**FORENSIC NETWORK ADVISORY BOARD**

**SHORT LIFE WORKING GROUP: Developing a Forensic Carers Strategy**

**REPORT AND RECOMMENDATIONS**

**September 2012**

1. Introduction and background

This report is the culmination of some months of work to develop a Forensic Carers’ Strategy that will form the basis of developing better services for carers supporting someone within forensic services. This Strategy will complement and add to the national Carers’ Strategy: ‘Caring Together 2010-2015’ and the recommendations have been built into a framework that acknowledges the integration of these two documents.

This content of this report is based on consultation with carers, stakeholders and voluntary sector carer organisations that have an interest in those we have labelled ‘forensic carers’. The consultation with carers took place over two one-day sessions facilitated by the Forensic Network Short Life Working Group on, brought together to develop a Carers’ Strategy, and the sessions were supported by Andrea Ridley from Edinburgh Carers Council and chaired by Carolyn Little from Support in Mind Scotland. The consultation with other stakeholders and organisations was via telephone conversations facilitated by Support in Mind Scotland, who also produced this report.

There was no distinction made in the consultation between the experiences across different levels of security or between different facilities within the network. The events did not highlight existing good practice where it exists, and this is picked up in the interviews with professional stakeholders and background reading.

The Short Life Working Group commends these recommendations to the Forensic Network Advisory Board.

1. Carers’ consultation:
   1. Carers’ Experiences of forensic services

The first consultation event highlighted the issues and themes of most concern to carers, through facilitated table discussions around the themes of *Information,* *Involvement* and *Recovery and Living Well*. (See detailed summary in Appendix 1) and the carers attending this session represented a range of experience, with many having been in the forensic system for a number of years.

There was acknowledgement that certain things had improved over the past decade, specifically the recognition of family members as people who needed information and support, and carers felt more aware of their own rights to be included. However, the overwhelming experience was still that carers – particularly those new to services – felt uninformed, confused and frightened, not understanding what was happening to their relative, or what they could do to help them and to manage their own stress and distress.

The issues identified reflect the kinds of issues all carer groups experience and are in line with the headline actions outlined in the National Carers Strategy: the need for information and communication; access to quality assessments; having a voice in services and planning; the need for training for both carers and professionals; the need for practical and emotional support; prioritising carers’ own health and wellbeing.

However, there are specific and unique issues faced by forensic carers that require the focus of a discrete Forensic Carers Strategy and Action Plan:

* *Stigma*: a relative being detained for their own and/or others’ safety adds even more stigma to that surrounding mental illness, making it difficult to seek and receive support, from first diagnosis and throughout treatment
* *Trauma:* carers experience additional trauma due to the circumstances surrounding their relative’s admission into care and treatment, involving the police and criminal justice services, and the removal of choice and control
* *Restriction through Security:* Secure environments bring additional layers of regulation, restriction and lack of choice and control not experienced elsewhere
* *Out of Area Care:* carers have no say in where their relative receives care, with no alternatives in local areas, bringing additional financial and practical pressures impacting on families
  1. Young carers, siblings and families

The specific needs of children and young people need to be considered. Whether Young people contribute to the care and treatment of their parent, sibling or other relative as ‘young carers’ or not, they still need to understand as much as is age appropriate as possible about what is happening to their relative, and those who are providing care, need appropriate information, support and even advocacy – such as is provided by some carers’ centres and other young people’s services. Family therapy approaches are also crucial as this helps to support and maintain family relationships during the difficult period within a secure environment.

* 1. Pathway through services: specific trigger points

In addition to the headline issues that affected carers’ experiences of forensic services, the consultation explored the pathway through services describing and contrasting an ‘ideal’ and ‘typical’ experience (see Appendix 2). This exercise reinforced the experiences highlighted by the facilitated discussions summarised above, but also indicated the key trigger or transition points in the system where specific consideration of carers’ contribution and needs should be in place:

* *Diagnosis*: response by GPs particularly
* *Entering services for the first time*: dealing with trauma and other agencies such as the police
* *Reviews and appeals*: understanding the system and navigating procedures of the mental health tribunal
* *Step down and discharge*: coping with and being part of the change in care and treatment
  1. Addressing the Issues: Guidelines for Good Practice

*Framework of a Forensic Carers’ Strategy*

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| ISSUE | GOOD PRACTICE RESPONSE |
| **Information provision** – carers did not want to have to search for information, especially on admission to services. First admission follows a crisis, often involving the police, criminal justice services, and this is completely unknown territory for carers who are also dealing with their own distress. | **Comprehensive information pack** available on initial visit covering technical and legal information, as well as information about services and what could be expected. Information should also be **tailored to the circumstances** impacting on each individual carer such as involvement with criminal justice and other services. |
| **Communication** – more than simply handing out information, but interaction between staff and carers. Staff should find ways of helping carers to understand the illness and how they could better support their relative. Communication also involves ensuring carers have contact with other professionals in other agencies, relevant to their situation | **A dedicated carers’ worker** would be invaluable in interacting with the carers from first visit and throughout their ‘journey’ through forensic services. Information proactively given at the right time, and co-ordination and facilitation of meetings/interaction with other relevant professionals  **Confidentiality** also needed to be addressed through clearer **guidelines** for staff and more skills and confidence in working with families. |
| **Partners in the delivery of care and treatment** – carers felt assumptions were made about their role and they were excluded from decision-making but expected to fill in the gaps in the care and treatment for their relative. Partnership requires involvement at key points of change and decision-making as part of the multi-disciplinary team. | **Staff training and awareness** should include understanding the need and right for carers to be fully involved in their relative’s care and treatment**;** and based on family therapy models of support to protect longer term relationships.  **Carers’ assessments**  should be offered routinely to carers, with a consistent and standardised approach covering all aspects of the caring role, and also carers’ individual needs |
| **Carers having a voice and being listened to** – carers need to be able to express their views and have a voice, and be supported through legal processes (such as Tribunal hearings) | **Access to *independent* information and support for carers** should be routinely available through a support organisation local to the carer. Dedicated carers’ advocacy might be available, but the crucial element is *independence* from forensic services and services provided to their relative.  **Information on how to access local and national forums for planning and decision-making** should be offered for carers who want to be part of wider strategic planning and who want to raise concerns in a wider forum |
| **Practical support** - consideration needs to be given to ‘out of area’ issues such as times and arrangements for meetings, expenses, minimising impact on work and other family life | **‘Out of Area’ support protocols** should be routinely applied to manage appointments, supporting carers to visit patients and attend meetings, pay expenses and minimise impact on carers’ family life outside of services |
| **Resilience and coping skills** – carers wanted to be better equipped to support their relative through knowing what to expect and how to deal with the illness | **Training for carers** both independently and jointly with paid staff should be developed and offered to increase confidence, awareness, skills and understanding of the system in which they are working |
| **Carers’ own mental and physical health and wellbeing** – carers felt their own health and wellbeing suffered and they wanted more support to keep well; they felt that they needed support to live a life beyond caring and have a care/life balance | **Emotional support/trauma support provided within forensic service** to address the immediate, and the on-going stress of coping with their relative’s illness should be offered  **Carers’ Support Group within the forensic service** set up and facilitated to provide a safe environment to share anxieties  **Access to local carers’ support services** should be routinely arranged to give access to generic as well as specialist local services, short breaks and wider educational/developmental opportunities |
| **Support for young carers, siblings and children and young people in families** | **Protocols for working with children and young people within the service** should be clear and supported with appropriate staff training and awareness-raising.  **Support for children and young people** should be provided as appropriate within services and through local projects and services |

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| **Recognising specific ‘trigger points’ to minimise stress and maximise involvement:** staff being aware of the specific points in the journey that need more focus to support carers would help to create a sense of moving through a process that promotes hope and recovery – carers expressed frustration that the system seemed not to ‘remember’ decisions made before and it could feel as though reviews were revisiting old issues. Carers wanted guaranteed involvement in planning for moving their relative, and clearer information about implications for moving and resources required for moving on. | **Protocols and procedures are put in place** opportunities to review and plan with carers, considering their needs as well as the needs of their relative. Points are: first admission; review – changes to care and treatment – and step down and discharge |

**Diagnosis and Early Intervention**

Although outwith the scope of this Strategy, it was clear that a primary issue for carers was the delay in recognising that their relative had a potential illness and in reaching a diagnosis. This delay resulted in years of stress and distress as challenging behaviour escalated and carers’ own emotional and physical health deteriorated. Being misunderstood, not being believed and being ‘fobbed off’ with medical professionals saying that carers were over-protective, or that their relatives were going through a phase, were common experiences, and all carers said that a crisis had to happen before they received any help.

Early intervention as a principle means raising awareness of GPs and other professionals, including in the education sector where identifying young people at risk was also considered a large gap, of signs and symptoms of potential mental illness and how important it is to listen to and support parents and guardians. A wider development is consideration of specific early intervention services to treat people with a diagnosis, as the multi-disciplinary model has been shown to have a significant impact on the likelihood of relapse and readmission (see Gumley, Schwannauer and Weir 2010).

1. Stakeholder consultation

Professionals working within and with forensic services were contacted for their views on current good practice and areas for development (see Appendix 3). This is a very brief snapshot of views that whilst reinforcing the main issues raised by our consultation events, also indicated a higher level of carer awareness and good practice than was experienced or expressed by the carers attending the events.

**Forensic Services**

Professionals working within forensic services were contacted for their views of current practice, and suggestions as to what was working well and what needed to be improved. This was a very small sample of staff and interviews were informal discussions. However, the conversations highlighted primarily the high level of awareness of the needs of carers and families within forensic services, and described significant areas of good practice.

The interviews also identified some areas of difficulty, partly concerning resources, but also the need to raise mutual understanding between staff and carers of the difficulties that working in a restricted and highly regulated environment can impose on different elements of practice.

Finally, it was reflected by staff that the areas covered by services were large and supporting carers and families living at a distance from their relative consistently across these large areas was challenging. Suggestions around rolling out good practice and sharing resources across the forensic network were issues to consider.

*Dedicated staff member for carers –* the State Hospital and the Rowanbank Clinic employed a dedicated staff member to support carers, and these staff provided a range of services from contacting new carers on first admission to the service through on-going communication and support, to linking carers into local services if available. The important principle was that this staff member was appropriately trained and was skilled in all aspects of communication – it was not an administrative role concerned only with co-ordinating appointments or dealing with enquiries.

In Tayside, it was recognised that the lack of such a member of staff was a drawback, but lack of resources prevented such an appointment being made. However, the existence of a very active carers’ support group helped to fill this gap to some extent.

*Staff Training –* in all areas staff were trained in identifying and working with carers and carer awareness was high. The State Hospital member of staff felt that training should go further in involving carers and staff jointly, promoting mutual understanding of the issues involved in working in a high secure environment and how these impacted on both staff and carers. Training in confidentiality was a primary feature of work in Glasgow, to ensure that this was not an unnecessary barrier to giving carers the information they needed to provide care.

*Family Therapy –* this model of working with carers and families was highlighted in all services as a fundamental way of supporting carers, the patient and ensuring that supportive family relationships could be protected and maintained through the worst of illness, and all spoke of the considerable investment of time that this needed. However, the benefits were clear and this is supported by the research underpinning this approach.

*Carers Support and Advocacy –* Carers were offered a range of support services within the services, such as group support, events, information and social activities. In the Glasgow services, the member of staff had made links into the local area to try to integrate carers into other generic services. Here, carers were able to access other groups and events (such as those provided in the Charlie Reid Centre and in the Princess Royal Trust Centres), and also WRAP training. However, in other areas, this was less well developed, with some resistance from carers who felt uncomfortable accessing generic support, fearing stigma and feeling embarrassed by their relative’s illness and behaviour.

In Tayside, the support was provided by a very well established and active Carers’ Support Group – Tayside Forensic Voices – and the member of staff acknowledged the vital role this group played. They recognised the limitations of supporting carers from across a huge geographic area and were aiming to try to set up satellite groups, but lack of resources was making this quite difficult. They also expressed concern about their dependence on the current group of very committed carers, and so were actively considering ways of sustaining this group long term.

*Service standard –* there was a need to establish guidelines for working with carers, and staff at The State Hospital felt that such guidelines should be rolled out to create a consistent approach. There was also agreement for creating a quality standard for carers’ services, and in Glasgow, work had started to develop this standard.

**Third Sector Agencies**

The agencies that had been part of the consultation events were consulted for additional views on current services and the needs from their perspective.

*Advocacy –* as advocacy had emerged as a key issue in the consultation, and is a headline action in the National Carers’ Strategy, the Scottish Independent Advocacy Alliance was contacted for an overview of availability of carers’ advocacy services. There are only two dedicated carers’ advocacy services in Scotland, and only one of those is specifically for mental health carers (Edinburgh Carers Council).

SIAA believes that advocacy should be provided by a totally independent service, raising issues of resources: the number of forensic carers within the carer population is very small, and they are also very scattered. Providing dedicated independent advocacy would be challenging.

The Princess Royal Trust and Support in Mind Scotland expressed the view that ‘pure’ advocacy may be a goal, but that in their experience, carers needed a blend of information, support and guidance that was not necessarily advocacy; however the important principle is that any carers service is provided independently from services provided for their relative so that they could have their own voice.

*Peer Support* – in Tayside the carers’ support group works hard to ensure that all new carers are identified and offered support by the group and within the service. This peer support has proved invaluable, particularly in a rural area where there are few local services for carers.

*Services through partnership –* all agencies recognised the difficulties in providing support to carers caring at a distance from their relative, and also the difficulties in linking carers into local support services when they felt some resistance to this in the early stages. The voluntary agencies felt that initial specialist support should be working towards helping carers to move into more integrated, generic carers’ services, giving access to the full range of information and support that they needed for their own health, wellbeing and wider development.

*Young Carers and Siblings –* specific attention needs to be paid to young people involved with a parent of sibling or other relative in forensic services. There is a Young Carers’ Alliance that is a network of young carers’ services in local areas, but making the links and ensuring that they are able to access these services would be the challenge.

*More Resources for relatives/patients –* the Tayside Forensic Voices carers’ group highlighted as a priority the importance of developing better services for patients and relatives as this was by far the biggest concern for carers. The lack of suitable resources for people stepping down to a lower security facility or into their local community, put pressure on families and carers and increased stress.

1. Evidence Base

A brief review of some relevant research and studies provide an evidence base for the recommendations (see Appendix 4).

**Caring Together: National Carers’ Strategy 2010-2015**

The primary document supporting these recommendations is ‘Caring Together – National Carers’ Strategy 2010 – 2015, providing the framework for these recommendations. Recognising carers as equal partners in providing care, ensuring carers have access to assessments, good information and local support and ensuring that their own health and wellbeing are taken into consideration are the key principles for good practice for any carer’s service. The specific and unique needs of forensic carers due to the circumstances of their relative’s care and treatment being provided within secure settings are detailed in the good practice recommendations for a Forensic Carers’ Strategy.

**‘Its their job, it’s my life’(Support in Mind Scotland, 2010)**

The key messages from the survey were that carers want to be partners in providing care and need mental health workers to guide them through the steps of supporting someone with mental health problems. Carers most need information about diagnosis, prognosis, medication, treatment and care; mental illness and its effect on behaviour; and what do to in a crisis, want that information to be given proactively, and do not want confidentiality to be used as an excuse to avoid giving carers the information they need.

**Collective Issues, Collective Voice**

This conference in 2011 initiated the move to establish a carers’ strategy and so it is not surprising that the issues raised were echoed by our consultation process. The significance is in the specific and unique needs of carers of people in the forensic system that were highlighted – specifically the need for trauma-focused services for carers, recognising the additional stress surrounding someone’s entry to forensic services and the range of complex needs involved.

**Combined Studies: Needs of Carers in Forensic Services**

Three combined studies have looked at developing the services offered to carers in forensic settings NIMHE (2004) proposed forensic carers should be involved in the care process as much as possible and services should seek the involvement of carers and respond to their views while Lindon (2007) advocated that interventions should involve the development of carers coping skills by receiving information about the various systems they are in contact with, as well as, learning coping strategies to deal with difficult situations

Qualitative Information - Three overlapping themes were identified as being important in supporting carers: Being given clear, accurate, and prompt information, having access to specific support when needed, and having some involvement in the making process regarding care and treatment.

**Involving carers in out of area treatments: a guide to good practice**

**(Rethink and CSIP, 2007)**

This good practice guide confirms the recommendations made through consultation with carers that produced this guide. Section 7 lists ‘what would help’ and this list includes: information, support, advocacy, carers’ assessments, training and involvement.

**Meriden Family Therapy Programme (Birmingham NHS Trust)**

Evidence shows that family therapy reduces stress and reduces relapse and hospitalisation rates, and that it helps families to develop communication and problem solving skills, and can assist with dealing with difficulties such as confidentiality. The Meridan programme was developed by…

**Triangle of Care (Princess Royal Trust for Carers and National Mental Health Development Unit, 2010 )**

The ‘triangle’ model was proposed by carers who wished to be seen as active partners within the care team, and it depends on a willingness of all to honour those relationships. It is described as a ‘therapeutic alliance between service user, staff member and carer clearly identifies the six key elements required to achieve better collaboration and partnership with carers in the service user and carers’ journey through a typical acute episode.

This is an Audit Tool that breaks down these six elements into indicators of good practice and asks services assess if they meet these standards using a ‘red, amber, green’ system.

**Carers and Confidentiality (Mental Welfare Commission for Scotland, 2006)**

This guideline from the MWC addresses the key issue of sharing information with carers, recognising the provisions of the Mental Health (Care and Treatment) (Scotland) Act 2003. The principles recognise the importance of giving carers the information they need to help them care for the person; listening to carers views about how the Act is applied to the person’s care and taking carers’ needs and circumstances into account.

The guideline stresses that confidentiality is in itself not a reason not to inform carers and that good professional practice in working with the patient could overcome some of the barriers.

1. Analysing the Outcomes

There are some gaps in the our understanding of these needs at the end of this initial consultation and review that are highlighted by the large distance there is between the experiences of the carers consulted and the level of support for carers that professionals know is in place within secure units and facilities. Dedicated carers’ support workers are employed, and in units without a dedicated worker, there are still trained and carer-aware staff who are offering support and referral to other services.

This raises additional questions that should be addressed:

* We know the numbers of people within forensic services at any one time, but we are less clear about the numbers who have carers actively involved and engaged in their care and support
* We do not know how many of those who are engaged and involved seek out and access carers support services
* We do not know why carers who don’t access support choose not to do so – is it a choice or are they unaware they exist. Our consultation suggests that carers do not believe support exists, but neither do they report receiving support. This is not proof that they don’t, as the event was designed to gather issues for a strategy and not record or research the detail of carers’ experiences over a period of time
* As carers are caring at a distance, it may be that carers are accessing local support services, although we could find no hard evidence of forensic carers doing so in any significant numbers; and we have anecdotal evidence from carers and professionals that carers don’t access generic services through embarrassment or fear of being stigmatised
* Anecdotal evidence suggests that dedicated forensic carers support is less evident as the patient moves through the system, particularly as people move closer to their own communities. We are not able to map enough carers through their journey to understand if they are more able to seek local support as time goes on, or if they simply return to their own coping strategies once the more intensive support is removed. Carers spoke of community resources for their relative being less appropriate and even inadequate, putting additional pressure on them; but there was no sense that they then accessed local carers’ support service, either generic of specialist.

1. Recommendations

Based on the consultation, the interviews and the evidence, the underpinning principles are:

* Carers as partners in the provision of care and treatment
* Involvement of carers in decision-making and planning
* The right of carers to achieve a ‘care/life’ balance to maintain their own health and wellbeing

There are three main recommendations with actions:

1. **Create and support a national infrastructure to promote the specific rights and needs of Forensic Carers, within the framework of the National Carers Strategy**

* **Forensic Carers Network**: Establish and support a Forensic Carers Network for collective voice and collective action: a forum for carers in the forensic system to be able to express their concerns and their needs, that has a formal role within planning for national carers’ support services
* **Forensic Providers’ Network**: Establish and support a specialist network of provider/carer organisations to explore new partnerships and ensure that services and developments are integrated and provide value for money
* **National Forensic Carers Champion**: Create and fund a National Carers Champion who supports these networks and works closely with the Forensic services to address emerging concerns and opportunities (employed within the voluntary sector)

1. **Develop best practice at service level to achieve the best possible outcomes for carers and the people they support**

* **Dedicated carers support role**: identify a dedicated Carers’ Support Worker trained to provide information and support to cares at reception and throughout their ‘journey’ in forensic services
* **Information pack**: ensure a dedicated information pack is developed for each service for carers on admission and first visit that is tailored to individual circumstances
* **Training**: (i) develop specific modular training for staff to understand the concept of carers as partners in the delivery of care; the needs of carers; and best practice standards for working with carers; (ii) develop and provide training for carers to increase skills, resilience and confidence; and (iii) develop joint training with carers and staff to encourage mutual respect and understanding
* **Assessments**: Development of a nationally agreed standard for quality carers’ assessments that recognise their role, respect their need for resources and focus on achieving a care/life balance for carers
* **Independent information and support**: Ensure carers are given access to independent specialist information and support services in their home area if available, or near to the secure service if not, to ensure carers have a voice in decision-making and planning
* **Confidentiality**: review and renew national guidelines on confidentiality and ensure that local protocols enable staff to observe the confidentiality of all involved without creating barriers to effective communication
* **Trigger points**: develop simple routine protocols for flagging up action at specific trigger points in the forensic journey: on reception, at review and on discharge.
* **Young carer, sibling and family support services**: (i) develop national and local good practice guidelines for supporting young people affected by a relative’s illness; (ii) introduce training and guidelines for family therapy approaches to supporting families
* **Carers’ service standard**: provide a framework for excellence in carers’ services
* **Audit tool to measure quality**: develop/adapt an Audit Tool to measure quality and introduce accountability for achieving excellence

1. **Explore new developments emerging from the consultation and research and develop service proposals**

* **Early intervention services**: establish a working group to explore potential for developing awareness, and achieving earlier diagnosis and intervention
* **Linking carers to local services**: explore models of creating better links for carers to local services and bridging the gap between specialist and generic services
* **Addressing stigma**: explore partnerships to address stigma for people receiving care within forensic services and their carers/families