



*A Practitioner's Guide to
Carers' Assessments
under the*

Carers and Disabled Children Act 2000

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Introduction

What is the guide for?

- 1 The guide is designed to be a good practice tool for practitioners carrying out carers' assessments. Children and Families assessors should make themselves aware of its contents to aid them in working jointly with their colleagues in adult services. However, it is not an alternative to the *Framework for the Assessment of Children in Need and their Families*. The Practitioner's Guide has been produced following national workshops involving a range of professionals, carers' organisations and carers. In addition, a number of local authorities provided carers' assessment materials that have been invaluable in putting this guide together.

Who is the guide for?

- 2 This guide is primarily aimed at staff carrying out carers' assessments of adults who are caring for adults. It is not solely for social services staff (see Practice Guidance paragraph 62 "Who can assess carers?")
- 3 Care managers (adults) who identify that community care service-users have parenting responsibilities will need to undertake an initial child in need assessment and/or involve staff from children's services to make sure the children's developmental needs are identified and addressed appropriately.

Why produce guidance now?

- 4 The Carers (Recognition and Services) Act 1995 has been in force since April 1996. Some Councils have gained considerable experience of carrying out carers' assessments. However, research shows that implementation of the 1995 Act and the quality of assessments carried out across the country are patchy.

- 5 The Carers and Disabled Children Act 2000 comes into force from April 2001. It presents care managers (and other assessors) with a number of new possibilities in supporting carers:
- The ability to assess carers of adults even where the cared for person refuses an assessment
 - The ability to be innovative and creative in providing 'carers' services' focused on the outcomes carers want to see
 - The extension of direct payments.

Contents of the guide

- 6 The guide is structured as follows:
- Eligibility and access
 - Purpose of the assessment
 - Process of assessment
 - The content of an assessment
 - Delivering outcomes

Appendices

- Four dimensions of outcomes which are important to carers
- Holistic assessment including carers' needs – flowchart (Appendix)

Eligibility and access

Fair Access to Care Services (FACS)

- 7 The Department of Health will issue statutory guidance on Fair Access to Social Care Services during 2001. The guidance will provide a common framework for determining eligibility for adult social care services, provided or purchased by councils with social services responsibilities.
- 8 There is no place for artificial divides in the assessment process. The assessor may need to involve other professionals as issues arise which are more complex.
- 9 As part of an overall holistic assessment process, like assessments under the NHS and Community Care Act 1990 and *The Framework for the Assessment of Children in Need and their Families* the carer's assessment will range along a continuum. At one end there will be situations where the involvement of staff from different agencies is not required at all, or it may be restricted to exchanges of information; at the other end, there will be situations calling for joint assessment visits and joint evaluation of the assessment information.

Carers with parental responsibility

- 10 Parents of disabled children will usually receive an assessment and services for their family under the provisions of the Children Act 1989. The assessment of carers who have parental responsibility for children with disabilities as defined in the Children Act 1989 should follow the statutory guidance, the *Framework for the Assessment of Children in Need and their Families*.

Children and young people affected by caring situations

- 11 An initial assessment of adult carers and service-users following guidance on FACS **must** always clarify whether they have a parenting role. This is because sometimes an element of the family situation will suggest that children of the family may be in need as a result of the impact of disability or illness on the family.

A child shall be taken to be in need if:

- a. he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local authority;
- b. his health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services; or
- c. he is disabled.

And 'family' in relation to such a child includes any person who has parental and family responsibility for the child and any other person with whom he has been living.

Children Act 1989 s17 (10)

- 12 'Young carers', as such children are sometimes called, should not be expected to carry inappropriate levels of caring which have an adverse impact on their development and life chances. It should not be assumed that children should take on similar levels of caring responsibilities to adults. An assessment of family circumstances is essential. Services should be provided to parents to enhance their ability to fulfil their parenting responsibilities. This will usually call for good quality joint work between adult and children's social services as well as co-operation from schools, health care workers and the developing Connexions service.
- 13 The Act makes a distinction between young carers under the age of 16 who should be seen as *children in need* under the Children Act 1989 and young carers over the age of 16 who, *in exceptional circumstances*, may be assessed under the Carers and Disabled Act 2000.

Example: Distinction between young carers under and over the age of 16

Janet is 45. She cares for terminally ill husband, Joe. Up to now he has refused to have anyone care for him but family members. His condition is worsening. Janet is desperately trying to keep her job, and, as it is the summer holidays her three children, Colette 13, Noel 15 and Ben 17 are taking on much of the caring during the working day.

Janet is worn out, stressed and anxious. She approaches social services, even though Joe is furious with her, because she is so very concerned about the impact of looking after Joe without outside help on Noel, Colette and Ben. Janet has an additional concern: how they will all manage if she loses her job.

The assessor undertaking an initial assessment is confident that Joe is eligible and that Janet is a substantial and regular carer.

He is also aware of the local council's responsibilities under the Children Act 1989, so he involves a Children and Families professional in the holistic assessment process.

The holistic assessment of the situation leads to the provision of home-care and hospice-at-home service for Joe, which he reluctantly accepts because the assessment process has helped him to think more clearly about the impact of his condition on his children.

Colette and Noel are assessed as children in need. Services are provided to make sure that they can go away for a break with their mother, meet other children in similar situations for mutual emotional support, and get back in to the swing of ordinary leisure activities with their peers with whom they have lost contact.

Ben, however, expresses a very strong wish to carry on being involved in the care for his father until he dies, minimising the impact on his father of care provided by 'outsiders'. As Ben is 17 and the assessors believes it would be in his best interests to be allowed to continue in his caring role, Ben is assessed under the provisions of the Carers and Disabled Children Act to support him in his caring role, rather than simply to reduce it.

Ben and his father have always been close and share an enthusiasm for modern art. Ben has taken a year off from education to care for his father. In lieu of a carers' service to help him engage in leisure activities, which everyone agrees he needs, he opts for direct payments. When his father is being cared for by home-carers or nurses (community care services), he uses these direct payments for trips to art galleries, all of which he discusses at length with his father on his return. Ben is hoping to go to Art College in due course. Ben is pleased to receive advice from the direct payment support service about direct payments.

Substantial and regular – the impact test

- 14 The term 'substantial and regular' is not defined in the Act. In any given situation where someone is choosing to be a carer for someone who is willing to accept that care, the test that a practitioner should apply will relate to the impact of the caring role on the individual carer. In particular the practitioner will need to address the following questions
 - Is the caring role sustainable?
 - How great is the risk of the caring role becoming unsustainable?
- 15 It is not only the time each week spent caring that has an impact on carers. For some, such as those caring for disabled children or adults with learning disabilities, the caring role can have the additional impact of being a life long commitment. For others, such as those caring for adults with severe mental health problems, caring can be a sporadic or cyclical responsibility. The carer may not be physically or practically caring at all at certain times, but still be anxious and stressed waiting for, or trying to prevent, the next crisis.
- 16 In addition, caring responsibilities may conflict with other family responsibilities, such as parenting or holding down a job. Any assessment of the carer's need for support has to look at the impact of the whole caring situation.

17 Key questions to identify levels of risk to the sustainability of the caring role (these are not exhaustive) may include:

- how long has the carer been caring?
- how much help does the carer get?
- how often does the carer get a full night's sleep?
- how much physical impact does the caring role have?
- how much emotional impact does the caring role have?
- does the carer understand the nature of the cared for person's condition?
- how much time does the carer have when they feel 'off duty'?
- how appropriate is the role for someone of the carer's age or in that particular relationship to the cared for person?
- how appropriate is the role for someone of the carer's culture, religion, gender?
- how many other roles (parent, employee, carer for someone else) impact on the carer?
- how does the caring role impact on the carer's other relationships and community networks?
- how sustainable does the carer's role appear?
- does the cared for person want the carer to continue in this role?
- how far does the carer gain any sense of satisfaction/reward from caring?

Example: Is the caring role sustainable?

Jane cares for her husband Patrick, who has a severe physical disability, with the help of his mother, Sandra. Jane is holding down a full-time job. Jane and Patrick have two school-age children.

At first sight, it might be argued that Jane is not a substantial and regular carer because the hours she spends each week physically caring for Patrick are limited. Sandra puts in five 8 hour days, on the other hand, and so is obviously a substantial and regular carer.

But the number of hours alone is not the test - it is the impact that matters. As well as being a mother and wife, Jane works all week and cares all weekend.

Jane may get on well with Sandra or she may hate having to share caring for Patrick with her mother-in-law, suffering additional frustration and guilt as a result. When Jane gets home unavoidably late from a tiring day at work, Sandra may make her a cup of tea and give her half an hour to unwind. Or a frowning Sandra may have her coat on ready to go. Sandra may feel that the housework is not part of her caring role, which is only whatever activity relates to Patrick's care. Jane may be thrown straight into cooking the family's evening meal, doing the laundry, helping with the children's homework, caring for Patrick and coping with whatever is going on.

At the same time, Patrick may take responsibility for doing the family accounts, paying the bills, shopping on the internet, attending school functions etc. His contribution to the household might exceed Sandra or Jane's. Or he may sleep much of the day and want to stay up half the night, affecting Jane's ability to do her job. Patrick's condition could be stable and his temperament likewise. Or it could be cyclical or unpredictable, accompanied by profound mood swings, or sudden deterioration in physical health.

Sandra has a defined caring role and it has boundaries around it. While clearly a substantial and regular carer, she may be perfectly happy with her responsibilities, enjoying her son's company and the chance to welcome her grandchildren home from school every day. If offered a carer's assessment, Sandra may refuse. The caring role may fill a hole in her life that work filled before she retired. She may be quite happy to clock off at 5.30 and go home to Patrick's father.

*It is the **impact** of her caring role that should determine whether Jane is a substantial and regular carer and eligible for a carer's assessment.*

If she is, the assessment should focus on what she thinks will make her caring role easier.

- 18 It is important that **all** substantial and regular carers have access to an assessment and that there is no assumption that a 'main' or 'primary' carer is the only substantial and regular carer.

Purpose of the carer's assessment

- 19 A carers' assessment under the Carers and Disabled Children Act 2000 is carried out at the request of the carer in order:
- to determine whether the carer is eligible for support
 - to determine the support needs of the carer (ie what will help the carer in their caring role and help them to maintain their own health and well-being).
 - to see if those needs can be met by social or other services.
- 20 Great sensitivity on the part of assessors may be required. It is important that the assessment process does not assume that the carer wants to continue to provide care, or should be expected to. Nor should it be assumed that the cared for person necessarily wants to continue to receive care from this carer. Discussion about the future will often be difficult.
- 21 Nevertheless, the assessment process can be important in itself even where additional service provision does not flow from a carers' assessment.

Carers say there are a number of positive outcomes for them in having an assessment even where practical services may be restricted because of financial constraints. They value:

- *Recognition of their role*
- *Peace of mind from knowing how to make contact in the future*
- *A chance to talk through the issues and consider their own needs*
- *Information which can be provided on other support, such as carer groups and local statutory and voluntary services*
- *A sense of shared responsibility, particularly where any support offered is on a regular basis*
- *Increased confidence to take up services¹*

Focus on outcomes

- 22 A carer's assessment should be focused on what the carer identifies as the best possible outcome. The best possible outcome will depend on the impact of caring on the particular carer. This impact is also the best test for 'regular and substantial' caring (see below).
- 23 While many carers may clearly be able to state from the beginning what it is they want to happen to make their lives easier, others may take time to identify their own needs. It will be for practitioners, in conversation with carers, to work out how complex an assessment is required. Some assessments may be simple, almost single-issue processes. Some will involve a hugely complex range of ties and obligations and practical and emotional issues.
- 24 It is very important to make a clear distinction between 'outcomes' and services. For example, a carer may feel tied to the house looking after someone who cannot be left for more than an hour. If the carer identifies as part of a holistic assessment that the outcome they want is not to feel tied to the house, then service provision of various types may meet their needs. This could be access to a mobile phone, the provision of a direct payment for taxi fares, the installation of an

¹ Taking Action to Support Carers, Penny Banks and Colin Cheeseman

alarm system or perhaps (if the cared for person wanted this also) the provision of a day service or a 'sitting' service. The best service to provide the outcome will depend on the individual circumstances.

- 25 A holistic approach to outcomes must also take into account the outcomes the cared for person would like to see for themselves and the carer, and the outcomes the carer would like to see for the cared for person as well as for themselves. Understanding these may be crucial in negotiating any conflicts of interest that might arise.
- 26 Research by The Social and Policy Research Unit at York University (SPRU) has identified a range of outcomes carers may see as desirable. These are set out in Appendix 1.

Carer-centred

- 27 The assessment is not a test for the carer. It should not be prescriptive but recognise the carers' knowledge and expertise
- 28 The assessment should listen to what carers are saying and offer an opportunity for private discussion so the carer can be candid.
- 29 It should not be a bureaucratic process based on ticking boxes. It must focus on the **outcomes the carer would want to see** to help them in their caring role and maintain their health and well-being.
- 30 It should be seen as part of a holistic assessment of the needs for support of the cared for person and the carer, identifying the outcomes desired by both and it should be reflected in the care plan (where it is appropriate for cared for person and carer's issues to be dealt with together) or in a separately held carer's plan (where there is a need for confidentiality).

The process of assessment

Telling carers about carers' assessments

- 31 Practitioners must always tell carers who are identified during a cared for person's assessment, or at a later stage, that they have the right to request a carer's assessment. They should also provide the carer with a copy of the Government leaflet: ***How to get help in looking after someone: a carer's guide to a carer's assessment.***

- 32 Wherever there is reason to suspect risk to the sustainability of the caring role, it will be good practice to **offer** a carer's assessment, and explain what it can achieve.
- 33 Research shows that carers often are not aware, or do not remember, that the process they are involved in is an assessment. Practitioners need to be clear, and be prepared to repeat, how the process works and why it is important.

Timing of assessment

- 34 A carer's assessment will often most naturally take place at the same time as the cared for person's assessment is carried out, though thought may need to be given to how best to allow both parties to have access to time alone with the assessor where this is wanted.
- 35 However, many carers may be more open to an assessment of their own needs (as opposed to those of the cared for person) once an immediate crisis has passed, or some support has been put in place. Assessment will often not be a one-off process.
- 36 It should be made clear to the carer that they can also ask for an assessment at other times.
- 37 Where carers are working, or where children may be affected by the situation, it may be important that a holistic assessment happens, at least partly, outside normal office hours.

Assessment separately or together?

- 38 Carers and cared for people may well wish to be assessed together. However both should be offered an opportunity to talk separately. Some of the assessment of their needs may have to be done separately. This may need to be sensitively handled.

Preparing for the assessment

- 39 It is important that the carer understands clearly what the assessment is for – ie outcomes for them – and that they are involved in discussions of when and how it will happen.
- 40 It may well be helpful if the carer has time to think through issues in advance, including whether there is anything they particularly want information about or whether there is anything they want to discuss separately.

- 41 Some forms have been developed in different parts of the country to help carers plan their assessment – research indicates such forms work well as an **introduction** to the a face-to-face assessment process, but poorly as a substitute for it.
- 42 Where time to prepare is not available, carers should be told who they can contact if there are other issues they want to raise following their assessment.
- 43 It is important for assessors to recognise that an assessment may be the first opportunity a carer has had to focus on their needs. This can be an emotional process, requiring time, and possibly a follow-up visit.
- 44 The carer should be told they can have a friend or advocate present at the assessment. In addition, there may be language, communication or comprehension difficulties requiring signers, interpreters or others to be present. Is there a need for an interpreter or signer or other communication aids?

One off versus ongoing

- 45 Needs change and so review of any assessment may be required. It should be agreed with the carer when any review of the assessment is likely to take place.
- 46 Some people's lives are more complex and their needs change more frequently than others. Some people take longer to open up. Sometimes an assessment will be an accumulative rather than a one-off process.

Who should carry out the assessment?

- 47 Often the person doing the carers' assessment will be the same care manager or assessor who assesses the cared for person.
- 48 In certain cases, it may be important to find care managers with particular skills eg a particular language or cultural understanding.
- 49 In certain cases, where there is conflict between cared for people and their carers or where there is a specific need for carers' advocacy, for example, it may be appropriate for another worker to be involved.

- 50 Where young carers are identified, children's services will need to be involved. The level of involvement will vary. It could consist simply of advice from a Children and Families professional. In complicated situations such a professional might need to be take part in the assessment. Where a range of services need to be arranged and provided, practitioners will need to be clear who has responsibilities for the various aspects of the package.
- 51 Where multi-agency assessments are taking place, it may be appropriate for health staff well known to the carer to undertake the carer assessment (see Practice Guidance paragraph 62, '*Who Can Assess Carers?*')
- 52 Protocols will need to be negotiated between agencies locally to allow for such assessments to be validated by the local council who would thereby be delegating their powers under the Carers and Disabled Children Act.

Confidentiality and recording the assessment

- 53 The carer may wish to discuss information they have not revealed to the person they care for. Such information can only be shared with the service-user with the carer's consent.
- 54 The carer must always receive a copy of their assessment including a statement of the carer's needs and any differences of view between carer and assessor, in writing or in other appropriate accessible format.
- 55 This should record any issues relating to confidentiality.

Summary of assessment and the care plan/carer's plan

- 56 These should be a result of careful discussion with user and carer and record their views of the assessment on the cared for person's care plan, or where confidentiality is required on their own carer's plan.
- 57 These documents should include a clear statement of outcomes intended for each person, which will form an important source of reference when implementing and reviewing the care plan/carer's plan.
- 58 Where differences (between user, carer or assessor) arise these should be recorded appropriately. Maintaining a clear view of *desired* outcomes is important because they should be revisited at a later

stage. They may represent an area for service development, where desired outcomes cannot be achieved immediately.

- 59 Where confidentiality has been asked for by user or carer, or where conflicts of interest arise, interviews should be recorded separately. Sometimes separate files may need to be set up.

Content of the assessment

- 60 The most important element of the content of the carer's assessment, will be the focus on what it is that the carer wants to happen (the outcome).

Example – Focus on the desired outcome rather than standard service provision

Rupinder 37 cares for her husband Gurudev who has severe depression. In addition, they are both being harassed by racist neighbours. She approaches social services because she is worried about Gurudev.

The assessor feels that it might be helpful to speak to Rupinder on her own, and explain the sorts of community care services that may be available. Over the phone, before carrying out the assessment she points out to Rupinder that a separate assessment is possible. Rupinder is very clear that she does not want to do this, because of her sense of loyalty. So clear in fact that the assessor thinks that Rupinder may refuse to let her visit.

Rupinder is not interested in community care services for Gurudev at this point, and neither is Gurudev. The assessor therefore focuses on getting appropriate support from the Police and from the Housing Authority to deal with the nuisance.

The assessor makes it clear to Rupinder and Gurudev that they can approach for additional support if their needs change. She will visit again in three months time to see how they are doing.

Two months later, made more confident by the positive experience of social services' intervention, Rupinder asks for a further confidential assessment meeting for herself, as she is becoming very anxious and stressed by her husband's deteriorating behaviour.

Modules

- 61 What follows is a series of modules that can be used by practitioners to help them identify, with the carer, what elements the assessment should contain. It is not to be seen as a tick box format.
- 62 Not all modules will be appropriate to all carers.
- 63 Where there are no confidentiality issues, any resulting service for the benefit of the carer can be recorded on the cared for person's care plan and a copy can be provided to the carer. Where there is need for confidentiality, service for the benefit of the carer should be recorded in a separate carer's plan.
- 64 These modules approach issues from the carer's perspective. However it is important to remember that in many caring relationships there is a high level of interdependency. Assessors should never fail to acknowledge the positive contributions that cared for people make to the health and well-being of the carer. For example, a key source of practical and emotional support may be the cared for person themselves.
- 65 The need for outcomes to be stated and agreed with cared for people and carers means that eligibility criteria and assessments must acknowledge the role of cultural and religious identification in individuals' lives. Without some shared understanding it will be difficult for carers and assessors to agree appropriate support or a carer's plan. Councils must ensure that their staff are culturally competent or can access relevant expertise so as not to disadvantage carers from black and minority ethnic communities.²

² The Good Practice Guide: Supporting Black Carers, put together by the National Black Carers Workers' Network will be available from Summer 2001

1. Carer's role

- Carer's choice – does the carer feel they have a choice?
- How willing and able are they to provide care?
- How much time is taken up with caring?
- Which parts of the role does the carer actively want to do (if any)?
- Which parts of the role can the carer manage without help?
- Which parts of the role does the carer find particularly difficult?
- Which parts of the role does the carer actively not want to do?
- Does the carer understand the condition of the cared for person?
- Does the carer feel they would like training in how to manage any part of their role? (moving and handling, stress, understanding the condition).
- Does the caring role conflict with or undermine other family roles such as parent or breadwinner?
- What is the carer's perception of their situation?
- What is/are the outcomes the carer would like to see to help them in their role?
- What is the carer's view of the most important outcomes to achieve for the person they care for? Are these in conflict with the cared for person's views?
- Is the carer also a service-user or eligible for support? as a community care service-user?
- Where appropriate a weekly time sheet may help demonstrate the extent of the role/lack of sleep etc.

2. Breaks and social life

- Can the carer regularly get a break (*at the appropriate time of day/week*) to enable them to have time for themselves/leisure/time with friends?
- When did the carer last have a break ie time off for themselves rather than time to go shopping or time to go to the dentist or doctor?
- Might the carer need a degree of active encouragement to take breaks and maintain their social life, to avoid social isolation becoming a problem at a later stage?
- Can the carer get a break to deal with wider responsibilities eg attending a child's sports day?

3. Physical well being and personal safety

- Is the carer well?
- Is the carer undertaking any tasks that put them at risk?
- Is there any aspect of risk in caring for the cared for person?
- Is the carer stressed, anxious or depressed?
- Is sleep affected, if so how badly?
- Is the carer receiving any treatment?

4. Relationships and mental well being

- Is caring having an impact on relationships, either with the cared for person or other members of the family, friends etc?
- If the carer is a parent, is caring making this role harder?
- Are stress, depression, anxiety present or likely without support?

- Is spirituality significant to the carer? Are they able to maintain any spiritual practices or faith-related activities which are important to them?

5. Care of the home/s

- Are there any issues about care of the home/s?
- Does it all fall to the carer?

6. Accommodation

- Are there any problems with where the cared for person lives? (long distance caring/lack of time to look after property)
- Can equipment/adaptations help?
- Is carer's own accommodation (if different) a problem?
- Should housing authorities be involved in the assessment?

7. Finances

- Are finances a problem?
- Can the carer get the advice they need on benefits, managing debt, charges etc?

8. Work

- There should be no assumption that carers will give up work to care – how can they be supported?
- Does the carer want to stay in work or return to work – what are the options?
- Is advice available on these issues, including advice for returners on benefits, charging etc so that the carer can make informed decisions on what is best for them in all the circumstances.

9. Education and training

- Does the carer want to develop their skills either work-related or otherwise?
- Are they at risk of having to give up education or training because of their caring role?

10. Current practical and emotional support

- Who/what helps the carer at the moment?
- Is there enough of this support and/or is the carer happy with receiving such support from these sources?
- Is the carer aware of carers' support groups/counselling services etc in the area?

11 Wider responsibilities

- What other wider responsibilities does the carer have – parent, childcarer, other caring roles, work, volunteering etc?
- Should other workers be involved to help advise on parenting and childcare issues or about services that might help?
- Is balancing these responsibilities causing the carer stress?
- Are other roles suffering/perceived to be suffering?

12 Future caring role

- How does the carer see the future?
- What factors are likely to affect the willingness/ability to care long term?

13. Emergencies/alternative arrangements

- If the carer suddenly became ill what would happen?
- What networks are there to support in an emergency?
- Can a contingency plan be made?
- Does the carer know who to contact in an emergency?

14. Access to information and advocacy

- Are carers aware of how to get more information and who from?
- Do they know about what to do if things go wrong or if they want to complain?
- Are there sources of carers' advocacy locally they should be aware of?
- If they have internet access, are they aware of www.carers.gov.uk?
- Are they aware of www.ukonline.gov.uk which is developing a portal for carers' information during 2001?

15 Agreed outcomes

- What are the agreed outcomes for the carer in relation to their health and well-being, quality of life, as well as the sustainability of their caring role?
- Is there conflict between the carer and cared for person's desired outcomes?
- Are Direct Payments appropriate in lieu of a service to give the carer flexibility?
- Where is there disagreement?
- Where may there be problems in delivering the outcome?

- Where particular services are identified as the best way to deliver certain outcomes, what are the carer's preferences about the way such services might be delivered (eg timing, fitting in with routine, are Direct Payments appropriate in lieu of a service to give the carer flexibility?)

16. Complaints and challenges

- It is important to ensure that carers and cared for people are aware of the local council's complaints procedure.

17. Review

- When will the assessment be reviewed?
- In considering timing of review - are needs likely to increase or fluctuate; is there risk to carer or user or frequent crises?
- Who will be responsible for setting up review?

18. Charging

- A financial assessment is completely separate from either an assessment under Section 47 of the NHS and Community Care Act or under the Carers and Disabled Children Act. However, it is important that information on charges and financial assessment are clearly explained to both the carer and the cared for person as part of the assessment process

Delivering outcomes

- 66 A holistic assessment (ie taking account of all parties' needs and aspirations) of the whole situation will lead to the best outcomes.
- 67 Carers' outcomes may be delivered through carers' services under the Carers and Disabled Children Act 2000, or through additional services for the cared for person through the provisions of community care legislation. They may be delivered through advice and information about other services easily available in the community.

- 68 Care managers should feel free to be innovative and imaginative in their use of Carers and Disabled Children Act powers. Services for carers are not defined. Any outcome valued by the carer may be a legitimate use of council resources **if it genuinely will support the carer** in their caring role or help them maintain their own health and well-being.

Example: Delivering desired outcome in cost-effective and service-user and carer-centred way

Mr Jones, 76, is being assessed and would be eligible for 14 hours personal care. Mrs Jones, his carer, 74, is actually happy to do the personal care. However, she is very anxious about the state of the garden.

Mr Jones would prefer his wife to carry on with the care, but shares the care manager's real concerns about the long term health and safety impact on Mrs Jones of moving and handling him.

Between them they come up with the following solution. Mr Jones will have a couple of hours homecare on a Wednesday, providing some personal care. This will be a break for Mrs Jones who can attend her bowling club. It will also help the couple get used to the idea of someone coming in to provide personal care, in case Mrs Jones' health makes this essential later on.

In addition Mrs Jones will receive Direct Payments in lieu of a carer's service of three hours gardening per week, to stop her worrying about the garden that Mr Jones loved so much and can no longer look after.

This 'care' package offers best value to the local council, and Mr and Mrs Jones will get the outcome they want and that is right for them under the current circumstances. A pragmatic response to their needs has been made and they will feel more confident about further contacts with social services if the situation changes and they require more or different help.

- 69 Other examples of how outcomes can be delivered for carers are described in the Practice Guidance case studies.

Appendix 1

Four dimensions of outcomes which are important to carers

These domains of outcomes have been put together following discussions between researchers from SPRU³ and carers of older people and carers of disabled people under retirement age.

The specific outcomes within the domains are not necessarily a comprehensive or exclusive list, nor will all be equally significant to all carers. They should be seen more as the type of outcomes which may be relevant and therefore worth bearing in mind in discussion with carers.

i) Achieving quality of life for the person they care for

Maintaining the quality of life for the person they cared for was a primary motivation for caring. It was crucial to carers that any external help maintained and complemented their unique, individualised approach and aimed to achieve the specific outcomes they were working towards. These outcomes were generally very similar to those identified by service users themselves: e.g. maintaining comfort, safety, social contact, and meaningful activity, although tensions could arise. Sensitive handling, and where appropriate, negotiation of differences may be dependent on first understanding the nature of the different perspectives.

ii) Achieving quality of life for the carer

Although carers were generally very committed to continuing caring for as long as they could, it was crucial that they could make informed choices about the extent of the caring role, retain a positive sense of self, maintain health, well-being, financial security and have sufficient freedom to maintain relationships, employment, interests and other commitments alongside their caring responsibilities. Attention to the carer's own quality of life, rather than focussing solely on their role as a carer, was greatly valued. Neglect of this dimension of outcomes for carers could have a negative impact on their ability or willingness to continue caring. Carers of older people with dementia particularly valued sensitive support in negotiating their own needs and interests where the older person's lack of insight led to conflict.

³ Source: Social Care Outcomes Programme, SPRU, University of York

iii) Supported in the caring role

A specific focus on their role as carer was another distinct dimension. Carers wanted to feel informed, prepared, equipped, and where appropriate, trained for the caring task. They stressed the value of a sense of shared responsibility both emotionally and practically. Feeling emotionally supported was often as significant as practical assistance with, or relief from, caring responsibilities. Being able to access such help on an emergency basis was also important.

iv) Service process outcomes

The way in which services are organised and delivered and the quality of interaction experienced can enhance or inhibit the achievement of desired impacts on the carer's quality of life and may also have serious repercussions for the carer (e.g. refusal of service by user or carer, dealing with additional agitation and distress). Participants valued services which: recognise their needs and expertise; are accessible (e.g. non-bureaucratic and available at the point of need rather than in six months time); treat them as unique individuals; and fit in with their existing routines and patterns of care. Equally important are positive relationships with staff, and value for money, due to the reduced incomes and increased costs often associated with caring. Taking time to establish the processes which are most relevant to individual carers will be an important condition for the achievement of quality of life outcomes.

Four dimensions of outcomes which are important to carers

A Quality of life for the person they care for

- Personally clean, comfortable and well turned-out
- Maintain maximum independence
- Personal safety and security
- To be in social contact with others (apart from carer)
- To have meaningful activity/stimulation
- Maintain dignity
- Improve mobility, morale

B Quality of life for carer

- Physical health or well-being
- Emotional/mental health
- Peace of mind (freedom from excessive anxiety re person cared for)
- Ability to have a life of their own (i.e. to work if they choose, pursue interests)
- To avoid social isolation
- To maintain a positive relationship with person cared for
- Adequate material circumstances (income/housing)

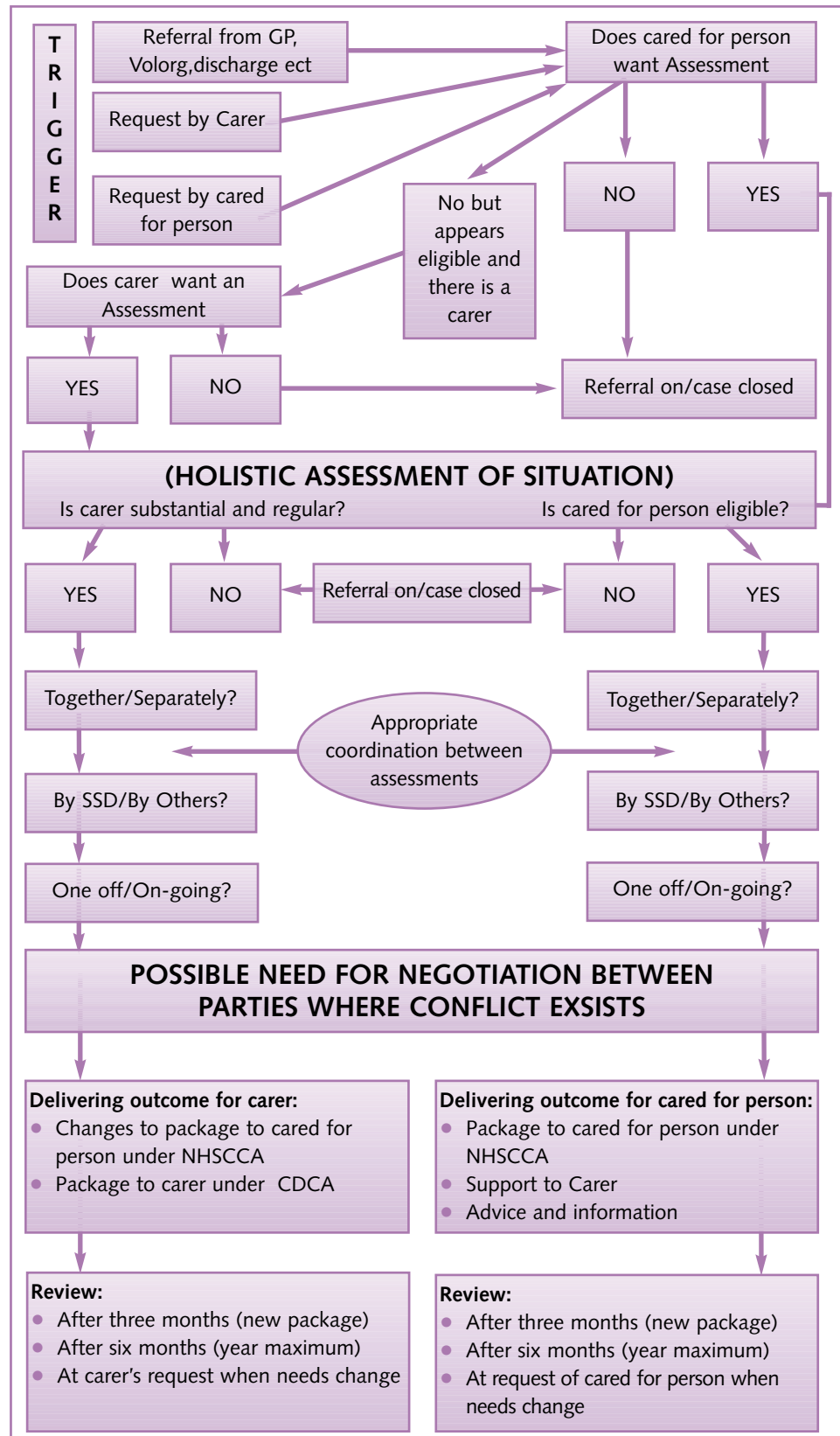
C Recognition and support in the caring role


- Able to define the limits of their role (level of involvement and nature of task)
- Feeling skilled, confident and knowledgeable
- A sense of satisfaction or achievement in caring
- Sense of shared responsibility/being emotionally supported
- Able to manage the physical/practical tasks of caring

D Process outcomes (impacts of the way help is provided)

- Valued/respected as an individual
- Expertise as a carer recognised
- Having a say in the way help is provided
- A “good fit” with existing life routines and care giving
- Value for money

Appendix 2 Holistic Assessment: including carers' needs (adults) – flowchart





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