



CARER SUPPORT AND INVOLVEMENT IN SECURE MENTAL HEALTH SERVICES TOOLKIT

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PRESENTATION OVERVIEW

- Introduction of the toolkit
- Audit of family involvement
- Embedding the toolkit and the way forward



Foreword

Carer support
and involvement in
secure mental health
services

A Toolkit

Start >



This toolkit is meant to be used in any way that is most helpful. You can find your way through the document by clicking through the pages or going directly to content that interests you by following links.
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For the first time, it feels as if a light has been shone on carers with loved ones in secure services. We have been in the dark for far too long; often unknown, ignored and undervalued whilst challenging the Criminal Justice System in the midst of a mental health crisis, and then continuing to support our family members and friends for many difficult years.

The toolkit was co-produced with professionals, carers and service users, who were all passionate about not only giving guidelines to commissioners and service providers, but raising the profile of forensic carers generally. We wanted the individual stories of forensic carers to be heard, the trauma and distress they feel to be recognised and the problems they are facing to be acknowledged so that lessons can be learned and changes made as a result.

This toolkit is a sign of hope for the future. We hope it is a beginning for more carer engagement, clear recognition of our worth and that services will see the importance of involving us throughout the care pathway.

Most importantly, for carers themselves, we hope we have used our experiences to enable them to better understand secure services so they feel more confident in their journey through them. With this confidence and information, we also hope that carers are empowered to challenge services if they do not reach their expectations. It is right and proper that we do now have clear expectations of secure services and a vision and commitment for how these can be met.

Sheena Foster
& Sue Stewart

EXPERIENCES OF FAMILY MEMBERS BEFORE ADMISSION TO FORENSIC MENTAL HEALTH SERVICES

- Personal account from a forensic carer who was the victim of her son's violent crimes.
- Prior to these crimes, she had tried to get help for her son and herself from multiple agencies, including health, police, domestic violence, to no avail over a period of years.
- She was then the victim of 3 life threatening assaults, the final of which led to her son going to prison and being transferred to a forensic mental health service.

Autism, mental health and offending behaviour: a mother's quest for healthcare

Sue Larch

Sue Larch is based in UK.

Abstract

Purpose – The purpose of this paper is to describe the experiences of a mother of a son who was diagnosed with Asperger syndrome and psychosis in adulthood, the impact of this on his behaviour, and her quest to obtain healthcare.

Design/methodology/approach – Case study.

Findings – While a striking story in its own right, the experiences described have a number of wider implications for the treatment of mental ill health in ASD, the exclusion of families and carers from the care of their adult children in services, and the impact of this on the individuals directly affected.

Research limitations/implications – The paper offers a number of practical recommendations for the understanding and management of autism in generic mental health services, and the involvement of families and carers in the care of their relative.

Originality/value – This is the first paper to describe mental ill health and offending behaviour in ASD, from the perspective of a mother.

Keywords Mental health, Forensic, Challenging behaviour, Mental disorder, Autism spectrum disorder

Paper type Case study

EXPERIENCES OF FORENSIC PROCESSES

We went to court, and I was to become very familiar with the procedures.

I also learned very quickly that the professionals involved did not understand autism or mental health. My son's barrister joined us for a pre-hearing meeting on one occasion, but I had to take him outside the room and ask him to restrict what he was saying as my son could not process it all which was stressing him out.

The subsequent court case dragged on for seven months, and as my son's victim I was not allowed direct contact. That was my worst time. I feared for my son in a prison environment, I feared for his sanity because he was not having any treatment and I could not assess how he was. It was agony, and took me very close to a breakdown.

RESEARCH

- Many carers reported not being listened to when raising concerns about their relative's deteriorating mental health prior to admission to forensic services.
- Feeling stigmatised was highlighted as a challenge for forensic carers, some losing friends and becoming isolated in their own communities.
- The impact of being a forensic carer was profound, impacting on all aspects of people's lives including their physical and mental health. For some, being able to share the responsibility for care helps mitigate the stress felt.

EXPLORING FAMILY CARER INVOLVEMENT IN FORENSIC MENTAL HEALTH SERVICES

University of Central Lancashire
Support in Mind Scotland
Forensic Mental Health Services
Managed Care Network

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RESEARCH CONT...

- Almost half of survey respondents had experienced challenges in travelling to and from forensic mental health services and 44% had been challenged by the lack of flexibility around visits.
- Forensic carers in this study reported feeling frustrated and blocked in their attempts to access information, from hospitals in particular, but also failing to get replies from agencies such as Mental Welfare Commission for Scotland. Issues surrounding confidentiality were also a barrier.
- The factors that can impact on the frequency and quality of visits include distance to and from forensic units and ease of travel; the environment and having a comfortable space for visiting and with some flexibility for visits; and, the level of privacy afforded for what can sometimes be quite fraught interactions.
- Carers felt that many of the places where visits took place were overly restrictive and unsatisfactory, even taking into account the need for certain levels of security.
- A key source of stress around visiting was not being consulted or kept informed about their relative. Having staff that were able to support the caring relationship made all the difference.

INTRODUCTION



- The toolkit was published in 2018.
- It has been co-produced by a steering group with wide involvement from a range of carers, service users, commissioners and service providers.
- The toolkit is based both on previous research, including a recent Scottish Study (Ridley et al. 2014), and a study into how carers' needs are met within secure services in England.

INTRODUCTION



- It is the first time a resource specifically for carers of patients in secure / forensic services has been developed (everything so far has been for families of people in mental health services, or prison). The toolkit outlines some key principles for family and carer involvement:
 - 1) The support and involvement of carers within secure mental health services, and recognition of a duty of care to carers themselves, should be prioritised by service providers and commissioners.
 - 2) All aspects of care planning, case review, and risk management are open to carer involvement if the service user wants this.
 - 3) Carers should have timely access to appropriate and relevant information and their questions answered with candour.
 - 4) Services and commissioners should proactively ensure that carers have access to emotional and practical support.
 - 5) Engaging with forensic carers should be recognised as everyone's job.
 - 6) Carers have a key role in the care of their loved one and should be involved if they wish and the service user also wants this.
 - 7) Carers should be involved in the design, planning and improvement of services.

AUDIT OF FAMILY / CARER INVOLVEMENT

- Services will be expected to be working towards the recommendations within the toolkit and this will be assessed during QNFMHS peer reviews.
- The toolkit outlines what family carers should expect at 5 key stages of, and throughout their relatives care:
 1. Admission to secure care
 2. Care in secure services
 3. Transition between different levels of security
 4. Preparation for discharge
 5. Carer involvement in service planning and design
- We developed an audit tool using the statements from the Family Toolkit to assess our services' compliance with the standards and principles.

1. ADMISSION TO SECURE CARE

Staff are welcoming and warm in their interactions with carers. This would include opportunities for carers to tell their own story and be asked about their own needs.	Yellow
Staff receive training about the value, rights and needs of carers.	Red
Clear information is provided to carers. This should be:	Green
a. Practical information that they can take away and read at their own pace – to enable contact with hospital and service user.	Green
b. Clear that the organisation values the role and contribution of carers.	Yellow
c. Displayed prominently in an area that carers can access.	Red
d. Informative about supporting carers to visit and maintain contact with their loved one (for example, by telephone and in person).	Green
e. Accessible and take into account diverse communication needs.	Green
f. Informative about facilities for virtual visits – using digital technology for maintaining contact between relatives/carers and care teams.	Red
g. Co-produced with carers and service users.	Red
Carers are given a named contact at the earliest opportunity and are offered a face to face induction meeting (or telephone meeting if this is more suitable for the carer) close to the point of admission, plus ongoing contact thereafter. This should include provision of key information that helps carers familiarise themselves with the unit, cope with stresses they may experience at this time, and tells them what to expect.	Green
Services should, wherever possible, signpost carers to alternative forms of support, for their own practical and emotional need for example independent carers' advocacy services.	Yellow
Services should have a clear confidentiality and information sharing protocol for carers which is positive and proactive and seeks to engage and involve carers wherever possible.	Green

2. CARE IN SECURE SERVICES

Secure settings should have a coordinated approach to support and involvement. Specific activities would include organising carers' groups and events, signposting carers to support groups nearer to home, and ensuring that policies for carer involvement are developed in partnership with carers and service users. These policies should cover the value of carer involvement in all aspects of care, including risk assessment and management.	Yellow
Dedicated member(s) of staff who support carers and coordinate service responses. Actual roles and numbers of such staff will depend upon the size of particular units. The objective of the staff is to facilitate direct communication with care teams. The existence of identified roles does not preclude all staff having an interest in supporting and involving carers.	Light Green
Secure services should develop visiting arrangements to ensure that:	Light Green
a. Staff are trained to minimise the intrusive impact of safety and security procedures.	Light Green
a. Skilled staff are on hand at visiting times to help talk through any specific upset or stress.	Yellow
a. Visiting times are seen as a possible opportunity for therapeutic engagement where this is appropriate, and for staff to introduce themselves to carers.	Yellow
a. Briefing and de-briefing sessions are offered for carers who find visiting times problematic.	Light Green
a. There are up to date picture boards of the staff team with a brief explanation of roles.	Red
Services should highlight when they can provide specific support for carers who are victims or signpost to another appropriate service. For these and other carers, options should include forms of psychosocial intervention and family therapy (where appropriate), which can be delivered face to face or using digital technology.	Light Green
Carers should be routinely involved at relevant points of care, potentially including Care Programme Approach (CPA), ward rounds, care planning and review meetings, including Care and Treatment Reviews (CTRs). Efforts should be made to work around the availability of the carer.	Light Green
Systems are in place and documented for maintaining contact with carers, for example in relation to the frequency of contact or responses to phone calls. This should include a provision that carers' concerns are adequately recorded, to ensure accountability for responding to such concerns.	Light Green
Support for service users to maintain active contact with family and friends, for example attending family occasions within the scope of leave restrictions.	Light Green

3. TRANSITION BETWEEN SECURITY LEVELS

Carers should be involved as early as possible in assessments and planning and their views should be taken into account when making decisions around transition. They should expect to know where, when and how the transition will take place.	
Information and advice is provided about the process, timescales and arrangements to alleviate uncertainties for carers.	
Carers should be given information about the unit their loved one is moving to and the opportunity to visit, as well as information about things like transportation, timings and arrangements for early visits.	
Carers should be linked to the carers' lead in the new unit.	

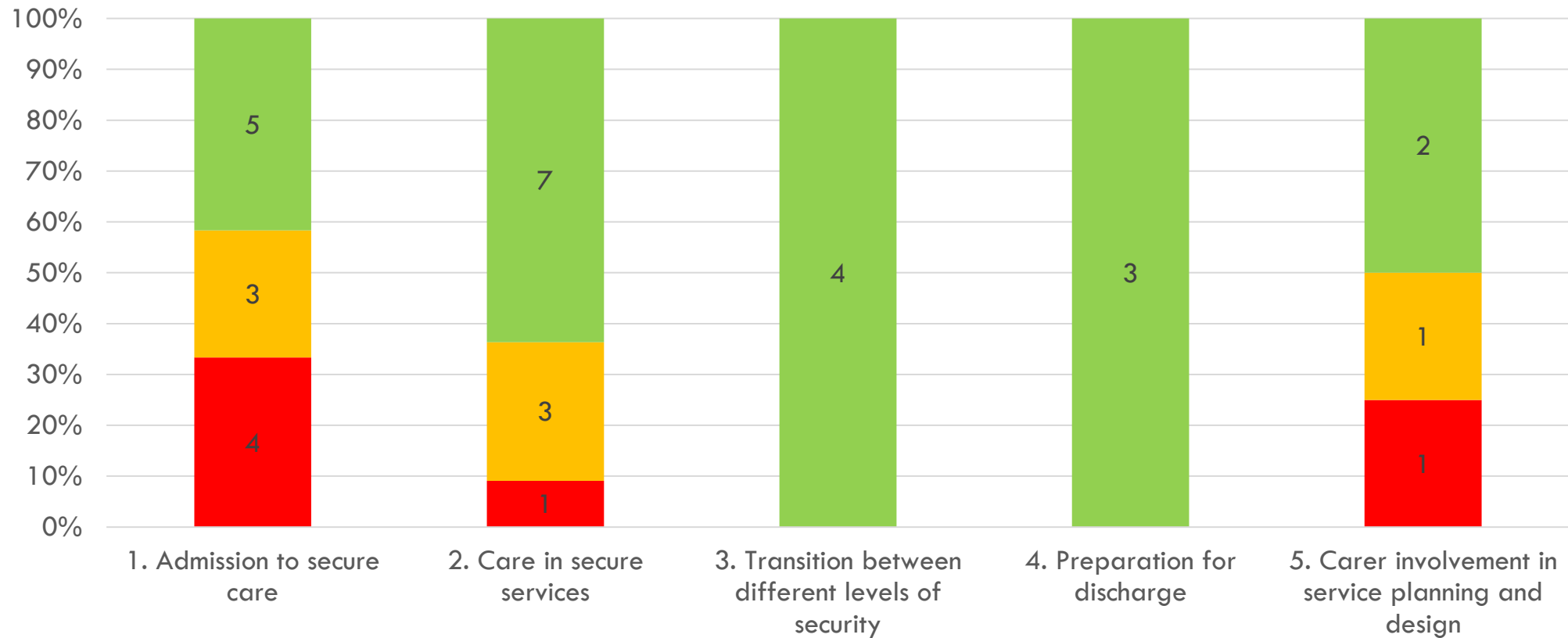
4. PREPARATION FOR DISCHARGE

Carers views are sought about their feelings and they are given advice about their loved one being discharged. Issues should be noted and action taken in response where possible.	
Services should invite carers to be involved in pre-discharge care planning and risk management processes and support them to be involved. This should include putting a plan in place that can be used if carers have concerns or if things begin to deteriorate in the period after discharge. After discharge, carers will not be able to attend MAPPA/MARAC meetings. But they should be able to contribute their views and have their perspectives taken into account.	
Carers should have a continued point of contact agreed prior to discharge, including where service users are moved out of their home area, to ensure they can seek advice and continue to provide insight and information to services.	

5. CARER INVOLVEMENT IN SERVICE PLANNING AND DESIGN

Services should consider the development of service development groups for carers (strategic forums). These would be separate to carers groups and focus on service development.	Yellow
Services should seek to address equality issues in services by engaging with carers with direct experience of those issues.	Light Green
The development of a network modelled on the Recovery and Outcomes Network should be explored.	Light Green
Co-production of information leaflets/activities/strategies/processes etc. This could include involvement in planning carer days, running support groups, planning conferences, planning courses in recovery colleges, developing information, sitting on key groups within services, attending Recovery and Outcomes groups, joint planning meetings with service users, and involvement in training.	Red

SUMMARY



WAY FORWARD

- Staff receive training about the value, rights and needs of carers.
- Displayed prominently in an area that carers can access.
- Informative about facilities for virtual visits – using digital technology for maintaining contact between relatives/carers and care teams.
- Information co-produced with carers and service users.
- There are up to date picture boards of the staff team with a brief explanation of roles.
- Co-production of information leaflets/ activities/ strategies/ processes etc.

Staff are welcoming and warm in their interactions with carers. Clear that the organisation values the role and contribution of carers.

Services should, wherever possible, signpost carers to alternative forms of support, for their own practical and emotional need for example independent carers' advocacy services.

Secure settings should have a coordinated approach to support and involvement.

Skilled staff are on hand at visiting times to help talk through any specific upset or stress.

Visiting times are seen as a possible opportunity for therapeutic engagement where this is appropriate, and for staff to introduce themselves to carers.

Services should consider the development of service development groups for carers (strategic forums).

SUMMARY

Forensic family carers have often had traumatic and harrowing experiences of their relatives mental health difficulties, trying to access support and services, and of the police/court process.

Following this they have to maintain relationships with their relative following detainment in prison, and/or admission to 1+ forensic mental health services.

Forensic services have diverse family carer policies, different visiting and contact rules, all of which can alienate and intimidate family carers.

The new family toolkit aims to offer some guidance to services in terms of what should be offered by services, and expected by family carers.

Services can audit their current practice against the toolkit and come up with a plan to improve any areas of weakness.

THANK YOU FOR LISTENING

Any Questions?



Oxford Textbook of the Psychiatry of Intellectual Disability

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Family Experiences of Psychiatric Services for their Relative with Intellectual and Developmental Disabilities



Chapter:

Family Experiences of Psychiatric Services for their Relative with Intellectual and Developmental Disabilities

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Introduction



When a relative develops a mental or behavioural issue that requires the support of services, it can be highly distressing for their families and carers. If that relative also suffers from an intellectual or

Home visits: a reflection on family contact in a specialist forensic intellectual disability service

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Abstract

Purpose – There is little published literature about the number of home visits provided to patients within forensic intellectual disability units, and there is no published data on variables that affect home visits. There is a need for a baseline audit that can formulate standards for future practice. The paper aims to discuss these issues.

Design/methodology/approach – This paper describes the home visit programme within a forensic intellectual disability service, and a baseline audit of the programme. The audit measured the number of home visits, any factors that adversely affect home visits, and the extent of family contact. The authors propose audit standards for evaluation of good practice in this area.

Findings – The audit involved 63 patients over a one-year period. In total, 81 per cent of patients had some form of family contact and 54 per cent of patients at least one home visit. However, 19 per cent of patients had no contact with their family due to a variety of reasons. There were no significant differences in the number of home visits between men and women, patients on civil vs criminal sections or those treated "within area" or "out of area". Patients in rehabilitation wards had significantly more visits than those in low or medium secure.

Originality/value – Conventional wisdom is that reduced family contact is the direct result of patients being placed "out of area". The results of this audit suggest that, at least in this group, the reasons may be much more nuanced and that the current definition of "out of area" has to be improved to incorporate the actual distance between the patient's current family home and the service. Audit standards have been proposed to monitor family contact and home visits. Future work should focus on the relationship between family contact and treatment outcomes.

Keywords Learning disability, Family contact, Forensic, Secure, Social support, Social work

Paper type Research paper