

Mental Health Care Coordination and Recovery Project

Briefing Paper

Emergent Key Themes and Findings August 2013

1. Service User and Carer Led Research

1.1 This research explores whether there is a pathway to mental health recovery through care coordination. The direct views and experiences of mental health service users and carers within Northumberland, Tyne and Wear have driven this project right from the start. They are the researchers designing the tools to be used, collecting and analysing data and disseminating the findings. This is referred to as **emancipatory action research**.

1.2 The project has three stages:

- 1) Questionnaire were sent out to service users', carers', professionals' and policy makers' to record their views of recovery and care coordination.
- 2) The training of service users and carers to be researchers and co-producers of the tools to be used in the study. These service users and carers subsequently conducting semi-structured interviews with service users and carers.
- 3) Conducting follow up in-depth interviews with professionals, service users and carers.

1.3 The data in this paper represents the partial findings of an ongoing piece of research. While the service user interviews are close to completion, carer interviews are at an early stage. As such this paper should be considered a work in progress, with updates to follow.

1.4 Some of the **benefits** of being a researcher in this project are reported as being:

'The achievement and advancement of personal aspirations'

'Development of confidence and high level analytical research skills, this has been transferable to our everyday lives and has led to a number of the researchers finding or seeking further employment.' (Service User and Carer Researchers)

1.5 There was an overwhelming majority of participants who felt there were **positive benefits** to being interviewed by a service user and carer.

'It makes a big difference but I mean you can tell that straightaway...Well he's not interviewing me in a suit, is he? He's got tattoos on his neck, he makes you feel normal, you know. You're dead straight forward. You're looking at me not looking at over there and saying yeah, yeah. So it is important, that is important.' (Service User)

'It's better to have talked to somebody who's kind of been through something and knows a bit a bit about it rather than somebody who studied it at college and supposedly knows what it feels like but like I say you can't until you've been through it.' (Service User)

2. What service users thought worked well

2.1 People describe how being **recognised** and **valued** as individuals in their own care and treatment is important for their recovery.

'I've always been listened to and felt they've worked with me, they've valued what my opinions are, I've not been pushed into anything. I've not been treated as someone who hasn't got anything to give in my recovery...I've been involved in every step of the way with them all.'

2.2 There was strong evidence of this in the **relationships** that were established particularly with occupational therapists, psychologists and in the voluntary sector. The importance of 'having a **concrete plan** on how you move forward with life without services' was seen as paramount.

2.3 **Accessible care plans** make a difference to how people engage with care coordination

'I think the one that they printed out...it just seemed all official to me, I just put my signature on the pages, but it didn't really mean anything to me. But the list that she [CPN] made, put down things that might affect me on a personal note'

2.4 **Peer support** was seen as instrumental in supporting a recovery focussed journey.

2.5 Very few people had heard about the concept of **recovery**. Where they had, recovery was generally viewed as a journey with targeted opportunities for developing **self-awareness**, taking **responsibility** for self-management and taking **positive risks** towards a meaningful future.

'Recovery doesn't mean cure, its...actively wanting to recover, and using self management and taking all the opportunities that have been there for me—psycho-education, expert patient courses, voluntary work. I don't think it has a definite end point.'

3. What service users thought didn't work well

3.1 Where care coordination does not work well, people comment that they have **limited power** and **control** in their communication and interaction with professionals, particularly doctors.

'You're talking about people trudging through your life...You don't want any bugger just being invited along all of a sudden'

3.2 Many people were **unclear** about care coordination and what should take place during the care coordination process.

3.3 Services were generally perceived as being **medication focussed** rather than personally meaningful or recovery focussed. Some people expressed a desire for services to be:

'more therapeutic, less centred on medication.'

3.4 Where services were medication focussed there was **limited discussion about recovery** or **signposting** to other services.

'It's like right I'll see you in the next 6 months time and then you can tell me that's not worked and that's what tends to happen.'

3.5 Generally people saw themselves as **being in services for life**.

'I think I'm always going to be in the mental health system...its part of who I am.'

3.6 **Risk** is talked about in a negative and constrained way. Professionals have limited discussion on the **positive risks** that are required to engage in **being well** and an active part of the community.

4. What carers thought worked well

4.1 The use of **Carers Centres** provides good emotional and practical support and information to carer. Carers didn't report getting formal support from anywhere else.

'I've used the carers centre when I've had counselling, because other than that where am I to go?'

4.2 **Peer support** through talking to other carers enables people to feel less isolated.

'it doesn't take away how you feel...but it makes you realise that there's other people who are going through a similar issue'

4.3 Evidence of positive involvement to date is scant both at the point of crisis and continuing over time, though when **signposting** works well, the carers feels positive about services.

'it was actually the CPN who got in touch with the Carers Centre. That's the one thing I can think of that did work.'

5. What carers didn't think worked well

5.1 Problems of **confidentiality**, clarity is needed about what information can be shared.

'obviously there's the confidentiality thing regarding my son being a service user. He would have to agree to it. But I think I would like more input and [information] regarding my son.'

5.2 Carers do **not feel engaged** in the discussions around the support of the person they care for. They find it distressing when the people they care for do not give what they perceive is an **honest picture** about the situation.

'I don't feel as if I'm much part of the team at the moment.'

5.3 The carer's role in supporting their family member has an **impact on the wellness** of the carer.

'when I look back, its absolutely killed my life...the role of the carer just takes the carer's life away.'

5.4 Lack of **clear signposting** information for carers.

'there didn't seem to be anything where there was like a flow diagram...where it said these do that and ...there was no centralised area when you understood how these people interacted'

5. What carers think didn't worked well

5.5 Some carers see asking for help as a sign of **failure**.

'by asking for an assessment you were showing that you couldn't actually cope with what was going on.' This contrasts with other carers who see **asking** for help as the only way to get the support they need.

5.6 Some carers live in a constant state of **tension** as they anticipate the next phase of mental distress

'you live on the edge all the time, wondering when the next episode is going to be...its 24 hours 7 days a week.'

5.7 Services that have been discontinued e.g. befriending and art therapy – this has resulted in a **loss of structure** and life outside of the home that is not replaced. People struggle to recover if there is no life outside the home.

5.8 For **older carers** what is going to happen and who is going to replace me?

5.9 If services are to encourage independence then they can't assume that **friends and family are doing the job** .

5.10 The level of **support** that is needed when for someone taking **positive risks** on their recovery journey is unclear. This puts more stress on the carer because the situations becomes more complex and challenging.

'in the past I've taken too much responsibility...I'm trying to step back and let him be as independent as he can be...That's a difficult one at times. But trying, definitely trying to do that.' (This stance is therefore seen as supporting recovery but challenging for carers.)

6. Key Messages so far

6.1 Care coordination needs to work using an approach to recovery which instils hope and promotes **aspirations and opportunity**.

6.2 Clear on-going service user and carer involvement in effective care and treatment that is goal oriented and **future focussed**.

6.3 Increased use of structured peer support to combat isolation and promote self-awareness, **proactive shared decision making** and wellness.

6.4 Risk is not something service users or carers felt they had ownership of, it is too clinical and focused on potential physical harm. Risk needs to be seen in a more balanced way to reflect the complexity of life. **Positive risk** taking should form part of recovery, supported through care co-ordination.

6.5 Service delivery is frequently perceived as a **tick box** exercise rather than having a positive impact and meaning in terms of every day life.

7. What Next?

In depth interviews with professionals, service users and carers will be taking place throughout the summer of 2013.

The outputs of this research will include: a practical tool for use by service users, carers and professionals in care co-ordination and recovery, providing evidence on delivering quality services; and a 'best practice' care coordination tool kit/guide. This project will make direct use of people's experiences of care coordination and recovery in shaping practice and policy both locally and nationally.

This document presents independent research funded by the National Institute for Health Research (NIHR) under its Research for Patient Benefit Programme (Grant Reference Number RfPB PB-PG-0808-17269). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.

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