

## **Carers and Co-Production: Enabling Expertise through Experience?**

### **Abstract**

#### *Purpose*

To provide a brief overview of the literature to date which has focussed on co-production within mental healthcare in the UK, including service user and carer involvement and collaboration.

#### *Design*

The paper presents key outcomes from studies which have explicitly attempted to introduce co-produced care in addition to specific tools designed to encourage co-production within mental health services. The paper debates the cultural and ideological shift required for staff, service users and family members to undertake co-produced care and outlines challenges ahead with respect to service redesign and new roles in practice.

#### *Findings*

Informal carers (family and friends) are recognised as a fundamental resource for mental health service provision, as well as a rich source of expertise through experience, yet their views are rarely solicited by mental health professionals or taken into account during decision-making. This issue is considered alongside new policy recommendations which advocate the development of co-produced services and care.

#### *Research Limitations*

Despite the launch of a number of initiatives designed to build on peer experience and support, there has been a lack of attention on the differing dynamic which remains evident between healthcare professionals and people using mental health services. Co-production sheds a light on the blurring of roles, trust and shared endeavour (Slay and Stephens, 2013) but, despite an increase in peer recovery workers across England, there has been little research or service development designed to focus explicitly on this particular dynamic.

#### *Practical Implications*

Despite these challenges, coproduction in mental healthcare represents a real opportunity for the skills and experience of family members to be taken into account and could provide a mechanism to achieve the 'triangle of care' with input, recognition and respect given to all (service users, carers, professionals) whose lives are touched by mental distress. However, lack of attention in relation to carer perspectives, expertise and potential involvement could undermine the potential for coproduction to act as a vehicle to encourage person-centred care which accounts for social in addition to clinical factors.

### *Social Implications*

The families of people with severe and enduring mental illness (SMI) assume a major responsibility for the provision of care and support to their relatives over extended time periods (Rose et al, 2004). Involving carers in discussions about care planning could help to provide a wider picture about the impact of mental health difficulties, beyond symptom reduction. The 'co-production of care' reflects a desire to work meaningfully and fully with service users and carers. However, to date, little work has been undertaken in order to coproduce services through the 'triangle of care' with carers bringing their own skills, resources and expertise.

### *Originality / Value*

This paper debates the current involvement of carers across mental healthcare and debates whether co-production could be a vehicle to utilise carer expertise, enhance quality and satisfaction with mental healthcare. The critique of current work highlights the danger of increasing expectations on service providers to undertake work aligned to key initiatives (shared decision-making, person-centred care, co-production), that have common underpinning principles but, in the absence of practical guidance, could be addressed in isolation rather than as an integrated approach within a 'triangle of care'.

## **Background**

Over the last three decades, an increasing recognition of the role of social factors in recovery from mental illness has resulted in the growth and development of community-based services. The last 5 years has seen a reduction in the numbers of inpatient beds available to mental health services due to the national economic situation in the UK and reducing resources to the NHS, but also to reflect the impetus to provide care closer to home and focus on the need to enhance self-management of long-term conditions. In order to support people with severe and enduring mental health problems to remain at home rather than be admitted to hospital services, crisis intervention and home

treatment teams have been introduced across the UK. The involvement of informal carers (commonly family and friends) has been recognised as a fundamental element of mental health service provision. Rethink (2006) has proposed that all people providing substantive care should be defined as carers. The families of people with severe and enduring mental illness (SMI) assume a major responsibility for the provision of care and support to their relatives over extended time periods (Rose et al, 2004). Indeed, it has been estimated that 1/3 – 2/3rds of all patients with SMI live with family members (Ingtagliata et al, 1986 cited in Rose et al, 2004) and work conducted in Australia suggests that these family members provide approximately 104 hours per week of care, more than 3x the average mental health nurse (cited in Goodwin and Happell, 2007). Carers UK (2008) have estimated that carers save the economy £87 billion per year. As a consequence, Lavoie-Trembley et al (2012) conclude that the impact of mental illness is often most strongly felt by the families of people with mental health difficulties.

Despite their prominent role, the carers of people with severe and enduring mental illness (SMI) have been described as a hidden and socially excluded group (Gray et al, 2010). Family members often feel marginalised in the support of their relative, that they have little encouragement to get involved, are not as involved as they would like to be in their care and feel their expertise is overlooked or devalued (Rowe, 2013; Lammers and Happell, 2004 cited in Goodwin and Happell, 2007). Many families have repeatedly reported that they need, but do not get, information about their relatives' illness and treatment, or assistance with managing illness symptoms (Rose 1997, 1998). Despite the significance and extent of family involvement in the care of people with SMI, Rose et al (2004) found great disparity between what families felt they needed from healthcare professionals and what they received.

The concept of caregiver burden of care is presently well recognised and has become an integral part of treatment programmes and policy decisions. Despite this, caregivers continue to struggle without adequate support or resources (Awad and Voruganti, 2008). By focusing on the mental illnesses of the people they care for, carers can neglect their own social networks leaving them isolated (Rose et al, 2002). Carers and relatives of people with mental health difficulties are at greater risk of psychiatric morbidity, lower health related quality of life and stress-related illness than either the general population (Yee et al, 2000; Chang and Horrocks, 2006; Stengard et al, 2001; cited in Yartalova O-Doherty and Doherty, 2008; Chiu et al, 2006) or those caring for people with somatic illness only (Hastrup et al, 2011). The caregivers of those who are either partners to, or children of, care recipients (Hastrup et al, 2011) appear at particular risk.

Theoretical explanations of caregiver burden have utilised psychological perspectives of stress and coping (Hastrup et al, 2011). Caring for people with SMI can generate fear, disbelief, guilt and chaos, and coping mechanisms may include the seeking of relevant information, optimism, routine living and re-evaluating social expectation (James, 1989 cited in Gray et al, 2009). Many carers feel at a loss as to what do in caring for someone with mental health problems and lack vital information and necessary training to provide adequate support (Pinfold et al, 2005 cited in Gray et al, 2009). Subjective assessments of the restriction imposed by informal caring are vital when exploring self-esteem and coping responses. The carers of people with SMI have been found to utilise a wide range of coping styles including:

- Active behavioural style strategies
- Active cognitive style strategies
- Avoidance style strategies (O-Doherty and Doherty, 2008).

Active strategies have been associated with lower levels of mental health distress amongst carers when compared to avoidance strategies. O-Doherty and Doherty (2008) conducted study with the carers of people with SMI and found few participants who combined the use of active coping strategies with avoidance strategies, leading to the suggestion that these strategies could be mutually exclusive within these relationships.

The notion of co-production has been explored within mental healthcare services and research in order to understand how to further involve service user views and experiences across service provision. This paper provides a critical overview of current literature relating to carer involvement, carer support and coproduction within the area of adult mental healthcare. A number of databases (PsychARTICLES, Academic Search Complete, CINAHL Plus with Full Text, MEDLINE) were searched using the following search terms: Carer OR caregiver OR family; AND mental health OR mental illness OR coproduction; NOT dementia NOT eating disorders or bulimia or anorexia; NOT intellectual disability or learning disability AND burden or stress NOT child or adolescent or children or teenager. Literature was considered from the year 2000 onwards.

In addition, the 'grey' literature was accessed, including policy and local literature from national databases, local NHS organisations. Information, discussion and debate with colleagues working and researching across the area of adult mental healthcare was a further key constituent. In terms of

finding relevant literature with a focus on carers and co-production, there was a notable absence of relevant research in this particular area, suggesting a gap for further research.

### **Carer Involvement and Adult Mental Healthcare**

Mental health professionals are persistently criticised for not adequately involving service users and carers in care planning (Anthony and Crawford, 2000). One explanation offered for this is that mental health workers are unwilling to trust the views and preferences of patients, particularly in relation to their treatment preferences (Hanson et al, 2004). Research has found disparity between health professional and service user preferences, with professionals placing greater emphasis on symptom reduction than service users who focus more broadly on improvements in other areas of their lives (Lelliot et al, 2001). Small et al (2010) suggest that this disparity between professional, family and service user views can be a factor in carer burden. Further to this, family members and service users do not always have shared interests or needs (Adams and Gardner, 2005; Cleary et al, 2005; Noble and Douglas 2004 cited in Cleary et al, 2006), and may have differing priorities in relation to treatment options (Rose et al, 2004) as well as need within the home (Pinfold et al, 2007). The views of carers and health or social care professionals are at times at odds with each other and, to resolve these differences, professionals must engage with carers rather than criticise them for not conforming to professional assumptions (Small et al, 2010). Chiu et al (2006) found that the sense of helplessness experienced by family members was largely sustained by the healthcare system. Indeed, scarce contact between caregivers and health professionals has been shown to increase subjective carer burden (Jacob et al 1987; Chang et al, 2010 cited in Hastrup et al, 2011). Ostman and Kjellin (2002) noted that relatives who acted as carers had deep-seated feelings of inferiority to staff, which could explain low levels of cooperation between relatives and professionals as well as subsequent difficulties with access to services (cited in Gray et al, 2009). Lack of carer involvement reinforced the view of some professionals that silence means acquiescence / acceptance (Chiu et al, 2006).

Involving carers in discussions about care planning could help to provide a wider picture about the impact of mental health difficulties, beyond symptom reduction. Families have reported concerns that service users behave differently when around health care professionals but, despite this, that they were rarely asked for their perspectives (Rose et al, 2004). The failure to speak with family members can represent a missed opportunity for obtaining crucial information that may not

otherwise be available to those who meet with service users only in defined circumstances and settings (Solomon et al, 2012). Carers have described feeling dissatisfied with the information they receive from healthcare professionals (Cleary et al, 2006), their limited input to treatment plans (Lavoie-Tremblay et al, 2012) and often feel marginalised during decision-making (Van de Bovenkamp, 2012). To address this, Patterson et al, (2011) propose further research with staff, carers and service users in order to transform these relationships.

Service user and family participation in care planning may be viewed as an issue of human rights (Perkins and Repper, 1998 cited in Goodwin and Happell, 2007<sup>2</sup>) and family involvement is a central theme in recovery literature (Jacobson and Greenley, 2001; Mancini, Hardiman and Lawson, 2005; Piat, Fleury, Boyer, Sabetti and Lesage, 2010 cited in Lavoie-Tremblay et al, 2012). Despite this, it is clear that family participation in care planning or decision-making remains marginal (Goodwin and HAppell, 2007) and that carers are in need of further information and support.

The importance of service user and carer involvement throughout mental healthcare has been acknowledged internationally and various countries have implemented national policies to highlight the importance of collaboration. Within the UK, policy development in this area has advocated the involvement of carers' with the planning, implementation and evaluation of mental health services (DoH, 1999; Wilkinson & McAndrew, 2008). Partnership working has been central to UK policy over the last 15 years with outcomes including improved efficiency, flexible working, enhanced service user experience (Meddings et al, 2014). The National Involvement Partnership (NIP) provides national minimum standards for the involvement of service users' and carers' in mental health which are framed within the principles of purpose, presence, process and impact (PPPI) (Robotham and Ackerman 2011). In 2013 The Carers Trust recommended a 'triangle of care' (service users, carers, healthcare professionals) for the purposes of decision making and establishing therapeutic alliance. Across Europe, in 2005 the European Union adopted the declaration and action plan on mental health (EOHSP, 2007 cited in Lavoie-Tremblay et al, 2012).

One of the particular challenges when attempting to further involve and support carers is that traditional models of mental health care have largely been patient-centred, have failed to acknowledge the interactions between patients and their social environment and, thus, proved to be an obstacle to collaboration (Jubb and Stanley, 2002 cited in Lavoie-Tremblay et al, 2012). Staff concerns about confidentiality have proved to be a major barrier to collaboration with family

members (Lavoie-Tremblay et al, 2012). Furthermore, there is an abiding assumption that nurses are responsible for and accountable only to service users, even when the complexities of the situation demand a wide inclusion of supporters (Rowe, 2014). Specific barriers to carer involvement include unhelpful staff attitudes, unsupportive services, poor communication, inadequate information sharing (Rowe, 2014) and insufficient knowledge with regards to family intervention (Nicholas and Pernice, 2009 cited in Lavoie-Tremblay et al, 2012). Family members have outlined staff characteristics deemed to be unhelpful for participation, these include refusing to listen to family members, discrediting family experiences, responding defensively when asked questions by family members and inadequately preparing families for a patient's discharge (Rose et al, 2004). However, if interventions or services are conceptualised, designed and delivered by professionals in isolation from service users (or vice versa), it is likely that they will prioritise certain kinds of knowledge or methods of support over others (Slay and Stephens, 2013).

Bourgeois et al (1997) report that caregiver's behavioural skills and effective self-management training programmes result in a lower frequency of patient behavioural problems and help to improve the caregivers mood (cited in Shah et al, 2010). Family intervention may reduce the number of relapse events and hospitalisations for service users (Caqueo-Urizar et al, 2014; Cassidy et al, 2001 cited in O-Doherty and Dohert, 2008) and the evidence seems to support the positive impact of therapeutic family interventions on improving family environment, coping abilities and reducing burden of care. Collaborating with families through the care process contributes to carer satisfaction with services and has also been found to ease carer burden (Perreault et al, cited in Lavoie-Tremblay et al, 2012; Clearly et al, 2006). Carers who feel supported by the healthcare system are more knowledgeable about the characteristics of mental illness and methods of management (Biegal et al, 1994 cited in Lavoie-Tremblay et al, 2012). However, unless family members were helped to go through the adjustment stages shortly following diagnosis, then could not become a resource (Mueser et al, 2002 cited in Chiu et al, 2006). Glanville and Dison (2005) suggest the term carer 'burden' is misleading and that carers may manage their situation better if they conceptualise it differently e.g a form of family support with reciprocal benefits (cited in Small et al, 2010). With such documented positive impact, Awad and Voruganti (2008) question why family interventions across adult mental healthcare are neither widely used nor well integrated in care plans. Lavoie-Tremblay et al (2012) suggest that professionals continue to under-estimate the value of carer involvement, viewing family appointments as time consuming and potentially unhelpful. Such findings suggest that those working within mental healthcare services remain pre-occupied with treatment, which may start to account for a mismatch between service provision and service user needs.

### **Shared decision making.**

Shared decision-making (SDM) is a model for patient-centred care that prioritises service user and family involvement in treatment decision-making, working alliance and satisfaction (Ishii et al 2014). SDM represents an inclusive approach to care provision which incorporates the expertise of the clinician whilst ensuring that decisions are focused on the patient's personal circumstances and values. Evidence suggests that when provided with the correct level of support and information, patients become less passive with decision-making and more comfortable with the decisions made about their care (Coulter, 2010). Over recent years, clinicians have been challenged to revise their communication practices to ensure that they and their patients engage in shared decision-making (Iedema and Veljanova, 2013). Two clinical trials conducted with service users diagnosed with schizophrenia have suggested that SDM can increase treatment knowledge (Hamann et al, 2006) and desire for greater responsibility in treatment decisions (Hamann et al, 2011 cited in Ishii et al, 2014). Despite this, the evidence base for SDM within mental health care remains limited and further research is required. There is a particular role for research to explore the qualitative impact of SDM on service users and their families, as well as the role of training for mental health staff in supporting the delivery of SDM.

There are clear, intuitive links between shared decision-making and other developments within mental healthcare, most notable recovery-focussed approaches and person-centred services. In order to support these developments, mental health policy in many countries now requires services to build upon the personal version of recovery, and to give credence to the knowledge derived from lived experience of mental distress and recovery (Slade et al, 2013). One commonly used tool developed to facilitate person-centred, recovery-focussed care is the Wellness Recovery Action Planning (WRAP) tool. WRAP is used to create recovery plans – to encourage staff and service users to think about what has kept people well in the past, consider strategies that have helped others to stay well and include recognising and dealing with triggers through crisis planning (Slade et al, 2013). The Mental Health Recovery Star is another tool which is commonly utilised by professionals and services to evaluate outcomes but also to inform care planning. Both the WRAP and Recovery Staff have the potential to encourage further SDM in practice and should be evaluated in relation to their impact on SDM in practice. The Recovery Star explicitly accounts for the role of family members / carers in developing understandings of recovery, indeed, tools such as the WRAP and Recovery Star provide opportunities for carers to make explicit their own aspirations for recovery, further

challenging the portrayal of service users and carers as passive recipients of what other people do to them (Boyle and Harris, 2009 cited in Laws, 2013).

### **What is co-production and how is it different?**

Self healing, self-management and co-produced care are becoming increasingly pervasive aspects of how people manage their health and illness (Iedema and Veljanova, 2013; Slade et al, 2013). Over recent years, the debate about how to address issues of self-management and develop person-centred care has continue to evolve. Involvement of carers has come sharply into focus, explicitly acknowledged by the National Institute for Health Research (NIHR), England with the changes in terminology from patient and public involvement (PPI) to Patient, Carer, Public Involvement and Engagement (PCPIE). The notion of involvement and consultation has also developed further towards a notion of co-production. Indeed, in 2012, The National Audit of Schizophrenia highlighted the need for a model of co-production within mental health services in order to improve outcomes for service users. Historical models of mental health care have been criticised for being service-led rather than service-user led, adopting paternalistic approaches towards service user involvement, as well as prioritising medicalised approaches to treatment. The ‘co-production of care’ reflects a challenge to this history, reflecting the desire to work meaningfully and fully with service users and carers through the delivery of contemporary care. Co-production was highlighted in a policy report by Wanless (2002) from HM treasury in order to challenge the belief that patients are passive recipients of care and that health services, and professional expertise within them, are all that is required in order to meet patients’ need and expectations. Co-production became a call for services to grant patients more say in their care and “co-production effectively completed the process of unhinging the patient’s positioning from the sick role” (pp 5, Iedema and Velajanova, 2013). Taking account of current debate and research which looks at the case for carer involvement, to enhance outcomes and experience for both carers and service users, the call for services should encompass the role of carers through the model of co-production. Such a move could prevent carer experiences such as those described by Chiu et al (2006) where carers feel disempowered and that their loved ones were in the hands of superior people with ‘private expertise’.

In 2013, MIND commissioned the New Economics Foundation (NEF) to carry out a review of existing evidence in relation to co-production – focussing on when, why, and how it has been used across mental healthcare, which aspects of co-production are being developed in the sector, what impact it

has had on mental health support and the recovery of people with mental health difficulties (Slay and Stephens, 2013). The NEF definition of co-production has been defined through work with practitioners and critical friends:

“A relationship where professionals and citizens share power to plan and deliver support together, recognising that both partners have vital contributions to make in order to improve quality of life for people and communities” (pg 3, Slay and Stephens, 2013)

Co-production is a form of partnership working and an approach to service delivery and practice (Meddings et al, 2014). There are 6 principles which underpin co-production:-

1. Taking an assets-based approach: perception of people as active and equal partners, not passive recipients, in designing and delivering services
2. Building on people’s existing capabilities – to recognise and grow capabilities, with active support to put to use at individual and community level.
3. Reciprocity and mutuality: range of incentives for people to work with professionals and each other, with a range of expectations and responsibilities
4. Peer support networks: engaging peer and personal networks alongside professionals as best way of transferring knowledge
5. Blurring distinctions: between professionals and service recipients, producers and consumers, by reconfiguring how services are developed and delivered
6. Facilitating not delivering: public service agencies as catalysts and facilitators, not main providers (Slay and Stephens, 2013) .

Co-production explicitly rejects the idea of service delivery to passive users, proposing they become active participants in the production of outcomes. Service users become equal partners in delivery, bringing resources and expertise to their interactions with providers (Ryan, 2012). Expertise derived from experience is combined with professional expertise to inform decision-making and to encourage growing autonomy and responsibility of ‘clients as citizens’ (Ryan, 2012). In making explicit the role of expertise from experience, the potential or further carer involvement throughout care planning and provision is highlighted. The involvement of carers, who continue to be members of families and the public, is vital to achieve a co-produced, recovery-focused approach to mental health provision, with potential benefits for service users as well as carers themselves.

Slay and Stephens (2013) observed that the term co-production was largely absent from the literature, with a stronger focus on peer support initiatives. However, even without explicit reference to 'co-production' the review outlined a number of initiatives and research studies, particularly those built around peer support and 'experts by experience' which demonstrated evidence of the underpinning principles of co-production, most notably:-

- Building on peoples capabilities
- Developing networks
- People as assets

The opportunity for people to discuss, define then shape their interactions with services is central to developing autonomy and dignity (Hunter and Ritchie, 2007 cited in Meddings et al, 2014).

However, despite highlighting a number of initiatives designed to build on peer experience and support, the review clearly demonstrated a lack of attention being placed by academics and policy makers alike in relation to the differing dynamic which remains evident between healthcare professionals and people using mental health services. This also further highlights the implicit assumption that carer and service user views will be aligned, an assumption that has already been challenged by the literature. It is notable that, to date, little work has been undertaken in order to coproduce services through the 'triangle of care' with carers bringing their own skills, resources and expertise.

Outcomes derived from co-production include:-

- Enhanced autonomy, through blurred distinctions, facilitation and not delivery, leading to increased feelings of control over mental health difficulties (Slay and Stephens, 2013)
- Increased potential for the redefinition of difficulties and how these might be addressed (Ryan, 2012)
- Relatedness through mutuality, reciprocity and the establishment of peer support networks (Slay and Stephens, 2013)
- Confidence and self-esteem (Slay and Stephens, 2013)

With respect to co-production and carers, a key aspect of relatedness is the focus on building relationships, including those with peers, family and social networks. Further research is required to establish the mechanisms by which family members, and social networks more broadly could be engaged with the work of mental health recovery. The focus of research has predominantly been the aspect of negative carer burden as experiences by those living with people with SMI, however,

research has been undertaken to focus on the positive aspects of caring that are experienced by family members with SMI. For example, early literature frequently pointed to the degree of tolerance of caregivers and families in spite of being subjected to significant burden. Similarly, it is striking in some situations how some families are able to cope better than others (Awad and Voruganti, 2008). Engaging with families across a range of experiences is important to further understand how collective views and action can be achieved across mental healthcare, particularly those communication and coping strategies which may be associated with positive outcomes for whole families.

Explicit recognition of the potential role of family members in order to achieve co-produced, person-centred services would be helpful in encouraging people to come forward and request further information as well as offer their expertise by experience. Cultural change and organisational support is paramount, with practical guidance needed in light of concerns about confidentiality as a starting point. A variety of interventions have been developed which support caregivers including formal approaches to planning care which take into account the specific needs of carers, sometimes using specially designated nurses or other members of the health care team (Woods et al, 2003 cited in Shah et al, 2010). This is particularly important for those service users being cared for within hospital settings whereby carers may be required to act as service brokers in important mental health matters e.g assessment / treatment (Chang and Horrocks, 2006).

Meddings et al (2014) propose that co-production requires a fundamental philosophical re-orientation for those working within services. Clifton et al (2013) considered the role of mental health nurses in delivering social inclusion outcomes with service users, questioning the extent to which mental health professionals and service users through co-production can overcome macro-level structures which often create 'multiply-deprived demographics' for this group. Professionals are advised to moderate their directive, expert role, in order to become facilitators and enablers of outcomes in a process of joint action in which clients are active agents (Ryan, 2012). It can be helpful for those working within services to have guidance about practical ways in which to implement new models of working, with a view to initiating cultural change over the longer term. One helpful example of the application of co-production for mental health services include mental health dialogues. Mental health dialogues are community forums where service users, carers, friends, mental health workers and others with an interest in mental health participate in an open dialogue (see Slay and Stephens, 2013). The meetings address different topics, can facilitate a discrete and independent form of production of knowledge, and drive recovery-oriented changes in

communication and structures. Those working to provide mental health services over recent years have been attentive to the implementation of further service user and carer consultation and SDM, the success of this has been patchy and dependent on the presence of those within services who fully understand the implications of further service user and carer involvement across mental healthcare. Coproduction, with the emphasis on social inclusion, input and participation in service delivery and planning, may prove challenging for those already trying to identify local mechanisms to enhance and develop new ways of engaging and involving service users and their families in care planning and delivery. Further, practical tools to enable short-term engagement to stimulate longer-term ideological and cultural expectations (of staff, family members and service users) are required. There is a danger, in a difficult economic climate, that a shift towards full coproduction of services and care will be regarded as a further mechanism designed to cut the costs of service delivery. There are further challenges for workload planning and the constitution of mental health teams, with the introduction of peer recovery workers and 'experts by experience' working alongside team members with professionally derived skills and experience.

## **Conclusions**

Despite the challenges, coproduction in mental healthcare represents a real opportunity for the skills and experience of family members to be taken into account and could provide a mechanism to achieve the 'triangle of care' with input, recognition and respect given to all (service users, carers, professionals) whose lives are touched by mental distress. However, lack of attention in relation to carer perspectives, expertise and potential involvement could undermine the potential for coproduction to act as a vehicle to encourage person-centred care which accounts for social in addition to clinical factors. There is a danger that carer expertise will remain on the margins of mental healthcare, despite representing a real and valuable source of information and support for people living with mental health difficulties and those supporting them. Furthermore, as services increase their focus on self-management and 'care closer to home', the pressure on family members will likely also increase. As carer involvement has been found to be a vital source of support and encouragement for those involved in caring for people with mental health difficulties, coproduction could become a vehicle to support the whole triangle of care. In this respect, the healthcare sector has a lot to learn from the voluntary sector, where peer recovery and family expertise is encouraged and utilised (e.g Macmillan cancer services, MIND) realising benefits for those with expertise by experience.

## References

Anthony P and Crawford P (2000) Service user involvement in care planning: the mental health nurses' perspective *Journal of Psychiatric and mental health nursing* 7: 425 – 434

Awad A and Voruganti L (2008) The Burden of Schizophrenia on Caregivers: A Review *Pharmacoeconomics* 26(2): 149-162

Boyle D, Clarke S and Burns S (2006) *Aspects of co-production: The implications for work, health and volunteering* NEF Report: The New Economics Foundation: London.

[http://www.neweconomics.org/page/-/files/Aspects\\_of\\_Co-production.pdf](http://www.neweconomics.org/page/-/files/Aspects_of_Co-production.pdf) Accessed 17.5.2014

Caqueo-Urizar A, Miranda – Castillo C, Giraldez S, Maturana S, Perez M, Tapia F (2014) An updated review on burden on caregivers of schizophrenia patients *Psicothema* 26 (2): 235 – 243

Chang K, Horrocks S (2006) Lived experiences of family caregivers of mentally ill relatives. *Journal of Advanced Nursing* 53 (4): 435 – 443

Chiu M, Fang-Wan G, Lee S (2006) Personal tragedy or system failure: a qualitative analysis of narratives of caregivers of people with severe mental illness in Hong Kong and Taiwan *International Journal of Social Psychiatry* 52 (5): 413 – 423

Cleary M, Freeman A and Walter G (2006) Carer participation in mental health service delivery *International Journal of Mental Health Nursing* 15, 189–194

Clifton A, Repper J, Banks D and Remnant J (2013) Co-producing social inclusion: the structure /agency conundrum, *Journal of Psychiatric and Mental Health Nursing* 20: 514 – 524

Coulter A (2010) *Implementing shared decision making in the UK: A report for the Health Foundation* London: Health Foundation

Gillard S, Simons L, Turner K, Luckock M and Edwards M (2012) Patient and public involvement in the coproduction of knowledge: Reflection on the analysis of qualitative data in a mental health study. *Qualitative Health Research* 22 (8): 1126 – 1137

Goodwin V and Happell B (2007) Consumer and carer participation in mental health care: The carer's perspective. Part 1 - Goodwin V and Happell B (2007) Consumer and carer participation in mental health care: The carer's perspective. Part 1 – the importance of respect and collaboration *Issues in Mental Health Nursing* 28: 607 - 623

Goodwin V and Happell B (2007) Consumer and carer participation in mental health care: The carer's perspective. Part 2- barriers to effective and genuine participation *Issues in Mental Health Nursing* 28: 625 – 238

Gray B, Robinson C, Seddon D, Roberts A (2009) An emotive subject: Insights from social, voluntary and healthcare professionals into the feelings of family carers for people with mental health problems *Health and Social Care in the Community* 17(2): 125-132

Gray B, Robinson C. Seddon D et al (2010) Patterns of exclusion for carers for people with mental health problems - the perspectives of professionals. *Journal of Social Work Practice*. 24 (4): 475-492.

Hamann J, Langer B, Winkler V, Busch R, Cohen R, Leucht S (2006) Shared decision making for inpatients with schizophrenia, *Acta Psychiatrica Scandinavica* 114: 265-273

Hamann J, Mendel R, Meier A, Asani F, Pausch E, Leucht S, Kissing W (2011) "How to speak to your psychiatrist": shared decision-making training for inpatients with schizophrenia, *Psychiatric Services* 62:1218-1221

Hansen T, Hatling T, Lidal E and Ruud T (2004) The user perspective: respected or rejected in mental health care? *Journal of Psychiatric and Mental Health Nursing* 11: 292 – 297

Hastrup L, Van Den Berg B, Gyrd-Hansen D (2011) Do informal caregivers in mental illness feel more burdened? A comparative study of mental versus somatic illnesses *Scandinavian Journal of Public Health* 39: 598 – 607

Iedema R and Veljanova I (2013) Lifestyle science: Self-healing, co-production and DIY. *Health Sociology Review* 22 (1): 2 – 7

Ishii M, Okumura Y, Sugiyama N, Hasegawa H, Noda T, Hirayasu Y, Ito H (2014) Efficacy of shared decision making on treatment satisfaction for patients with first-admission schizophrenia: study protocol for a randomised controlled trial, *BMC Psychiatry* 14: 111  
<http://www.biomedcentral.com/1471-244X/14/111>

Kartalova O-Doherty Y and Doherty D (2008) Coping strategies and styles of family carers of persons with enduring mental illness: a mixed methods analysis, *Scand J Caring Sci* 22: 19 – 28

Lavoie-Tremblay M, Bonin J, Bonneville-Roussy A, Briand C, Perreault M, Piat M, Lesage A, Racine H, Laroche D and Cyr G (2012) Families' and Decision Makers' experiences with mental health care reform: The challenge of collaboration. *Archives of Psychiatric Nursing* 26: 4 (August) ppe41-e50

Laws J 2013 'Recovery work' and 'magic' among long-term mental health service users. *The Sociological Review* 61(2): 344 – 362

Lelliot, Beevor A, Hogman G, Hyslop J, Lathlean J and Ward M (2001) Carers' and Users expectations of service-user version (CUES-U): A new instrument to measure the experience of users of mental health services *British Journal of Psychiatry* 179: 67-72

Meddings S, Byrne D, Barnicoat S, Campbell C, Locks L (2014) Co-delivered and co-produced: creating a recovery college in partnership *Journal of Mental Health Training, Education and Practice* 9(1): 16-25

Patterson M, Nolan M, Rick J *et al* (2011) *From Metrics to Meaning: Culture Change and Quality*

*of Acute Hospital Care for Older People. Report for the National Institute for Health Research Service Delivery and Organisation programme, SDO Project (08/1501/93).* Stationers Office: London

Pinfold V, Rappaport J, Bellringer S (2007) Developing partnerships with carers through good practice in information-sharing. *Mental Health Review Journal*. 12. 2. 7-14.

Robotham D and Ackerman J 2011 *Service user and carer involvement in the national mental health development unit* Mental Health Foundation: London

Rose L, Mallinson RK, Walton-Moss B (2004) Barriers to Family Care in Psychiatric Settings *Journal of Nursing Scholarship*, 36:1, 39-47.

Rowe J (2013) Enhancing carers' experiences of mental health services *Mental Health Practice* 17(2): 24-26

Ryan B 2012 Co-production: Option or obligation? *Australian Journal of Public Administration* 71 (3): 314-324

Shah A, Wadoo O, Latoo J (2010) Psychological distress in carers of people with mental disorders *British Journal of Medical Practitioners* 3 (3): 18 – 25

Slade M, Amering M, Farkas M, Hamilton B, O'Hagan M, Panther G, Perkins R, Shepherd G, Tse S, Whitley R (2013) Uses and abuses of recovery: implementing recovery-oriented practices in mental health systems. *World Psychiatry* 13: 12 – 20

Slay, J. & Stephens, L. (2013). Co-production in mental health: A literature review. London: new economics foundation

Small N et al (2010) Carer burden in schizophrenia: Considerations for nursing practice. *Mental Health Practice* 14(4): 22 - 25

Solomon P, Molinaro M, Mannion E, Cantwell K (2012) Confidentiality Policies and Practices in Regard to Family Involvement: Does Training Make a Difference? *American Journal of Psychiatric Rehabilitation*, 15: 97–115

Wanless D (2002): *Securing Our Future Health: Taking a long-term view*, H M Treasury, London.

Wilkinson C and McAndrew S 2008 'I'm not an outsider, I'm his mother!' A phenomenological enquiry into carer experiences of exclusion from acute psychiatric settings *International Journal of Mental Health Nursing* 17, 392–401