MAKING A DIFFERENCE?

IMPLEMENTATION OF THE COMMUNITY CARE REFORMS TWO YEARS ON

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EXECUTIVE SUMMARY

INTRODUCTION

This paper reports on the second and final phase of a joint King's Fund Centre and Nuffield Institute for Health initiative on monitoring community care implementation. It provides an independent account of progress in implementing the community care changes which is based on sampling the experience and perceptions of a vertical cross-section of stakeholders in a range of localities across England.

For the second year running we have worked with the same five focus groups established in a range of localities (an inner and an outer London borough; two shire counties, and a metropolitan authority).

The report on the 1994 meetings produced conclusions which were broadly in line with those emerging from central monitoring. That is, the picture was one of relatively smooth transition and steady progress. However, the report also identified the problems of increasing workloads for front line staff, and the consequences of 'learning by doing'. Problems at the interface of health and social care were generally being managed, but their underlying causes remained, and much practice rested on the foundation of goodwill. At the end of the first year of the community care reforms we concluded that without adequate investment in support to individual staff; in organizational development, and attention to policy clarification, the capacity to maintain momentum and address the continuing change agenda was in doubt.

The 1995 round of focus group meetings took place against a changed background. Despite continuing affirmation from central monitoring that the reforms were contributing to "a steadily improving picture", the impression of smooth transition was subject to more qualifications than had previously been the case. The Department of Health highlighted the "considerable progress" which had still to be made, and identified the difficulties which some local authorities were experiencing "in coming to terms with providing services in such a way as to meet needs within available resources." Such difficulties had also been identified towards the end of 1994 when concerns about local authorities running out of money for community care became commonplace.

1995 FOCUS GROUP FINDINGS

A comparison of findings from 1994 and 1995 indicates the persistence of some implementation issues; the disappearance of others, and the emergence of some new difficulties. Overall, however, the picture in March 1995 was one of significant progress, and of systems bedding down. Two key areas of improvement were identified:

Improved joint working

Improved working relations between health and social services, and between the local authority and the independent sector, were widely reported (as indeed they had been 12 months previously). Relations with the independent sector also reflected the emergence of a more pragmatic approach to market development necessitated by the need to expand community based services. Almost everywhere, the impetus which had been attached to preparing for the community care changes had been maintained. This testified not only to the personal commitment of staff, but to their continued faith in the capacity of the community care reforms to deliver real change.

Greater flexibility and responsiveness of services

Related to the development of a greater range of service providers was the availability of more responsive services, offering greater flexibility around the hours and intensity of support. However, while care packages for complex needs were generally regarded favourably, there was concern that individuals with less intense needs were often being overlooked, and that this was increasing the pressures and demands falling on users and on carers.

Alongside these two broad areas of improvement (and of many other individual examples of 'good news'), were areas of problematic implementation.

Service rationing

The community care reforms have produced both gainers and losers. While one of the five localities had benefited from changes to the Special Transitional Grant formula, the remaining four experienced varying degrees of pressure on resources. This necessitated reduced levels of service and the tightening of eligibility criteria in order to keep within budget. In practice this has also meant that resource constraints have made it increasingly difficult for local authorities to maintain their ideological commitment to developing needs-led services, and the rationing of services has become more explicit. In one locality this saw the introduction of major changes in an atmosphere of crisis, and in most of the localities resource pressure has been damaging both to staff morale, and to the confidence and trust of service users.

Strains on the health and social care boundary

While changes in the nature and pattern of services were generally viewed positively, the shift towards new models also had its down side. In particular, the boundary between health and social care seemed to be increasingly strained. This reflected: the increased demands falling on the community in supporting people at home (and changes taking place in the nature of home care); the impact of hospital discharge practices, especially when changes in acute care were driving earlier discharges; and changes resulting from the impact of GP fundholding which were viewed as being in tension with community care objectives.

Uncertain responsibilities for long term care remained an issue in all localities, and responses to recent guidance from the Department of Health in this area were still being considered. In addition to the issues of agreeing respective responsibilities of health and social care purchasers, in most focus groups there was concern about the consequences for individual clients of a perceived shift in responsibility away from the NHS and towards means-tested provision.

Uncertain role of residential and nursing home provision

In all localities independent residential and nursing home owners were concerned about the changes taking place in their business. A fall in business overall, increased vacancy levels and a rise in the dependency of new admissions were all identified. While all of these changes might have been predicted, they had surprised some providers (particularly those who had been in the market during times of plenty). Some providers demonstrated an unwillingness or inability to respond to changed conditions, and had chosen not to diversify into other services. These providers also believed that an emphasis on supporting people in the community prevented individuals exploring the options which residential care might offer.

Users and Carers

The views of service users and of carers were sought both within the focus group meetings, and through a brief questionnaire.

There was general support for the view that community care had improved, although this was subject to many caveats. Some of the best experiences reported underlined the changes taking place in community care services, and the development of more flexible and responsive care. Nonetheless, this judgement must be set alongside some damning indictments of poor care in individual cases, and of the failure of much practice to match up to the promise of change offered in policy. Particular criticisms addressed: lack of information and general uncertainty; lack of reliability of provision; and the consequences of power imbalance in every aspect of the relationship between service users and service providers.

In considering what changes service users and carers wished to see taking place in community care, a range of issues were identified. However, the dominant themes were of genuine empowerment, and of positive changes in the organization and delivery of services. For some respondents, there was a strong belief that such change depended upon the greater representation of disabled people as employees of care agencies.

MEASURING SUCCESS

Numerous indicators which might be utilised in evaluating community care performance were proposed by focus group participants. We classified these under four headings of: outcomes for users and carers; service changes; policy and resources, and access to services. The list of potential indicators should not be viewed as a 'wish list'. Rather, it offers an imaginative and comprehensive methodology for evaluating the impact of the community care reforms. Moreover, building upon these indicators could address precisely the inadequacies of local monitoring which have been identified by the Department of Health, namely: to use improved outcomes for users and carers as a central criterion against which to evaluate community care arrangements.

The need for development work at both central and local levels to be directed towards this key area of monitoring is further underlined by evidence from the five focus groups which demonstrates their current reliance upon limited proxy indicators of success. To-date, much of the monitoring of community care implementation has focused on processes, rather than on outputs, or outcomes. There is a need to change the balance of methodologies, and to build on current approaches in order to adequately address crucial aspects of service quality. This will require attention to both quantitative and qualitative measures.

CONCLUSIONS

The focus groups painted a picture of community care which included extremes of good and bad features, but which also included a significant gradation of light and shade. There have undoubtedly been achievements, particularly in the development of a more mixed economy of service provision, and in the development of a greater range of services and support. At the same time, several implementation problems remain. These are especially focused on issues on the health and social care boundary, and on the practical problems of trying to run a needs-led service within a framework of resource constraint.

The experiences of service users, and of carers, reported to us highlighted on the one hand the difference which good quality services and caring staff can make to an individual's quality of life, and on the other hand - the consequences of poor quality and insufficient support. The perspectives of service users and carers are especially important because they provide the first hand accounts of service outcomes which are otherwise largely unavailable from existing monitoring channels.

The community care changes which were introduced in April 1993 were always going to take time to evolve, and that seems to be supported by current evidence. What is important is that the policy has retained its integrity, and the central objectives continue to command widespread support. However, that support may be increasingly undermined by resource shortfalls and other stumbling blocks which we have identified. There remains a considerable development agenda to address. In particular, the need to link monitoring, and outcome evaluation to a clear policy and practice development strategy at both central and local levels is increasingly evident. The contributions of the focus group participants which we have reflected in this report provide an important opportunity to address such a strategy, and to develop methodologies which will indicate the degree to which new service systems and processes are succeeding in delivering greater choice, opportunity and independence to individuals.

1.0 INTRODUCTION

1.1 Since 1992 the King's Fund Centre for Health Services Development, and the Nuffield Institute for Health have been working together to identify progress and problems in implementing the community care changes. This monitoring has focused, in particular, on issues arising on the boundary between health and social care. It was believed that a focus on this interface would highlight problems arising, and requiring remedial action either by central government, or by health and local authorities. It was also believed that it would be valuable to identify where and how service changes along this boundary were having a positive impact on the lives of service users and their carers.

1.2 A national 'focus group' has been meeting on an annual basis since 1992. The group comprises 30 individuals from different parts of the country, including managers and practitioners from the NHS and local authorities, together with representatives of the independent sector, and of users and carers. Three reports reflecting the views of the group have been produced,[1] [2] [3] and the group is continuing to meet on an annual basis.

1.3 To complement the work of the national focus group, in 1994 the King's Fund and the Nuffield Institute for Health established five local focus groups across the country. Groups were convened in an inner and an outer London borough, in two Shire counties, and in one Metropolitan authority. Each group brought together a vertical cross-section of local stakeholders, including purchasers of health and social care, managers and front line providers (including representatives of the independent sector), and users and carers. A meeting of each group was held at the end of the first year of the community care reforms (March/April 1994), and the groups were reconvened for a further meeting one year on. This is the report of the second round of meetings, but we begin by summarising the findings from the first phase of meetings.

1.4 1994 Focus Group Meetings

A report on the 1994 meetings provided the first independent review of progress with implementation of the community care reforms.[4] The findings from the five local focus groups were broadly supportive of the conclusions which emerged from central monitoring by the Department of Health and by the Audit Commission; i.e, a general picture of smooth transition and steady progress. However, the focus groups also indicated the price of achieving this transition, and highlighted the contrasting perceptions of strategic and operational staff. Some front line staff, in particular, faced increasing work load demands, and had to manage the consequences of 'learning by doing'.

1.5 One year into the community care changes there was still a sense that it was 'early days', and that it was too soon to judge the success of the reforms. However, the hopes which people held for community care showed some signs of realisation, while many of the fears which had existed prior to April 1993 proved to be over-pessimistic.

1.6 2a In the 1994 meetings it had proved difficult to secure the involvement of service users and carers in the local groups, or to reflect a diversity of interests. However, where users and carers did participate in the meetings, it was clear that they had low expectations of the community care reforms, and that they were less likely than service purchasers and providers to judge there to have been substantive improvements over the first year.

1.7 Problems at the interface of health and social care were in evidence, but were not as overwhelming as some had predicted. However, the consequences of these problems were being more or less successfully managed, rather than their underlying causes being resolved. Uncertainty and confusion around responsibilities for continuing care were widely identified.

1.8 At the end of the first year of the community care changes, the findings from the five focus groups indicated that the situation remained fragile. Underlying problems remained, and many of the real achievements were built on the uncertain foundation of good will. Without adequate investment in support to individual staff; in organizational development, and attention to policy clarification, we concluded that the capacity to maintain momentum and to address the continuing change agenda of community care, was in some doubt.

2.0 FINDINGS: CENTRAL MONITORING

2.1 Department of Health

The programme of national monitoring of the community care reforms changed substantially during the second year of implementation. Special monitoring arrangements were established by the Department of Health from the Spring of 1991, in order to parallel the phased implementation of the community care changes. The monitoring programme featured a mix of traditional monitoring and inspection work, alongside development projects and in-depth analysis of specific issues.[5] Monitoring during 1994-95 linked the activity of the SSI and the NHS Executive (monitoring during 1993-94 had - unusually - been carried out jointly). A self-monitoring questionnaire was developed for social services, and two rounds of national survey questionnaires for all Health Authorities and FHSAs (in September 1994 and April 1995) were conducted by the NHS Executive.

2.2 Conclusions from central monitoring at the end of the first year of the reforms emphasised that implementation had progressed relatively smoothly. However, the reliability of information on which such judgements were made is - in some instances - in doubt. As the Chief Inspector of the SSI observed in his Third Annual Report,

> "One of the most important, and most often repeated findings was that management information, monitoring and review systems were not yet sufficiently refined to enable managers fully to assess the effectiveness of the strategies they were implementing."[6]

2.3 A report of the 1994 national monitoring exercises was published at the end of March 1995. This report reiterated concerns that the lack of well developed information and financial management systems was a common shortcoming, but observed that:

> "Generally, the monitoring returns suggest a steadily improving picture (...) However, it is evident that there is considerable progress to be made in a number of areas in order to deliver the full benefits of the new community care arrangements for users and carers."[7]

2.4 The report of findings from the local authority self-monitoring surveys, and from national NHS surveys addressed progress under a number of themes, and here we summarise the key findings on each:

Meeting Users' Needs

Most responses indicated progress in developing systems which were flexible and efficient, and services which more accurately reflected the real needs of users.

Support to Carers

Most authorities were confident that they had made progress in this area, and described services and systems designed to support carers.

Assessment Arrangements

Systems were gradually maturing, and many local authorities had reviewed and revised their assessment methods and materials. Genuinely needs-led, as opposed to service-led, approaches were, however, difficult to realise.

Care Management

Effective care management systems were in evidence, although problems remained, particularly around the workload of care managers and their capacity to undertake reviews.

Joint Working

Commitment to joint working was widely reported, but difficulties remained particularly at the operational level.

Community Care Market

The market was continuing to develop, although sometimes slowly and unevenly.

Hospital and Community Care

In many areas systems for monitoring hospital discharges and admissions had still to be developed. There was a consequent lack of reliable information on the possible impact of earlier discharge on community health services.[8]

2.5 Audit Commission Findings

In addition to central monitoring being undertaken by the Department of Health, other national monitoring has been conducted by the Audit Commission. The first bulletin on the community care reforms was published in December 1993, and also reported "steady but cautious progress" during the early months.[9] One year later, a second bulletin highlighted a number of findings on continuing progress, emphasising the importance of authorities continuing to increase sensitivity to needs, achieve greater flexibility in expenditure, and increase the responsiveness of services:

* authorities have become more sensitive to the needs of their populations;

* authorities need to develop more sophisticated ways of gathering and using information;

* authorities must become more flexible in purchasing care for individual clients;

* some authorities are experiencing financial difficulty;

* services should become more responsive;

- continuous effort will be needed to ensure a balanced range of quality services.[10]

2.6 Towards the end of 1994 concerns began to surface in newspapers and the professional trade press which suggested that all was far from well with community care, and which highlighted in particular the problems of inadequate funding. As Gerald Wistow has pointed out, whereas financial embarrassment was more likely to be associated with underspending during year 1 of the reforms, year 2 became "dominated by concerns about local authorities running out of money".[11]

It was against this backdrop of mixed reviews of community care that we undertook the second round of meetings with our local focus groups.

3.0 FINDINGS: THE FOCUS GROUPS

3.1 The five focus groups which were established by the Nuffield Institute for Health and the King's Fund Centre in 1994 were reconvened for a further round of meetings in 1995. In most instances, individuals who had taken part in last year's discussions were again present this year. In addition, there were some new members of the groups. In part this reflected the availability of people on the day, and some of those who had been unable to attend last year were free to do so this year. However, it also indicated a deliberate attempt to extend the invitations to attend meetings, and in particular to increase representation of stakeholders who were believed to be under-represented in last year's meetings. In particular, we sought to increase the representation of: GPs and other members of the FHSA; independent sector providers (especially from the non-residential side), and service users and carers. These efforts had some success.

3.2 Overview

Before turning to identify key issues and concerns which arose from the five groups, it is worth reflecting on some general impressions and themes. Almost two years into the community care reforms, there was a strong sense in all five localities of significant development, and of the changes beginning to bed down. A comparison of this year's findings with last year's indicates the persistence of some issues, the disappearance of others, and the emergence of yet others.

3.3 Last year, discussions had tended to be concentrated on issues around residential services. In only one of the five localities in 1994 was there any substantial development of a domiciliary care market. In contrast, this year there was far more discussion of issues around supporting people in the community and in their own homes. The domiciliary social care market had undergone rapid (and sometimes fairly uncontrolled) development, and the management of this market was presenting new challenges to social services authorities.

3.4 In 1994 there was a widespread sense of loss, and a feeling that the reforms were driving out the 'essence of social work skills'. This year, there was a growing acceptance that the processes of assessment and care management are also professional tasks, demanding distinctive skills.

3.5 In some, but not all, of the localities, resource pressures have had a significant impact. Financial crisis in one locality in particular has had a substantial impact and has changed the approach to service provision from one which was needs-led to one which is resource-dominated with accompanying reductions in levels of service, and tightening of eligibility criteria. Introducing major policy changes in an atmosphere of crisis in this locality has been damaging both to the morale of staff, but also to the confidence and trust of service users.

3.6 Some smaller scale providers of independent residential and nursing home care are continuing to have problems adjusting to the changes. Some had not anticipated the possible consequences of the community care reforms (such as a fall in the numbers of people entering residential care, and increased dependency of new residents who are entering homes at a later stage than their predecessors). Consequently, there is scope for mistrust and poor relations between these providers and local authority purchasers whose first priority is supporting people in the community.

3.7 Mistrust, or - at least - insufficient appreciation of respective professional skills, was also apparent in the lack of involvement of independent providers in the assessment process of individuals and in poor sharing of information and care plans when individuals were referred to the services of independent providers.

3.8 The shifting boundary between health and social care continued to feature as a major concern. This was evident both in relation to continuing care, and to uncertainties around respective responsibilities between health and social care, but also in the blurring of the definition between home care workers and community nurses. By and large, operational difficulties were being resolved at grass roots rather than strategic policy levels.

3.9 A further aspect of the relationship between health and social care concerned the impact on the community of changes **within** the NHS, particularly around the expansion of GP fundholding, and of changing practices within acute hospitals resulting in faster throughput and increased demands on social services.

3.10 Service users and carers reported mixed experiences of community care. The critical test of community care must be to ask what difference services are making to outcomes and to the quality of life of individuals. Too frequently that test demonstrated few grounds for optimism.

3.11 Objectives of Focus Group Meetings

In 1994 the focus group meetings had examined the following themes:

* Hopes and fears which had preceded April 1993, and the extent to which these were being realised;

* Good news and bad news: progress and problems;

* Ways forward - local and national agendas.

3.12 In 1995 the approach was slightly different, and our methodology was deliberately informed by issues identified within the King's Fund/Nuffield Institute for Health national level focus group. The national focus group met in November 1994 and provided a further opportunity for a stock-take of progress and problems emerging during year two of the reforms. In addition, the group also produced a framework for conceptualising success criteria which might be employed in monitoring the implementation of the community care reforms. The framework addressed four separate, but linked, domains of:

- Outcomes for users/carers
- Policy and resources
- Service changes
- Access to services

In working with the five local focus groups in 1995 we deliberately used this classification in order to focus the consideration both of success criteria and of approaches to monitoring and evaluation.

4.0 THE BEST AND WORST OF COMMUNITY CARE IN YEAR 2

4.1 In asking the groups to identify the best and worst aspects of community care during 1994/95, we lifted the lid on a diverse range of issues and experiences. While some of the perceptions which we recorded were highly generalised, and indeed were reflected to a lesser or greater extent across all of the groups, other examples were highly personalised and indicated the individual experiences of group members.

4.2 THE BEST OF COMMUNITY CARE

The list of 'best things' identified below summarises a much longer list generated by the five groups individually. However, there was considerable similarity between the groups in the issues identified. The largest group of issues could be classified in terms of service changes. This is a positive conclusion. However, a comparison with the much shorter list of issues identified in terms of improved outcomes raises some important questions.

4.3 Although similar issues were identified across the five groups, there were also significant differences both within and between the groups. The five localities varied in a number of ways, and indeed were chosen to reflect a range of locality types and experiences. The good news in one locality (an inner London authority) in which resource availability had greatly facilitated developments and a more proactive approach to commissioning, was by no means the universal experience. Other localities were ranged along a continuum of experiences of resource pressure or scarcity, as is reflected in the list of the worst aspects of community care, which we will examine below.

The experiences within the focus groups also varied between different stakeholders. The experience of individuals actually using community care services is addressed elsewhere in this report.

4.4 Developing the Mixed Economy of Care

Improved working relations, both between health and social services, and between the local authority and the independent sector, were widely identified. In some instances, particularly in changing relations with the independent sector, it was clear that this was a pragmatic response to changed circumstances. In the focus group which met in a metropolitan authority, which historically had adopted a paternalistic, or traditionalist, approach to service provision, and attached considerable civic pride to its services, this change in attitude was described as "learning to live with it" (i.e. with the independent sector). In another locality, rapid expansion of the independent home care market had also been necessitated in order to meet increased demands for care. In this locality too, the response of the local authority was a pragmatic one - seeking the involvement of the independent sector because it could not otherwise cope. However, this development was by no means problem free, and the reservations which existed were expressed by a social services manager who remarked that the undeveloped independent home care market meant there were "more people needing help than could be placed, or could be placed with faith."

4.5 The shift towards greater use of independent home care providers, and changing attitudes towards the sector, is consistent with other research. A study of the 'mixed economy of care' in a representative sample of 25 social services authorities conducted by the Nuffield Institute for Health, University of Leeds, and the Personal Social Services Research Unit of the University of Kent, has found pragmatism replacing anti-commercialism which was identified previously:

> "For most respondents, markets were fast becoming an accepted fact of life. Sixteen directors perceived overall advantages compared with only three who saw overall disadvantages. However, the vast majority of the former group could best be described as 'market pragmatists' rather than 'market enthusiasts'."[12]

4.6 Joint Working

Good working relations between health and social services meant that practical difficulties could often be resolved on the ground, without recourse to management and the need for formal policy resolution. Such instances were particularly likely to arise on the uncertain boundaries between the two services. In one locality, for example, social services home care staff had reached local agreements with District Nurses that they would empty catheter bags. Such agreements were by no means formal policy, and the legitimacy of the practice was strongly refuted by a social services manager. However, on the ground, front line staff adopted a stance which involved renegotiating rules, or being tacitly unaware of rules, in order to ease day to day practice. In another locality, some of the grey areas between health and social care were also being tackled through health working closely with local authority home care staff, and training them in techniques and skills required for personal care.

4.7 In one locality improved collaborative working between health and social services included improved relations with General Practitioners. This had been facilitated by the involvement of two individual GPs who were especially interested in the implications of the community care reforms. Elsewhere, however, the lack of engagement of GPs was a recurrent theme (as indeed was the case last year).

4.8 Greater Flexibility

Greater flexibility and responsiveness of services were widely reported across the five focus groups, and were related in part to the development of the mixed economy of service provision. The competition from private and voluntary services was believed in some localities to have been a healthy influence on the development of in-house services. The diversification of services was also believed to be increasing choices for individual users of services, and actively enabling more people to stay at home or in the community. While more innovative and better tailored services were believed to exist for individuals with complex needs, it was widely reported that this was at the cost of a poorer service to individuals of lower dependency. In turn, there was concern that this was increasing the pressures and demands falling on carers.

4.9 We turn now to examine more fully the best aspects of community care which were identified by the focus groups, and we do so in terms of the framework summarised in paragraph 3.12 above.

4.10 Outcomes for Users & Carers

Very few changes were identified which could be counted as improved outcomes. As we shall see below, this is partly because greater attention was paid in all of the groups to other achievements over the year, particularly in terms of substantive changes in the range and type of services. However, the relative neglect of outcomes also highlights some of the deficiencies of the monitoring and review processes being employed. Again, we shall examine this more fully below. The outcomes which were identified were the following:

* Increased user-empowerment.
* Greater choice of service options.
* Better community support for individuals with complex needs

4.11 **Service Changes**

Improvements during Year 2 which we grouped under this heading were principally concerned with changes in service systems and processes. These included:

* Increased diversity of service providers.
* Greater flexibility and innovation in services.
* More joint working.
* Better sharing of information and improved communication.
* Improved relations between statutory and independent sectors.
* Better collaborative working with GPs in some areas.
* Better working relations between health and social services.
* Informal agreements on the ground between health and social services practitioners on the sharing of responsibilities.

4.12 Henwood and Wistow have argued that the requirements of the eight key tasks which informed central monitoring of local progress with community care implementation "were the basic necessities of administrative and managerial change for meeting the demands of the system."[13] The eight key tasks for local authorities implementing Caring for People addressed the following elements:

Agreeing the basis for assessment systems;

clarifying and agreeing arrangements for residential and nursing home care;

ensuring robust hospital discharge arrangements;

clarifying the roles of GPs and primary health care teams;

ensuring adequate purchasing and charging arrangements are in place in respect of residential and nursing home care;

ensuring that financial and other management systems can meet the new demands;

ensuring that staff are suitably trained (jointly where appropriate);

ensuring the public are informed of the new arrangements.

4.13 All of the positive service changes identified in the five focus groups can be seen as more or less consistent with achievement of the eight key tasks. The joint letter from the SSI and the NHS Executive in 1992 which established the eight key tasks stated that:

> "The aim of the legislation and guidance is to ensure that services are planned and delivered in ways which ensure that users and carers are at the centre of the process and that services are flexible and meeting individual need."[14]

It is easy to assume that changes in ways of planning and organising services, or in the increased diversity and flexibility of services, can serve as proxies for other changes taking place, and are indicators of services delivering greater choice, opportunity and independence to individuals. However, the limited set of improved outcomes for service users and carers which have been identified across the five localities, must cast doubt on such assumptions.

4.14 Policy and Resources

Clear policies, and adequate resources are necessary as a foundation for developing community care services. In our five localities it was evident that policy commitment to achieving change was being maintained, but the adequacy of resources to support this commitment was increasingly being questioned. However, the following items of good news were identified around policy and resources for community care implementation:

* Resources available to support people at home and purchase diverse care packages.

* Impetus for change around community care reforms maintained.

* More proactive approach to commissioning and market development.

4.15 The experience of resource plenitude was the exception rather than the rule. One locality had benefited from the change in formula for the calculation of the Special Transitional Grant (STG) and had more resources available than it had anticipated. It was in this locality in particular (although also in others) that a proactive approach to commissioning and to stimulating the independent domiciliary care market was identified. Elsewhere, as we shall see below, degrees of pressure on resources necessitated the downward adjustment of purchasing plans and the tightening of service eligibility criteria.

4.16 Almost everywhere, the impetus which had been attached to preparing for the community care changes and implementing them in the early months, had been maintained. This testified to the commitment of individual members of staff, and to the sustained belief that the community care changes have the potential to deliver improved results to individuals.

4.17 Access to Services

A few examples of improved access to services were identified in the focus groups as indicators of success. In all five localities, improvements were believed to have developed in the operation of assessment procedures. In part this probably reflected the general bedding down and refinement of new procedures, and increased familiarity with their operation. A further aspect of this was the clarification of eligibility criteria. One locality, in particular, had invested considerable effort in the development of inter-agency guidelines which built upon the 'blue book' model familiar to child protection.

4.18 Some improvements were also judged to have taken place in the involvement of service users and of carers, although this was patchy, and in some localities it was believed that consumer-led intentions, which had been stated in community care plans and elsewhere, had failed to be followed through in practice. In one locality it was reported that at the micro level some individuals were being empowered and assisted to manage their own care packages.

Specific issues identified were the following:

- Assessment of high dependency cases working well.
- Better involvement of carers in planning process.
- Better consultation with users and carers.
- Eligibility criteria for access to services clarified.

4.19 THE WORST OF COMMUNITY CARE

Alongside this picture of positive developments, and progress in achieving the objectives of the community care reforms, must be placed the 'bad news'. It must also be said that this is a considerably longer list. Although this in no way detracts from some of the very real achievements, it does point to some of the costs and associated difficulties of such progress.

4.20 Outcomes for Users and Carers

In contrast to the very brief list of positive outcomes identified previously, there were many negative outcomes. The variety of issues listed below can be grouped together into a few key themes. It is also worth emphasising that while some of these features were perceived from some perspectives as 'failures' of the community care reforms, from other standpoints it might be argued that in fact these developments might be seen as indicators of successful implementation. For example, a number of issues were identified around the rationing of services. Clearly, the community care reforms have produced both losers and gainers. However, far from being an unintended consequence of the changes, it is apparent that this was a very specific objective of the legislation. The White Paper, Caring for People, was explicit in stating the view that services would respond flexibly and sensitively to needs; that they would allow a range of options and would foster independence, but they would also "concentrate on those with the greatest needs."[15] The corollary of this is that those judged to have lesser needs would receive less attention or no attention at all. In practice, it is clear that this aspect of implementation is proving problematic. The judgement about who is in greater or lesser need is a complex one, and some of the negative consequences identified in the focus groups point to the increased burdens which this can place on carers, and to the lack of attention to preventive support.

4.21 There is a tension within the policy objectives of Caring for People between making practical support for carers a high priority, while also ensuring that services are targeted on those in greatest need.[16] The recent debate of the Carers (Recognition and Services) Bill in committee stage and third reading in the House of Commons, highlighted the concern that carers are too often viewed as substitutes for other support. As Malcolm Wicks MP, the proposer of this Private Member's Bill observed:

> "There is now some concern that, because of resource constraints, many hard pressed social services departments are using the existence of a carer to withdraw services from the cared for person (...) That is wrong. It is not recognition, but the reverse, and the Bill aims to end all that."[17]

4.22 Other main themes which were identified under poor outcomes included: the failure of services to measure up to the raised expectations they had generated; lack of real choice; poor continuity of care resulting from the mix of providers; and the consequences of the unequal distribution of power between service users and service purchasers and providers. We will examine some of these issues in greater detail when we address user and carer perspectives below. The specific concerns identified under poor outcomes included the following:

* Lower dependency cases receiving less attention.

* Gulf between policy vision and rhetoric, and experience of some individuals.

* Rhetoric about choice, but in practice less rather than more.

* Increase in hospital discharges which are badly planned and happen too quickly.

* Balance of power concerns between service user and service providers.

* Sharing of information between staff may compromise individual confidentiality.

* Consumer-led intention of policy not been followed through in practice.

* Loss of continuity of care - mixture of services and variety of providers acting in uncoordinated way.

* Impact of resource pressures on hospital discharge - people being diverted to residential or nursing homes who might have been rehabilitated given time and resources.

* Social workers no longer viewed as champions for individuals' rights.

* Service confusion between purchaser and provider roles - who is providing what? How to access services? Who to complain to when things go wrong?

* Lack of continuity and problems of multiple assessments.

* Loss of preventive work - focus only on crisis intervention.

* Quality issues - different standards applying to public and private sectors.

* Increased stress and pressures on carers coping at home.

* Increased disputes over free/means-tested services.

* Lack of continuity - problems of multiple assessment.

4.23 **Service Changes**

Changes in the nature and pattern of services which were taking place were, as noted above, generally viewed positively. Nonetheless, the shift towards new models was taking place in the context of other changes - particularly within the NHS - which had often unforeseen negative consequences. The boundary between health and social care was becoming more strained. This reflected: the increased demands falling on community services in supporting people at home; the impact of hospital discharge practices (especially where discharge was thought to be happening too quickly), and the changing nature of the tasks being undertaken by home care staff. In the case of the latter, home care was often moving closer to what in the past would have been seen as a nursing responsibility. This shift had implications for individual users in terms of a move from a free to a means-tested service. In some localities these difficulties were overlaid by a further set of factors resulting from the impact of GP fundholding on the role of community nurses. In one locality a community nursing manager described how the emergence of fundholders as purchasers was impacting on the role and remit of nurses, and was introducing nursing priorities within practices which might differ from those of community trusts:

> "...nurses are constantly pulled from the community to do things which meet the contractual requirements, but that work is different to the community requirements."

4.24 Other negative service changes which were identified concerned the impact on independent providers. In all of the localities independent nursing home owners were concerned about the change in their business. This was being felt both in a fall in business overall, with increased vacancy levels, and in a rise in dependency of new admissions. Both of these features might have been predicted, and again, could be seen as a clear objective of the policy reforms which emphasised community alternatives wherever possible. Both features have also been reflected at a national level.

4.25 The latest market survey from Laing and Buisson found a fall of 9,000 in the total numbers of people in care homes and long stay hospitals between April 1993 and April 1994. While most of this reduction occurred in the public sector, demand was also dipping in the private sector towards the end of the financial year.[18] A survey of 230 privately run homes conducted by the Independent Healthcare Association has also documented changing referral patterns, and estimated a 15 to 30 per cent increase in people defined as high dependency.[19]

4.26 In two localities in particular (one a metropolitan authority, and the other an outer London borough), the capacity of the market to respond to these changed demands seemed in doubt. In one of these localities a nursing home owner believed that many of the referrals which they were now receiving should really be in the care of hospitals since they required intensive nursing care. In both localities the home owners argued that maintaining people in the community was depriving individuals of choice, and that service users were not made sufficiently aware of the alternatives to care at home. In neither locality was there any attempt by providers to adjust their service to meet the changing needs. Vacancies were seen as preferable to coping with very high dependency cases, and no attractions were seen in diversifying into other services, such as rehabilitation, day care or domiciliary care.

Other service changes which were identified included the following:

- Increased pressure on community nurses.
- Pressure on domiciliary care - becoming more like nursing care.
- Community nursing tasks changed by impact of GP fundholding.
- Boundary between acute and community services strained.
- Smaller independent residential and nursing home providers being squeezed out.
- Nursing homes admitting higher dependency cases.
- Nursing homes vacancy levels causing concern to providers.
- Quality of domiciliary care - market insufficiently developed.

4.27 Policy and Resources

Many of the bad news issues identified under this heading related to market management. The increase in pressures on resources has already been mentioned. The change in fortune in some localities led to rapid adjustment in market management strategies. We have already discussed the position of a London authority which was able to develop a more proactive purchasing strategy and had to rapidly develop contracting arrangements with independent home care providers; elsewhere, however, the pressures on social services to be prudent with resources slowed considerably the pace of possible development. In one locality, for example, the process of putting home care services out to contract was viewed by independent providers to have been handled in a very destructive and disruptive manner. Contracts were short term, and were reviewed after only three months. Not only was this problematic for the providers, but service users were not informed about the changes taking place.

4.28 In another locality resource pressures led to a two-pronged crisis strategy being implemented. Service packages were rationed both by total cost ceilings to individual packages of support, and by the introduction of a charging policy following reviews of individual care plans. The net effect was that many service users found themselves paying for a reduced level of service. There were major implementation problems with the strategy which were still reverberating through the locality at the time of our meeting - some three months into the new approach. In this locality too, inadequate information to service users about what was happening and the likely consequences caused much alarm. It was believed that up to a third of home care users were choosing to drop out of the service as a result of reviews, and there was considerable concern (particularly on the part of the local voluntary sector) about the likely consequences of failing to support people with lower levels of dependency, and those who were unwilling or unable to pay for support.

4.29 If the overall resource environment was a significant factor shaping developments during Year 2, other factors were also important. The prospect of local government reform was casting a shadow in two localities. In one of these, the situation was described as "mayhem", and it was recognised that there had been substantial planning blight and lack of service development. In another locality lack of development and generally poor staff morale was due not to the prospect of organisational change, but to financial compression across the local authority overall, with fears over staff redundancies and the introduction of short term contracts. Also, this was happening in a locality in which the current changes presented particular challenges to some local authority officers and members who subscribed to an ethos of strong public services, and found the newly emergent contract culture in social care extremely difficult.

4.30 Other concerns surrounded the planning process, and the failure to engage adequately with particular stakeholders, such as GPs, or housing authorities. In one locality, a social services manager described how negotiations would take place with the health authority, and the assumption that the FHSA could be treated as in some way representing the interests of non-fundholding GPs. However, there seemed to be no equivalent mechanism for engaging with fundholders, and the social services department was resigned to the position "that it can't be done." In only one of the five localities were relations with GPs described positively.

4.31 While social services were concerned about adequate planning with other public sector purchasers and providers, some independent sector providers were frustrated at not having what they regarded as adequate access to, and information about, the planning process, or indeed about assessment. We will examine this below under the heading of 'Access to services'.

4.32 Hospital discharge was identified as a matter of continuing concern, and issues relating to discharge arose under each of the four domains we are addressing (outcomes; service change; policy and resources, and access to services). New guidance on responsibilities for continuing care was issued by the Department of Health in February 1995[20], and when the meetings of the focus groups were held (during March) it was too early for tangible progress with revised eligibility criteria or new agreements on local continuing care policies.

4.33 In one locality which was experiencing particular resource difficulties, it was recognised that this had affected discharges. While hospital ward staff had been sympathetic and supportive to social services staff facing cutbacks, nonetheless collaboration became more difficult in such circumstances. Social services were not in a strong position to bargain with hospitals, and could not always negotiate the extra time which would allow some patients to be sufficiently rehabilitated to return to the community. As a result, some people were being referred to residential or nursing home care, when this might have been avoidable.

4.34 In another locality, discharge practices, and relations between health and social services around such practice, varied between the different health providers involved. There were particular difficulties with one hospital which provides a national (and international) service for the treatment of mental illness. This role sits uneasily alongside objectives of providing a local service for local people, and co-operation and consultation with other local agencies, or with carers of patients, was generally poor. In another locality, continued poor practice in hospital discharge was exacerbated by an apparent deterioration of standards of acute hospital care. Low levels of staffing and poor morale were seen as responsible for poor standards, and contributed to patients being anxious to leave as soon as possible. Anecdotal evidence was mounting in this locality of very high death rates among individuals discharged to nursing home care.

4.35 Other specific concerns around policy and resources included the following:

- Slowness of local authority payment to independent providers.
- Independent providers isolated (lack of access to information).
- Home care contracting poorly handled.
- Voluntary sector facing increased demands but fewer resources.
- Inadequate information systems restricting monitoring capacity.
- Local authority under increasing pressure to be prudent - slowing pace of change.
- Impact of impending local government reform in some localities.

* Minimal planning involvement of GP fundholders or housing.

* Failure to implement/stick to hospital discharge agreements.

* Lack of appropriately trained staff for residential or home care.

* Sheer volume of work.

* Low morale in social services, particularly where other changes were taking place.

* Budgetary pressures on social services.

* Overall impact of health and social services changes and turbulence.

4.36 **Access to Services**

The bad news on access to services covered a range of topics which included not only direct access questions for service users and carers, but also matters around the access of particular (independent) providers to the policy and planning process. The providers in question felt not only that they were being denied legitimate access to decision making, but that their exclusion restricted the information and choices available to clients.

4.37 The lack of engagement of some health purchasers and providers in community care issues has been mentioned previously, and this was again identified as an issue under this heading.

4.38 Uncertain responsibilities for long term care, and the effect of this on access to care, were also identified. There were two main dimensions to this. The one which was identified most frequently, and which was the cause of most concern, was the impact on individuals of an apparent shift for long term care responsibilities from health to social care. In one locality a voluntary sector representative described the feelings of many elderly people she came across, and her words encapsulate a situation which was recognised to a lesser or greater degree in all five localities:

> "Many older people feel insulted about the means-testing of services. They believe they have paid in all their lives and they are now being cheated by changing rules. The result is a great deal of anger, and people feeling they are being penalised for being thrifty. There is a considerable fear factor - people are afraid of the financial implications of asking for help, so they don't."

4.39 The other problematic dimension of this issue reflected the genuine uncertainty about the most appropriate form of care to be provided. This was not a matter of disputing funding responsibilities. In one locality in which the dilemma was described, both health and social services purchasers were clear that if they could identify what to do about an individual case, they could reach agreement about ways of funding the care (either individually or jointly). The problem was in identifying the appropriate locus of care. The particular case example was of a client with continuing physical care needs, and who was also mentally unpredictable. Health and social services managers were unable to decide what an appropriate service would comprise. The particular circumstances meant that residential, nursing home, or

continuing in-patient care were all deemed inappropriate. There were clearly risks that the individual (and others like him) might be placed in a facility which failed to meet his needs, or that he would increasingly experience problems with support in the community (as was the experience in this particular instance).

4.40 A concern that assessments were not wholly 'independent' (i.e. they were undertaken by social services), was expressed by independent residential and nursing home proprietors in several localities. Similar concerns were also voiced last year. Although expressed in terms of concern over the unmet needs of individuals, this was principally a concern that too many people were being diverted into community based care, rather than being placed in care homes.

4.41 The lack of direct involvement of independent providers in the assessment process reflected similar concerns, but was also an indictment of the poor information and care plans which accompanied individuals being referred to the care of independent providers. In one locality, a voluntary sector domiciliary care provider believed the local authority to be in breach of its contract with them because of the total lack of information provided. In effect, this necessitated a duplication of assessment effort. In this particular locality (a Metropolitan authority), in which relations with the independent sector were developing, against the background of a traditionalist local authority, the lack of shared information may have been symptomatic of the state of relations in general. The independent home care provider believed there was little respect for their own professional judgements and expertise.

4.42 Another important issue of access to services concerns people with learning disabilities. It highlights the tensions between the policy objectives of community care espoused by the local authority on the one hand, and the legitimate concerns of parent carers who want residential provision to be available on the other. This issue leads us to the particular concerns of both service users and carers. This is the focus of the following section of this paper, where we also return to the particular concerns of parent carers.

4.43 Other issues identified as bad news in terms of access to community care services, included the following:

* Complacency/lack of involvement of some health purchasers and providers in community care matters.

* Complexity/funding issues around some assessments (especially where cases cross locality boundaries).

* Uncertainty over appropriate care - health or social services.

* Lack of consultation with users and carers.

* Assessment not independent - unmet needs inadequately recognised.

* Independent providers not involved in assessment process.

* Carers' concerns over absence of residential provision for people with learning disabilities.

* Response times slowed down by new processes.

5.0 FINDINGS: THE PERSPECTIVES OF SERVICE USERS & OF CARERS

5.1 The attempt to reflect the views of service users and of carers within the focus groups in 1994 was unsatisfactory. It proved difficult to secure their representation, and it was rarely possible to reflect a diversity of interests. Moreover, when users or carers had raised issues within the groups which were not wholly consistent with those of service purchasers or providers, there were risks of them being sidelined.

5.2 Building on the experiences of working with the groups in 1994, we wished to better reflect user and carer views in the 1995 meetings. Ideally, and resources permitting, we would have established a parallel but separate focus group in each locality, which brought together a range of individuals representing various user and carer interests. In practice, this was not possible, and when organising the meetings we emphasised to the individual with whom we liaised in each locality, that we wished to involve users and carers wherever possible. In addition, we designed a brief questionnaire which we left with any users or carers who attended the groups, in order to give them a further opportunity to express views or experiences that they may have been unable to express during the meeting. We assured individuals of complete confidentiality, and questionnaires were returned from all five localities.

5.3 Inevitably there are shortcomings in such an approach, but some of the previous weaknesses were redressed. Moreover, the strength and richness of comments returned indicated how worthwhile it was to develop the questionnaire, and how much it was appreciated by those who participated. Some individuals had difficulties which would have made the completion of a written questionnaire problematic. One such questionnaire had been completed by a carer on behalf of a disabled person, and in another situation, a disabled person telephoned the researcher and they were able to use the questionnaire as the basis for a telephone interview.

5.4 Below, we analyse the information from the returned questionnaires. This analysis does not follow the exact format of the four-fold typology employed elsewhere in this report, since that classification is largely focused on a service perspective. The findings reported below do, however, reflect on similar themes, and comparisons are therefore possible.

5.5 Good News and Bad News

The bulk of resources used in community care are directed towards services for elderly people who comprise the largest group of service users. This factor was reflected in the users and carers who participated in the focus groups. However, the interests of younger physically disabled people, and of individuals with learning disabilities were also represented. The individual service users and carers who attended the focus groups differed in terms of their age, their particular disability or need for assistance. Almost all were female.

5.6 Perceptions of the value of community care services were similarly diverse. There was a general view that community care had improved over the last year (although this was subject to many caveats), although in some localities this was now being undermined by resource pressures.

5.7 Individuals were asked to identify their best and worst experiences of community care over the last year. Some of the best experiences point to changes taking place in community care services, and to the development of more responsive and flexible care. A carer, for example, described how social services responded immediately when she reached a crisis in her capacity to cope with her elderly mother, and organised respite support the same day. Similarly, another carer described the "impressive" care package assembled for her husband, and the arrangements for his discharge from hospital:

> "The way in which the medical team looking after my husband meshed with the SSD hospital discharge team to assess his needs, and my needs in caring for him after his return home."

5.8 Other comments indicated how an apparently small change could make an enormous difference to the lives of individuals. A disabled service user described how a mobile bath scheme had done so much to help in cutting through the delays and bureaucracy around the supply of aids and adaptations. Instead of the usual nine month wait which many disabled people had experienced with social services, the mobile scheme was able to assess individual needs and arrange the loan of equipment within a month or two. Other improvements which might appear minor on one level, were also far reaching and of great importance to the quality of life of this particular service user. Changes had taken place at a day centre which she attended, including the departure of the manager, and staff attitudes had been transformed. The staff had all learnt more about disabilities and were now reported to be treating disabled service users "more as normal people, and not like children". This change in attitude was also apparent in a wider range of activities on offer at the day centre which reflected what service users actually wanted, and their rejection of traditional activities. The new facilities included aromatherapy, and there were plans to establish separate women's and men's groups.

5.9 Service users recognised the enormous potential of the community care reforms (although they did not believe this potential was being realised), and welcomed the real changes which were possible through greater flexibility of services, and the development of a more mixed economy of service provision. It was also emphasised that individual home care workers could make a great difference to the lives of individuals:

> "Some home care workers can be responsive to individual disabled peoples' needs and are kind and supportive."

5.10 While there was some support for the belief that community care services were improving, there were also, however, damning indictments of poor care in individual situations, and of the failure of community care to match up to the promise of change. A carer described the lack of information as the worst part of her experiences:

> "...the help that is on offer is not advertised well enough and people are often reluctant to seek help, feeling that they ought to be able to cope."

Another carer highlighted the problem of "uncertainty", and the worry about how much residential care for her husband would cost her. Alongside this was the sense that whatever happened, and what support was provided would to a large degree be down to the carer's own persistence; in short, "the feeling that it was up to me."

5.11 As we observed in the previous section, uncertainty, and fear about the future was also the experience of other carers, particularly of parents caring for their children with learning disabilities. As the parents age, and the children become adults, the question of future care looms large, and for some parents the most pressing issue is the availability of residential accommodation. In one locality in particular this arose as a central concern both in the course of the meeting of the focus group, and in the subsequent questionnaire responses from carers. One such carer commented that despite much lobbying within the locality, residential provision remained "of low priority". A joint development between health and social services in the locality had just secured a small residential unit, a respite care unit and a dedicated resource centre for people with learning disabilities. However, the residential provision was believed to be 'earmarked' for people with learning disabilities being discharged from long stay hospital accommodation, and did nothing to address the concerns of carers in the community.

5.12 The apparent demand for additional residential provision attracted the interest of an independent provider in the course of the focus group meeting in this locality. It is understood that subsequent discussions have taken place between the provider and the local Mencap. However, the local authority social services department seemed unlikely to wish to fund such care, preferring to support people with learning disabilities in the community. Nonetheless, if such support does not meet individuals' needs (or those of their carers), there are risks that services for people with learning disabilities may become reinstitutionalised, and that this may happen within the inappropriate setting of residential facilities developed for the care of elderly people.

5.13 Other criticisms of care centred on lack of reliability. A person with physical disabilities remarked that there was:

> "No regularity of assistance, for example - home carers are changed from day to day, without prior notice or the disabled person's consent."

Another disabled person observed that while a community nurse visited her "for about ten minutes every day", there was no substitute cover provided if the nurse was ill or on holiday.

5.14 Perhaps the most worrying issues identified concerned the power imbalance between service users and providers, and the consequences which this could have. As one disabled person commented:

> "If someone has a complaint about the service they receive, the process takes too long. The complaint is heard by social services (who are providing the service) and the disabled person receives little support. Meanwhile they are still dependent upon that service to survive within the community."

Another disabled person made similar remarks, and described her own experience of suffering "physical violence" from the very people who she was reliant on for care, and of her complaints being disbelieved. As she concluded:

> "Accountability is a fallacy; there is none. A person who wishes to complain stands alone against the brick wall of the whole of the SSD."

Certainly, these comments underline the extreme vulnerability of people being cared for in their own homes, and the central importance of adequate safeguards and proper complaints procedures.

5.15 Vision of the Future

In addition to providing a unique perspective on good and bad experiences of community care, service users and carers also had a clear view about how they wished to see changes made. Two key themes emerged. The first addressed issues of genuine empowerment, while the second was concerned with various aspects of change in patterns of service.

5.16 i) Involvement and Empowerment

Perspectives on this issue ranged from the general request for "greater user involvement", to more specific proposals on how this might be secured. One carer emphasised the need to incorporate involvement within the organisation of services:

> "Much more involvement of the service user and carer in planning and management teams within the various authorities, and having real power to ensure that they receive the services that they want, and not what the professionals perceive their need to be."

5.17 There was recognition that this process of liaison was not typically part of the 'culture' of health or social services authorities, and that entrenched attitudes were difficult to overcome when "they regard us as opponents." Another carer emphasised that attitudes needed to change in order "to accept the user of social/medical services as an expert on their circumstances."

5.18 Others emphasised the need to tackle attitudes of those providing and managing services. A lack of understanding of what it really means to be disabled, or to be dependent on others, was identified as a key issue. As one carer commented:

> "The professionals should practice using more compassion and less officiousness. The vast majority have no concept of the problems in caring or being cared for 24 hours per day, 7 days per week, 365 days per year."

5.19 Disability awareness training, accordingly, was seen as an important part of the education which needed to be provided for all staff. More radically, there was an emphasis on employing more disabled people at all levels of care organisations (such as social services), in order to shape the service from within and get away from tokenism:

> "Working in partnership with disabled people means working with disabled people, not just a token sentence or gesture."

5.20 Lack of understanding or awareness of disability was recognised as a wider issue confronting society in general. One disabled person described how a group of friends from the day centre try to get out for some social life in clubs and restaurants from time to time, and the lack of acceptability of their behaviour to the general public:

> "People look at you like you shouldn't have a laugh or a good time if you are in a wheelchair."

5.21 **ii) Changing Services**

The changes which services users and carers wished to see develop were of various types, but essentially addressed different aspects of flexibility and responsiveness. One carer vividly described the importance of a service that could respond when it was actually needed:

> "Caring for someone full time takes all the spontaneity out of our lives. We can never do anything on the spur of the moment, because cover for the person being cared for has to be in place before we can do anything."

5.22 The problems of having to plan a long time in advance also confront disabled people. One person described the frustrations of trying to get out of the house:

> "If you 'phone 'Dial-a-Ride' you can be on the 'phone for a couple of hours just trying to get through. Then when you do get through - they can't help."

This particular person had been unable to attend the focus group meeting because the transport which had been arranged simply did not arrive.

5.23 The shortcomings of information about services have already been mentioned, and for some respondents redressing this situation was of particular importance. Accessible information about services and benefits was emphasised, and it was recognised that this might mean different information strategies for different people, and that printed leaflets did not address all needs (particularly where there were problems of visual impairment, or a learning disability, or lack of familiarity with English). A disabled person also recognised the need to find out more about entitlements, and was currently trying to involve the Citizens Advice Bureau in running sessions at the local day centre. Information about advocacy support was also said to be lacking.

5.24 Finally, accessibility of services was emphasised, both in terms of physical access issues, but also in terms of access to processes. For example, care plan meetings were criticised for being organised in ways which excluded or marginalised the service user:

> "..eight professionals versus one disabled person is not acceptable or useful practice."

5.25 In this section we have drawn together the views of service users and of carers which were reflected in the course of the focus group meetings, and in responses to our questionnaire. These views provide a powerful critique of the experience of community care, but also an important endorsement of the contribution which good quality services and support can make to individuals' quality of life.

5.26 We do not claim that the views reported here are 'representative'. We did not assemble a group of individuals which was selected to typify a sample of service users or of carers. However, the similarity of issues identified in all five localities, and between different groups of service users and of carers, suggests that the views of users and carers more generally may not be dissimilar.

6.0 MEASURING SUCCESS

6.1 Criteria of Success

Following our detailed examination of good news and bad news in each focus group, we moved on to consider criteria of success in community care. This was intended to explore the developments which different stakeholders perceived should characterise community care, and to examine the ways in which this vision might differ from the pattern experienced currently.

6.2 As previously in this paper, we have classified the various criteria proposed by the different stakeholders in the groups within the four separate, but linked, areas of:

- outcomes for users/carers
- service changes
- policy and resources
- access to services

6.3 The indicators or criteria of success summarised below should not be dismissed as a 'wish list'. Perhaps, the most striking feature of the indicators is that they are realistic, and couched in terms which are wholly consistent with the stated objectives of the community care reforms. However, the inclusion of objectives concerned with increased choice; flexibility and responsiveness, and of meeting real needs both of service users and of carers, underlines the gap which still exists in many people's experiences, between 'aspiration and reality'.

6.4 Outcomes for Users and Carers

A range of criteria of success were proposed around outcomes. Most of these might be said to describe intermediate outcomes associated with the experience of using services, rather than with final outcomes in terms of any changes or benefit received as a result of the service. Intermediate outcomes included the following:

* User and carer satisfaction - reflecting smoothness and seamlessness of services.

* User and carer can sleep at night.

* Choice is on-going rather than one-off.

* Service quality is consistent.

* Services that empower users/carers (reinforcing independence and rehabilitation rather than dependence).

* Recognition that needs of users and of carers may differ.

* Services which address prevention and not just crises.

* Greater client control of services.

* Positive response of service to user-dissatisfaction or complaint.

6.5 Service Changes

We have commented earlier in this paper that changes which are taking place in services are currently doing so at the margins. Such changes refer to increased flexibility, responsiveness, and out of hours provision. Further changes of this nature were identified by the focus groups as essential components of continued service change. Specific criteria for evaluating service changes included:

- Genuinely needs-led services.
- Choices about the various ways in which needs might be met.
- Greater number and range of service providers.
- Improved hospital rehabilitation and after care.
- Flexible respite available (not just 9 to 5 service).
- Services which promote and enhance individuals' dignity.
- Services which are culturally and ethnically sensitive.
- Real user/carer involvement in planning and designing services.
- Flexible service which respond to changing needs.
- Individual care plan goals agreed with individual service user.
- Genuine choice between residential and non-residential services.

6.6 Policy and Resources

For changes to take place in services, what corresponding changes would be required at the level of policy and resources? The following were suggested by the focus groups:

- More even distribution of resources between client groups.
- Political ownership of community care objectives (alongside professional ownership).
- Decisions reached over health and social care boundary to produce services with no gap in the middle.
- A value-led approach to policy expressed in key standards of service contracts.
- Strategic approach to developing and managing the market.
- Appropriate joint training (across all providers).

* Good management of community care resources.

* Improved communication with the independent sector.

* Good community care planning:

  - assessing macro needs
  - recognising hidden needs
  - allocating resources at the local level.

* Provision of services which are co-ordinated and accountable:

  - to users
  - to the purchaser.

* Resources consistent with objectives (adequate time and staff, adequate systems and procedures).

* Management support to staff.

* Real involvement of users and of carers in planning at macro and micro levels.

* Clarity of eligibility criteria.

* Complementarity of eligibility criteria between NHS and social care.

* Responsive commissioning (moving from contract relationships to partnerships).

* Problem solving mechanisms established and operational.

6.7 Access to Services

Many of the success criteria around access issues identified the need for a more holistic approach to community care both within and between health and local authorities. Other issues emphasised the improvements needed in facilitating access through better information and advocacy, consultation and communication.

* Involvement of all relevant statutory agencies (not just health and social services).

* Seamlessness and continuity of service facilitated by one generic worker.

* Close linkages with primary health care services.

* Availability of advocacy and independent advice at all stages.

* Sensitivity to social, cultural and age differences.

* Comprehensive information about what services are available.

* Open access complaints procedure.

- Education for service providers in attitudes to disability.
- Mechanisms for improving dialogue and consultation with service users.

6.7 The above lists reflect the breadth and depth of criteria generated by the focus groups. In addition to highlighting issues which clearly still need to be addressed and improved, the criteria point the way to linking processes of monitoring and development.

6.8 **Monitoring Success**

In contrast to the long and wideranging list of criteria for monitoring the success of community care implementation which was proposed by the focus group members, was a far shorter set of indicators actually being employed to monitor local community care performance. Earlier in this report we observed that much of the central monitoring of community care implementation has focused on service systems and processes. Moreover, as we have remarked elsewhere, "much more important is the extent to which these processes are succeeding in delivering greater choice, opportunity and independence to individuals."[21] It is just such questions which future monitoring (at central and local levels) must address, and indeed the list of criteria presented above seems to provide explicit recognition of these issues. At present, however, this linking of monitoring to outcome indicators and development questions is conspicuously absent.

6.9 The shortcomings of local monitoring approaches have also been identified by the Department of Health. As the latest monitoring report comments:

> "...few LAs were yet attempting systematically to use improved outcomes for users and carers as the main criterion against which their arrangements were evaluated."[22]

In the absence of such outcome data, localities demonstrated progress with "accounts of systems working smoothly and new services in place." The Department of Health found various 'proxy criteria' were, however, being used as measures of progress. These included:

- sampling the suitability or flexibility of care packages;
- user and carer satisfaction data;
- take-up of new systems and services;

- increasing local placement options;
- growth in the range of care providers;
- increase in complex or intensive care packages;
- diversion rates from institutional to home care.[23]

6.10 Across our five localities very similar approaches were being employed, which also relied upon such 'proxy indicators'. In one locality a social services manager told us "we don't measure quality." This was not said with pride, nor was it a statement which failed to recognise the importance of quality; rather, it described the position which this locality had reached in the development of monitoring mechanisms which, to- date, had been largely concerned with systems and processes. The range of approaches to monitoring and sampling services included the following:

- Contract compliance monitoring of independent providers.
- Care plan reviews.
- Review of complaints.
- Bed utilisation audit.
- Hospital discharge (assessment arrangements).
- Hospital discharge audit.
- Diversion rates from residential/nursing home care.
- Assessment response targets.
- Inspection procedures.
- Budgetary monitoring.
- Monitoring unmet need.

6.11 In only one locality was inter-agency work underway on developing a local Community Care Charter which was intending to include both quantitative and qualitative performance indicators.

7.0 CONCLUSIONS

7.1 The five focus groups painted a picture of community care implementation featuring a considerable range of light and shade. In line with other findings, such as from central government monitoring, the focus groups reported areas of substantial achievement and development. Particular changes were evident in respect of the expansion of the social care market in community based services, and the emergence of more flexible and adaptable support.

7.2 Implementation difficulties were identified, associated with increasing strains on the boundary between health and social care, and with the consequences of resource compression for a policy based fundamentally on services being needs-led.

7.3 The views of service users and of carers provided an invaluable perspective on the realities of community care. While largely confirming a broad conclusion of improvement, continued experiences of poor quality care; lack of reliability of services; inadequate information; and insufficient consultation with, and accountability to, service users, provided a powerful critique.

7.4 Monitoring of local implementation remains dominated by process measures. That this should be the case is unsurprising given that the information requirements from the Department of Health have also focused to-date principally on measures which assess progress with the introduction of community care systems and processes. Such procedures needed to be put in place, but monitoring needs now to expand to address what is actually being achieved by these changed models of working. At present, many measures in use provide, at best, an indirect and partial indicator of achievement. However, the focus groups generated a substantial set of indicators which might provide the foundation for a more comprehensive evaluative methodology addressing the four domains of: outcomes for users and carers; service changes; policy and resources, and access to services. There is an opportunity to link monitoring and outcome evaluation to a clear policy and practice development strategy at both central and local levels, and to address directly whether and to what extent new service systems and processes are succeeding in delivering greater choice, opportunity and independence.

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