. bread, milk, information on support groups).

- Help to unpack.

- There should be a budget for setting someone up on discharge.

What else would help?

Practical assistance:

- Explore all options for short term support.
- Offer short term support
- Respite/extra support for a short time
- Pampering
- Cups of tea and a listening ear
- A hug service!