

rethink

severe mental illness



Care Services
Improvement
Partnership

**involving carers
in out of area
treatments**
a good practice guide

who we are

Rethink

Rethink is the largest voluntary sector provider of mental health services in the UK, supporting around 7,500 people every day of the year. Rethink works to help everyone affected by severe mental illness recover a better quality of life. We provide hope and empowerment through effective services and support to all those who need us, and campaign for change through greater awareness and understanding. The views of those with direct experience of mental illness are at the heart of everything we do. Our current focus is on keeping mental health high on the political agenda, developing and delivering quality services, and strengthening our voice by involving more people in Rethink. To continue our work and build on what we have already achieved, we depend on your membership.

CSIP

CSIP, the Care Services Improvement Partnership, supports positive changes in services and in the wellbeing of vulnerable people with health and social care needs. CSIP is part of the care services directorate at the Department of Health. Our aim is to provide high-quality support to help services improve, help services to put national policies into practice and provide them with a link into government, involve people who use services and their carers in all improvement work, share positive practice and learning about what works and what doesn't, pass on research findings to organisations to help them improve services, and encourage organisations to work in partnership across all sectors. We work with the statutory, voluntary and private sectors to make the best use of the full range of resources and expertise available to improve services.

Rethink and CSIP would like to thank everyone who contributed to the preparation of this guide especially the carers, care coordinators, commissioners and service providers who not only came to meetings and commented on materials, but also provided consistent encouragement, ideas and inspiration.

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using the guide

This guide has drawn on three main sources:

- Carers who have described their experiences, wishes and needs in relation to OATs
- Service commissioners who have set out what they think could and should happen when people are placed out of area
- Good practice demonstrated or aspired to by service providers

Not every element of good practice set out in the guide will be open to every service provider. Secure units and special hospitals, for example, may have additional constraints on how much they can involve people. However, every service commissioner and every service provider can act within the spirit of the guide and try, at every opportunity, to ensure that carers are involved as fully as possible.

Foreword by Paul Jenkins

**Rethink
Chief Executive**

When people with complex health needs are placed out of their local area the voice and the needs of individual carers can be overlooked. It becomes more difficult to involve them in the decision making process, to provide them with information, or even to listen to what they have to say. In addition, carers may have to manage additional practical and financial difficulties – such as travelling long distances, taking time off work, and maintaining a relationship with someone they only rarely see. Rethink is committed to ensuring that carers have a voice, that they are perceived as partners in care, and that they receive the practical and emotional support they need, whatever their circumstances. This document makes an emphatic statement about the need to involve carers in out of area treatments and provides a comprehensive step-by-step guide for carers and professionals to follow. It provides a blueprint for carer involvement and sets a minimum standard for commissioners, care coordinators, and service providers to adopt.

Foreword by Louis Appleby

**National Director
for Mental Health**

This guide is intended to help carers who find that the person they care for needs treatment in a different area, away from families, friends and social supports. For services – commissioners, mental health trusts and professionals – it describes how to keep carers informed and involved at all stages of the placement. For carers, it details what they should expect, including:

- being informed about how out of area treatments work
- identifying an appropriate placement
- making arrangements for admission
- getting and giving information
- visiting and leave arrangements
- meeting carer needs
- preparing for transfer or discharge

Mental health services rely on the skills and dedication of carers – we could not do our job without their help. This simple fact is behind what is presented here – a guide for working in partnership at a difficult time for patient and carer alike.

Section 1 Introduction

When the needs of people with complex and long term mental health problems cannot be met locally they are sometimes placed out of area. Someone living in Liverpool may receive care or treatment in Yorkshire; someone else from Ipswich may be cared for in London. In the most extreme cases, where highly specialised care is needed, people may need to move to the other end of the country for their treatment or care.

In these cases it can become difficult for family and friends to stay involved. Carers* of people receiving treatment out of area often face additional complications as a result of not being near their relative or friend.

This guide aims to provide a framework for good practice to ensure that carers are appropriately involved in their relative's and friend's care when they are placed out of area.

What are Out of Area Treatments?

Out of Area Treatments happen:

- When someone with a complex mental health need is placed in another area for treatment or support.
- When someone is judged to be a risk to themselves or other people and is placed in a secure mental health unit, which is not near their home. This might be under a section of the Mental Health Act.
- When someone with a mental health problem has committed an offence and is placed in a secure hospital which is not near their home.

* **Carer** - The government uses the word Carer for people who provide "regular and substantial care". This can be a family member or a friend. You don't have to live with a person to be a Carer.

Out of Area Treatments are often called OATs. Sometimes people talk about Out of Area Placements instead but these are also often called OATs, for short.

There are other occasions when people receive treatment away from their home area. For example:

- When someone chooses to seek treatment in a different area from where their family or friends live because they want a particular service, or because they want to have a particular psychiatrist.
- When someone who happens to live in a different area from their friends and family becomes severely unwell and needs treatment.
- When someone with an acute mental health need is placed out of area because there are temporarily no beds available on their local wards.

This guide is not specifically aimed at such cases but much of what it covers will apply.

The Carer's Experience

For some carers the experience of having the person they care for placed out of area is wholly positive. Carers sometimes go out of their way to help the service user* get treatment in another area – either to get a particular service (such as a specialised eating disorder service) or to work with a particular psychiatrist. Some carers describe being routinely informed, included and involved in the person's care, being welcomed, talked to and listened to when they visit. Their overall experience is that the time and cost of travelling is a worthwhile price to pay if the person they care for is being well looked after.

For others this is not the case. Some carers feel that they have been routinely excluded from decision making and never provided with sufficient information. Even if they are informed and included there are practical difficulties – often to do with visiting and leave arrangements – to manage.

*** Service User** - This guide uses the term service user to refer to anyone who is receiving mental health care in any setting. This includes people in hospital who might also be called patients. Social services may also refer to service users as clients.

Care Coordination

When people move out of area care coordination remains the responsibility of the care coordinator* from the home area. Many care coordinators remain closely in touch with the service user and their carer and take a key role in ensuring that all parties are appropriately involved. However, in a minority of cases, care coordinators lose touch with the service user or carer and care coordination either becomes ad-hoc or the responsibility falls to someone else. Some carers describe playing such a key role that they effectively become the care coordinator. In other cases it may be the named nurse* or key worker* where the service user is placed who takes on the role.

Service Commissioners

Few service commissioners* make explicit demands concerning carer involvement in their contracts with out of area service providers. Generally they assume that carer involvement out of area will occur to the same extent as it does within area. This is often not the case. In addition carer involvement, wherever mental health care is provided, often falls short of good practice. Service commissioners need to take the lead role in ensuring that carer involvement has sufficient emphasis.

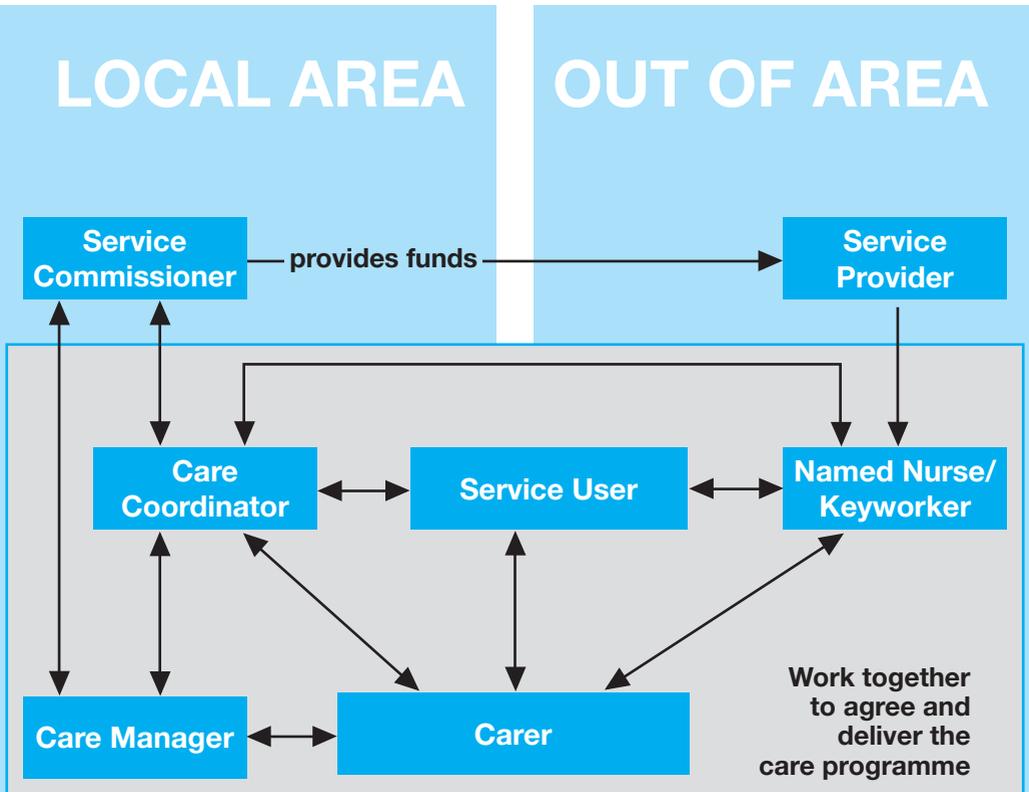
Service Providers

Some mental health service providers* who care for people from different areas have a very pro-active attitude towards carer involvement. Some secure units and special hospitals, in particular, go out of their way to involve carers even though a secure environment makes this more difficult. Other service providers, however, are less committed to carer involvement. They do not routinely involve carers or keep them informed and there is little pressure on them to do so.

* Please see glossary on page 40

Roles and Relationships How the Partnership Works

When someone is placed out of area the service user, carer, care coordinator, service commissioner, and service provider need to work together. The relationship is complex. In order for it to work well there must be an equal partnership and the service user must always be at its heart. The following diagram shows how the partnership works.



The terms used in this diagram are explained in the glossary on page 40

Why should carers be involved in OATs?

Continuing Care

In the majority of cases, after discharge from an OAT, people will return to their original home area where their family and friends still live. Often, family and friends will again take on a direct or indirect caring role. If carers are not involved during the OAT they will be out of touch with the individual's progress, and their relationship with that individual may have deteriorated.

Some service users will not want to involve their former main carer in certain aspects, or any, of their care. Obviously these wishes must be respected but even in such cases it will be necessary to provide the carer with certain information, and receive information from them, especially if they are going to take up a caring role again at some point.

Working with families

Some people in long-term care are unlikely ever to be discharged. But it is important to maintain their social contacts – to help them keep up their relationships with family and friends – so that they have as normal a life as possible. Working with families and friends is an important part of the approach in secure units and hospitals.

Carers' health

Not being involved, and not knowing what is happening to the service user, can be a major cause of stress and anxiety and may lead to ill-health. All too often carers themselves become ill because of the stresses and strains of being a carer. By working with the carer, service providers can reduce anxiety and develop a partnership which is likely to have beneficial results for both the carer and the service user.

Cost and Benefits

Involving carers also has cost benefits. Well-informed and involved carers, working in partnership with the service provider, are more likely to contribute to the recovery of the service user. They are also less likely to become ill themselves and so less likely to call on further health resources.

Encouraging independence

Encouraging independence is an important part of individual mental health care. This means creating systems and structures which give service users the best chance of taking control of their own lives and finances. Carers can have an important part in working with service users to regain control of their lives.

Research evidence

There is research to suggest that working with families and friends is beneficial for the service user and carer. Admissions and numbers of days in hospital can be reduced; quality of life can be improved. This will apply to OATs as much as to other types of situation.

Section 2 Seven Key Principles

This guide is based on 7 key principles:

- 1.** In all cases the interests of the mental health service user come first. However, carers also have rights, needs, and responsibilities. They should be involved and included in the programme of care wherever possible unless this is directly against the interests, or clearly expressed wishes, of the service user.
- 2.** Involving and including carers in the programme of care, subject to the first principle above, is often a major contributory factor in promoting the service user's recovery.
- 3.** Information should be provided to, and accepted from, carers where they wish to be involved in the programme of care. A certain amount of information, advice and support can be exchanged even where the service user does not wish the carer to be directly involved in his or her care.
- 4.** Carers should be perceived and treated as genuine partners in care with valuable expertise, experience, understanding and knowledge.
- 5.** All service commissioners and providers should have a policy on involving carers in Out of Area Treatments or placements.
- 6.** All carers of people placed out of area should have their needs assessed and be provided with practical and emotional support in accordance with their needs and means.
- 7.** All carers should be encouraged and supported to fulfil their responsibilities and to work as partners with service commissioners and providers to the best of their ability, in order to respond to the needs of the person they care for.

Section 3 For Carers

What should you be able to expect when the person you care for is placed out of area?

You may find it helpful to ask the care coordinator, care manager*, or someone from the placement to go through this section with you and explain what you can expect.

Admission Stage

Before the OAT

You should be able to expect that:

- Any views the service user has about involving you will be acknowledged and respected. These views may have been written or recorded in an Advance Statement*.

“There were times when my son was considered incapable of making simple decisions, such as when he wanted a cup of tea. But he was allowed to make much more complex ones, such as whether he wanted to involve me in his care”

Finding out about OATs

You should be able to expect that:

- The Primary Care Trust* or Local Authority* which is paying for the placement has a written policy on involving carers in OATs.
- The care manager or care coordinator will explain how the OATs process works and answer any questions you may have.
- If the service user does not want you to be involved at this point, the care manager or care coordinator will continue to provide you with an appropriate level of information and listen to information provided by you.

* Please see glossary on page 40

- The care manager or care coordinator will tell you about any carer's support or advocacy services from your local area which might be able to support you during the OAT.
- The care manager or care coordinator will tell you about any specialised Black and Minority Ethnic (BME) groups which might be able to support you during the OAT.

Identifying the right placement

You should be able to expect that:

- The care manager or care coordinator will discuss the effect of the location of the OAT with you and you will be consulted if there is more than one option.
- Where no options are available, the reasons for this will be made clear from the beginning.
- The care coordinator or care manager will ensure that your needs and concerns are addressed. Any unmet needs will be placed on record and passed to the OATs commissioner.
- The care manager or care coordinator will arrange for you to visit any potential placement, or for staff from the potential service to visit you.
- You will be involved in any assessments designed to establish whether a placement is appropriate.

“I wasn't told anything about what was wrong, or treatments, or any plans for my sister. I was frightened what might happen to her.”

- The ability of potential service providers to meet your cultural and spiritual needs will have been assessed.
- The Primary Care Trust or Local Authority funding the OAT will have a policy on requests for second opinions*.
- When the placement is confirmed the care manager or care coordinator will explain the key points in the contract with the service provider, subject to the service user's wishes.

* Please see glossary on page 40

- If the placement is urgent or compulsory powers under the Mental Health Act need to be invoked, then those making decisions should still try and work with you in the above way and keep you informed. If you are the nearest relative*, your rights under the Mental Health Act should also be respected, for example to be consulted on the use of compulsory powers.

“They started off being very open and friendly but as soon as I started asking questions they said they couldn’t tell me anything because of confidentiality. “

On Admission

You should be able to expect that:

- The service provider will have a policy on involving carers in OATs.
- The care coordinator, care manager, or someone from the OAT service will discuss admission arrangements with you.
- Visiting arrangements will be discussed and agreed with you before admission.
- The care manager, care coordinator, or service provider will ask you about your travel and other possible expenses. They should also arrange an appropriate level of financial assistance or practical help if you need it.
- Potential arrangements for the service user to visit home (take leave*) will be discussed with you before the placement begins.
- You will be given a booklet providing practical information about the placement, including how to make a complaint.
- Any assessment will take account of your cultural and spiritual needs.
- You will be given a rough idea of how long the placement is intended to last .
- You will be given advice, or told where you can find advice, concerning any benefits (yours or the service users) which may be affected by the placement.

* Please see glossary on page 40

During the OAT

Getting and Giving Information

You should be able to expect that:

- You will always be treated with courtesy and respect and as part of the care team.
- You will be able to speak to the appropriate psychiatrist and other senior staff when you need to
- ‘Confidentiality’ will never be used as a blanket excuse for excluding you from information sharing.
- The care manager or care coordinator will regularly review your relationship with the service user and the extent to which he or she wants you to be involved.
- You will be kept up to date about the service user’s progress and any changes to the placement which might occur.
- You will be given a named nurse or key worker to contact who will be able to answer your questions and update you on the service user’s progress, and receive information you want to give. Other staff should help you find information if the named nurse or key worker is unavailable.
- You will be given information on how the Care Programme Approach* (CPA) works, if the service user is on CPA, and how care management meetings* work.
- You will be given information on your rights if you are the nearest relative of someone who is detained under the Mental Health Act.
- You will be invited to CPA and care management meetings, if the service user gives consent for you to do so. They will be arranged at times suitable for you.

“I’m always invited to the CPA meeting. And I can ring up the key worker or social worker at any time.”

* Please see glossary on page 40

- You will be given access to any written information about yourself. Consent will be required from the service user if this is in their notes.
- When information of a sensitive nature is given to you, it will be given at an appropriate time and in an appropriate way.

“The travel was 3 hours each way – but it was worth it to see my daughter getting well!”

Visiting and Leave Arrangements

You should be able to expect that:

- When you first visit you will be properly greeted, offered refreshment, given any information you need, and shown around the building and the areas that you can use.
- Visiting arrangements should stay as agreed, but should be flexible to your needs.
- There will be a dedicated, comfortable space for you to meet with the service user when you visit.
- You will be encouraged to seek and provide information about the service user’s progress when you visit.
- Your views and needs will be addressed when arranging service user’s leave.
- Contingency plans will be put in place to manage any difficulties which may arise for you when the service user is on leave.
- After leave the staff will debrief you about how the leave went and any issues which arose during your contact with the service user. This may be through a follow up phone call.
- If your visits need to be supervised, you should receive an explanation why this is the case. Supervised visits may occur on security or clinical grounds, especially in secure hospitals.
- If you need to be searched prior to visiting, because you are visiting a secure establishment you should receive an explanation and this should be done with regard to your dignity.

- Your right to visits should be respected. Any decision to exclude you from visiting is a serious interference with the service user's entitlement to be visited and this decision should only be made in exceptional circumstances. The Hospital Managers should monitor and review any exclusions.

Meeting Your Needs

You should be able to expect that:

- A formal assessment of your needs will be carried out and you will be given a complete and honest account of how your needs can be met.
- Your needs will be reviewed and re-assessed during the course of the placement.
- If the placement is long-term you will be supported in getting to know facilities, services and opportunities in the area which might be useful to you or the service user.
- Your need to stay informed will be respected and you will be provided with a level of information appropriate to your needs and the wishes of the service user.

Carer's Assessment

Standard six of the National Service Framework for Mental Health states that "all individuals who provide regular and substantial care for a person on CPA should have an assessment of their caring, physical and mental health needs, repeated on an annual basis, and have their own written care plan which is given to them and implemented in discussion with them". You should ring or write to your local council social services to request an assessment. See page 44 for where you can get a copy of Rethink's Fact-sheet on carers' assessments.

Planning for Transfer or Discharge

You should be able to expect that:

- You will be involved in any discussions about transfer or discharge and how it might impact on you.
- The service user will not be transferred or discharged without discussion with you.
- If you are the nearest relative and the service user is detained under the Mental Health Act, your legal rights to be informed of the transfer and discharge of the patient should be respected, unless you or the service user have requested that this information should not be given.
- You will be provided with advice on what to do and who to contact in the event of crisis or relapse following discharge.
- On transfer or discharge your needs as a carer will be re-assessed.

“What helps is knowing that people take my daughter seriously and show personal understanding of her problem.”

What can you do if you are dissatisfied?

If you are dissatisfied with the service that you or the service user are getting there are places you can get advice or help:

- Contact the Rethink National Advice Service on 0208 974 6814 Mon, Weds, Frid 10am-3pm, and Tues to Thurs 10am-1pm.
- At the back of this guide is a list of leaflets and fact sheets which you might find helpful.
- Ask the care manager or care coordinator how you can make an official complaint.

Section 4 For Care Coordinators

A checklist for care coordinators to ensure that carers are appropriately involved in OATs

Stage One

Setting up the out of area placement

Prior to the Placement

- Does your organisation have a policy for involving carers in OATs?
- Does your organisation have a policy on requests for second opinions?

“My daughter wants me involved in her care. The service provider wants me involved, but the local care coordinator is more reluctant and thinks the service provider should withhold information from me.”

Identifying the Placement

- Has the carer been informed and consulted about the need for an OAT, and the practical and personal impact on them assessed?
- Has the process of placing someone out of area been explained to the carer, and their questions and concerns addressed?
- Has the carer been involved in assessing whether the placement is appropriate?
- Has the service user expressed any views about carer involvement?
- Have they prepared an Advance Statement in case of loss of mental capacity?
- Have the available options for the placement been discussed with the carer and, where no options are available, has this been made clear?
- Has the carer had an opportunity to visit or be visited by potential service providers?
- Has the carer been provided with an information booklet (or brochure) which describes any potential placement?

- Has the ability of potential service providers to meet the carer's and service user's cultural and spiritual needs been assessed?
- Has the carer been given information about available carer advocacy or other support?
- Where appropriate, has the carer been informed about Black and Minority Ethnic (BME) advocacy, information or support groups?
- Has the carer been given information (or signposted to an information service) about their or the service user's welfare benefits which may be affected by the OAT?
- Have attempts been made to follow the spirit of good practice even if the placement is urgent or compulsory powers under the Mental Health Act need to be invoked?

Confirming and Preparing for the Placement

- Has the carer been informed about where the placement will be?
- Have the carer's needs in relation to the OAT been formally assessed and has s/he been informed of how those needs will or will not be met?
- Have arrangements been put in place for travel or other expenses that the carer might need during the OAT?
- Have admission arrangements been discussed with the carer?
- Have potential visiting and leave arrangements been discussed with the carer?
- Has the carer been provided with a copy of the contract with the service provider or have the key points in the contract with the service provider been explained to them, subject to the service user's wishes?

“When my daughter was admitted to the home they asked her for the names of all the people she might send birthday cards to in order to stay in touch.”

- Has the carer been given a rough idea of how long the placement is intended to last?

Stage Two

During the placement

“My daughter is being cared for in Bury but her CPA meetings take place in Preston, her home town. Everyone attends – including the home manager, the care coordinator, the psychiatrist, my daughter and myself.”

Getting and Giving Information

- Is the relationship between the service user and carer regularly reviewed and the carer involved accordingly?
- Is the carer routinely kept up to date with the service user’s progress?
- Has the carer been given information on how the Care Programme Approach (CPA) works and how care management meetings work?
- Is the carer routinely invited to care management and CPA meetings, if the service user consents to this? Meetings should be at a suitable time and place for the carer.
- Does the carer have questions or concerns which need to be addressed?
- Does the carer have access to all members of the care team including the psychiatrist?
- Is the carer treated with courtesy and respect and as part of the care team?
- Has the carer been told how to make a complaint if they are dissatisfied with the service being provided?
- Where the service user does not want the carer involved is the carer given an appropriate level of information in accordance with good practice on sharing information?

Visiting and Leave Arrangements

- Are visiting arrangements satisfactory for the carer?
- Are the carer's travelling and any other expenses to which they are entitled being met?
- Are visiting arrangements regularly reviewed to ensure they are suitable for the carer?
- Are the carer's views and needs taken into consideration when leave arrangements for the service user are put in place?
- Have contingency plans been put in place to manage any difficulties which may arise for the carer when the service user is on leave?
- Is the carer debriefed after periods of leave to find out any issues which arose during contact with the service user?
- Have any decision to exclude a carer visitor been properly considered?

"I had arranged to go and visit my son at an independent hospital. When I got there I was told that because of disruption on the ward my visit was cancelled. This meant I had spent the whole day travelling for nothing."

Carer Needs

- Have the carer's needs been formally assessed and a carer's plan developed?
- Have the carer's needs been regularly reviewed and recorded during the course of the placement?
- Have the carer's cultural and spiritual needs been regularly reviewed and recorded during the course of the placement?
- If the placement is long term has the carer been supported in getting to know facilities, services and opportunities in the area which might be useful to them or the service user?
- Is the carer routinely informed and involved subject to the wishes of the service user and carer?

Stage Three

Transfer or Discharge from the Placement

- Has the carer been consulted about any transfer or discharge being considered, and the impact of this on them taken into account?
- Has the carer been given advice on what to do and who to contact in the event of crisis or relapse following discharge?
- Have the carer's needs been re-assessed following transfer or discharge?

“My son has been moved around a lot while he has been unwell. However, when he was moved temporarily from Blackburn to Bradford two members of staff from Blackburn visited him to keep in touch.”

Section 5 For Service Commissioners

A checklist for service commissioners to ensure that carers are appropriately involved in OATs

(Note: in this guide the service commissioner responsible for OATs is referred to as the care manager).

Stage One

Setting up the out of area placement

Prior to the Placement

- Does your organisation have a policy for involving carers in OATs?
- Does your organisation require evidence of appropriate carer involvement in its contracts with service providers?
- Does your organisation have a means of ensuring that carers can claim travel and other expenses in relation to OATs if they are entitled?
- Does your organisation have a policy on requests for second opinions?

“I tried for a long time to talk to the consultant and to get some information. When I did finally get to talk to him he wouldn't tell me anything on the grounds that my son was unstable and might change his mind about involving me.”

Informing and Consulting with Carers

- Has the care manager or care coordinator consulted with the appropriate carer in relation to placing someone out of area? Has the practical and personal impact of this on them been established?
- Has the care manager or care coordinator established the nature of the relationship between the service user and carer and the extent to which s/he wants them to be involved at this point? Has the service user prepared an Advance Statement concerning carer involvement?

- Has the process of placing someone out of area been explained to the carer and their questions and concerns addressed?
- Has the carer been consulted about where the placement will be?
- Have the available options for the placement been discussed with the carer and, where no options are available, has this been made clear?
- Have visits to potential facilities (or visits to the carer by the potential service provider) been organised for the carer?
- Has the carer been involved in assessing whether the placement is appropriate?
- Has the ability of potential service providers to meet the carer's and service user's cultural and religious needs been assessed?
- Has the carer been given information about available carer advocacy or other support?
- Where appropriate, has the carer been informed about Black and Minority Ethnic (BME) advocacy, information or support groups?
- Has the carer been given information (or signposted to an information service) about their or the service user's welfare benefits which may be affected by the OAT?

“At the meetings they all know what is happening, they all use the same language, and I'm the only one who doesn't understand.”

Confirming the OAT

- Has the carer been informed which service provider will be used and why?
- Have admission, visiting and leave arrangements been discussed with the carer?
- Has the carer been provided with a copy of the contract with the service provider, or have the key points in the contract with the service provider been explained to them, subject to wishes of the service user?

- Has the carer been given a rough idea of how long the placement is intended to last?
- Has the carer been told how to make a complaint if they are dissatisfied with the service being offered or provided?

Stage Two

During the placement

“I sometimes felt that I was the Care Coordinator because I had to keep everyone in the loop.”

Getting and Giving Information

- Is the relationship between the service user and carer regularly reviewed and the carer involved accordingly?
- Is the carer routinely kept up-to-date with the service user’s progress?
- Has the carer been given information on how the Care Programme Approach works and how care management meetings work?
- Is the carer routinely invited to care management and CPA meetings, if the service user gives consent for this? Meetings should be held at a suitable time and place for the carer.
- Is the carer treated with courtesy and respect and as part of the care team?
- Does the carer have access to all members of the care team including the psychiatrist?
- Where the service user does not want the carer involved is the carer given an appropriate level of information in accordance with good practice on sharing information?

Visiting and Leave Arrangements

- Are visiting arrangements satisfactory for the carer?
- Are the carer's travelling and other expenses to which they are entitled being met?
- Are visiting arrangements regularly reviewed and kept flexible in accordance with the carer's needs?
- Are the carer's views and needs taken into consideration when leave arrangements for the service user are put in place?
- Have contingency plans been put in place to manage any difficulties which may arise for the carer when the service user is on leave?
- Is the carer debriefed after periods of leave to find out any issues which arose during contact with the service user?

“The Occupational Therapist and the Social Worker from the placement brought my son home to assess his cooking skills in a proper home environment.”

Carer Needs

- Have the carer's needs in relation to the OAT been formally assessed and a carer's plan developed?
- Have the carer's needs been regularly reviewed, recorded, and re-assessed during the course of the placement?
- Have the carer's cultural and spiritual needs been regularly reviewed and recorded during the course of the placement?
- If the placement is long term has the carer been given assistance in getting to know facilities, services and opportunities in the area which might be useful to them or the service user?
- Is the carer routinely informed and involved in accordance with their wishes and with respect for the service user's wishes?

Stage Three

Transfer or Discharge from the Placement

- Has the carer been consulted about any transfer or discharge being considered and any impact of this on them being taken into account?
- Has the carer been informed of any transfer or discharge which is about to take place? This is particularly important if the carer is also the nearest relative as a nearest relative has a legal right to be informed of transfers or discharges.
- Has the carer been given advice on what to do and who to contact in the event of crisis or relapse following discharge?
- Have the carer's needs been re-assessed following transfer or discharge?

“My son still needs close support but he is ready to move out of a secure environment. He could move temporarily to somewhere nearer home until a permanent place becomes available but the consultant doesn't want him shifting about and getting unsettled and ill again. I agree. It makes me feel that the consultant has got my son's interest at heart.”

Section 6 For Service Providers

A checklist for service providers to ensure that carers are appropriately involved in OATs

Stage One

Setting up the out of area placement

“The Psychiatrist told me, ‘I don’t just treat your daughter – I treat the whole family’.”

Prior to the Placement

- Does the service have a policy for involving carers in OATs?
- Does the service have a carer information booklet?
- Does the service have a carer involvement worker?
- Does the service have a means of ensuring that carers’ financial and practical needs can be met during placement?
- Is there a comfortable and private space for carers to meet with service users?
- Is the service able to meet the cultural and religious needs of carers from different BME groups?

Preparing for the Placement

- Has the service user expressed any views about carer involvement? Have they prepared an Advance Statement in case of loss of mental capacity?
- Has the carer had an opportunity to visit or be visited by the service?

- Has the carer been involved in assessing if the placement is appropriate?
- Have the key requirements in the contract which you hold with the commissioner been explained to the carer?
- Has the carer been given a rough idea of how long the placement is intended to last?
- Have admission, visiting and leave arrangements been discussed with the carer?
- Has the carer been provided with a carer information booklet?
- Has the carer been told how to make a complaint if they are dissatisfied with the service being provided?
- Has the carer been given information about carer advocacy or other carer support in their local area?
- Has the carer been given information (or signposted to an information service) about their or the service user's welfare benefits which may be affected by the OAT?
- Where appropriate, has the carer been informed about Black and Minority Ethnic (BME) advocacy, information or support groups?
- Has the carer been consulted on their cultural and spiritual needs and those of the service user?

“The hospital were very helpful. They helped me find a cheap, friendly family run hotel I could use when I came to visit my daughter.”

Stage Two

During the Placement

Getting and Giving Information

- Has the carer been given a named nurse or key worker who will keep them involved?

“Nobody told me anything about his case. People were very nice to me but nobody talked to me about his treatment or about what would happen.”

- Is the relationship between the service user and carer regularly reviewed and the carer involved accordingly?
- Is the carer routinely kept up-to-date with the service user’s progress?
- Has the carer been given information on how the Care Programme Approach works and how care management meetings work?
- Is the carer routinely invited to care management and CPA meetings, if the service user gives consent for this? Meetings should be held at a suitable time and place for the carer.
- Does the carer have questions or concerns which need to be addressed?
- Does the carer have access to all members of the care team including the psychiatrist?
- Is the carer treated with courtesy and respect and as part of the care team?
- Where the service user does not want the carer involved is the carer given an appropriate level of information in accordance with good practice on sharing information?

Visiting and Leave Arrangements

- Was the carer properly met and greeted, given appropriate information, and shown around the building on the first visit?
- Are visiting arrangements satisfactory for the carer?
- Are the carer's travelling and other expenses to which they are entitled being met?
- Are visiting arrangements regularly reviewed and kept flexible according to the carer's needs?
- Are the carer's views and needs taken into consideration when leave arrangements for the service user are put in place?
- Have contingency plans been put in place to manage any difficulties which may arise for the carer when the service user is on leave?
- Is the carer debriefed after periods of leave to find out any issues which arose during contact with the service user?
- Does the service provider have a policy on the exclusion of visitors that asserts the right to be visited but explains the exceptional grounds on which visitors/carers may be excluded and how such decisions are monitored and reviewed?
- If searching or supervised visits are necessary due to clinical or security reasons, are carers given proper explanation of why such measures are necessary and proportionate?

“They would arrange meetings and cancel them without telling me even though I was travelling 3 or 4 hours to get there. My husband would tell me they had been cancelled on the phone. Maybe the hospital thought he would tell me – but they were relying on someone who is ill.”

Carer Needs

- If the placement is long term has the carer been given assistance in getting to know facilities, services and opportunities in the area which might be useful to them or the service user?
- Is the carer routinely informed and involved in accordance with the wishes of the service user and carer?

Stage Three

Transfer or discharge from the placement

Getting and Giving Information

- Has the carer been consulted about any transfer or discharge being considered, and any impact of this on them taken into account?
- Has the carer been informed of any transfer or discharge which is about to take place? This is particularly important if the carer is also the nearest relative, as the nearest relative has certain legal rights.
- Has the carer been given advice on what to do and who to contact in the event of crisis or relapse following discharge?

Section 7 What Helps?

Most of the things that help in this section were suggested by carers. Other helpful ideas have come from service providers and commissioners.

Providing Information

- An information pack which is designed specifically for the carer (rather than for the service user).
- Proper, written information about the place and the placement e.g., how they work with families, carers' rights, policies in relation to family, procedures for keeping in touch.
- A named contact at the placement to be contacted at any time.
- Being kept informed even when things are not going well.
- Being given a rough idea of what plans are in place, even if not confirmed.
- A carers' week as an opportunity for carers to find out more and get involved more.

Providing Support

- Having someone to talk to is valued by carers.
- Being welcomed and listened to from the beginning.
- Support from people in the same position, such as a carers' group (including internet support).
- Being phoned by the placement after a visit, or after periods of leave, to see how things went.
- Support if things are not going well.
- Greater use of email to help service users, carers and staff keep in touch.

Visits and Meetings

- Information on how to get to the place you are visiting.
- Flexible visiting times.
- Someone to welcome carers, show them around, and introduce staff to them when visiting for the first time.
- Asking carers who they would like to see when they visit.
- Non-denominational prayer areas, or a quiet place set aside for carers.
- Access and facilities for everyone including older people, people with hearing difficulties, wheelchairs users, and so on.
- Meeting times which are convenient for the carer as well as staff.
- Virtual visiting is being developed in secure settings – where the carer can visit a local secure establishment and talk to the service user over a video link.

Working Together

- Management and staff who will keep carers informed, respond to requests and value carers as part of the care team.
- Staff who are empathetic and non-judgemental.
- Staff visiting carers at home to gain a better understanding of their life.
- Health and social services working together.
- Carers being involved in the whole assessment and placement process – genuine partnership.
- Advance Statements, which set out how the service user wants the carer involved.

Practical Help

- An advocacy service specifically for mental health carers.

- Someone to help with drafting and sending letters.
- Providing help and guidance on benefits can help carers to manage.
- A good solicitor, who understands mental health issues, can be very helpful if there is a tribunal or other formal hearing.
- Arranging travel and other expenses before the OAT starts, rather than asking the commissioner afterwards.
- A dedicated carers' support or carers' outreach worker from the service provider.

Choice

- Some choice of provider.
- Being able to meet service staff or visit the service, ask questions, and talk to other families before accepting a placement.

Carers' Assessments

- The care coordinator, service user and carer decide together whether the carer should have a combined assessment with the service user, or whether they should have an individual one.

Training

- Carers can be trained to handle difficult situations (such as how to de-escalate) which may arise during visits or leave.
- Carers can be empowered by receiving training about local mental health services and structures, communications, etc.
- Involving carers in training staff (e.g. social workers, nurses and support staff). This is beneficial for staff (it expands their understanding of carer issues) and for carers (it contributes to their confidence and gives them a part in the system).

Involving Carers from Black and Minority Ethnic (BME) Communities

When someone from a BME community is placed out of area their cultural and spiritual needs should be assessed and catered for appropriately.

The cultural and religious needs of the carer should also be considered. Care coordinators, service commissioners and service providers need to consider, for example:

Diet

- When the carer visits are food and drink available which are culturally appropriate?

Hygiene

- Are there appropriate hygiene facilities for carers from different ethnic groups?

Language

- Is the carer's first language English?
- Does the carer need an interpreter?
- Does the carer need translations of documents?
- Do staff know how to address the carer appropriately?

Religious and Cultural Events and Practices

- Are there spiritual or cultural events and practices which the service needs to accommodate? (eg Ramadan)
- Does the carer need a quiet place to reflect or pray?

Staff

- Do staff receive training in cultural and religious issues in relation to mental health?
- Is the staff's 'cultural competence' regularly reviewed and updated?
- Is there an appropriate mix of staff from different ethnic backgrounds to be able to provide a culturally sensitive service?

Section 8 Developing the Guide

How was this guide developed?

The guide was developed mainly by interviewing and meeting with carers, commissioners and service providers.

Interviews with carers were by telephone. They explored, for example, people's experience of caring for someone who is out of area, the situations they have had to manage, the benefits and disadvantages of being an out of area carer, how much they have been involved or excluded, how much they know about the mental health system, their own care needs, any examples of good practice that they could bring to mind, and anything that would have helped them during the experience.

Interviews with commissioners and service providers were face-to-face. They explored, for example, the circumstances under which people were placed out of area, what were the key issues when placing someone out of area, what emphasis they put on involving carers, what measures they already take to ensure that carers are involved, what further measures they could take, and examples of good practice.

Carers, commissioners and service providers also came to meetings where they had the opportunity to share perspectives and ideas on OATs and to comment on the information that had been gathered through this project.

Rethink also looked at research into involving carers. There is no direct research on carers and OATs. However, there is research which suggests that involving carers can benefit service users and carers. If you want to know more about this area you can look at research by Kuipers (2006), Pharoah (2006), Pilling (2002), and Fadden (1998).

Section 9 Glossary of Terms

Advance Statements

These are also sometimes called ‘Advance Directives.’ They are an expression of the wishes of someone who experiences mental illness about the type of care and treatment to be provided if they become unwell. They can include the service user’s wishes on carer involvement. Rethink has a fact sheet on this issue. See page 44

Care Coordinator

The professional with responsibility for co-ordinating assessment, care planning and service delivery of care services under the Care Programme Approach. The care coordinator will usually be a Community Psychiatric Nurse, a Social Worker or an Occupational Therapist.

Care Manager

A social service care manager usually has several service users to purchase care for and arranges for services to be provided, but does not usually provide them themselves. Primary Care Trusts often have someone with the same types of responsibilities – to purchase and arrange for health services to be provided – but their job title is likely to be different.

Care Management Meeting

Care management refers to the process through which social service departments try to ensure that the service users referred to them are assessed for social problems and have their problems addressed. A care management meeting would be convened to discuss someone’s care needs. This is similar to a Care Programme Approach (CPA) meeting but might be concerned with funding issues rather than the details of the care provided.

Care Programme Approach (CPA)

The Care Programme Approach is designed to ensure that everybody with a mental health problem who needs support gets properly planned, co-ordinated and agreed care. Its four main elements are:

- A system for arranging to assess the health and social needs of people accepted into specialist mental health services.
- Drawing up a care plan which identifies the health and social care required from different agencies e.g. GPs, psychiatric units, psychology departments.
- The appointment of a care coordinator to keep in close touch with the service user and to monitor and co-ordinate care.
- Regular review and, where necessary, agreed changes to the care plan.

In some settings, such as secure hospitals, CPA may be referred to as Effective Care Coordination (ECC).

Carer

The government uses the word Carer for people who provide “regular and substantial care”. This can be a family member or a friend. You don’t have to live with a person to be a Carer.

Carers’ Assessment

Standard Six of the National Service Framework for Mental Health states that ‘all individuals who provide regular and substantial care for a person on CPA should have an assessment of their caring, physical and mental health needs, repeated on an annual basis, and have their own written care plan which is given to them and implemented in discussion with them.’

For more information Rethink has a fact sheet on carers’ assessment. See page 44

Key Worker

This is the professional who is assigned to oversee care and act as link person for someone who has a mental health problem in a particular setting. The key worker may also be referred to as the ‘named nurse’. They would also act as link person for the carer.

Leave

Sometimes people who have been placed out of area have the opportunity to leave the placement for short periods. This might be a for few hours or a few days.

Local Authority (LA)

A Local Authority is the body which has responsibility for local social services. The LA usually works with the Primary Care Trust to put health and social care services in place.

Named Nurse

A nurse specifically allocated to a service user in a particular setting. The named nurse may also be referred to as the 'key worker.' They would also act as link person for the carer.

Nearest Relative

A person can be both a carer and a nearest relative for the purposes of the Mental Health Act 1983. The term "nearest relative" is applied to one person defined in law who has certain rights in connection with the treatment and care of a person who is detained or being considered for detention Rethink has a fact sheet on this issue. See page 44

Primary Care Trust (PCT)

A Primary Care Trust is an organisation which has responsibility for putting in place and funding all health services in a certain geographical area. It will also provide funds for local people who are placed outside of its geographical area. The PCT usually works with the Local Authority to put health and social care services in place.

Second Opinion

There is no legal right to a second opinion but sometimes service users and carers may feel the need to contest a diagnosis and the most appropriate care or treatment. It can be very helpful to get an independent second opinion from a doctor who specialises in severe mental illness, who can make a firm diagnosis and also recommend the most appropriate treatment.

Service Commissioner

This is either a Primary Care Trust or a Local Authority which provides the funding for mental health care

Service Provider

A service provider refers to a hospital, a residential home, a secure mental health unit, a supported housing scheme, or anywhere else which provides a mental health service

Service User

This guide uses the term service user to refer to anyone who is receiving mental health care in any setting. This includes people in hospital who might also be called patients. Social services may also refer to service users as clients.

Section 10 More Information

For information or advice on carers and OATs the following are useful resources.

Rethink has fact sheets on the following issues:

- Access to health records (RET0175)
- Advance statements (RET0168)
- Carers assessment (RET0172)
- Complaints (RET0098)
- Confidentiality (RET0174)
- Care and aftercare (RET0132) (For information on CPA and Care Management)
- Second Opinions (RET0123)
- Nearest Relative (RET0261) (For information on carers' rights under the Mental Health Act 1983)
- Personality disorders – information for carers (RET0236)

Rethink National Advice Service can be contacted at:

28, Castle Street
Kingston-upon-Thames
Surrey, KT1 1SS.

Tel: 020 8974 6814
Email: advice@rethink.org
Web: www.rethink.org

For general information about mental health issues visit **www.rethink.org**

For the latest information on the Care Programme Approach contact the Care Programme Approach Association

Tel: 01246 515 975

Email: cpa.association@chesterfieldpct.nhs.uk

Web: www.cpa.co.uk

Other useful leaflets or sources of information include:

- A guide for carers: Reach out to help someone cope with severe mental illness. Rethink, 2006
- How to get help in looking after someone: a carers' guide to a carers' assessment. Department of Health, 1992
- A checklist for carers of people with mental health problems. Royal College of Psychiatrists. These can be downloaded from www.partnersincare.co.uk For hard copies of the checklist phone 020 7235 2351 or email dhart@rcpsych.ac.uk.
- A National Service Framework for Mental Health (See in particular Standards 4, 5 and 6) Department of Health, September 1999
- Valuing carers: a charter for those who provide help and support to individuals experiencing mental health problems. National Institute for Mental Health in England, 2004
- Guide for carers: A guide for those who care for people with mental health problems. National Institute for Mental Health in England, 2004

For more general information on being a carer visit:

<http://www.csip.org.uk/resources/publications/service-users--carers.html>

For information on sharing information with carers see:

- Briefing Paper: Sharing mental health information with carers: pointers to good practice for service providers. Department of Health, January 2006

For further information on good practice in relation to OATs see:

- A Good Practice Guide for Commissioners, CPA Care Coordinators, and Independent Sector Providers (to Support Placements for Mental Health Service Users). Department of Health/Care Services Improvement Partnership
- Out of Area Treatments for working age adults with complex and severe psychiatric disorders: review of current situation and recommendations for good practice. Faculty of rehabilitation and social psychiatry, The Royal College of Psychiatrists, Working Group Report, September 2005
- Working with carers: a handbook for professionals working with those who provide help and support to people with mental health problems. National Institute for Mental Health in England, 2004

For information on caring for people with personality disorder see:

- Carers and Families of People with a Diagnosis of Personality Disorder. Jointly published by CSIP North West Development Centre, Bolton, Salford and Trafford Mental Health NHS Trust, Together, Working for Wellbeing, January 2007

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Care Services
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Working together to help everyone
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Email ask@csip.org.uk
www.csip.org.uk

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