GRiP
Getting Research into Practice

Carers Outcome Agreement Tool

A new approach to working with family carers

Äldre Väst Sjuhärad

Socialstyrelsen

The University Of Sheffield.

“I could say what I thought, nobody talked over my head either.
I was involved, and that was good.”

COAT: The Carers Outcome Agreement Tool

A new approach to working with family carers

Elizabeth Hanson[1]
Janet Nolan[3]
Lennart Magnusson[1]
Eva Sennemark[1]
Lennarth Johansson[2]
Mike Nolan[3]

[1]ÄldreVäst Sjuhärad Research Centre, School of Health Sciences,
University College of Borås, Sweden
[2]Socialstyrelsen, National Board of Health and Welfare in Sweden
[3]School of Nursing and Midwifery, University of Sheffield, UK

ISBN 1-902411-43-9

Design and Print: NORTHEND CREATIVE PRINT SOLUTIONS
TUOS033

Acknowledgements

We would like to thank all those carers and practitioners who gave so generously of their time in participating in the development of the Carers Outcome Agreement Tool (COAT), to Socialstyrelsen National Board of Health and Welfare in Sweden, The ÄldreVäst Sjuhärad Research Centre, University College of Borås, and the Community, Ageing and Rehabilatation Department at the School of Nursing and Midwifery, University of Sheffield for financial support, and to Helen Mason for producing the final manuscript, without her help this report would not have been possible.

About the Authors

Elizabeth Hanson is Senior Lecturer and Scientific Leader in elder care at ÄldreVäst Sjuhärad Research Centre, University College of Borås, Sweden and Visiting Reader at the University of Sheffield School of Nursing and Midwifery. Her research interests include family care support, palliative care needs of older people and empowerment in research and practice.

Lennarth Johansson is a Psychologist and Associate Professor in Gerontology, he has over twenty years experience of working as a Senior Research Associate, specialised in housing services and care for older people. His main field of interest is informal caregiving and social policy aspects of elderly care. During recent years he has also been involved in several international comparative studies on the care of older people. Since 1993 he has held a position at the National Board of Health and Welfare, as a research leader, responsible for the evaluation of recent reforms in elderly care.

Lennart Magnusson is a Lecturer in the Department of Health Sciences at the University College of Borås, Sweden. He is an engineer, nurse and founding director of ÄldreVäst Sjuhärad Research Centre. He has a long-standing interest in the needs of family carers of frail older people and in the design and evaluation of innovative service responses to these needs.

Janet Nolan is a Lecturer in Nursing at the University of Sheffield. She worked as a health visitor before moving into nurse education. Janet has particular interests in health care in the community, especially the care older people receive from district nurses, practice nurses and health visitors.

Mike Nolan is Professor of Gerontological Nursing at the University of Sheffield. He has long-standing interests in the needs of family carers and of vulnerable older people in a range of care environments, and has published extensively in these areas. He has worked in the field of assessment of family carers' needs for over 15 years.

Eva Sennemark is a Nurse and a Social Anthropologist. Eva works freelance and has experience of running educational initiatives for care practitioners and carrying out research and evaluation projects concerning integration and diversity issues. For the last three years she has worked as a part-time research assistant at ÄldreVäst Sjuhärad Research Centre.

Welcome to the GRIP - 'Getting Research into Practice' Reports

Since its inception the School of Nursing and Midwifery at the University of Sheffield has been committed to undertaking research of the highest quality that generates new knowledge and insights of direct relevance to practitioners and other user groups. It has demonstrated this commitment by developing innovative approaches to engaging users at all stages of the research and development process and by disseminating the products of such efforts in a wide variety of forms other than traditional academic outputs.

Recent changes have seen the emergence of a Graduate Division of Nursing and Midwifery at Sheffield, and with it new opportunities to further enhance our established national and international reputation in the field of user involvement. One of the first acts of the new Graduate Division is therefore to launch a series of occasional 'Getting Research into Practice' or 'GRIP' reports. GRIP will be used to showcase studies on topics of considerable interest to a variety of user groups, that have employed methods in which user involvement and partnership working have been central features. Of course the Graduate Division undertakes other forms of research, and is not exclusively concerned with practice. Nevertheless 'getting research into practice' is a major goal. As a means of dissemination GRIP reports will complement other approaches, such as peer reviewed journals, by making research findings available to audiences that might not routinely consult or have ready access to such publications.

We are delighted that the inaugural GRIP report fully meets the series aims. Its subject, that of developing new approaches to working with family carers, has been a long-standing interest of several members of the Graduate Division and is a top policy priority for countries throughout Europe and beyond. However, policies are of little use if they do not translate into better practice, and despite extensive research and policy initiatives in this field, changes on the ground have been slow to happen. For example, whilst there has been a series of legislative changes in the UK over the last 10 years, family carers continue to report feeling marginalised by health and social care systems.

The publication of the 'Carers Outcome Agreement Tool' (COAT) potentially marks a way forward by promoting a means of family carers and professionals working together. COAT is the result of a joint Anglo-Swedish project, supported by the Swedish National Board of Health and Welfare, the ÄldreVäst Sjuhärad Research Centre at the School of Health Sciences, University College of Borås, Sweden and the former CARER (Community, Ageing, Rehabilitation, Education and Research) Department at the School of Nursing and Midwifery, University of Sheffield. Although underpinned by 15 years of previous research, COAT was developed in close collaboration with both family and professional carers, who were involved at all stages. As such it exemplifies the philosophy underpinning the GRIP series and we hope that it is the first report of many.

GRIP Editorial Team

Foreword

Stimulating formal services to work in partnership with family carers is a major policy priority in Sweden, the UK, and indeed throughout Europe and beyond.

Early in 2005 the National Board of Health and Welfare in Sweden was commissioned by the Swedish Government to consider how support for family carers could be enhanced between 2005-2007. The development of the Carers' Outcome Agreement Tool (COAT) provides a potential way forward.

COAT has been developed as a way of working with carers to identify their need for support and to plan, agree and evaluate the help they receive. The study was a joint project between Sweden and England involving researchers at the ÄldreVäst Sjuhärad (ÄVS) Research Centre, University College of Borås (Elizabeth Hanson, Lennart Magnusson and Eva Sennemark), the School of Nursing and Midwifery at the University of Sheffield (Mike Nolan and Janet Nolan) and the National Board of Health and Welfare (Lennarth Johansson). The work was supported financially by the National Board of Health and Welfare, ÄVS and the School of Nursing and Midwifery at Sheffield.

COAT has already been published in Swedish, and this more detailed report provides a fuller description of the extensive development work that was involved. We hope that COAT will make an important contribution to fostering partnerships between family carers and formal support systems.

National Board of Health and Welfare in Sweden

Socialstyrelsen

Contents

Executive Summary

- This report describes a joint Anglo-Swedish project to develop and pilot both a new instrument, the Carers Outcome Agreement Tool (COAT), and a new model of working with family carers based on creating partnerships between carers, practitioners and service systems.

- Most countries are pursuing a policy of community care for older people and the vast majority of the help that older people need to remain at home is provided by their family. Ensuring appropriate and sensitive support services for family carers is therefore a major policy priority.

- Despite a research literature spanning some forty years, and numerous policy initiatives, there is relatively little evidence of the effectiveness of current support services for carers. Moreover, carers often have concerns about the quality of care they, or their relative, receives, and many reject help as a result.

- Much of the available research has adopted a stress-coping model, and interventions have been designed primarily to reduce carer burden. Far less attention has been paid to the nature and quality of relationships and the potential satisfactions of caring.

- The outcomes used to measure the 'success' of carer support have largely been designed by researchers and have recently been criticised for being too abstract and not reflecting the goals that carers themselves see as important.

- From a policy perspective there has been much recent talk about the need for practitioners to work in partnership with family careers, but the majority of services are still 'allocated' to carers based upon predetermined eligibility criteria. The role of the practitioner/assessor is largely to act as a 'gatekeeper' to such services.

- COAT has been designed to help overcome existing limitations by promoting a new approach to carer assessment and service provision. It builds on several years of research on carer assessment, and is based on a model that views the carer as a 'co-expert'. Carers and practitioners therefore work together to agree the type of goals and outcomes that carers see as important, and the support needed to achieve these.

- COAT has been developed in close collaboration with carers and practitioners and field tested to determine its relevance, usefulness and acceptability.

- COAT explores four aspects of caring:

  - Helping you to care – considers the type of help, information and skills that carers may need.

  - Making life better for you – explores support that might improve carers' quality of life.

  - Making life better for your relative – explores what might improve the quality of life of the cared-for person.

  - Getting good quality help – considers what carers want from a quality service.

- Field testing indicated that carers considered that COAT:

  - allowed them to raise issues that were causing concern;
  - helped them to discuss such concerns in an open and frank manner;
  - provided new insights into their caring situation;
  - helped them to focus on issues that they had not previously considered;
  - helped to structure their discussions with practitioners;
  - helped to validate their experiences as carers.

Importantly all of those carers taking part enjoyed the experience of a practitioner spending time talking to **them** about **their** needs, and a number compared this experience favourably with previous 'assessments' that had not allowed them to fully express their views.

- Practitioners also identified a number of benefits including:

  - All practitioners felt that COAT worked well in promoting a personal and detailed discussion about individual caring situations.

  - Despite practitioners having detailed prior knowledge of the caring situation, completing COAT provided new insights for many of them.

  - Practitioners considered that COAT enabled them to get to know the carers well, and provided a comprehensive view of the caring situation from the carers' perspective.

  - COAT enabled carers to talk openly about their situation, and helped them to focus on areas that they had not previously considered, such as their own quality of life.

  - The process of completing COAT allowed practitioners to begin to address some of the carers' concerns, for example, for further information.

  - Completing COAT was seen by some as potentially therapeutic in its own right.

- As a result of the pilot work and field testing, COAT was modified to maximise the above benefits.

- Following completion of COAT carers and practitioners discuss a series of action plans and decide upon the type of support needed, who will provide it and when, the goals of the support, and when/how it will be evaluated.

- Using COAT in routine practice will require a change in culture and ways of working. Adequate education and preparation is essential. The next phase in the development of COAT is to produce a more detailed carer and practitioner guide, together with an educational package for practitioners.

Background and context: the emergence of family care

> *'With its strategic importance, and the unresolved issues surrounding it, we expect that the family will continue to be centre stage for many years to come.'*
>
> (Pearlin et al 2001, p55)

This report describes a joint Anglo-Swedish project to develop and pilot both a new instrument, the Carers Outcome Agreement Tool (COAT), and a new model of working with family carers based on creating partnerships between them and formal carers. We begin by providing a background and rationale for the project, highlighting the emergence of family care as a major focus of attention for researchers, policy makers and practitioners. However, despite several recent developments, we argue that there is still a need for significant changes in the way that family caring is understood if the situation of carers is to improve, and they are to receive more appropriate and sensitive support services. This will require remodelling existing relationships between family carers, practitioners, and those services and systems designed to support carers. COAT is offered as a potential means of making progress towards such ends.

Our proposed new way of working with family carers is compared with existing conceptual and methodological approaches to supporting carers, and the limitations these have in light of recent research and current policy initiatives. The extensive theoretical and empirical work underpinning COAT is then outlined briefly. Subsequently, we describe how COAT was developed and refined by a process of close collaboration between ourselves and both family and professional carers. Finally, suggestions for further work and the practical application of COAT are made. COAT itself is presented as an appendix to this report (see Appendix 1).[1]

The past 30 years have witnessed a remarkable growth in interest in 'family carers' as the main source of support for people who need help to remain living within their own homes. As the above quote suggests, there is no sign of this interest abating; indeed in many respects it is on the increase. Moreover, such interest spans several areas, ranging from the academic to policy and practice. From an academic perspective family, or informal care, as it was referred to, was 'hardly mentioned in the 1960's' (Brody 1995) and yet 30 years later it had become one of the most researched areas in social gerontology (Kane and Penrod 1995). The result has been a 'voluminous literature' (Schulz and Williamson 1997) and an 'explosion' in research activity (Fortinsky 2001), much of it focussing on interventions designed to support family carers in their role. Yet despite this, and the fervent hope of most researchers that their efforts will in some way 'make a difference' (Pearlin et al 2001), there is still remarkably little evidence for the effectiveness of existing interventions (Braithwaite 2000, Thompson and Briggs 2000, Cooke et al 2001, Pusey and Richards 2001). This paradox requires further exploration.

Similar considerations apply in policy and practice fields. In response to their ageing populations welfare systems throughout the world have for some time pursued a policy of community care, in which the aim is to enable older people to live for as long as possible in their environment of choice, usually their own homes (Davies 1995). As approximately 80% of any help they need is provided by the family (Walker 1995) it is hardly surprising that family care has become highly politicised (Chappell 1996). Consequently policy initiatives and services designed to support family carers have proliferated to the point where they have become one of the most 'striking developments' in the policy arena (Moriarty and Webb 2000).

---

[1] The CD Rom at the back of this report contains English, Swedish and French versions of COAT, the Swedish report on the development of COAT and a brief user guide/manual in Swedish.

In England, for example, the last decade has seen the introduction of several pieces of legislation including the Carers (Recognition and Services) Act (DoH 1995), the Carers and Disabled Children's Act (DoH 2002), and most recently the Carers (Equal Opportunities) Act (DoH 2004), all intended to give more formal recognition to the rights and circumstances of family carers. Realisation that the 1995 Act was having a limited effect prompted the Government to launch the Carers National Strategy (DoH 1999). This introduced a range of initiatives intended both to empower carers to take greater control of their lives, and to promote a change of culture so that carers are not only recognised but also respected and admired. However, notwithstanding a considerable investment of time and money, a recent major review of support for family carers in the UK concluded that the situation remains unsatisfactory to the extent that:

> *'The Government's aspirations for carers of older people are not being realised in practice for the majority of them. A clearly articulated and coordinated approach is needed from all concerned if this is to change.'*
>
> (Audit Commission 2004)

The UK is not alone in focusing attention on how formal services can best support and work in collaboration with family carers, and this issue has also received increasing government attention in other countries, including Sweden.

In the 1990s Sweden 're-discovered' the important role of the family in supporting older people. There are several explanations for this development. First was the realisation that the success of a policy of home-based community care was largely dependent on extensive family input. Second, as a result of economic recession, there was a growing interest in the informal care sector and its potential to substitute for costly formal service provision. Third, there was increasing research evidence pointing to the crucial role of families, their care burdens and their need for support. Finally, there has been the recent emergence of carer organisations that are now lobbying the public elder care system for increased recognition and support.

As a result of the above 'Carers' Issues' have been the subject of recent legislation. In 1998 there was an amendment to the Social Service Act stating that local authorities should support families and next of kin when caring for elderly, sick and dependent family members. The law sends a strong message to municipalities to provide services for carers. Subsequently, the ways in which formal services can best support and work in collaboration with family caregivers has received increasing government attention (Johansson 2001), with the need to further develop support systems for family carers being an integral part of the national plan for the care of older people (Board of Health and Welfare Sweden 2002a). In order to underpin and sustain the new legislation, and to stimulate service development, between 1999-2001 the Swedish Government allocated 300 million crowns to be distributed amongst municipalities in Sweden who provided services such as respite care for family carers (Family Carer 300 Initiative, Board of Health and Welfare Sweden 2002b).

An evaluation one year after the Family Carer 300 Initiative noted that the key benefits had been that family carers gained greater formal recognition of their role and need for support (Board of Health and Welfare Sweden 2003). However, although carers received improved help and support in a number of municipalities, it was also acknowledged that much needs to be done to improve the overall range and quality of services available. Indeed, in some cases carers rejected the help offered because the service was seen to be of insufficient quality, too expensive, and/or was not geared to the carers' routines and preferences. It also remains unclear as to how many eligible carers actually received the support they require, highlighting the need for a system of routinely monitoring the receipt and effectiveness of family care support services (National Board of Health and Welfare Sweden 2004).

Another study of current developments, carried out in 2005 by the National Board of Health and Welfare, suggests that there has been a slight decrease in the number of support programmes offered, but that core services such as respite programmes have now become an integral part of public services for elderly people and their families. However, problems with targeting and the quality of supportive services seem to prevail.

Overall, therefore, whilst recent legislation has spurred the development of carers' support with an increase in the number of programmes, there is still a need for greater innovation rather than simply 'more of the same' familiar old programmes. However, the growing 'carers movement' lobbying local and national governments to provide easily accessible, flexible and tailored support for carers will ensure that carers' issues remain high on the policy agenda.

Despite these recent developments legal rights to support for carers have yet to be instituted, but the Swedish Government is still seeking ways to ensure that services for carers can be improved. To this end, new state grants to stimulate developments in support for carers will be available between 2005-2007.

Clearly, therefore, despite considerable efforts and the best of intentions, recent policy initiatives intended to support family carers in both the UK and Sweden have only achieved qualified success. As noted above, services and support are often rejected if they are not seen as consistent with carers' own wishes and aspirations. What is required is a more effective way of aligning the support provided with the qualities desired by carers themselves. This will mean working more closely with family carers as partners and co-experts (Nolan et al 1996, 2003a).

Creating partnerships with family carers: the way forward?

The need for services to work in partnership with family carers is now widely promoted (DoH 1999, Audit Commission 2004), and an appropriate and sensitive assessment is seen as the key to success (Audit Commission 2004). But, as will be discussed in detail later, existing approaches to assessment often fail fully to involve and engage family carers, and as such represent a 'lost opportunity' to forge positive relationships between carers, practitioners and service systems (Audit Commission 2004). There are several potential explanations for this relating to the way in which family care is understood and the rationale underlying the type of support and help carers are offered.

A careful consideration of the academic, policy and practice literatures suggests that there is now a greater appreciation of the need for a change in emphasis if the present situation is to improve (see Nolan et al 2003a for a full account).

From the academic literature it is possible to identify a number of conceptual and methodological strengths and limitations in the way that support for family carers has evolved. Conceptually there can be no doubting the contribution made by the application of a stress/coping paradigm to the study of family care (Schulz and Williamson 1997, Zarit et al 1999, Fortinsky 2001). Indeed this has become a major focus for gerontological policy and practice (Zarit et al 1999). Consequently the vast majority of intervention studies have been directed towards stress reduction in an effort to relieve carer burden.

In marked contrast '*relatively little attention has been paid to the assessment of positive aspects of caregiving*' (Schulz and Williamson 1997), and there have been calls to look beyond '*the usual recitations of burdens experienced*' (Ory 2000) to capture more fully the multidimensional nature of family care and the way that it is experienced over time (Nolan et al 2003a). However, the outcomes used to indicate the 'success' or otherwise of intervention studies would not appear to reflect such a wider perspective. For example, a recent meta-analysis of 78 studies in the field of family care indicated that 57 used some form of burden measure, and 40 included depression as an outcome, whereas only 3 considered the uplifts or satisfactions of carers (Sörenson et al 2002).

The issue of choosing an appropriate 'outcome' is a critical one, and developing a more sensitive approach is the rationale underpinning COAT. Outcomes have both conceptual and methodological elements and provide a bridge between the theoretical and the empirical worlds. Yet efforts to address the relative failure of 30 years of research to demonstrate the effectiveness of current interventions have been primarily methodological, with the answer being seen to lie in the creation of ever more sophisticated outcome 'measures' that can be administered to more carefully selected samples, in more rigorously controlled trials to eliminate the perceived methodological weakness of current studies (Beck 2001, Cooke et al 2001, Pusey and Richards 2001).

More recently dissenting voices have emerged with it being suggested that part of the difficulty may lie in the fact that the majority of current 'measures' are grounded in the views of the researcher (Bond and Corner 2001) and, as a result, do not capture the outcomes that carers themselves see as important and relevant (Thompson and Briggs 2000). As Zarit and Leitsch (2001) argue, success depends in '*no small measure*' on whether the support offered and the outcomes used are consistent with carers' own expectations. They call for researchers to develop ways of engaging carers in a '*meaningful dialogue*'. This, as will become apparent, is one of the main aims of COAT.

To compound existing difficulties the outcome measures used in large-scale intervention studies are frequently insensitive, inappropriate, or unrelated to the intervention (Zarit and Leitsch 2001). In other words there is often a tenuous or non-existent theoretical link between the nature of the support provided and the type of outcomes used to measure or indicate its success. Frequently such outcomes are also several steps removed (or distal) from the intervention (Schulz 2001). Why, for example, might we expect that increasing a carer's knowledge of the signs and symptoms of dementia would have a significant impact on their overall health and well-being? Yet such assumptions are often made. Consequently, the type of outcome measures used are often too global or generalised (Zarit and Leitsch 2001). This raises several questions about expecting existing problems to be resolved simply by applying 'more of the same', albeit refined, techniques. What we need are different ways of identifying the outcomes that carers see as important, and of designing support that addresses them.

This will mean shifting attention away from the experiences of large groups of carers and focussing instead on individual circumstances. Large-scale surveys and trials rely primarily on aggregating data to produce composite or summary scores on standardised measures (Berg-Weger et al 2001, Croag et al 2001) that can be used to identify statistically significant differences, usually between large groups of carers who have received or not received support (Russell et al 1999). While these approaches may be useful when testing generalised models, they have severe limitations when it comes to designing support tailored to individual caring circumstances. This highlights the tensions between the world of (certain forms of) research and that of practice, where it is recognised that in order to be successful support for individual family carers has, amongst other things, to:

- take account of the unique constellation of issues within a particular family;
- have goals that are based on a 'particular configuration of conditions' at a 'specific' point in time;
- comprise a broad and comprehensive range of interventions;
- use multiple evaluative criteria.

(Aneshensel et al 1995)

Consequently, as Aneshensel et al (1995) assert, caring (and we would add support for carers) can only be fully understood in its specific context, a context of which too little account is taken in most existing studies.

In seeking a way forward Schulz et al (2002) set out to 'take stock' of the intervention literature in dementia care, and whilst their focus was specifically on dementia their conclusions apply equally elsewhere. They suggest that too much emphasis is currently placed on the pursuit of 'statistical significance' with too little attention being paid to 'clinical significance'. In introducing the concept of clinical significance they draw upon Kadzin's (1999) work where clinical significance *'generally refers to the practical value of the effects of an intervention, or the extent to which an intervention makes a* ***'real'*** *difference (original emphasis) in the everyday life of the individual'* (Schulz et al 2002, p590). Subsequently, Schulz et al (2002) identify four dimensions of clinical significance, these being:

- Symptomatology - the extent to which individuals return to normal functioning or experience a change in symptoms.
- Quality of life - the extent to which interventions broadly improve an individual's quality of life.
- Social significance - the extent to which interventions are important to society, as evidenced, for example, by their impact on service use, such as reducing admission to care.
- Social validity - the extent to which treatment goals, procedures and outcomes are acceptable, as assessed by the client or expert ratings of the interventions and their effects on participants' lives.

(Schulz et al 2002, p590)

On the face of it such arguments appear to have a great deal to offer in terms of reconciling several of the tensions apparent in current intervention studies. Unfortunately, in our opinion, the authors significantly limit the force of their conclusions by asserting that in order to be clinically significant results firstly have to be statistically significant, seemingly contradicting their earlier carefully rehearsed arguments. Moreover, they rely primarily on expert (as opposed to client) ratings when defining social validity, and also state that of the dimensions of clinical significance:

> *'Researchers and policy makers would likely agree that social validity is important but that it is probably not the most valued indicator of clinical significance.'*
>
> (Schulz et al 2002, p598)

It seems to us that within these few lines Schulz et al (2002) reveal the Achilles heel within their own position, and also powerfully illustrate two of the major barriers to developing more effective support services for carers. The first is the widespread failure to grasp the fact that social validity is the single most important criterion; for if the goals, procedures and outcomes of services are not acceptable to carers then, unless they are in the most dire of circumstances, they will reject the support offered. Secondly, the continued emphasis on the views of *'researchers and policy makers'* reflects a professionalised view of the world in which the *'terms of engagement'* remain substantially defined by academics and professionals (Humphries 2003). This manifestly fails to recognise carers as partners and co-experts (Nolan et al 2003a), a situation that reflects current practice, as a brief consideration of the policy and practice literature illustrates.

Recognising 'social validity'

As noted previously, support for carers has become one of the most 'striking' policy developments in recent years (Moriarty and Webb 2000), and yet despite this many existing services are not fully utilised by carers. Respite care provides a prime example. Some type of relief or break from the demands of caring is one of the most frequently requested forms of support (Briggs and Askham 1999), but not all the available places are filled (Moriarty 1999, Zarit and Leitsch 2001). There are a number of potential explanations for this but two of the most compelling are that carers either do not see services as relevant to their needs (Pickard 1999, Braithwaite 2000), or they do not consider that the service provides care of sufficient quality (Moriarty 1999, Pickard 1999, Whitehouse 1999). The recent evaluation of the Family Carer 300 initiative in Sweden, cited earlier, reinforces this conclusion (Board of Health and Welfare Sweden 2003), with carers rejecting services that were not of sufficient quality, or not consistent with their routines and preferences.

However, in order to reject a service, carers have to be offered one in the first place, and they frequently face several barriers before even reaching this point. Often carers simply do not know what support is available nor how to access it. In other words, they do not know how to get into the 'system'. Take, for example, obtaining an assessment of their needs. In England carers have a statutory right to such an assessment yet the majority are not aware of this (Audit Commission 2004).

Even if carers are able to access the 'system', the reaction they receive is often not welcoming. As Wuest (2000) suggests, carers' experiences of interacting with 'helping systems' largely determine whether or not they will seek further help. Assessment may be the first point of contact and therefore should provide the opportunity to engage family carers as 'real partners' (Audit Commission 2004). Yet all too often this is not the case. Firstly, assessments are not as widely promoted as they might be (Audit Commission 2004), thereby limiting access. Secondly, assessors frequently adopt a 'gate-keeping' role and see the process as a means of rationing existing resources rather than thinking creatively about a range of potential, and possibly unconventional, solutions to existing problems (Audit Commission 2004). As such assessment represents a lost opportunity to explore the issues that are of real concern to carers. Carers have a not unreasonable expectation that services and professionals will be 'connected' with their concerns (Wuest and Stern 2001), yet they are frequently disappointed. This has been summarised in the following way:

> *'Thus the caregivers not only had to deal with the demands and stresses related to the care of the ill person, they also had to battle the health care system and the professionals who worked within it. Rather than becoming allies and partners, the health professionals were seen as a barrier to what the caregivers considered to be necessary care and the best interventions for the cared-for person.'*
>
> (Jeon and Madjar 1998, p703)

To make matters worse, professionals' interactions with carers are not always positive, with the Audit Commission (2004) reporting that the attitudes of some care managers was *'surprising'* and that the subsequent *'anger and frustration'* of carers was worrying. They stress the need for services in general, and individual practitioners in particular, to be far more *'carer aware'*. Again it is hoped that COAT will help to address some of the above issues.

Even if carers are able to navigate their way through the 'system' and obtain services they still encounter problems. Once again respite care is a good exemplar. The service provided is often not sufficiently flexible or responsive and frequently does not fit in with carers' routines, nor is it necessarily provided at a time or in a form that best suits carers or the person they support (Moriarty 1999). Moreover, carers have concerns about poor quality of care and the lack of continuity of paid carers that further inhibits use, not only of respite care, but of a range of support services (Pickard 1999, Brereton and Nolan 2003).

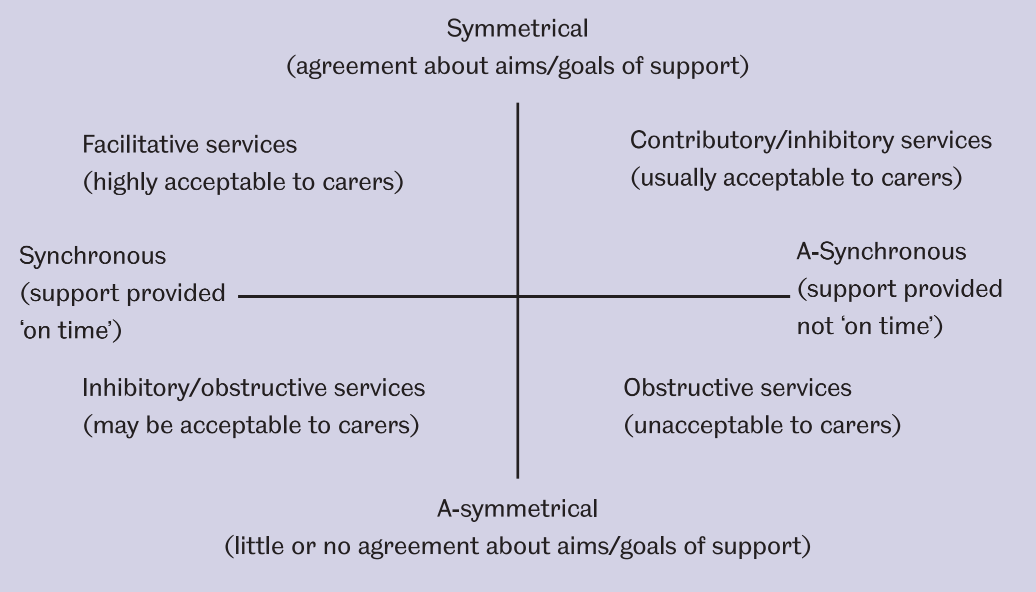
In terms of the quality of services Nolan et al (1996) argue that they can be thought of as forming a continuum ranging from facilitative through contributory, to inhibitory and finally obstructive. Facilitative services are those in which there are overt, planned and systematic attempts by service providers to complement carers' efforts and to provide support that is sensitive and responsive to the caregiving dynamic and the 'expert' knowledge held by carers. While some of these characteristics apply to contributory services, they arise largely by chance or good fortune rather than resulting from negotiation and agreement. Inhibitory services rarely achieve the attributes of facilitative support but are sometimes accepted out of necessity or desperation. Obstructive services are seen by carers to be at odds with their own goals and quality standards and are generally quickly rejected.

Nolan et al (2003a) have recently suggested that two other factors help to determine whether services are acceptable or not; these are the degree of symmetry and synchronicity that exists. Symmetry reflects the extent to which there is agreement between carer and service provider as to the intended goals and outcomes of the service, and when, where and by whom it will be provided. Synchronicity concerns the timing of support so that it is consistent with carers' needs at differing stages of their caring 'career' (Aneshensel et al 1995). So, for example, the support needs of family members or others who are just entering a caring role are likely to differ from those of carers who have been in their role for some time. Similarly, carers' needs will also change when decisions have to be made about looking for alternative caring arrangements (see Nolan et al 2003a for a detailed discussion).

The dimensions of 'symmetry' and 'synchronicity' are likely to be key determinants of social validity, and presenting them as an axis is useful in deciding how acceptable services are likely to be. This is illustrated in Figure 1.

As is suggested in Figure 1, Nolan et al (2003a) argue that when there is agreement about the intended goals and outcomes of services, and when support is delivered 'on time', then services are likely to be facilitative, and accepted readily. Conversely, when neither of these two criteria are met, then services are likely to be seen as obstructive and therefore rejected. It is suggested that achieving agreement about the goals of care is probably more critical than the timing of support, and such services are likely to be viewed more positively than when the reverse is true. Assessment is the main means by which agreement can be reached and therefore the way in which assessments are conducted is crucial.

Figure 1: The influence of symmetry (agreement) and synchronicity (timing) on service acceptability



(Adapted from Nolan et al 2003a, p286)

Some time ago Smale et al (1993) suggested that the assessment process, during which decisions about service allocations are usually made, often follows one of three models: the questioning model; the procedural model; or, the exchange model. In the questioning model the assessor is the 'expert' who asks a series of questions to which the carer or disabled person responds, with the appropriate service being determined largely on the basis of their answers. Here the power lies essentially with the individual assessor. The procedural approach is dominated by the expectations of the service agency, based on relatively fixed eligibility criteria which determine if a carer has a 'right' to services. These usually comprise objective criteria, such as the amount and type of help that the carer has to provide. Once again the balance of power does not lie with the carer/disabled person. In contrast the exchange model assumes that all parties have knowledge and expectations that will influence the type of service that is needed, and that an 'exchange' of views is essential.

Most assessment processes currently adopt a procedural or questioning approach, and Nolan et al (2003a) suggest that this usually results in services either being 'allocated' or 'imparted'. The 'allocation' of services is based mainly on considerations such as the amount or intensity of help and support that the family carer provides. Here eligibility for services is determined mainly by the objective circumstances of carers. This is typical of the currently dominant approach to the assessment of carers' needs in the UK, in which services are targeted primarily at carers providing 'regular and substantial' care, which is generally equated with more than 20 hours of care per week (Hirst 2001). Procedural models of assessment are likely to result in services being 'allocated', with the assessor adopting the role of 'gatekeeper' (Audit Commission 2004).

The 'imparting' model is underpinned by the belief that the service provider is in possession of information or other expertise that the carer or disabled person needs. Such as model implicitly or explicitly underpins several psycho-educational interventions targeted at family carers. However, for new carers and newly disabled people the 'imparting' model may be appropriate, as there is general consensus that all carers are likely to benefit from knowledge of the disease condition, the caregiving role, the resources available, and require some training in problem-solving and related skills (Schulz et al 2002). On the other hand carers also have 'expert' knowledge of various types and it is important that such information is considered fully when assessment takes place (Nolan et al 1996, 2003a). It is here that the exchange model is more likely to ensure that services are 'negotiated' and are agreed as the result of all parties sharing their expertise and knowledge. Facilitating such an exchange is one of the main purposes of COAT. These models are illustrated in Figure 2.

Figure 2: Models of assessment and their impact on services

Model of assessment	Role of practitioners/assessor	Services
Procedural – usually based on predetermined objective eligibility criteria	Gatekeeper	Allocated – little opportunity for innovation or flexibility
Questioning – with questions being determined largely by the assessor	Expert	Imparted – as from an expert to a novice
Exchange – based on the assumption that everyone has something to contribute	Co-expert/facilitator	Negotiated – between partners, more opportunity for agreement and innovation

(After Smale 1993) (After Nolan et al 2003a)

The goal of developing COAT was to provide a means of promoting an exchange between family carers and practitioners/assessors so that support can be negotiated, rather than allocated.

The conceptual and empirical basis for COAT

COAT builds on over 15 years of research into assessing carers' needs (see for example Nolan et al 1990, Nolan and Grant 1992, Nolan et al 1994, 1996, 1998, Nolan and Philp 1999, Nolan et al 2003a) and is underpinned by the 'carers as experts' model, that recognises carers and professionals as 'co-experts' each with differing but complementary forms of knowledge and expertise which, when considered together, provide a more complete picture of the caring situation (see Nolan et al 1996, 2003a for a fuller account). Previous empirical work using such an approach has indicated that when adopting it even experienced professionals, who may have known certain family carers for a number of years, gain new insights into their situation (see Nicholas 2001, 2003, Lundh and Nolan 2003). The 'carers as experts' model has also been used to explore carer-relevant outcomes in previous studies.

Underpinned by the 'carers as experts' model, and drawing on three detailed carer assessment tools, the Carers' Assessment of Difficulties Index (CADI), Carers' Assessment of Satisfactions Index (CASI) and the Carers' Assessment of Managing Index (CAMI) (see Nolan et al 1996, 1998) Nicholas (2001, 2003) undertook an action orientated study exploring the implementation of a new approach to carer assessment in order to promote an 'outcomes' focussed model of assessment and review. Consistent with the 'carers as experts' framework she argued that fundamental to any attempt to define or assess outcomes for carers was the need to *'understand the nature and complexities of caring and the relationships between unpaid carers and those who provide services to support them'*. Basic to her approach was the belief that 'success' has to be defined in terms of outcomes that are relevant to carers themselves and based on a partnership that gives due consideration to both carer and professional expertise. However, she also recognised that to be acceptable any approach has to be seen as reasonable by practitioners and also deliverable in terms of the resource and other constraints under which services operate. In other words, the outcomes agreed should reflect *'the purposes and concerns of carers, practitioners and managers'* (Nicholas 2003).

Using CADI, CASI and CAMI as *'tools to assist in the identification of desired outcomes as an integral part of carer assessment'* (Nicholas 2001), and following focus groups with carers and practitioners, Nicholas (2001, 2003) identified four broad domains of outcomes that were seen as important, especially from a carers' perspective. These were:

- Achieving a good quality of life for the cared-for person.
- Achieving a good quality of life for the carer.
- Recognition and support in the caring role.
- Service process outcomes – support that is consistent with carers' values, routines, expertise and so on.

These domains have been used to help inform the development of COAT.

Again drawing on the existing literature, and the results of her own work, Nicholas (2001, 2003) identified a number of key principles that should guide further work. These included:

- The definition and recording of outcomes should be carer-centred, specific and relevant to the individuals concerned.
- Reaching a common understanding of the intended outcomes requires a thorough and sensitive assessment.
- The carer should be actively engaged as an ‘expert’ in the process of identifying and reviewing outcomes.
- The evaluation of outcomes should begin with clarity about the goals intended.

These are all principles to which we subscribe and are implicit within the development of COAT. With the ‘carers as experts’ model, the desire to generate a way of negotiating outcomes that combines ‘carer’ and professional expertise at its heart, and drawing on items from existing carer assessment tools (CADI, CASI, CAMI, Nolan et al 1998) a pilot version of COAT was produced. This comprised 5 main components, 4 sets of questionnaires, and a series of action and evaluation plans for each of the questionnaires. The four questionnaires addressed the following areas:

Helping you to care – contained items concerning the knowledge, skills and support that carers might need to help them to care more effectively. Carers were asked to indicate if each item might be useful to them: very, quite, not. For example:

HELPING YOU TO CARE

Below is a list of the types of help and support that some carers have found useful. For each type of help please indicate how useful it would be to **you** by putting a tick (✔) in the box that applies:

To have more information about: My relative’s illness and treatment

☐ **This would be VERY useful to me**

☐ **This would be QUITE useful to me**

☐ **This would NOT be useful to me**

Making life better for you – contained items that might enhance a carers’ quality of life. Carers were asked to indicate if each item would potentially make life: a lot better, a little better, no better. For example:

MAKING LIFE BETTER FOR YOU

Below is a list of things that some carers have found makes life better for themselves. For each item in the list please indicate whether it would make life better for you by putting a tick (✔) in the box that applies:

FOR ME To have more private time for myself

☐ **This would make life a LOT better for me**

☐ **This would make life a LITTLE better for me**

☐ **This would NOT make life better for me**

Making life better for your relative – contained items that might make life better for the person they cared for. Carers were asked to respond on a 3-point scale: a lot better, a little better, no better. For example:

MAKING LIFE BETTER FOR YOUR RELATIVE

Below is a list of things that some carers have found makes life better for their relative. For each item in the list please indicate whether it would make life better for the person you care for by putting a tick (✔) in the box that applies:

FOR MY RELATIVE To have more contact with their family

☐ **This would make life a LOT better for my relative**

☐ **This would make life a LITTLE better for my relative**

☐ **This would NOT make life better for my relative**

Getting good quality help – contained a list of items about the characteristics of help and support with carers indicating, whether they thought these were: very important, quite important, not important. For example:

GETTING GOOD QUALITY HELP

It is important for carers that any help and support they get is of good quality. Below is a list of things that carers have said are important to them. For each item please indicate how important it is for **you** by putting a tick (✔) in the box that applies:

For those providing help to: Treat my relative with dignity and respect

☐ **This is VERY important to me**

☐ **This is QUITE important to me**

☐ **This is NOT important to me**

Although, as indicated above, the philosophy underpinning COAT and the varying dimensions of which it comprises drew on extensive previous work with family carers, the content and format were at this point seen as indicative and subject to extensive negotiation and change during the development phase, both with carers and practitioners (see later).

The need to create a better assessment process that engages carers in a *'meaningful dialogue'* (Zarit and Leitsch 2001) was clearly evident from both the research literature and recent policy and practice initiatives. As noted above, COAT is based not only on a consideration of such literature, but detailed prior theoretical and empirical work involving family carers. However, it was considered essential that COAT should be true to the 'exchange' model of working, and fully engage carers and practitioners in any further work. In order to achieve this it was decided to use the ÄldreVäst Sjuhärad model to develop and test COAT.

Developing COAT: the ÄldreVäst Sjuhärad model

The ÄldreVäst Sjuhärad (ÄVS) model is a user-focused approach to research and development adopted by ÄldreVäst Sjuhärad Research Centre based at the University College of Health Sciences, Borås, West Sweden. ÄldreVäst Sjuhärad was established in 1999 as a centre of excellence for research, development and education in the care of older people, with the support of the Department of Social Affairs for Sweden, six municipalities in West Sweden (Bollebygd, Borås, Mark, Svenljunga, Tranemo and Ulricehamn), the County Council of West Sweden, and the University College of Boräs. Today, the municipality of Herrljunga is also a partner. Its mission is to enhance the quality of life of older people and their family carers by working in partnership with them and by supporting the stakeholders of ÄVS in the provision of high quality care. This is achieved in a number of ways. First, by promoting co-operation and partnerships in shaping the direction and quality of health and social care services. Second, by enabling the sharing of perspectives and experiences between older people and their families, professionals, voluntary organisations, health and social care providers, politicians and researchers. Third, by increasing the opportunities for professionals to work with older people and for older people and their families themselves to initiate, participate in and evaluate new research based interventions and service developments. Finally, by raising the awareness and competence of care professionals to ensure the future quality of health and social care services through their involvement in programmes of research, development and education (Magnusson et al 2001, Nolan et al 2003b).

From the outset an important consideration for the ÄVS Centre was how its work could be evaluated in a way that reflected the views and concerns of all the stakeholder groups, rather than being dominated by the interests of researchers, politicians and service providers. This required an approach consistent with the principles upon which the Centre is based.

Consequently users are closely involved in the research and development work of ÄVS, with a broad definition of users being adopted. Therefore, whilst older people and their families are the main target group, anyone who has a stake and/or interest in care of older people and their families, namely health and social care providers, representatives of voluntary and pensionist organisations, politicians and researchers, are also viewed as important stakeholders. To meet the needs of such varied groups the ÄVS model comprises the following key elements:

- Listening first and foremost to the voices of older people and their families. This means gaining their views and suggestions for developing and improving services.
- Hearing the voices of service providers and managers including voluntary organizations for older people and their families.
- Focusing on the quality of the entire research and development process and not simply the end product or service.
- Initiating change and action whilst at the same time contributing to knowledge building.
- Bringing together research and theory building with participation and action.

(Magnusson et al 2001)

Thus the ÄVS Centre aims both to develop and improve services for older people and their families in Sjuhärad, whilst at the same time providing insights into the relationships between service providers, older people and their families, to help to inform developments in a wider geographical context. Consequently, a key aim of ÄVS is to bridge the gap that often exists between theory and practice by generating new knowledge that is presented in a way that is as widely understood as possible.

In order to make judgments about whether or not the Centre is doing 'good work' (Bradbury and Reason 2001) it has adapted the authenticity criteria originally proposed by Guba and Lincoln (1989) to make them more readily understood by all the ÄVS stakeholders (see Nolan et al 2003b for a fuller account).

Four sets of questions are therefore asked of all the work that the Centre undertakes. Namely, does it:

- Promote **EQUAL ACCESS** for all - Are the voices of all the major interest groups heard? Does everyone have their opinions listened to and valued?

- **ENHANCE AWARENESS** of self and others - Does the study help participants better to understand their own situation and those of others in the same group? Does the study help participants to better understand the position of the other interest groups that are involved?

- **ENCOURAGE ACTION** - Does the study stimulate or identify areas for change?

- **ENABLE ACTION** - Does the study actually facilitate, enable or empower change?

(Nolan et al 2003b)

Addressing such questions means that all the different users involved in a given project need the opportunity to come together, discuss issues with one another and put forward their views in order to 'construct' a shared understanding(s) of a range of issues and situations that affect the care and circumstances of older people. This does not mean that all the groups necessarily agree, but as a result of sharing their views there is an enhanced awareness of their own situation, as well as a deeper understanding of the views and the situation of other stakeholder groups present. This may act as a stimulus for identifying areas for further education and training for staff working with older people, or to develop support services and/or promote further research (Magnusson et al 2004).

Finally, over time, as a result of engaging with a range of users in projects and seminars, real change may occur at individual, group, or organisational levels, with the overall aim being to improve the quality of life and quality of care of older people and their families.

The ÄVS Model and the research and development process

Within ÄVS it is considered important to address issues of *Equal Access, Enhanced Awareness*, and *Encouraging* or *Enabling Action* at all stages of the research and development cycle. To assist this a matrix has been developed that can be used as a basis for reflection at several points in the research process (Nolan et al 2003b). This is illustrated below:

		Planning	**Process**	**Product**
Equal Access				
Enhanced Awareness	**- Self** **- Others**			
Encourage Action				
Enable Action				

Clearly, it is not feasible or desirable to tick all the boxes for every project, as this depends on its particular aims. Therefore, the overall goals of a project, and whether or not change is expected, is discussed and agreed at the outset by key stakeholder groups involved (Nolan et al 2003b).

However, ensuring *Equal Access* is a key consideration at all stages. At the initial planning phase user involvement is actively sought so that the main stakeholder groups can play a key role in determining the nature and direction of projects and the type of activities that take place. Such discussions occur at several levels, not only with respect to the individual research and development projects that are undertaken and supported by ÄVS, but also by the User Advisory Board that informs the overall management and direction of the Centre (Magnusson et al 2004).

User involvement is also integral to the conduct of each project (the process stage) and ranges from regularly seeking the views and experiences of the users, to users playing a major role in undertaking the work itself. Finally, users are also engaged at the final stage of a project when it is written up and disseminated (the product stage) to ensure that the results are accessible both physically and intellectually to as many people as possible. To assist in this ÄVS publishes a regular newsletter, which gives a clear and concise summary of project findings and is widely distributed across West Sweden. A series of reports are also produced and advertised within the newsletter, and are available free of charge on request. In addition ÄVS members actively respond to the professional and academic community by ensuring that accounts of research and development work and research findings are published nationally and internationally in a range of professional and academic peer reviewed journals. In this way ÄVS hopes to actively contribute to knowledge building, to stimulating change, and to facilitating critical dialogue between older people and their families, practitioners, researchers and policy makers in the field of ageing (Magnusson et al 2004).

Developing COAT further: applying the ÄldreVäst Sjuhärad model

As noted earlier, COAT is a collaborative project between the ÄVS Research Centre at the University College of Borås and the School of Nursing and Midwifery at the University of Sheffield, with financial and other support being provided by the ÄVS Management Board, the National Board of Health and Welfare for Sweden, and the Community, Ageing and Rehabilitation Department at the School of Nursing and Midwifery, University of Sheffield. The COAT project comprised three main phases: the initial conceptual work on COAT described above; a consultation phase; and a trial implementation phase. Due to the far greater financial resources available in the Swedish setting it was decided that whilst both ÄVS and the School of Nursing would be involved in the conceptual and consultation phases, the trial implementation of the system would be confined to Sweden. The study therefore comprised two main empirical elements.

Phase One - The consultation phase: The intention here was to consult family carers and practitioners to seek their views on:

- The appropriateness of the overall approach and philosophy underpinning COAT.
- The content and format of the draft questionnaires, including their comprehensiveness and whether they were understandable, easy to complete and provided the required information.
- The 'conceptual' relevance of the items. As the original items had been developed in English and translated into Swedish it was considered very important to determine if they were seen as appropriate in a Swedish context. However, this was considered highly likely as CADI, CASI and CAMI have all been translated into Swedish and used in several studies (Lundh 1999, 2001, Lundh and Nolan 2001, 2003).
- The best way of using COAT. For example, was it considered better to send out the questionnaires in advance so that the carer had the opportunity to read them beforehand, or was it preferable for the assessor to bring COAT with them on the day of the assessment?
- The content and format of a draft 'user guide' that might be sent to the carer in advance so that they knew what to expect of the assessment process.

Phase Two – The trial implementation: The goal here was to provide an opportunity to try out the use of COAT in practice. At this early stage in its development it was considered inappropriate to use COAT to conduct 'real life' assessments. Therefore a number of carers who were already in contact with services were identified and asked if they would be willing to take part in a 'trial' assessment in order to provide their views on the process and how it might be improved.

Consulting with carers and practitioners

For the first phase of the project two differing means of engaging with carers and practitioners were used. In Sweden, a series of face-to-face focus groups were organised, one for carers and one for practitioners, with the carer group meeting for three half days and the professional group meeting twice for two full days. Two group facilitators were available at the focus group discussions, one leading the discussion and the other taking notes and ensuring that the views of all the participants were heard. With the participants' permission, the discussions were tape-recorded and transcribed. In addition the opinions of carers and practitioners attending two carer conferences were obtained during round table discussions.

In Sheffield email was used as a medium to contact working carers at the University of Sheffield. Prior contact with these individuals had been established during another project about carers' needs and those taking part were approached again to see if they would be willing to contribute to the present project. Thirteen agreed to do so and were forwarded copies of the documentation with a set of questions to respond to. A differing means of recruiting carers was used in Sweden.

Three municipalities in West Sweden were chosen due to their well-established family care support services and the existence of active carer organisations. These were Mark, Borås and Varberg. In each municipality one dementia organisation and one family carer organisation was approached. Initially the chairperson of the six organisations was contacted and assisted in identifying two volunteer members to participate in the three focus group discussions. To gain as mixed a group as possible, one person of each gender, one younger and one older person, and those with differing relations to the person they cared for, or had previously cared for (eg husband/wife or son/daughter) were identified.

The initial reaction of the chairperson and the majority of carers was very positive. After being fully informed about the project aims a final sample of twelve people, nine women and three men participated in the development process. Their ages ranged from 34-81 and there was a mix of spouses caring for partners and children caring for parents. Their caregiving experience ranged from 1-12 years and 7 members were no longer caring for their relative. These individuals were invited to the first focus group, which took place in October 2003. Respite care was offered to those carers who needed it, and all expenses were met.

Practitioners participated in Sweden only and were recruited by Åke Fagerberg, officer of the Swedish Municipality Board for Family Care Support and family carer advisor in Varberg, who has an extensive range of contacts, hosting a network with representatives from each area of the country. He also frequently visits carer networks throughout Sweden.

Staff participants were mostly chosen on the basis of personal experience and by recommendation. The aim was to have an experienced and varied group comprising different disciplines and positions, with a range of knowledge and skills relevant to family care. Another criterion was to generate as geographically diverse a sample as possible within the limits of the project's travel budget. A group of 12 participants (9 women and 3 men) with a mean age of 45 years from different occupations and various parts of the country were recruited. Most had extensive experience as officers in charge, or as municipality care staff.

The meetings of the carer and professional focus groups were held separately between October 2003 and February 2004. Two carer focus groups were held prior to the first professional focus group and the third carer focus group was held prior to the second professional focus group. In this way the views and experiences of the carers were elicited first. Between focus group meetings the project team met to discuss the results, to make necessary changes to COAT, and to forward the revised documentation for consideration at the next focus group. Where there was a discrepancy between carer and professional comments, carer comments took precedence in keeping with the user focused design of COAT. Due to their caring responsibilities, or ill health for themselves or the person cared for, some carers were unable to attend all of the groups, but these individuals were sent copies of COAT for comment.

In addition to the above the project team attended two conferences on carer support during the Autumn of 2003. On both occasions the initial version of COAT was shared during round table discussions attended by family carers, representatives from voluntary organisations and pensionist organisations, politicians and staff working in municipalities, with about 15 people being present at each event. The comments and suggestions received were combined with those from the first round of focus groups and these informed the modifications that were made.

Results

Carers' perceptions

The focus groups generated lively debate and, together with the email exchange, several useful suggestions for minor modifications to COAT were made.

Carers in both Sweden and the UK were very positive about the overall content of COAT and generally found the approach to be easy to understand, with the items being of relevance to their situation. In Sweden, the COAT items acted as natural prompts for carers to expand upon their own caring situation thereby validating them, as highlighted by a female dementia caregiver:

> *I think they're all important things. To be able to get some time for myself for instance. When my husband goes away to the day centre, then I think to myself, what shall I do today? That's very important when you can't have a lot of communication. It gets very boring. To have a social life is also very important.*

However, several issues arose that highlighted differences between caring situations and the need to try and ensure clarity of meaning. Of note were:

- Differences in opinion between people caring for a person with dementia and those caring for a person with physical disabilities as to the relevance to their situation of some of the items. For example, dementia caregivers considered that several items relating to activities and communication with the person they cared for were less irrelevant, whilst this was not the case for other carers.

- Differences in opinion between spouse carers and child carers as to the relevance of some items for their situation. For example, spouse carers said that they did not want to burden their children and requested the item relating to *'getting more help from my family'* be removed. In contrast, several child carers considered that this item was highly relevant as they felt they did not always get the help they needed from their siblings.

This is captured in the exchange below:

> *I'd like to delete question 14 – 'to get more help from my family'. We all have a generation after us, but they are busy in their own way. You cannot expect them to help.* Husband carer
>
> *No, you cannot burden your children.* Wife carer
>
> *Yes, that's how it is for you. But for me, my mum is elderly and I have siblings and I feel that they can also help and take some responsibility.* Son carer

Such differences are not surprising, and the identification of both common and unique aspects of caring would be expected in a diverse group of carers. Moreover, as COAT is intended to be used across a range of caring situations, not all items will be relevant to all carers.

This is consistent with the findings of Nicholas (2001) who concluded that not all outcomes will be equally important to all carers. Rather a comprehensive individualised assessment should allow the relative priorities for each carer to become clear. In addition to the above differences, other areas requiring attention included:

- Areas of potential overlap and omission were identified, as was the need to clarify the use of certain terms and phrases. Changes to COAT were made to reflect these, either by adding or deleting items, or rephrasing them as appropriate. For example, it was considered important to add items addressing the needs of working carers. Furthermore, as well as needing knowledge about the types of help and support available, carers wanted to know **HOW** to access existing services.

- The importance of there being sufficient time to conduct the assessment was stressed, as was the need for subsequent action so that something actually happened as a consequence. This concern was voiced most strongly by carers in the UK, where previous experience indicated that action did not always follow assessment.

- Consideration was given as to whether or not it would be advantageous for the carer to receive the documentation in advance of the assessment.

Both pros and cons were identified as follows:

Pros

- The carer can give prior thought to the issues and identify questions and areas that need particular attention.
- There is more time to reflect on important issues.

Cons

- The questions on COAT might be misunderstood by carers.
- It is better to be able to discuss the issues with the assessor.
- Older carers in particular might be worried if the documents were sent in advance.

No overall agreement was reached but generally younger carers were more positive about COAT being sent in advance of the assessment. Once again this is consistent with the field trials conducted by Nicholas (2001), who noted that some carers preferred to complete their assessment proforma in advance, whilst others benefited more from talking it through with the assessor. The latter was more time consuming but generally produced a more in-depth understanding.

- Comments were also made about the ‘user guide’, and whilst this was considered to be a good idea it was thought to be too long and the language rather academic, again primarily for older carers. However, this was not generally seen as a problem by those carers present.

- Overall each of the four questionnaires that COAT comprises were seen as helpful, but space for further comment was recommended by some. Carers saw the items about getting good quality help as being particularly important.

Staff focus groups

It was apparent that those attending the staff focus groups had given careful consideration to COAT and its accompanying documents prior to attending, and most had reflected upon both the content of COAT and the implications of its use. The overall tone of the meetings was very positive and generally the questions and the format were seen as both important and relevant. Over the course of the two full day meetings the group provided several very valuable insights. Amongst these were:

- Based on their professional experience they commented on the conceptual equivalence of some of the items, and whether the translation from English to Swedish had fully captured the meaning in everyday Swedish. A number of changes were made on the basis of this. Interestingly the Swedish word for assessment was thought to convey the wrong impression, implying a fairly formal and official procedure. By coincidence on-going work at Sheffield also suggested that carers themselves often misinterpret the word assessment, taking it to mean a judgement of their ability to provide care rather than a consideration of their needs. Following discussions within the project team it was therefore decided to change the meaning of the A in the acronym COAT from the original 'assessment' to 'agreement'. This not only eliminated potential confusion about the meaning of assessment but was also felt to be more in-keeping with the principles of 'exchange' and 'negotiation' that underpin the COAT philosophy.

- As with the carer focus groups, some areas of potential overlap were identified, and a small number of items were thought to contain two questions. These were modified accordingly.

- It was suggested that some of the questions might be reordered so that more positive items appeared first, thereby setting the 'tone' for the remainder of the exchange.

- Again, as with the carer focus groups, it was considered important to have items explicitly addressing the needs of employed carers.

- Two questions in particular generated extensive debate within the practitioner focus groups. The first concerned the item addressing the importance of the cared-for person feeling 'clean and comfortable'. This was seen by some as potentially insulting. However, this was not raised as a concern by the carers, and several large-scale surveys undertaken in a number of countries have identified this item as being important to carers. It was therefore decided to retain it. The second area of contention was that concerning 'value for money' in services. Members of the group did not think that this was appropriate in a Swedish context. However, the carer focus groups had identified this as an important issue and therefore this item was also retained.

As well as providing very useful feedback on the content of COAT participants drew on their experience to reflect on the practical issues that using COAT might raise. These are summarised in Table 1.

Table 1: Practical issues in using COAT

The risk of COAT identifying needs that could not be addressed and/or were not the responsibility of the municipalities. It was considered that this should be made clear from the outset so that carers did not have unrealistic expectations. However, it was felt that the identification of unmet needs could be used to heighten awareness of carers' issues amongst politicians. This concern was also raised by practitioners taking part in Nicholas' (2001) study, but was not seen as problematic by the carers involved in our study.
The need to ensure that there was sufficient time to complete COAT without undue haste. This had also been stressed by carers. It was considered that more than one visit might be needed, again something noted by Nicholas (2001).
A system of prioritising the needs that carers identified in order to reflect those seen as most important and useful. It was felt that COAT could assist in this.
Privacy and confidentiality were raised as important issues if COAT was to be of maximum use, especially if voluntary staff conducted the assessment.
Continuity of relationship between carer and assessor was seen as essential if trust were to be established.
The importance of providing carers with sufficient high quality information in order that they could make informed judgements was stressed.
Those conducting the assessment needed a good working knowledge of what services were available/possible and also the necessary authority to act as a result of the issues that COAT raised.
Better cooperation between the municipality and the primary health care sector was seen as essential.
Flexibility and innovation in service responses were identified as an issue.
Comments were also received on the user guide and the action/evaluation forms. Consistent with the views of carers it was felt that the user guide could be made more user friendly and accessible, possibly by using some illustrations and bold text, and breaking the guide up into sections. It was considered that an expanded version of the user guide would also be helpful to assessors, something recommended by Nicholas (2001).
The importance of regular follow-up and review was highlighted.

In conclusion both the carers and practitioners endorsed the principles upon which COAT is based and considered that the majority of the items were relevant. Generally the format was also felt to be appropriate. As a result of the suggestions received appropriate amendments to COAT and the supporting documentation were made prior to the trial implementation.

Trial implementation of COAT

The second phase of the initial development of COAT was to consider its feasibility for use in a practice context. In order to do this it was decided to identify 6 assessors, working in 3 municipalities, who would each conduct 'trial' assessments with 5 carers whom they already knew. The time available for this was limited, only 2 months in total, and as this was an addition to existing workload for the assessors, it was recognised that this would provide only a preliminary indication of the usability of COAT and that more extensive work with 'real life' assessments would be required at a later date. Nevertheless, this phase was considered an important part of in the initial development of COAT.

Three municipalities were chosen to pilot the COAT instrument. These were Gothenburg, Ulricehamn and Härnosand, as these municipalities already had well-established family care support services, and representatives from the municipalities had expressed an interest in participating. Importantly these municipalities reflected differing geographical locations with varying populations. Municipalities were asked to select two members of staff to take part in the feasibility testing. The test assessors consisted of seven persons in total, as Gothenburg asked to send an additional member of staff. There were six females and one male and all had extensive experience in nursing/social care and all had nursing/social care qualifications. Five test assessors actively worked with family carer support in their current role.

Prior to the feasibility testing, those staff involved met for a day's training and discussion about COAT. Training took place at the University College of Borås. COAT, and its philosophy was introduced and practical issues such as who was going to carry out the assessment and which carers would be involved were discussed. This was followed by an opportunity to role-play the assessment process in order to clarify any points of uncertainty at this stage.

The remainder of the feasibility study was then agreed as follows. After completion of the 'trial' assessment 'assessors' would send carers a copy of the completed and agreed action plan and ask if their details could be sent to the project team. Later a member of the research team would telephone the carers to explore their experiences. Assessors would also attend a focus group to share their views. In the event those assessors from Gothenburg and Ulricehamn attended the focus group and a videoconference was held with those from Härnosand.

Each person agreed to carry out five assessments in the next month. It was suggested that only carers who were not currently experiencing too much stress, and who could provide feedback on the process, should be asked to participate. Assessors would seek their consent to forward their details to the research team so that they could be contacted about taking part in a telephone interview. Agreement was also reached about how the carers should be approached, and a letter rather than the user guide was felt to be more appropriate at this point given that it was a 'trial' assessment.

Results

The 35 carers that took part in the trial COAT assessment consisted of 26 women and 9 men between 50 and 83 years of age. The majority perceived their health to be good or quite good, whilst five considered their health was poor. All except five were retired. The majority were spouse carers and lived together with their partner. The remainder were children, a sibling and a niece. Most had been caring for at least five years, and many of the cared for persons had heavy personal care needs. Several carers received support in the form of carer support groups. A number had a significant amount of home help services. In contrast, seven persons had no statutory help whatsoever. Approximately half had no other informal sources of help from friends, family or voluntary organisations, whilst the remainder had help from their adult children.

Telephone interviews were held with 31 of the 35 carers who had participated in the trial COAT assessment, with the assessors mailing or calling the interviewer with the name and contact details of those carers who had agreed to be interviewed. Four carers declined to take part in the follow up interview due to the stressful nature of their caring situation and/or for personal reasons.

Due to some initial delay with forwarding copies of the COAT action plans, a number of carers were not interviewed until 2-5 weeks after the assessment. Consequently, some had difficulty in remembering what had occurred, and this time delay may explain the limited recall of a number of carers. The interviews lasted about half an hour and, with the participant's permission, were tape-recorded and transcribed verbatim. Subsequently, comprehensive summaries of the interviews containing quotes from the original transcripts were entered into the NUD*IST qualitative data analysis programme.

As a result of the analysis three groups of carers were identified. The first comprised about a quarter of those interviewed. This group was very positive about the experience and provided several very valuable insights. These individuals were not unduly stressed and they were able to actively participate in the telephone interview. Some had experience of taking part in carer support groups, and others were active in voluntary organisations so that they were used to talking about their problems/issues. These carers were highly satisfied with COAT and felt that it enabled them to reflect on their own caring situation with someone else. Although not all the items were seen as relevant by all carers, they nevertheless thought their experience of COAT was positive. A number gave thoughtful and constructive advice and suggestions about several items.

About half of those interviewed had difficulties recalling the detail of the COAT assessment and could provide relatively fewer insights. Such individuals had been caring for a longer period of time and were generally more stressed. As a result, they were more passive during the interview and gave less detailed answers and critical comments about the questionnaire. Their conversations tended to focus on their current situation, rather than their reactions to COAT. However, some did provide constructively critical feedback. The third group of just under a quarter of the carers were currently very stressed as they had been caring for a considerable period of time and their relative had significant care needs. With hindsight they probably should not have been included in the sample.

Despite this variation all of the carers had enjoyed the experience of having an assessor come to their home and spend time with them. However, for several of the middle group, and the majority of the latter group, the relevance of the process to their needs was questioned. Aside from the assessor having time with them, they felt that they got very little else out of the assessment because of the demanding nature of their caring situation. A number felt that they should have been asked such questions much earlier in their caring career. They also commented that they should have received more help and support from the municipality earlier.

Of those who were able to reflect on the experience more fully a number indicated that they felt that COAT allowed them to address their concerns in an open and frank manner with the assessor. The attitude and approach of the assessor was crucial in these instances:

> *I could say what I thought. Nobody talked over my head either. I was involved and that was good.*

> *I thought it all went well because* [the assessor] *is calm and tells me things in an objective way. There were no difficulties talking to her in any way. It felt good and I told her so too.*

> *It's very good [this way of working] and as far as I understand this is new. Everything that opens up new possibilities for developing better care is very very good. This then is a step in that direction.*

Some carers compared their experience with COAT to less positive experiences of previous assessments in which they had not had the opportunity to express their views:

> *She* [the previous assessor] *treated me like I was rather stupid. I know what can make our day-to-day life better... it doesn't help if someone else comes and says 'In my opinion what you need is so and so'... surely it's to make things easier for me?*

Several others also commented that COAT enabled them to reflect on their own situation and to raise issues that they might otherwise have been reluctant to, or that they had not previously thought about:

> *I thought all these questions were good in the way that there were many things that I hadn't thought about before. When you see it on paper you think that that wouldn't be such a bad idea and that was good. That you need more information. That's for sure. And this issue about needing help with the emotional side of things and a lot about how to behave in different situations. Sometimes you need to use small white lies and things like that. Everything to make the one who is poorly feel well. I can understand that these questions have come forward from many interviews* [with carers].

Others suggested that COAT had been useful in structuring discussion but that not all of the questions were relevant. Numerous carers indicated that the section on ‘getting good quality help’ was so obvious as not to be required:

> *I thought it worked out well because we went through it question by question. She asked me and I told her my thoughts. We sat there together and read* [the questions] *and it worked out very well. But I thought that one of the forms was unnecessary. Everything there was obvious.*

However, it is important to remember that most of the carers participating in this phase were already service users and issues seen as obvious to them may not be so to carers new to services. Indeed the carers in the initial focus groups felt that the items about quality services were very important.

Responses to the action plan element were mixed, with some carers having little recollection of it, whereas others valued the fact that it highlighted their needs:

> *I don’t remember what was on the paper* [support plan]*. I can’t remember so much.*

> *Well, I guess I could say that it was a good summary.*

> *It was good because we came to the things that were important just for me. Those areas where you can get information and support and help and things like that.*

Some, particularly amongst the very stressed carers, found it difficult to decide between the options available to them; others would have valued space for additional comment:

> *I don’t really remember. I thought it was an awful lot. Sometimes it was very difficult. It should be Very useful for me, it should be Quite useful. It should Not be useful. There were so many choices and no in between. I don’t know what I answered.*

> *The only thing I thought about was that there shouldn’t have been fixed answers. Those alternatives. There should’ve been an empty box where you could write your opinions. Because they didn’t always fit and you couldn’t tick the right box because of that.*

As with the carer focus groups the possibility of reducing the number of questions by eliminating perceived overlap was raised, but few could provide specific examples of where they thought that this should happen. The grouping together of like questions, for example, those relating to information needs, was suggested as helpful in this regard. Similarly, some thought that the action plan was not needed but those that could remember it, valued it. One useful suggestion was the addition of a named individual responsible for ensuring that the plan was implemented.

Assessors’ reflections on the COAT assessment process

Each assessor had all carried out a minimum of 5 ‘trial’ assessments and had differing experiences, partly because some had engaged carers with whom they had already been in contact, whereas others had involved carers new to them. Both positive aspects and areas for improvement emerged.

Positive aspects

All assessors agreed that COAT worked well in promoting a personal and detailed discussion about individual caring situations. Furthermore, even though some assessors knew the carers beforehand, new insights nevertheless emerged as a result of the way in which the questions were asked and the amount of time that was set aside for the assessment. The benefits of carers being able to talk to someone was emphasised, and several assessors considered that COAT provided a comprehensive picture from the viewpoint of carers themselves.

> *Well the good discussion that came out of it. There was a good talk, an in-depth discussion and you got a broader view of the person. Even though you knew the carer from before there was more. While going through these questions they recounted many personal experiences around many of the questions.*
>
> *I came there* [to their home] *as a municipality officer. But I didn't feel that they looked on me like that. Instead, they talked widely and in depth about how they experienced other contacts with the municipality and the primary health care. So the contact was very positive I think. A very good discussion.*
>
> *I feel I got some very good information and I feel we can help them further with these issues. You can't do so much when you meet at a carer's group once a month or have a couple of phone calls. But here you could get to know them very well and from many aspects due to the questions. So to me it was very interesting getting to know them like that.*

The questions were seen as highly relevant, enabling carers to talk openly about their situation. Some experienced carers found it exciting to think about their own quality of life; they had not previously done this. Several assessors mentioned that the questions also worked as triggers, making carers aware of their situation, with this being therapeutic in its own right.

> *I think it works like an alarm clock going through all these questions. The last carer I interviewed cried all through the interview as she realised how much she has done and how much she has had to give up. So this is also therapeutic.*

Such insights sometimes resulted in carers asking new questions about their situation. Consequently, the assessment not only gave the assessor a better awareness of the carer's situation, but also provided an opportunity to give information that the carer specifically required. One assessor recounted an assessment with a new carer, and told of the multiple benefits that ensued. This provides a better indication of the likely impact of COAT when it is used at an early stage:

> *I had an opportunity to do this* [assessment] *with a man that was new to us* [as a carer]. *Then it was much more interesting and enjoyable to see what kind of support we could offer. It was totally different. He's called several times afterwards and talked. He thought it was very good since he could paint his picture about his situation and what he wanted*

> *us to know more about. It took only one day and then he called for more information because he'd ticked that box. The solution was a carer's group and he could join right away. He liked that because he'd ticked that too. So it was kind of a different situation and I felt delighted to be able to do something. So what we agreed together from the instrument became real.*

Several assessors also commented that they considered there was a good 'fit' between the questionnaire and the action plan, as identifying issues and transferring responses to the action plan made needs clearer and thereby easier to agree upon.

> *I think this support plan is very good. To be able to merge several different questions felt good. It felt more achievable because otherwise it becomes so terribly huge. While merging them like this it became possible to grasp.*

Areas for improvement

COAT was considered too detailed by some and a few carers were fatigued by the end of the assessment. Several assessors found that it took a great deal of time to go through all the questions. Moreover, as some of the questions were thought to overlap there was scope to reduce the number.

> *They were exhausted because there was so much material. And yet they were prepared for it to take two hours, but it was too much. They couldn't manage the last bit and asked, 'are there more questions?' And I could feel the concentration wasn't the same.*

Some of the questions did not apply to all carers, and this caused confusion about the most appropriate response. The addition of a 'not relevant' or 'not applicable' column was seen as one solution to this:

> *I miss that and we discussed it - another column for 'Not applicable' or 'Not current'. I mean this question isn't relevant for my caring situation. There should have been an extra column.*

> *I saw they had difficulties thinking about the different alternatives to the questions. Very, Quite and Not valuable. It was confusing for many of them. And sometimes I felt they had difficulties understanding. That they interpreted the meaning of the question in different ways.*

As with the carers, some assessors thought that the questions concerning 'getting good quality help' were rather too obvious and queried if they were needed. Overall it was felt that these needed to be included but might not be relevant to every situation.

Specific suggestions emerging from the trial assessments included:

- It was advantageous to send the questionnaire out in advance to give the carers an opportunity to prepare for the assessment and to get the most out of it.
- It would be preferable if only a few individuals in each municipality carry out the assessment, since it requires preparation and good knowledge about the municipality and the services available.
- The assessment could be tailored to each carer's individual circumstance depending on which items were seen as the most relevant.

Suggestions for changes to the COAT format included:

- add an extra column for 'not applicable/not current';
- make room for additional comments beside each item;
- reduce the number of overlapping questions;
- add a column on the support plan indicating who was responsible for service delivery;
- conduct the assessment over more than one visit;
- start with a short session to get to know the carer, and save the full assessment for a subsequent visit;
- use specific examples to help train assessors in the use of COAT.

In addition to the focus group/videoconference discussions the assessors had kept field notes and a review of the completed action plan was also undertaken. Not surprisingly the reflections in the field notes mirrored those emerging from the focus groups. The issue of allowing sufficient time and of ensuring that the carer did not become too tired were raised, as was the potential for the cared-for person to disturb the process. With regard to this latter point Nicholas (2001) found that some carers wanted the cared-for person present, whereas others did not, highlighting the need for a flexible and individualised approach.

From an analysis of the completed COAT questionnaires it emerged that a number of carers had found the section on 'getting good quality help' to be rather obvious. Moreover, it seems that many of the assessors had not recorded the carers' responses by 'ticking' the box but rather by writing comments in the margins. This reinforced the need for additional space for comments, possibly under each of the questions/items, or if these were grouped, under a linked set of items.

A number of questions had not been answered but rather a question mark had been placed next to them, suggesting some uncertainty as to their meaning. These questions were reviewed and changed.

Amending COAT following the consultation and trial implementation

As a result of the user consultation and the trial implementation further changes were made to COAT. These were to:

- add an extra column for ‘not applicable/current’;
- add space for further written comment;
- shorten the questionnaire to reduce overlapping questions and group similar questions under broader ‘themes’;
- indicate who was responsible for providing the agreed support in the action plan.

The amended version of COAT therefore comprises four questionnaires with each questionnaire consisting of a number of items which the carer can discuss with the assessor in relation to his/her individual caring situation. For each questionnaire, there is also an action plan for agreeing and evaluating the help that has been identified by both the carer and the assessor. In this way, the needs that have been prioritised by the carer as most important are addressed within the action plan, as advocated by Nicholas (2001). Based on these prioritised needs, the carer and assessor also agree on the type of help and/or support that is needed and when it can be expected. A follow-up date for evaluation is recorded on the action plan. It is suggested that this is 6 months but this is subject to negotiation.

A user guide that briefly explains the purposes of COAT to the family carer accompanies the instrument and includes a description of the key areas of the questionnaires, their content and a clear rationale as to why they are included. This is followed by a concise description of how the assessment will take place and what the family carer can expect from this process. In keeping with the carer and staff feedback obtained during the consultation, the guide was made more accessible by simplifying the content, having larger text, and including pictures.

Following these changes the revised COAT package was posted to the carers, practitioners and the trial assessors in Sweden to gain their views. Comments were received from six practitioners who had attended the focus group and from four of the seven test assessors. Apart from suggesting minor changes to the Swedish translations all of those who responded thought that COAT had been significantly improved as a result of the modifications made.

Whilst COAT was always seen as relevant by practitioners, it was now considered more user friendly and feasible for use in routine practice. The grouping together of similar questions, the addition of a ‘not applicable’ column, and space for further comment were seen to have enhanced the usability of the tool. Having had time to reflect on their experiences since the trial implementation some practitioners commented that they believed that COAT would promote the whole issue of carer assessment, give clearer direction to their individual practice, and also provide a means of collecting data over time on the type of needs that carers identified and the services to address these. The feedback provided reflects the enthusiasm that the project seems to have generated:

> *After reading through the instrument I can see quite a few improvements. You’ve managed to condense the questions and have grouped them in an appropriate way. Adding ‘not relevant to my caring situation’ is good.*

> *What a fantastic amount of work, I feel it covers everything now! The only thing I wonder about is how and where should it be documented and by whom? You've all done a great job!*
>
> *We think it looks very good now. We think that the new alternative 'not relevant' is good. There are also fewer questions now, which makes it easier to work with the instrument. We think it's appropriate to do a follow up every six months like you've written in the text. Moreover, we feel that we'll be able to work much better with this instrument now that some time has elapsed since the testing period and we have thought about how we can carry out this work in the best possible way. Perhaps the focus must lie on the individual action plans and the family carer answers the questions themselves before the assessment. Of course we must also help them fill it in. But as we've already said, we've got a better structure for the work now and we feel that the new layout is more manageable.*
>
> *We said to one another that it'll be fun to work more with this now. So to sum up we're positive about working together with you more regarding the whole thing if you feel that this would be useful for you. Then we wondered if you could write some sort of certificate that says we've taken part in this project. We see our participation as a privilege and a merit. It's always good to be able to show that our little municipality has been involved in a project of this sort that strengthens our work* [with carers]. *We think this is important, not least because this work* [family care support] *is not legally binding for the municipality.*
>
> *I think the user guide is fine, just enough text, easy to read and gives an overview of what it's all about.*
>
> *The questionnaire seems shorter and more manageable. Good with the dividing up of the areas.*
>
> *Action plan: the responsible person perhaps isn't always the municipality but it can be the family carer him/herself. Suggest that there is a separate box with the responsible person.*
>
> *In the description of COAT in 1.3, perhaps there should be some more clarification about what is meant by partnership. I don't think everyone is aware that you can see family carers from different perspectives and that you can also take into account their knowledge in a working partnership.*
>
> *I think COAT is an instrument for individual planning of family care support, but it can also be used to see the whole development of family care support in the municipality. Can a system be developed to do a summary/statistics of which services are in demand?*

The primary aim of COAT is to promote a means whereby family carers and service providers can 'negotiate' the support that is best suited to a particular set of caring circumstances and agree upon the type of outcomes that are most appropriate. However, it is intended as a flexible **process** rather than a rigid **procedure**, and the content of COAT is indicative rather than prescriptive. We suggest that it can also be used in conjunction with other tools as long as they are consistent with the overall 'exchange' model of working, and provide a platform for negotiation. Inevitably no single tool can be fully comprehensive and cover every eventuality. Our aim in developing COAT was that it should address the major issues that carers see as important, and encourage full discussion between carers and professionals so that relevant issues might be recognised and addressed. The extent to which it can be considered to have done so is now discussed, together with areas for further development.

COAT: Where to from here?

Some time ago Pearlin et al (2001) asserted that due to the strategic importance of family carers in realising a policy of community care, and the numerous unresolved issues surrounding the best way of supporting carers, that the family would remain *'centre stage for many years to come'*. The programme for the XVIIIth World Congress of Gerontology (Rio de Janeiro 2005) would certainly lend support to such an assertion, with their being numerous symposia on a range of related topics including: Family responsibility for care (Guberman 2005a); Intergenerational support (Bengston 2005); The use of information and communication technology to support family carers (Magnusson 2005); Family caregiving in a changing world (Zank 2005a); Profiles of family caregivers (Goncalves 2005); The assessment of family carers (Nolan 2005, Guberman 2005b); and Evaluating the impact of family caregiver support programmes (Huyck 2005a). In the context of this report the latter two issues concerning carer assessment and the evaluation of the outcomes of carer support are particularly relevant. Interestingly these symposia all reinforced the need for an approach such as COAT, especially if the everyday provision of support for carers is to improve. As Guberman (2005b) noted, carers' needs are still not routinely considered by practitioners and, even when they are, the dominant focus remains on burden (Guberman 2005b, Turner 2005, Huyck 2005b). Furthermore, eligibility criteria for services, in the form of an assessment of the activities of daily living that carers are required to perform, still predominate (Albert 2005, Bedford 2005). This perpetuates the role of assessment as a form of service rationing rather than as an opportunity to create innovative forms of service response. Consequently, whilst assessment should provide a 'new lens' through which to view the carers' situation (Fancey et al 2005), ideally leading to expanded and customised support tailored to individual needs and priorities (Zank 2005b), this is rarely the case. It was just such concerns that prompted the development of COAT.

In the conclusion to her symposium Guberman (2005b) called for a 'paradigm' shift in carer assessment, and for the underlying rationale and philosophy to be made clear. She advocated a carer focussed model rather than a service driven approach to support, the aims of which should not be simply to 'shore up' carers but rather to give them genuine choice. We believe that COAT potentially meets these goals.

In identifying the need for a new approach to carer assessment we have noted that, despite over 30 years of research and considerable policy emphasis, much remains to be done. Existing research has of course generated many new insights, significantly raised the profile of family carers, and provided a far better understanding of their situation and circumstances. But, with a few notable exceptions, the focus has been rather narrow, both conceptually and methodologically. Conceptually burden has provided, and in many instances still provides, the main theoretical lens used to view family caring. Consequently most interventions have concentrated on reducing carer stress, with only qualified success. Methodologically studies have drawn on large samples, wherever possible using controlled designs relying on measurement techniques and statistical manipulation to identify 'significant' results. Equivocal results have been blamed on poor design and measurement, with solutions seen to lie in better sample selection, improved randomisation and the development of more robust measures. Indeed considerable effort is still being expended in the generation of new multidimensional measures of 'caregiver' stress, albeit with some recognition of the potential for caring to have positive outcomes (Zank 2005b).

Whilst there is a place for studies of this kind, there has been a growing critique of such approaches, and increasing realisation that all too often outcome measures:

- are based mainly on the views of researchers rather than those of carers;
- fail to capture the outcomes that carers see as important;
- may be unrelated to the type of help/support provided;
- are too global and non-specific.

Furthermore, some have questioned the reliance on statistical significance (Schulz et al 2002), arguing instead that, at least in so far as the circumstances of individual carers are concerned, clinical significance, or the extent to which support makes a real difference in everyday life (Kadzin 1999), is a more relevant consideration. Unfortunately, in our view, the force of these arguments have been undermined by the authors' assertion that of the dimensions of clinical significance they identified (change in symptoms; improved quality of life; reduced use of other services; and social validity – that is the acceptability of goals and outcomes) that social validity was not the most important (Schulz et al 2002).

COAT is based on the belief that 'social validity' is pre-eminent because, if support is not seen as acceptable by carers, it will be rejected by the majority. COAT was designed to overcome some of the limitations of existing approaches listed above, and engage carers and service providers in a *'meaningful dialogue'* (Zarit and Leitsch 2001). It is not intended to be a 'measure', producing some form of summary score, but rather to enable carers and assessors/practitioners to identify issues relevant to their situation and to define outcomes in terms of *'what works for the carer'* (Nicholas 2001).

COAT builds on over 15 years of prior conceptual and empirical work with family carers that highlights the interactional, contextual and temporal nature of the caring experience (see Nolan et al 1996, 1998, 2003a). It is underpinned by the 'carers as experts' model (Nolan et al 1996), and also draws on three detailed carer assessment instruments (CADI, CASI and CAMI, Nolan et al 1998) and earlier development work by Nicholas (2001, 2003). This latter study also used the carers as experts model and CADI, CASI, CAMI, and identified four broad domains of outcome that carers see as important. These have been elaborated upon by us following extensive consultation with carers and practitioners, with COAT exploring the following four areas:

- Helping you to care
- Making life better for you
- Making life better for your relative
- Getting good quality care

COAT is intended to promote an 'exchange' of views between carers and practitioners, in contrast to the still dominant 'procedural' model of assessment that is based on the application of eligibility criteria relating largely to the physical act of caring. Consequently, as a result of using COAT, support is 'negotiated' rather than 'allocated', leading to more sensitive, appropriate and acceptable services that have high 'social validity'. The overall goal is to promote partnerships between family and formal carers that recognises the expertise of both. Following Guberman's (2005b) advice we have tried to make the underlying rationale and philosophy for COAT explicit and ensure that it is underpinned by considerable previous theoretical and empirical work, and also subject to extensive consultation with carers and practitioners. The key question now therefore is: will it produce the 'paradigm' shift in practice that is required?

At this stage it is too early to say but the work undertaken in developing, refining and field-testing COAT gives grounds for considerable optimism. We used the ÄVS model of involvement and participation and engaged carers and practitioners fully in the process both of refining the early drafts of COAT and in using COAT to conduct 'trial' assessments. It must be re-stated at this point that these assessments were only 'trials' and that this inevitably introduced an air of artificiality into proceedings. Moreover, as we have already described, the majority of carers taking part were already known to the professionals involved and therefore the 'trial' assessment was not conducted at the point in the caring situation that it would usually be. Consequently, some carers found it difficult to engage fully with the process. Notwithstanding these caveats the trial assessments provide some encouraging indications of the potential benefits of adopting COAT, for both carers and assessors.

Carers considered that COAT:

- allowed them to raise issues that were causing concern;
- helped them to discuss such concerns in an open and frank manner;
- provided new insights into their own situation
- focussed on issues that they had not previously considered;
- helped to structure their discussion with the assessors;
- helped to validate their experiences as carers.

Importantly all of those carers taking part enjoyed the experience of an assessor spending time talking to **them** about **their** needs, and a number compared the experience favourably with previous 'assessments' that had not allowed them to fully express their views.

The practitioners adopting the 'assessor' role identified a range of benefits to using COAT, and also some potential difficulties:

- All the assessors felt that COAT worked well in promoting a personal and detailed discussion about individual caring situations.
- Despite assessors having detailed prior knowledge of the caring situation, completing COAT provided new insights for many of them.
- Assessors considered that COAT enabled them to get to know the carers well, and provided a comprehensive view of the caring situation from the carers' perspective.
- COAT enabled carers to talk openly about their situation, and helped them to focus on areas that they had not previously considered, such as their own quality of life.
- The process of completing COAT allowed the assessors to begin to address some of the carers' concerns, for example, for further information.
- Completing COAT was seen by some as potentially therapeutic in its own right.

It is therefore clear that for both carers and assessors, COAT provides several potential benefits. However, it also represents a rather different approach to work with carers and, as such, inevitably raised areas of concern. Some of these related to the perceived overlap in questions, the inclusion of potentially irrelevant items, and a response format that was unclear at times. These concerns were addressed through a process of consultation with carers and practitioners, and subsequent changes made. The final set of comments indicated that most initial concerns had been addressed. The two outstanding concerns are the length of time that COAT takes to complete, and the risk of raising issues or identifying need that cannot subsequently be addressed. Both the potentially positive effects of adopting an outcomes focussed approach to assessment such as COAT, and the challenges that working in this way presents, have been identified in previous studies.

The study most directly comparable to our own is that of Nicholas (2001, 2003) who used the 'carers as experts' model and CADI, CASI, CAMI (Nolan et al 1996, 1998) to develop and implement an outcomes focussed approach to carer assessment in one local authority in England. There is a remarkable consistency between her results and our own.

With regard to carers Nicholas (2001, 2003) found that an outcomes focussed approach:

- was helpful in enabling carers to talk over and reflect on their situation;
- allowed carers to release 'bottled up' feelings;
- provided the opportunity for them to be more honest about the difficulties they were facing;
- enabled them to state more clearly the things that they wanted.

Practitioners found that the approach:

- raised their awareness of the complexities of caring situations;
- challenged pre-existing expectations and assumptions about carers;
- encouraged a more proactive and comprehensive carer assessment;
- shifted their thinking about the type of outcomes that carers wanted.

With regard to the ÄVS authenticity criteria, both our study, and that of Nicholas (2001, 2003), provide clear evidence of the potential for an outcomes approach to carer assessment to enhance the awareness of both carers and practitioners about their own situation, and possibly, more importantly, about the situation of others.

This is highly significant for carers because, as Nicholas (2001) notes:

> *'Sensitive assessment where the carer is given the opportunity to think more broadly about their situation can open up whole new opportunities for carers.'*

Nicholas (2001) believes that such an assessment helps carers and practitioners to *'think outside the box'* with regard to the provision of new and innovative forms of support, encouraging carers to develop more effective coping strategies and enabling them to accept help that would previously have been rejected. The insights that approaches such as COAT generate should also facilitate the development of a more 'reflective' approach to assessment amongst practitioners. This has been identified as an essential prerequisite for the more widespread adoption of an outcomes approach, with one of the principal benefits being to enhance practitioners' reflective practice resulting in a more collaborative review of treatment goals and priorities with users and carers.

With regard to the ÄVS criteria for success the potential for COAT to generate enhanced awareness is apparent but in the present context this is of limited use unless such insights also encourage and enable action. That is, can change be introduced and sustained? As we only conducted 'trial' assessments our own conclusions must be speculative. But in one instance, when a new carer received a first time assessment, it was obvious that both he and the assessor could identify the benefits of an approach such as COAT. Nicholas (2001) went a stage further and introduced change to services following assessments in her study. However, this was also a demonstration project and therefore the results must again be treated with caution. Notwithstanding this, the assessments produced more focussed, creative and individualised care plans, and face-to-face assessment (as opposed to self completion) provided practitioners with a more in-depth understanding of the carers' situation. Other studies are currently underway exploring the longer term outcomes of a more holistic approach to carer assessment, for example in Canada (Fancey et al 2005).

The demands that an approach such as COAT may place on practitioners' time has been identified as a concern in several studies (Nicholas 2001, 2003, Guberman 2005b), as has the fear of raising expectations amongst carers' that cannot subsequently be met. These are real issues that require further attention. However, as Guberman (2005b) points out, it must be recognised that good assessments do take time, but that investing this resource in carers is time well spent, even if a thorough assessment may take more than one visit (Nicholas 2001, 2003). Furthermore, as this study and others have indicated, a good assessment can be therapeutic in its own right (Nicholas 2001, Fancey et al 2005, Guberman 2005b). We believe that COAT therefore has considerable potential to improve carer assessment not simply by enhancing awareness, but also by encouraging and enabling action.

However, COAT is only a tool and not an end in itself. If things are to change then COAT, and the model of working underpinning it, need to be introduced as part of a comprehensive strategy, linked to developments in service delivery and organisation (Guberman 2005b). This requires a longer term commitment to introduce approaches such as COAT into routine practice. Recent work would suggest that success in such an endeavour is critically dependent upon engaging positively with practitioners, providing a clear understanding of the rationale for, and benefits arising from, any new initiative and producing the training and support necessary to sustain change. This then is the next stage in the development of COAT.

Conclusions

As efforts to introduce systems of integrated care for older people continue throughout Europe, there is increasing recognition of the need to *'support family carers and strengthen the integration between formal and informal systems of care'* (Banks 2004). Good assessment practice is the first step towards such integration and requires a *'well balanced dialogue between professionals and family carers'* (Nies 2004a). This interplay has to date received relatively little attention, and is a key area for future research (Nies 2004b). However, research alone is not enough and must also be accompanied by changes to both policy and practice.

Recent work in Scotland has called for a *'bold new vision'* for supporting family carers, underpinned by two primary goals: to ensure that there is greater recognition of family carers as partners in, and providers of, care; and to ensure a rights based policy for such individuals, with the receipt of appropriate support, being a core right (Scottish Executive/OPM 2005a). Once again, good assessment is seen to be the key (Scottish Executive/OPM 2005b). However, reinforcing the conclusions of previous work, current assessment practice frequently results in a poor fit between carers' perceived need for support and the views of service providers (Scottish Executive/OPM 2005b). Consequently, carers often see assessments as offering *'empty promises'* (Scottish Executive/OPM 2005c), and if services are offered at all these are usually *'off the shelf'* rather than being *'bespoke and responsive'* (NHS Scotland/Scottish Executive 2005). If things are to improve then assessment needs to be more interactive and holistic, giving carers the opportunity to determine more fully what they need by facilitating an open and reciprocal exchange of information between carers and professionals (Scottish Executive/OPM 2005c).

We believe that COAT can promote such an exchange, and future work is planned to determine the usefulness of COAT in practice and its potential for remodelling the change in culture that is required if real progress is to be made. This will involve the introduction of COAT into seven municipalities in Sweden and its implementation and evaluation over a three year period. Only in such a way will the full benefits and potential pitfalls become fully apparent.

References

Albert, S. (2005) Rethinking the activities of daily living from a family caregiver perspective. Presentation in Guberman, N. (2005b) Caregiver Assessment: What's new and where do we go from here? Symposium at 18th Congress of the International Association of Gerontology, Rio de Janeiro, Brazil, 26-30 June 2005.

Aneshensel, C.S., Pearlin, L.I., Mullan, J.T., Zarit, S.U. and Whitlach, C.J. (1995) *Profiles in caregiving: the unexpected career*. Academic Press, San Diego.

Audit Commission (2004) *Support for Carers of Older People*. Audit Commission, (www.audit-commission.gov.uk).

Banks, P. (2004) *Policy Framework for Integrated Care for Older People* (developed on behalf of the CARMEN Network). King's Fund, London.

Beck, C. (2001) Identification and assessment of effective services and interventions: the nursing home perspective. *Aging and Mental Health*, 5(Supplement 1): S99-S111.

Bedford, U.H. (2005) Assessing family systems of carers of a frail relative. Presentation in Huyck, M.H. (2005a) Evaluating the impact of family caregiver support programmes. Symposium at 18th Congress of the International Association of Gerontology, Rio de Janeiro, Brazil, 26-30 June 2005.

Bengston, V.L. (2005) (Convenor) Families, generations and social change – families, ageing and intergenerational support. Symposium at 18th Congress of the International Association of Gerontology, Rio de Janeiro, Brazil, 26-30 June 2005.

Berg-Weger, M., Rubio, D.M. and Tebb, S.S. (2001) Strengths-based practice with family caregivers of the chronically ill: qualitative insights *Family in Society*. *The Journal of Contemporary Human Services*, 82(3): 263-72.

Board of Health and Welfare Sweden (2002a) *Nationell handlingsplan för äldrepolitiken: Slut rapport [National Guidelines for Elderly Policy: Final Report].* BHWS, Stockholm.

Board of Health and Welfare Sweden (2002b) *Anhörig 300: Slut Rapport [Family Carer 300 Project: Final Report].* BHWS, Stockholm.

Board of Health and Welfare Sweden (2003) *Ett år efter Anhörig 300 [One Year Later: Family Carer 300 project].* BHWS, Stockholm.

Board of Health and Welfare (2004) *Framtidens anhörigomsorg [Family Carer Support in the Future].* BHWS, Stockholm.

Bond, J. and Corner, L. (2001) Researching Dementia: Are their unique methodological challenges for health services research? *Ageing and Society*, 21(1): 95-116.

Bradbury, H. and Reason, P. (2001) Conclusion: Broadening the Bandwidth of Validity: Issues and choice-point for improving the quality of action research. In Reason, P. and Bradbury. H. (Eds) *Handbook of Action Research: Participative Inquiry and Practice* pp447-456. London: Sage.

Braithwaite, V. (2000) Contextual or generic stress outcomes: Making choices through caregiving appraisals. *The Gerontologist*, 40(6): 706-17.

Brereton, L. and Nolan, M.R. (2003) Seeking partnerships between family and professional carers: stroke as a case in point. In Nolan, M.R, Lundh, U., Grant, G. and Keady, J. (Eds) *Partnerships in Family Care: understanding the caregiving career*. Open University Press, Maidenhead, pp 50-68.

Briggs, K. and Askham, J. (1999) *The needs of people with dementia and those who care for them: A review of the literature*. Alzheimer's Society, London.

Brody, E.M. (1995) Prospects for family caregiving: response to change, continuity and diversity. In Kane, R.A. and Penrod, J.D. (Eds) *Family Caregiving in an Aging Society: Policy Perspectives.* Sage, Thousand Oaks, CA.

Chappell, N. (1996) The sociological meaning of caregiving and social support: Issues for older people, the family and community. In V. Minchiello, V. Chappel, H. Kendig and A. Walker (eds) *Sociology of Aging: Interactional Perspectives*. International Sociological Association, British Columbia, Victoria, Australia, pp148-51.

Cooke, D.D., McNally, L, Mulligan, K.T., Harrison, M.J.G. and Newman, S.P. (2001) Psychosocial interventions for caregivers of people with dementia: a systematic review. *Aging and Mental Health*, 5(2): 120-135.

Croag, S.H., Sudilousky, A., Burleson, J.A. and Baune, R.M. (2001) Vulnerability of husband and wife caregivers of Alzheimer's disease patients to caregiving stressors. *Alzheimer's Disease and Related Disorders*, 15(4): 201-10.

Davies, B. (1995) The reform of community and long term care of elderly persons: an international perspective. In T. Scharf and G.C. Wenger (eds) *International Perspectives on Community Care for Older People*. Avebury, Aldershot, pp21-38.

Department of Health (1995) *Carers (Recognition and Services) Act*. HMSO, London.

Department of Health (1999) *The Carers National Strategy*. HMSO, London.

Department of Health (2002) *Carers and Disabled Children's Act*. HMSO, London.

Department of Health (2004) *Carers Equal Opportunities Act*. HMSO, London.

Fancey, F., Keefe, J, Guberman, N. and Barylark, L. (2005) Caregiver assessment: caregivers' views on whether it makes a difference. Presentation in Guberman, N. (2005b) Caregiver Assessment: What's new and where do we go from here? Symposium at 18th Congress of the International Association of Gerontology, Rio de Janeiro, Brazil, 26-30 June 2005.

Fortinsky, R.H. (2001) Health care triads and dementia care: integrative framework and future directions. *Aging and Mental Health*, 5(Supplement 1): S35-S48.

Goncalves, L.H.T. (2005) Profile of the caregiver in a family with a live in frail elderly relative in the domestic context. Symposium at 18th Congress of the International Association of Gerontology, Rio de Janeiro, Brazil, 26-30 June 2005.

Guba, E.G. and Lincoln, Y.S. (1989) *Fourth Generation Evaluation*. Newbury Park: Sage.

Guberman, N. (2005a) (Convenor) Who's supposed to care? Changing norms and values with regard to family responsibility for the frail elderly. Symposium at 18th Congress of the International Association of Gerontology, Rio de Janeiro, Brazil, 26-30 June 2005.

Guberman, N. (2005b) (Convenor) Caregiver Assessment: What's new and where do we go from here? Symposium at 18th Congress of the International Association of Gerontology, Rio de Janeiro, Brazil, 26-30 June 2005.

Hirst, M. (2001) Trends in informal care in Great Britain during the 1990's. *Health and Social Care in the Community*, 9(6): 348-57.

Humphries, B. (2003) What *else* counts as evidence in evidence-based social work? *Social work Education*, 22(1): 81-91.

Huyck, M.H. (2005a) (Convenor) Evaluating the impact of family caregiver support programmes. Symposium at 18th Congress of the International Association of Gerontology, Rio de Janeiro, Brazil, 26-30 June 2005.

Huyck, M.H. (2005b) Evaluating the impact of the senior care programme. Presentation in Huyck, M.H. (2005a) Evaluating the impact of family caregiver support programmes. Symposium at 18th Congress of the International Association of Gerontology, Rio de Janeiro, Brazil, 26-30 June 2005.

Jeon, Y.H. and Madjar, I. (1998) Caring for a family member with chronic mental illness. *Qualitative Health Research*, 8(5): 694-706.

Johansson, L. (2001) *Recent developments in caregiver support in Sweden*. Paper given at the 17th World Congress of the International Association of Gerontology, Vancouver, 3 July 2001.

Kadzin, A.E. (1999) The meanings and measurement of clinical significance. *Journal of Consulting and Clinical Psychology*, 67: 332-39.

Kane, R.A. and Penrod, J.D. (1995) *Family Caregiving in an Aging Society: Policy Perspectives*. Sage, Thousand Oaks, CA.

Lundh, U. (1999) Coping strategies among family carers in Sweden. *British Journal of Nursing*, 8(11): 735-40.

Lundh, U. (2001) Impact on professional carers of structured interviews with families. *British Journal of Nursing*, 10(10): 677-81.

Lundh, U. and Nolan, M.R. (2001) Informal care of older people – views of family carers and professional carers. Report to the Swedish National Board of Health and Welfare. http://www.sos.se/plus/dokinfo.asp?valPubl_id=2001-124-6

Lundh, U. and Nolan, M.R. (2003) ‘I wasn’t aware of that’: creating dialogue between family and professional carers. In Nolan, M.R., Lundh, U., Grant, G. and Keady, J. (Eds) *Partnerships in Family Care: understanding the caregiving career*. Open University Press, Maidenhead, pp 108-127.

Magnusson, L. (2005) (Convenor) Supporting frail older people and their family carers via the use of ICT. Symposium at 18th Congress of the International Association of Gerontology, Rio de Janeiro, Brazil, 26-30 June 2005.

Magnusson, L., Nolan, M.R., Hanson, E., Berthold, H. and Andersson, B-A. (2001) Developing partnerships with older people and their family carers: The ÄldreVäst Sjuhärad model. *Quality in Ageing* 2(2): 32-38.

Magnusson, L., Hanson, E., Andersson, B-A., Karlsson, P-A., Höglund, E. and Nolan, M.R. (2004) *‘Let research work for you: the ÄldreVäst Sjuhärad Model,* a paper given in Swedish at the Swedish Evaluation Conference, Stockholm, April 2004 (an English summary is available on request, lennart.magnusson@hb.se).

Moriarty, J. (1999) Use of community and long-term care by people with dementia in the UK: a review of some issues in service provision and carer and user preferences. *Aging and Mental Health,* 3(4): 311-19.

Moriarty, J. and Webb, S. (2000) *Part of Their Lives: Community Care for Older People with Dementia*. Policy Press, Bristol.

NHS Scotland/Scottish Executive (2005) ‘Building a Health Service Fit for the Future’:- A National Framework for Service Change in the NHS in Scotland (The Kerr Report). Volume 2, A Guide for the NHS. NHS Scotland/Scottish Executive (www.show.scot.nhs.uk/sehd/nationalframework).

Nicholas, E. (2001) Implementing an outcomes approach in carer assessment and review. In Qureshi, H. (ed) *Outcomes in Social Care Practice*, SPRU, University of York, 65-119.

Nicholas, E. (2003) An Outcomes Focus in Carer Assessment and Review: value and challenge. *British Journal of Social Work*, 33: 31-47.

Nies, H. (2004a) Integrated Care: Concepts and Background. In Integrating Services for Older People: a resource book for managers (www.euro.centre.org/procarel), 17-31.

Nies, H (2004b) A European Research Agenda on Intergenerational Care for Older People (on behalf of the CARMEN Network). European Health Management Association, Dublin.

Nolan, M. R. (2005) (Convenor) Developing, testing and utilising COAT: The Carers’ Outcome Agreement Tool. Symposium at 18th Congress of the International Association of Gerontology, Rio de Janeiro, Brazil, 26-30 June 2005.

Nolan, M.R. and Grant, G. (1992) *Regular Respite: an Evaluation of a Hospital Rota Bed Scheme for Elderly People*. Ace Books, Age Concern Institute of Gerontology Research Papers Series No 6, London.

Nolan, M.R. and Philp, I. (1999) COPE: towards a comprehensive assessment of caregiver need. *British Journal of Nursing*, 8(20): 1364-72.

Nolan, M.R, Grant, G. and Ellis, N.C. (1990) Stress is in the eye of the beholder: reconceptualising the measurement of carer burden. *Journal of Advanced Nursing*, 15, 544-555.

Nolan, M.R, Grant, G., Caldock, K., Keady, J., Iphofen, R. and Jones, B. (1994) *Walk a Mile in My Shoes: A Framework for Assessing the Needs of Family Carers*. Rapport Productions, Bangor, in conjunction with the London Provincial Nursing Services and BASE.

Nolan, M.R., Grant, G. and Keady, J. (1996) *Understanding Family Care: A Multidimensional Model of Caring and Coping*. Open University Press, Buckingham.

Nolan, M.R., Grant, G. and Keady, J. (1998) *Assessing Carer's Needs: A Practitioner's Guide*. Pavilion Publications, Brighton.

Nolan, M.R., Lundh, U., Grant, G. and Keady, J. (2003a) (Eds) *Partnerships in Family Care: understanding the caregiving career.* Open University Press, Maidenhead.

Nolan, M.R., Hanson, E., Magnusson, L. and Andersson, B-A. (2003b) Gauging quality in constructivist research: The ÄldreVäst Sjuhärad model revisited. *Quality in Ageing - Policy, practice and research,* 4(2): 22-27.

Ory, M.G. (2000) Dementia caregiving at the end of the 20th Century. In M.P. Lawton and R.L. Rubenstein (eds) *Interventions in Dementia Care: Towards Improving Quality of Life*. Springer Publishing Company, New York, pp173-9.

Pearlin, L.I., Harrington, C., Powell-Lawton, M., Montgomery, R.J.V. and Zarit, S.H. (2001) An overview of the social and behavioural consequences of Alzheimer's disease. *Aging and Mental Health*, **5**(Supplement 1): S3-S6.

Pickard, S. (1999) Coordinated care for older people with dementia. *Journal of Interprofessional Care*, 13(4): 345-54.

Pusey, H. and Richards, D. (2001) A systematic review of the effectiveness of psychosocial interventions for carers of people with dementia. *Aging and Mental Health*, 5(2): 107-19.

Russell, C.K., Phillips, L.R., Cromwell, S.L. and Gregory, D.M. (1999) Elder caregiver care negotiations as changes of dependency. *Scholarly Inquiry for Nursing Practice, An International Journal*, 13(4): 283-98.

Schulz, R. (2001) Some critical issues in caregiver intervention research. *Aging and Mental Health*, 5(Supplement 1): S112-S115.

Schulz, R. and Williamson, G.M. (1997) The measurement of caregiver outcomes in AD research. *Alzheimer's Disease and Related Disorders*, 11 (Supplement 6): 1-6.

Schulz, R., O'Brien, A., Czaja, S., et al (2002) Dementia caregiver intervention research: in search of clinical significance. *The Gerontologist*, 42(5): 589-602.

Scottish Executive/Office of Public Management (2005a) *The future of unpaid care in Scotland: headline report of recommendations*. Report of the Care 21 Unit, Scottish Executive/OPM, London.

Scottish Executive/Office of Public Management (2005b) *The future of unpaid care in Scotland: Appendix 2 – Review of research and institutional case studies*. Scottish Executive/OPM, London.

Scottish Executive/Office of Public Management (2005c) *The future of unpaid care in Scotland: Appendix 4 – Voices of carers: report of focus group and interviews with unpaid carers in Scotland*. Scottish Executive/OPM, London.

Sörenson, S. Pinquart, M. and Duberstein, P. (2002) How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, 43(3): 356-72.

Smale, G., Tilson, G., Biehal, N. and Mars, P. (1993) *Empowerment, assessment, care management and the skilled worker*. National Institute for Social Work Practice and Development Exchange. HMSO, London.

Thompson, C. and Briggs, M. (2000) *Support for Carers of People with Alzheimer's Type Dementia*. Cochrane Review, Oxford, Issue 4.

Turner, B.F. (2005) Intergenerational dynamics of family caregiving: impact implications. Presentation in Huyck, M.H. (2005a) Evaluating the impact of family caregiver support programmes. Symposium at 18th Congress of the International Association of Gerontology, Rio de Janeiro, Brazil, 26-30 June 2005.

Walker, A. (1995) Integrating the family in the mixed economy of care. In Allen, I. and Perkins, E. (eds) *The Future of Family Care for Older People.* HMSO, London.

Whitehouse, P. (1999) Quality of life in Alzheimer's Disease: future directions. *Journal of Mental Health and Aging*, 5(1): 107-111.

Wuest, J. (2000) Negotiating with helping systems: an example of grounded theory evolving through emergent fit. *Qualitative Health Research*, 10(1): 51-70.

Wuest, J. and Stern, P.N. (2001) Connected and disconnected support: the impact on the caregiving process in Alzheimer's Disease. *Health Care for Women International*, 22: 115-30.

Zank, S. (2005a) (Convenor) Family caregiving in a changing world. Symposium at 18th Congress of the International Association of Gerontology, Rio de Janeiro, Brazil, 26-30 June 2005.

Zank, S. (2005b) Predictors of caregivers mental health and domestic violence. Presentation in Zank, S. (2005a) Family caregiving in a changing world. Symposium at 18th Congress of the International Association of Gerontology, Rio de Janeiro, Brazil, 26-30 June 2005.

Zarit, S.H. and Leitsch, S.A. (2001) Developing and evaluating community based intervention programes for Alzheimer's patients and their caregivers. *Aging and Mental Health*, 5(Supplement 1): S84-S98.

Zarit, S.H., Gaugler, J.E. and Jarrott, S.E. (1999) Useful Services for Families: Research Findings and Directions. *International Journal of Geriatric Psychiatry,* 14: 165-77.

APPENDIX 1

COAT Questionnaires and Action/Evaluation Plans

Socialstyrelsen
THE NATIONAL BOARD OF HEALTH AND WELFARE

The University Of Sheffield.

Carers Outcome Agreement Tool (COAT) - Questionnaire 1

A. HELPING YOU TO CARE

Below is a list of the types of help and support that some carers have found useful. For each type of help please indicate how useful it would be to you by putting a tick (✓) in the box that applies:

	This would be VERY useful to me	This would be QUITE useful to me	This would NOT be useful to me	This is not relevant to my caring situation
To have more information about:				
1 My relative's illness and treatment				
2 The type of help available and how to get it				
3 The financial benefits available and how to get them				
4 How to make the home more suitable for caring				
5 Who to contact in an emergency				

Comments/Additions: ....

....

....

....

....

....

....

....

....

....

....

....

MAY BE USED FREELY AFTER REGISTRATION AT www.aldrevast.hb.se

Carers Outcome Agreement Tool (COAT) - Questionnaire 1

A. HELPING YOU TO CARE (CONTINUED)

Below is a list of the types of help and support that some carers have found useful. For each type of help please indicate how useful it would be to you by putting a tick (✓) in the box that applies:

	This would be VERY useful to me	This would be QUITE useful to me	This would NOT be useful to me	This is not relevant to my caring situation
To have help to talk openly:				
6 With my relative about the caring situation				
7 With my family about the caring situation				
8 With my employer about my caring situation				
9 About alternatives to caring at home				
10 About how I feel about my caring situation				
11 With other carers about my caring situation				

Comments/Additions: ....

....

....

....

....

....

....

....

....

....

....

Carers Outcome Agreement Tool (COAT) - Questionnaire 1

A. HELPING YOU TO CARE (CONTINUED)

Below is a list of the types of help and support that some carers have found useful. For each type of help please indicate how useful it would be to you by putting a tick (✓) in the box that applies:

	This would be VERY useful to me	**This would be QUITE useful to me**	**This would NOT be useful to me**	**This is not relevant to my caring situation**
To have more help:				
12 With the physical/practical aspects of caring				
13 To reduce the stress I feel				
14 From my Family				
15 To learn the skills I need to care				

Comments/Additions: ....

....

....

....

....

....

....

....

....

....

....

....

....

Socialstyrelsen
THE NATIONAL BOARD OF HEALTH AND WELFARE

The University Of Sheffield.

Carers Outcome Agreement Tool (COAT) - Questionnaire 2

B. MAKING LIFE BETTER FOR YOU

Below is a list of things that some cares have found makes life better for themselves. For each item in the list please indicate whether it would make life better for you by putting a tick (✓) in the box that applies:

	This would make life a LOT better for me	This would make life a LITTLE better for me	This would NOT make life better for me	This is not relevant to my caring situation
For:				
1 Me to have more private time for myself				
2 Me to be able to spend more time with my family				
3 Me to have a social life outside of caring				
4 Me to be able to get a good nights sleep				
5 Me to be able to take a break or a holiday				
6 Me to be able to relax and not worry about my relative				
7 Me to be able to continue with my hobbies and interests				
8 Me to be able to carry on working				
9 Me to do enjoyable things together with my relative				
10 My relative to show that they appreciate my caring				
11 My family to show that they appreciate my caring				

Comments/Additions: ....

....

....

....

....

Please use another sheet if necessary

Socialstyrelsen
THE NATIONAL BOARD OF HEALTH AND WELFARE

The University Of Sheffield.

Carers Outcome Agreement Tool (COAT) - Questionnaire 3

C. MAKING LIFE BETTER FOR YOUR RELATIVE

Below is a list of things that some carers have found makes life better for their relative. For each item in the list please indicate whether it would make life better for the person you care for by placing a tick (✓) in the box that applies:

	This would make life a LOT better for my relative	**This would make life a LITTLE better for my relative**	**This would NOT make life better for my relative**	**This is not relevant to my relative**
For my relative:				
1 To have more contact with their family				
2 To have more contact with their friends				
3 To be stimulated and challenged				
4 To feel that they are still valued as a person				
5 To continue to enjoy their hobbies and interests				
6 To be free from pain and discomfort				
7 To feel clean and comfortable				
8 To remain living at home				
9 To have someone understanding to talk to				

Comments/Additions: ....

....

....

....

....

....

Please use another sheet if necessary

Carers Outcome Agreement Tool (COAT) - Questionnaire 4

D. GETTING GOOD QUALITY HELP

It is important for carers that any help and support they get is of good quality. Below is a list of things that carers have said are important to them. For each item please indicate how important it is for you by putting a tick (✓) in the box that applies:

	This is VERY important to me	This is QUITE important to me	This is NOT important to me	This is not relevant to my caring situation
For those providing help to:				
1 Treat my relative with dignity and respect				
2 Treat me with dignity and respect				
3 Get to know and care about my relative as a person				
4 Value my knowledge and expertise				
5 Have the right knowledge and skills				

Comments/Additions: ....

....

....

....

....

....

....

....

....

....

....

Carers Outcome Agreement Tool (COAT) - Questionnaire 4

D. GETTING GOOD QUALITY HELP (CONTINUED)

It is important for carers that any help and support they get is of good quality. Below is a list of things that carers have said are important to them. For each item please indicate how important it is for you by putting a tick (✓) in the box that applies:

	This is VERY important to me	This is QUITE important to me	This is NOT important to me	This is not relevant to my caring situation
For the help we get to:				
6 Arrive at the time promised				
7 Fit in with our routines and ways of doing things				
8 Be provided by people we know and trust				
9 Be good value for money				
10 Focus on my needs and those of my relative				
11 Be agreed following discussion with me and my relative				

Comments/Additions: ....

....

....

....

....

....

....

....

....

....

....

Carers Outcome Agreement Tool (COAT) - ACTION AND EVALUATION PLAN

A. HELPING YOU TO CARE

Areas where help is needed	Type of help agreed, when it can be expected, and who will provide it	Goals of help and how we will know if it is working	Review and evaluation date	Further action agreed following evaluation

Carers Outcome Agreement Tool (COAT) - ACTION AND EVALUATION PLAN

B. MAKING LIFE BETTER FOR YOU

Things that would make life better for me	Type of help agreed, when it can be expected, and who will provide it	Goals of help and how we will know if it is working	Review and evaluation date	Further action agreed following evaluation

Socialstyrelsen
THE NATIONAL BOARD OF HEALTH AND WELFARE

Carers Outcome Agreement Tool (COAT) - ACTION AND EVALUATION PLAN

C. MAKING LIFE BETTER FOR YOUR RELATIVE

Things that would make life better for my relative	Type of help agreed, when it can be expected, and who will provide it	Goals of help and how we will know if it is working	Review and evaluation date	Further action agreed following evaluation

Carers Outcome Agreement Tool (COAT) - ACTION AND EVALUATION PLAN

D. WHAT I EXPECT FROM GOOD QUALITY HELP AND SUPPORT

Date for Review:

I expect good quality help and support to:	Review of quality of help	Action needed to improve quality
	Fully met ☐ Partially met ☐ Not met ☐ Comments:	
	Fully met ☐ Partially met ☐ Not met ☐ Comments:	
	Fully met ☐ Partially met ☐ Not met ☐ Comments:	
	Fully met ☐ Partially met ☐ Not met ☐ Comments:	

Socialstyrelsen
THE NATIONAL BOARD OF HEALTH AND WELFARE

CONTACTS

School of Nursing and Midwifery
University of Sheffield
Professor Mike Nolan
Tel: 0114 226 6849, Email: m.r.nolan@sheffield.ac.uk
www.snm.shef.ac.uk

ÄldreVäst Sjuhärad, Sweden
Elizabeth Hanson, Senior Lecturer
Tel: +46 703614846, Email: elizabeth.hanson@hb.se
www.aldrevast.hb.se

National Board of Health and Welfare, Sweden
Lennarth Johansson
Tel: +46 8783 3261, Email: lennarth.johansson@socialstyrelsen.se
www.socialstyrelsen.se