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**IMPLEMENTING THE NHS AND
COMMUNITY CARE ACT:
Opportunities and Pitfalls**

Policy Seminar organised
by the

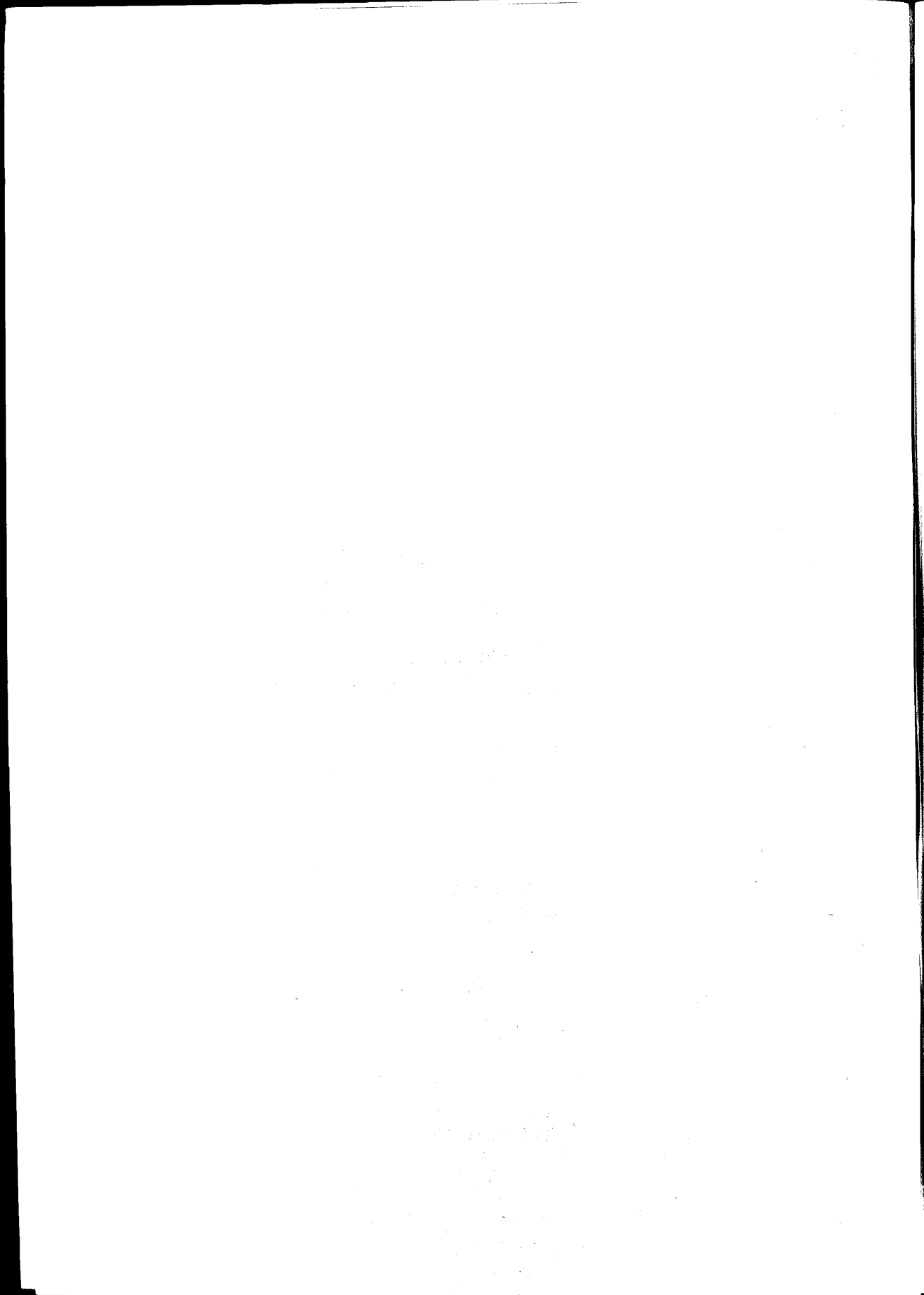
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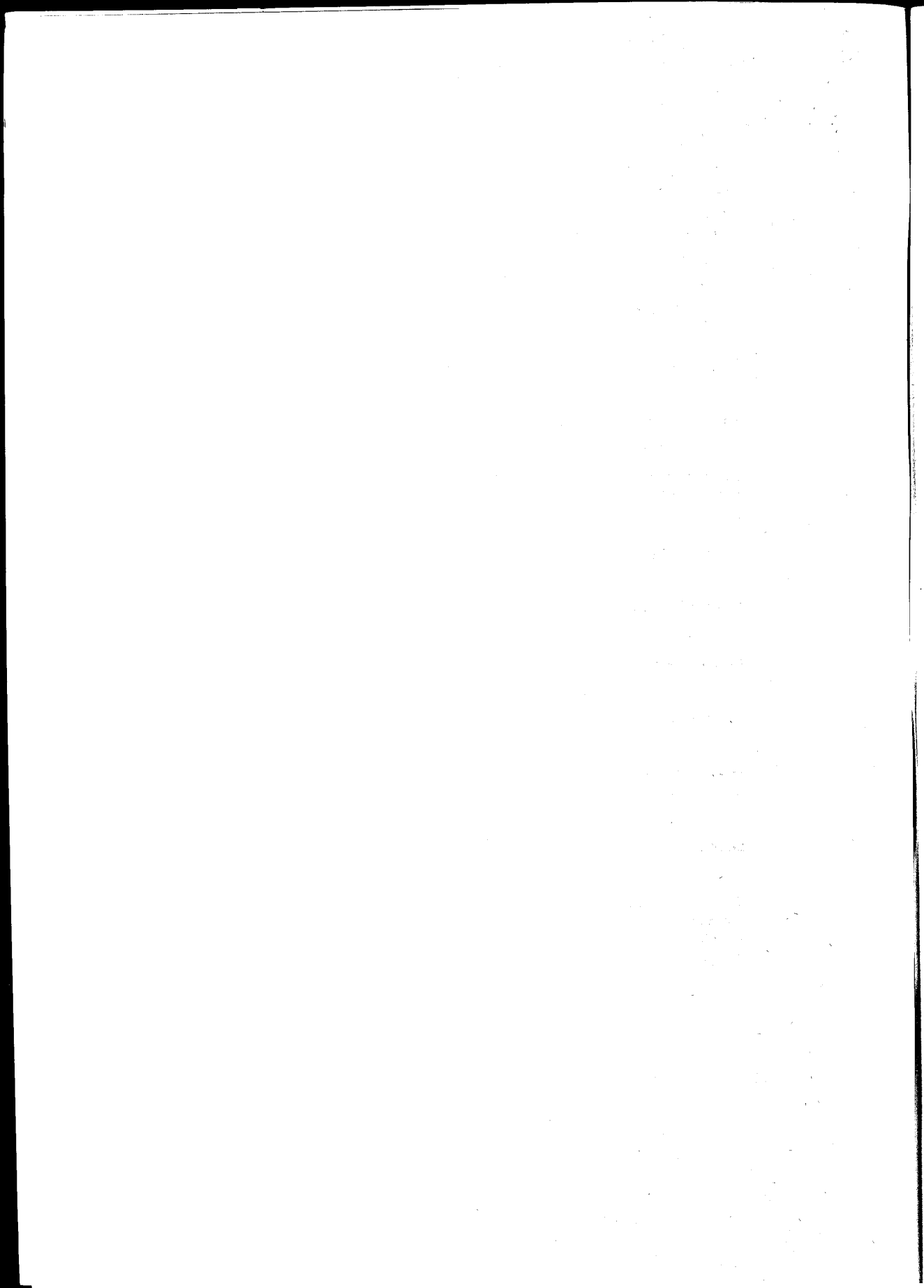
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30 January 1991



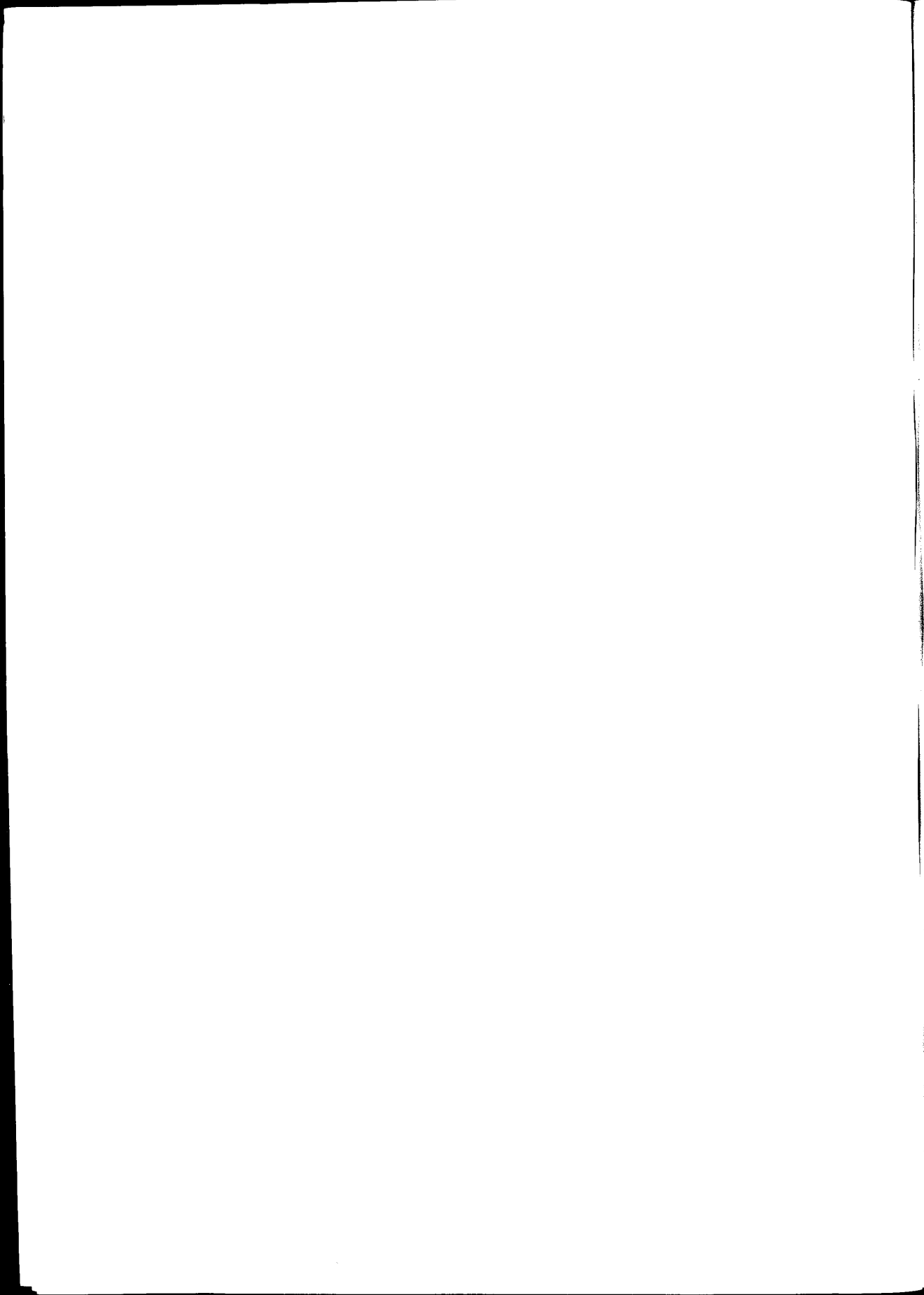
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REVISED AGENDA

- 9:45 Arrival and Coffee/Tea
- 10:00 **OPENING SESSION**
Judy Turner-Crowson, Roger Blunden and Rose Echlin welcome participants and outline the context and intentions for the day.
- 10:20 Introductions
- 10:40 **CHANGING PATTERNS IN MENTAL HEALTH SERVICES:
GOOD NEWS AND BAD NEWS**
Discussion takes place in twos, and each pair identifies one positive and one negative trend, with reports back starting at 10:55.
- 11:15 Coffee/Tea
- 11:35 **STRENGTHS, WEAKNESSES AND GAPS IN LOCAL SERVICES**
Two groups meet to identify priority needs for service improvement in Britain.
- 12:30 **FINDINGS OF GROUP MEETINGS**
A spokesperson chosen by each group sums up their conclusions.
- 1:00 Lunch at the King's Fund Centre.
- 2:00 **CHALLENGES AND OPPORTUNITIES IN IMPLEMENTING THE NHS
AND COMMUNITY CARE ACT**
Two groups meet to identify the most promising opportunities and the most serious risks in implementing the Act, and to suggest positive steps at each level.
- 3:15 Tea/Coffee
- 3:35 **FINDINGS OF GROUP MEETINGS**
Each group sums up opportunities and pitfalls and suggests how to ensure that the reforms are used to create better futures for individuals and families affected by disabling mental illnesses.
- 4:00 **SUMMARY, CLARIFICATION AND CONCLUSIONS**
- 4:30 Adjourn, with many thanks to everyone who came.
(Tea/Coffee available to those who can stay.)



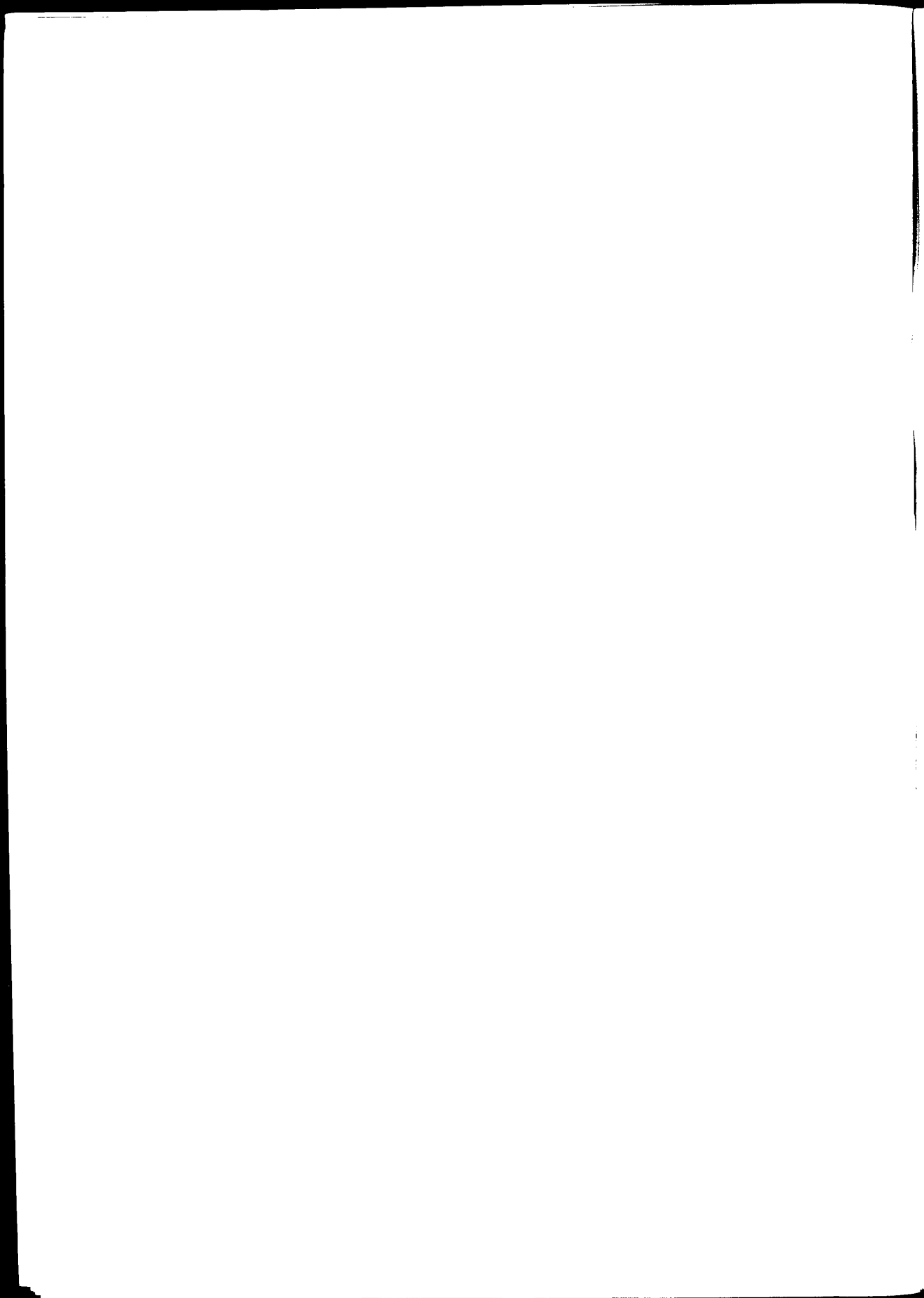
SUGGESTED OUTLINE FOR DISCUSSIONS
Implementing the NHS and Community Care Act - Opportunities
and Pitfalls

1. Positive and Negative Trends in Services and Settings
 - a. Where people are living and receiving treatment
 - b. Employment and meaningful daytime activity
 - c. Quality of environment and quality of life
 - d. Quality of treatment and rehabilitation services
 - e. Education, support and respite care for families

2. Strengths and Weaknesses of Local Services
 - a. Availability
 - b. Quality and appropriateness
 - c. Comprehensiveness
 - d. Accessibility and relevance to special groups
 - e. Priorities for service improvement
 - f. *Coordination*

3. Challenges and Opportunities in Implementing NHS and Community Care Act
 - a. Promising opportunities
 - b. Potential pitfalls
 - c. Promising local implementation strategies
 - d. Issues for further consideration at regional or national levels

4. What is missing, if anything, in national policy? What can be done to ensure that better and more appropriate living options, health and social services are available on a co-ordinated basis in every locality throughout the UK?



PARTICIPANTS IN POLICY SEMINAR

CONVENOR

Judy Turner-Crowson, Visiting Fellow in Mental Health Policy, King's Fund Institute (former Chief, Community Support Program, US National Institute of Mental Health) 126 Albert Street, London NW1 7NF. Tel. h (0689) 891320

FACILITATORS AND PARTICIPANTS

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John Jenkins, Mental Health Advisor, Department of Health, Elephant & Castle, London. Tel. 071-972 2000

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Tessa Jowell, Community Care Programme, Rowntree Trust, c/o King's Fund Institute, 126 Albert Street, London NW1 7NF. Tel. 071-485 9589 (from 1:00 pm onwards)

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Christina Murphy, Assistant Director, Community Care, North West Thames Regional Health Authority, Room 48, 40 Eastbourne Terrace, London W2 3QR. Tel. 071-262 8011

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Louise Pembroke, Secretary, Survivors Speak Out, 1 Brierfield, Arlington Road, London NW1 4LG. Tel. 071-387 8124

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Karen Salcock, CONTACT, Chesterfield Community Centre, Tontine Road, Chesterfield, Derbyshire S40 1QR. Tel. (0246) 74898 or 200111

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7880 (Mainline)

Dr Graham Thomas, Health Services
London W14 9JL
12:30

GOOD AND BAD NEWS ON LIVING OPTIONS AND SERVICES

Living options and service settings for people with mental health problems have been changing steadily in Britain for more than a decade. An unpublished draft report recently produced by the Department of Health includes the following facts which highlight some of the major changes from 1975 to 1989:

Beds available:	<u>1975</u>	<u>1989</u>	<u>Change</u>
specialist mental hospitals	86,967	40,637	-53%
local hospital units	10,996	18,233	+66%
total	<u>97,963</u>	<u>58,870</u>	<u>-40%</u>
Day places available for treatment, social support or vocational rehabilitation			
health authority sponsored	*	17,154**	
local authority sponsored	5,275	7,680	+46
Residential places available			
local authority	2,545	4,568	+79
voluntary	894	2,066	+131%
private	472	3,123	+562%
total	<u>3,911</u>	<u>9,575</u>	<u>+150%</u>
Consultants in mental illness	835	1,119	+34%
Community psychiatric nurses	*	3,535	?

(* Figures being obtained.)

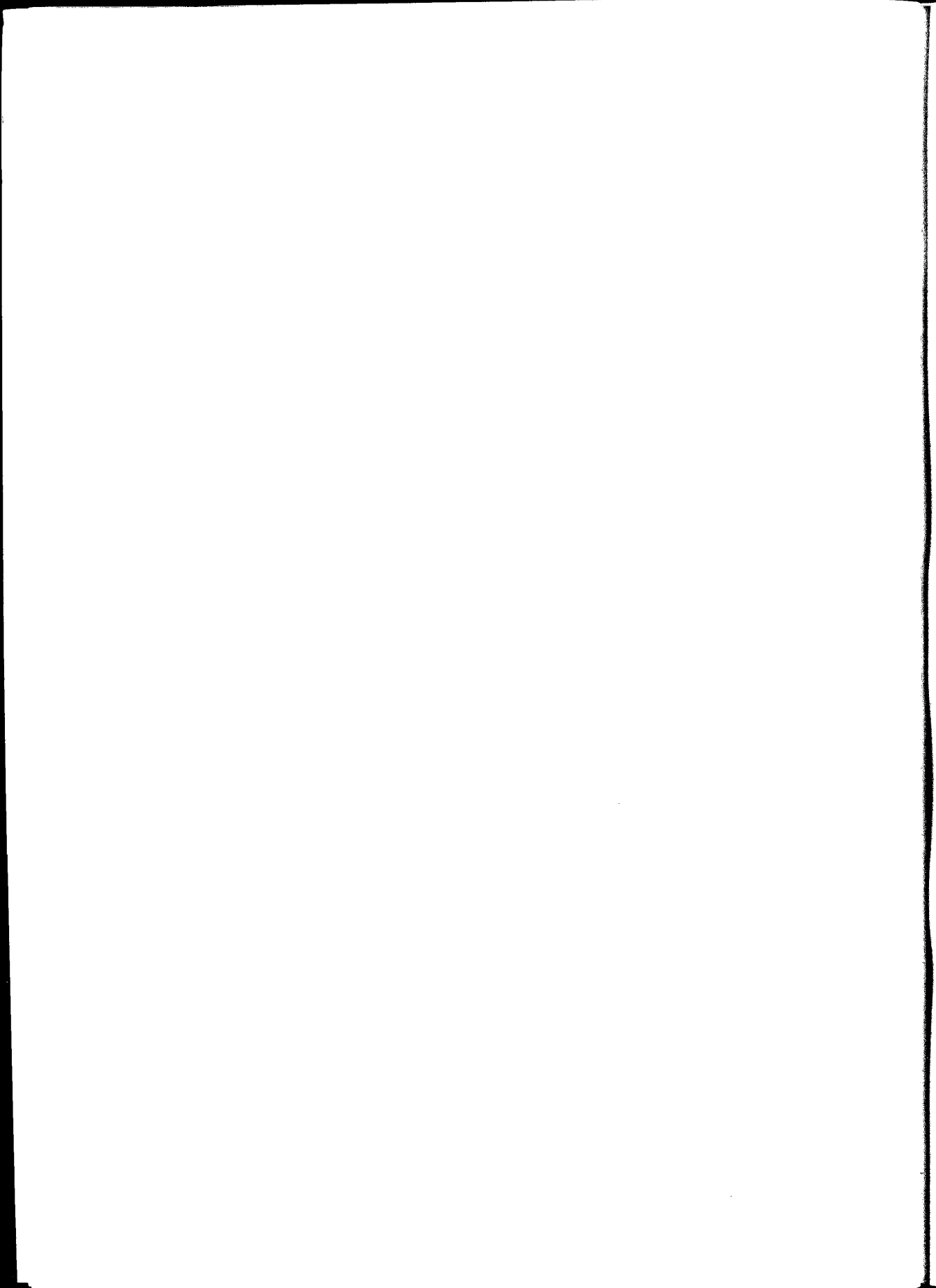
(** Based on 13 regions)

Questions for reflection and discussion are:

WHAT ARE THE MOST ENCOURAGING TRENDS INDICATED BY THESE FIGURES?

WHICH TRENDS GIVE CAUSE FOR CONCERN AND WHY?

WHAT KINDS OF FURTHER CHANGES WOULD YOU EXPECT OR WOULD YOU WANT TO SEE IN THE FUTURE?



AN ALTERNATIVE APPROACH TO LIVING OPTIONS AND SUPPORT SERVICES

A major goal of the NHS and Community Care Act is to promote greater consumer choice about where to live and what type of support services to use. It has been estimated that the numbers of people in Britain living in particular settings include:

Psychiatric hospital or psychiatric ward of a general hospital	50,000
In prison under psychiatric care	15,924
In residential homes	9,000
At home with family	?
Living in ordinary housing linked to support services	?
Homeless or living a marginal and isolated existence	?

There is also a total of 1,700 residents in special hospitals, of whom it has been estimated nearly half do not need to be there, and another 600 residents in regional secure units. Clearly many of them should be considered amongst those with disabling mental health problems.

QUESTIONS:

FROM YOUR OWN EXPERIENCE, WHAT ARE THE MOST ENCOURAGING DEVELOPMENTS IN RECENT YEARS ABOUT CHOICES OF PLACES FOR PEOPLE TO STAY WHEN SUFFERING FROM MENTAL DISTRESS?

WHAT ARE THE POSITIVE TRENDS IN THE QUALITY OF LIFE IN DIFFERENT KINDS OF SETTINGS?

WHAT ARE THE POSITIVE CHANGES CONCERNING EMPLOYMENT OR OTHER DAY TIME ACTIVITIES?

HOW MUCH CHANGE HAS THERE BEEN SO FAR ABOUT INFORMATION AND SUPPORT TO FAMILIES AND CARERS?

ARE THERE ANY NEGATIVE TRENDS THAT CONCERN YOU ABOUT LIVING OPTIONS OR SUPPORT SERVICES?

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STRENGTHS, WEAKNESSES AND GAPS IN LOCAL SERVICES

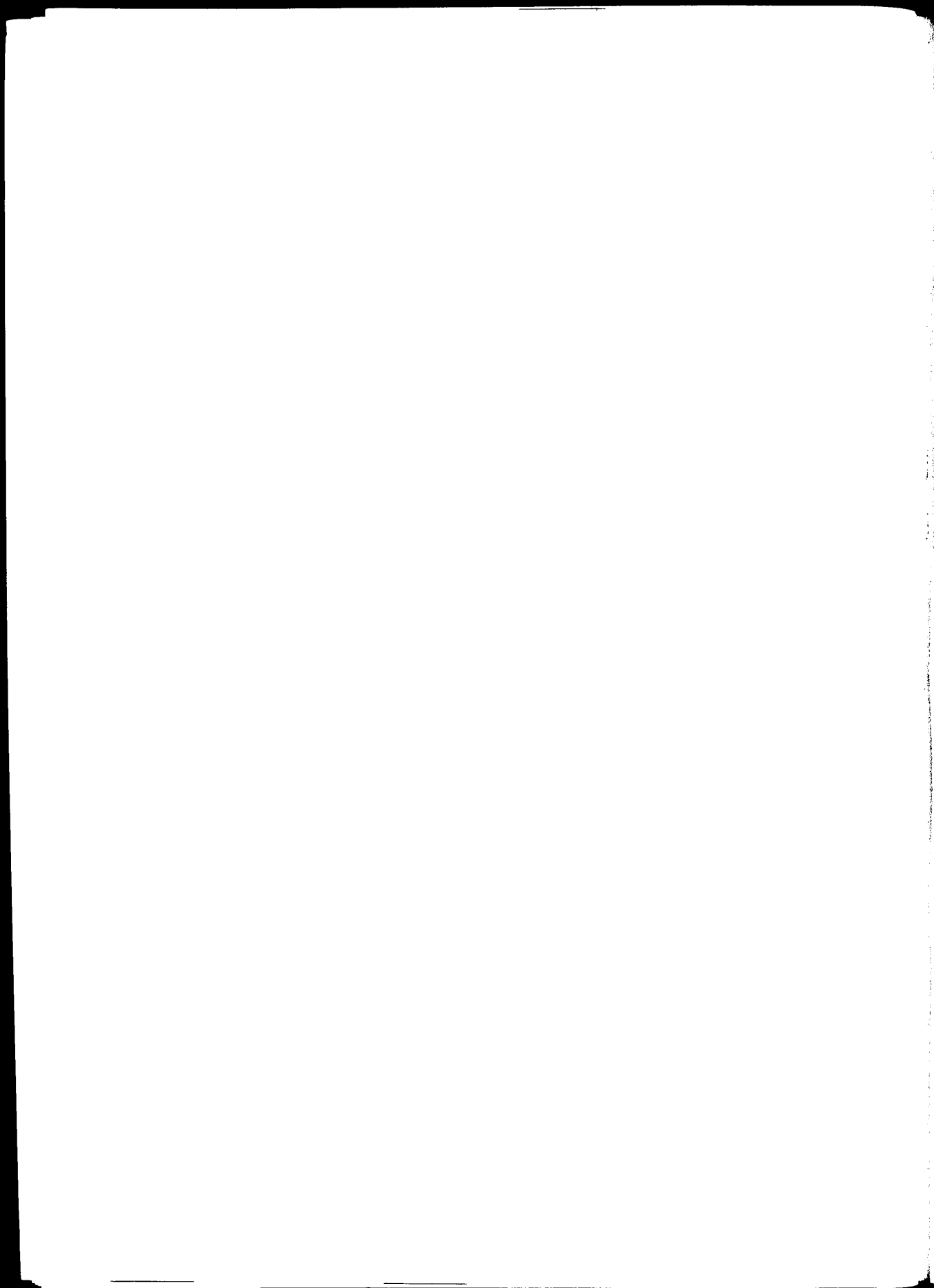
Most people agree that there is a great need to build up more community services into a comprehensive network that can meet the needs of the whole population of each locality.

The attached list of COMPONENTS OF A COMMUNITY SUPPORT SYSTEM which was developed in America as a basis for planning comprehensive local services can be used as a way of thinking of all the different kinds of services that may be needed. (You may note that inpatient services are considered here as one element in a community-based system, to be used only when other possibilities for coping with psychiatric crises are insufficient.)

Working in two small groups, please try to identify the main strengths and weaknesses of community services now available in a typical district in Britain (if there is such a thing.) Don't be confined to the service list if something you think is important is missing.

QUESTIONS TO CONSIDER

1. Are there important service elements missing from this list that should be available in every locality?
2. Which service elements are widely available in Britain and generally working well?
2. Which service elements are most likely to be provided in in hospitals more often than would be necessary?
4. Which service elements are most likely to be available only in a form that is insensitive to client preferences?
5. Which service elements are least developed in proportion to the need for them.?
6. How freely can clients move from one service to another or use several services at once? How well are the services co-ordinated at the client level?
7. Are there particular sub-groups of clients with needs in common, who are most likely to be unserved, underserved or inappropriately served?
8. Which localities in Britain are considered to have the best example of a comprehensive service, and how are their services similar to or different from this list?
9. Based on all this discussion, what does your group think would be a short list of priority goals for improving services so each locality offers a more comprehensive network throughout the country ?



DISCUSSING IMPLEMENTATION CHALLENGES

In considering the various provisions of the NHS and Community Care Act, groups may want to consider what can or should be done to deal with issues and challenges such as:

- a. Creating effective structures and processes for building agreement amongst key stakeholders about priorities for retaining, downsizing or expanding existing services and purchasing or providing new ones.
- b. Building clarity and generating agreement about critical elements in an integrated service.
- c. Making sure priority is given to those whose needs are greatest, and safeguarding against "cost-shunting," "creaming," and "dumping."
- d. Overcoming patchiness and inequities from one district to another.
- e. Safeguarding against erosion of resources for mental health services, and making better use of currently available funds, facilities and personnel, including the resources from specialist psychiatric hospitals.
- f. Making creative use of the greater amount of local flexibility and authority to create more innovative services and to offer more choice.
- g. Integrating or co-ordinating resources to create new settings to meet high priority needs in each locality, and overcoming the fragmentation amongst various public and independent health, housing and support services.
- h. Developing effective partnerships with the independent sector, safeguarding against over-development of profitable services and under-development of others, and monitoring quality and appropriate utilization.

CRITICAL QUESTIONS ABOUT THE REFORMS ARE:

1. What are the most promising opportunities?
2. What are the potential pitfalls?
3. What are the most promising local implementation strategies?
4. What, if anything, is missing from national policy?
5. What needs to happen at local, regional and national levels to maximize opportunities and avoid pitfalls?

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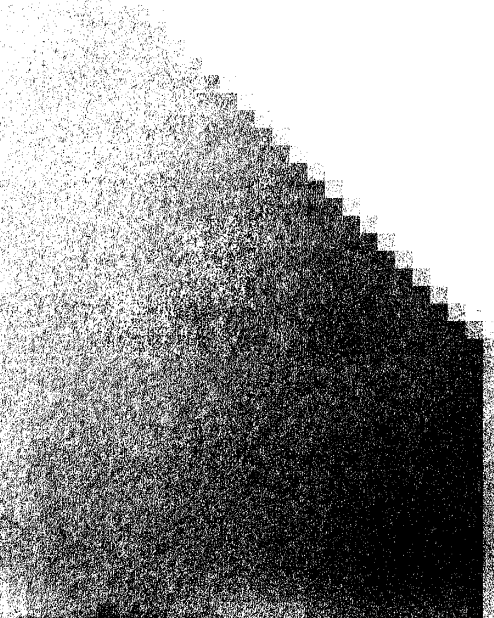
SOME KEY ASPECTS OF THE NHS & COMMUNITY CARE ACT

1. NHS Reforms
 - a. Changes in management and finance of hospitals
 - b. Separation of purchasing and provision
 - c. Independent trust options
 - d. Guaranteed local access to certain "core services"
 - e. Contracting out with the private sector
 - f. Changes in primary care services
 - g. Medical audit
 - h. New consultant posts
 - i. Other particularly relevant provisions

2. Community Care Reforms
 - a. Local authorities as lead agencies
 - b. Individual assessment, care planning, etc.
 - c. Community care plans, consistent with DHA plans
 - d. Specific grants
 - e. Contracting out with the private sector
 - f. Removing the "perverse incentive"
 - g. Arms length inspection units
 - h. Other provisions

3. Issues concerning Health Authority/Local Authority Collaboration
 - a. Incentives and disincentives
 - b. Encouraging total resource management, joint strategic planning and ongoing collaboration
 - c. Involving users, carers and other stakeholders
 - d. Linking with housing agencies
 - e. Overcoming patchiness and fragmentation

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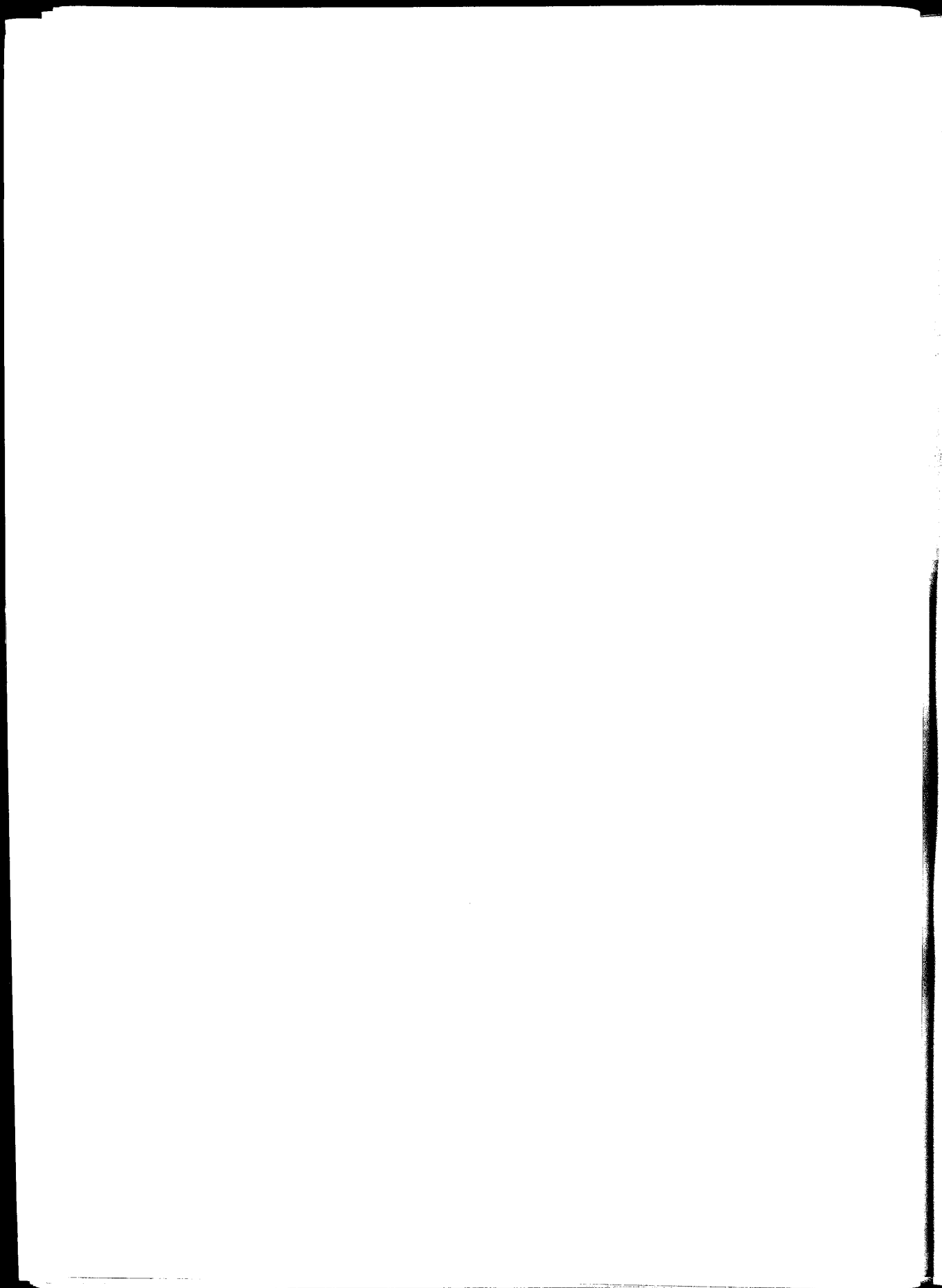
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US POLICY LESSONS FOR BRITAIN:
Summary of a Seminar at the
Mental Health Policy Resource Center, Washington, D.C.

What has the US learned about mental health policy since the 1960's that should inform future planning and might also be relevant to Britain? This was the focus of a seminar held October 22, 1990, co-chaired by Center Director, Leslie Scallet and Judith Turner-Crowson, Visiting Fellow at the King's Fund Institute in London.

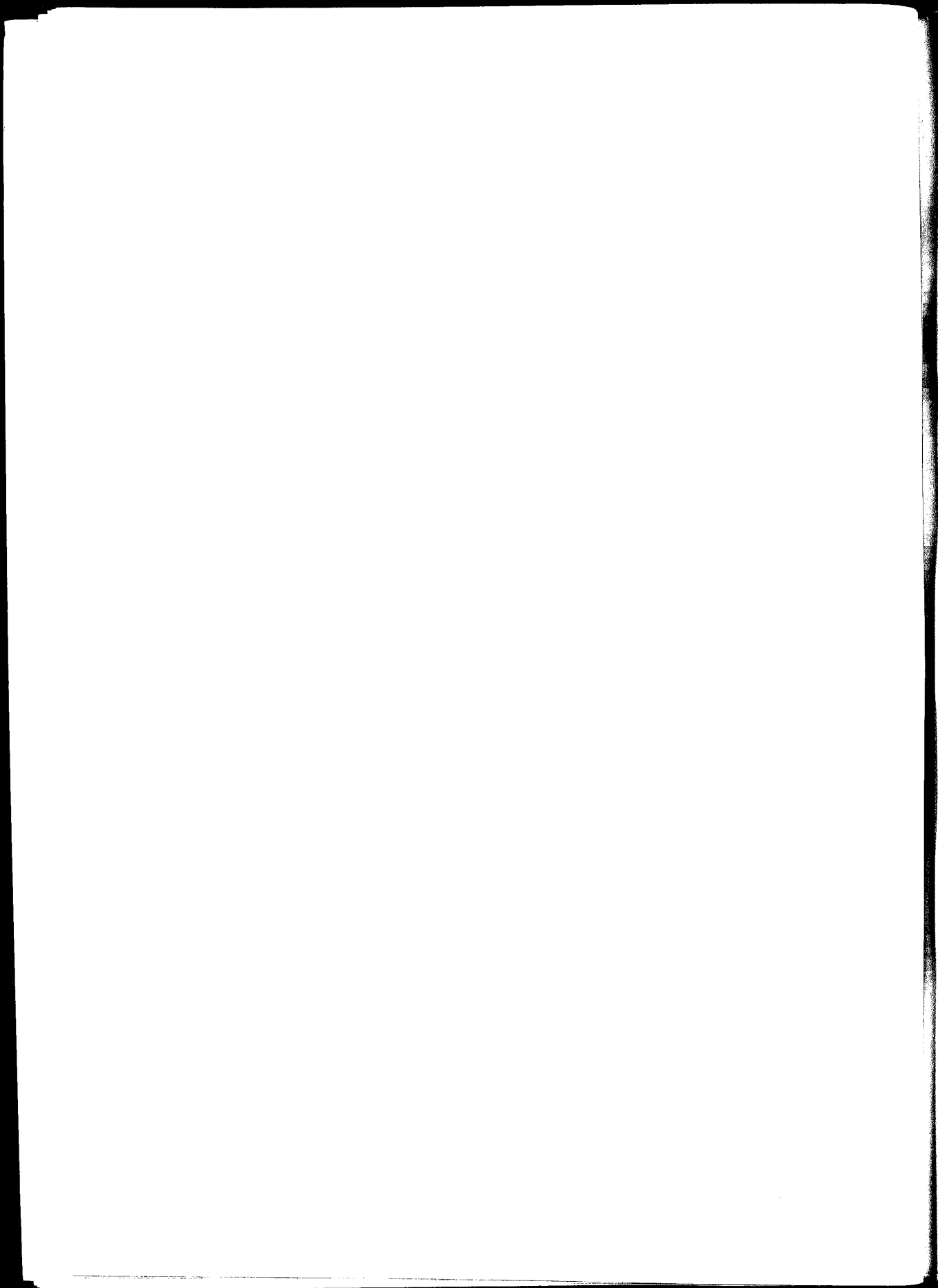
Co-sponsored by the Institute and the Mental Health Policy Resource Center, a nonprofit organization in Washington, D.C., the seminar included over twenty leading US thinkers and activists, including "psychiatric survivors," family advocates, State commissioners, managers, clinicians, researchers, and policy analysts. (See attached.)

Noting that British leaders sometimes cite US mental health policy as the kind to be avoided, Judy Turner-Crowson explained that the aim of her one year King's Fund project is to enhance the quality of the British policy debate through a publication on policy lessons emerging from both positive and negative aspects of the US experience, drawing in particular on her work as former Chief of NIMH's Community Support Program, (CSP).

Seminar Outcomes

Reflecting on US developments from the 60's to the 90's, participants agreed that the following lessons were most critical:

- Sound policy should consider and balance the perspectives all the relevant stakeholder groups -- primary and secondary consumers, clinicians and system employees, program managers and policy makers and the general public. Whenever particular interests have been neglected, serious problems have resulted. For example, though large public hospitals worked well for providers, researchers, families, the public, etc., they were stigmatizing and disabling for those they were primarily intended to serve -- people in need of asylum and care. When the federal CMHC (community mental health centers) initiative bypassed the interests of the state governments, a major stakeholder group, many problems arose.
- Participatory planning, with periodic reassessment and modification, is effective in balancing competing interests and securing the broad-based collaboration required for effective community-based services. Both the National Institute of Mental Health's CSP and CASSP (the Child and Adolescent Service System Program) have had positive experience in consensus building and strategy development which could be relevant for Britain or other countries.



- Clarity is essential about the numbers, location, needs and preferences of population groups to receive priority for publicly funded services. There must also be adequate incentives for provision of appropriate opportunities and services to people at highest risk of being unserved, underserved or inappropriately served; policies must, therefore, take into account the natural tendency of providers to focus on more rewarding clients and those from familiar cultural backgrounds.
- Plans should be function-specific, focusing on needs of the whole system and its clients, rather than on goals of establishing, preserving or abolishing particular organizational units. Many problems with deinstitutionalization came from insufficient attention to functions State hospitals had performed in the past, e.g., housing, welfare, employment of local staff, etc. The NIMH "community support system" CSS concept demonstrates a function-specific needs-based approach to planning for adults with disabling mental illnesses, and can be adapted for other groups, as it has been already for children.
- Desired policy outcomes should be clearly defined, e.g., improving the quality of life for primary and secondary consumers in particular ways. Data-collection and monitoring should inform planning and policy refinement; user and family leaders and other stakeholder representatives should participate in selecting outcome measures.
- Adequate, stable and predictable funding is essential, with appropriate fiscal incentives toward co-ordinated, continuous, community-based services. Fiscal incentives should be precisely tailored and periodically modified to avoid unintended negative consequences. Mandates, where necessary, should allow maximum flexibility.
- Sustained national leadership is needed, by government or other appropriate entities, to monitor emerging system issues, and develop conceptual approaches, goals and strategies, involving relevant stakeholder groups. Much can be achieved toward positive system change at relatively modest cost through strategic use of demonstration projects, conferences, and learning networks, e.g. CSP and CASSP, which have established State and local coalitions of people with a shared vision of system improvement and a commitment to positive change. Support of policy-relevant research is another vital national role.
- Unified local management and funding is needed for both acute and long-term mental health services. Important local leadership functions include constituency building and ongoing involvement of local level stakeholder groups to maintain broad-based community support.

... is essential to the success of the program and should be given the highest priority. The program should be designed to provide a comprehensive and coordinated effort to address the needs of the community. This includes the development of a clear vision and mission statement, the establishment of a strong organizational structure, and the implementation of effective communication and marketing strategies. The program should also be evaluated regularly to ensure that it is meeting its goals and making a positive impact on the community.

Plans should be developed to ensure that the program is sustainable and can continue to provide benefits to the community in the long term. This includes the development of a financial plan, the establishment of a governance structure, and the implementation of a monitoring and evaluation system. The program should also be designed to be flexible and adaptable to changing circumstances and needs. This includes the development of a contingency plan and the implementation of a risk management strategy. The program should also be designed to be inclusive and participatory, involving the community in the development and implementation of the program.

Desired results should be clearly defined and measurable, and should be based on a thorough understanding of the community's needs and the program's goals. The program should be designed to achieve these results through a combination of direct services, community development, and advocacy. The program should also be designed to be cost-effective and efficient, and should be able to attract and utilize resources effectively. The program should also be designed to be replicable and scalable, so that it can be implemented in other communities and on a larger scale.

Additional goals and objectives should be developed to address the specific needs of the community and the program's goals. These goals and objectives should be based on a thorough understanding of the community's needs and the program's goals. The program should be designed to achieve these goals and objectives through a combination of direct services, community development, and advocacy. The program should also be designed to be cost-effective and efficient, and should be able to attract and utilize resources effectively. The program should also be designed to be replicable and scalable, so that it can be implemented in other communities and on a larger scale.

Sustained national leadership is essential to the success of the program and should be given the highest priority. The program should be designed to provide a comprehensive and coordinated effort to address the needs of the community. This includes the development of a clear vision and mission statement, the establishment of a strong organizational structure, and the implementation of effective communication and marketing strategies. The program should also be evaluated regularly to ensure that it is meeting its goals and making a positive impact on the community.

Unified local management and leadership is essential to the success of the program and should be given the highest priority. The program should be designed to provide a comprehensive and coordinated effort to address the needs of the community. This includes the development of a clear vision and mission statement, the establishment of a strong organizational structure, and the implementation of effective communication and marketing strategies. The program should also be evaluated regularly to ensure that it is meeting its goals and making a positive impact on the community.

Unresolved Issues

In addition to broad policy lessons, a few controversial issues emerged. Among these was the question of whether some sort of long-term institutions will be needed in the future for a small residual population. There was also a lack of consensus on whether involuntary treatment was ever appropriate.

Another complex issue raised was the benefits and drawbacks of targeted services, focusing on well defined "priority populations." Priorities are important to make sure that people with serious needs are served first; however, there is always the problem of thereby excluding people who could benefit from treatment but do not meet precise criteria. Another concern about targeting is the tendency toward too much labeling, stigmatization, and segregation, and the fear that services designed for people with persistent problems may inadvertently perpetuate dependency and disability, whereas more optimistic approaches may help people recover more fully.

It was suggested that where possible, there is value in using ordinary service settings and in avoiding unnecessary segregation of people by disability or diagnosis. Said one "psychiatric survivor," "It should not always be necessary to show your schizophrenia card."

The issue of CSP and other services research was briefly discussed. It was pointed out that there has been an extensive and positive formal evaluation of CSP as a national program of system change, but that not all the services models generally promoted by CSP have been fully evaluated. It was agreed that basic human needs of people diverted or discharged from hospital must be met -- with or without in depth research. While it is clear that research is needed on how best to design, organize, manage and fund local components, programs and systems, research alone cannot substitute for continuing national leadership toward system improvement.

Applications for Britain

Judy Turner-Crowson is now consulting with colleagues about application of these and related ideas in Britain, where certain key features of the system offer an enviable simplicity and stability in comparison with the US: (1) free medical care is provided to all citizens from national taxation; and (2) there are only two tiers, national and local.

Patients enter the National Health Service (NHS) through a nationwide system of general practice medicine, and referrals are made to NHS psychiatric services as necessary. NHS's mental hospitals have been phasing down gradually over a long time, shifting services to psychiatric units in general hospitals, CMHCs, etc., managed by District Health Authorities, also

Three (3) copies

In addition to the above mentioned copies of the report, one copy shall be furnished to the Chief of the Bureau of the Census, Washington, D.C., and one copy to the Director of the Office of Management and Organization, Washington, D.C.

Approved: _____
Special Agent in Charge

Approved: _____
Assistant Director

The following information was obtained from the Bureau of the Census, Washington, D.C., on the subject of the above mentioned report:

Additional information is being furnished to the Bureau of the Census, Washington, D.C., and the Office of Management and Organization, Washington, D.C., for their information.

part of the NHS. Limited "bridge funding" is being provided during the transition period, but is far short of the need.

Local social services authorities have recently been designated "lead agencies" for "community care" and case management. As part of county government, these are funded primarily from the controversial "poll tax." Collaboration between these two levels and sectors historically has been difficult: boundaries, politics and mentalities conflict; capital and revenue are in short supply; and there are limited incentives to fill service gaps.

The recently-enacted NHS and Community Care Act seeks to improve efficiency and expand choice by bringing in market forces, encouraging both the NHS and local social services authorities to purchase or contract for some services from a variety of other public, nonprofit or private agencies. Hence, US experiences are particularly relevant.

Comments, Materials, Contacts and Visits Requested

As the seminar ended, it was clear that much further specificity is required to develop the implications of the US policy experience for Britain. Additional ideas and information would be particularly welcome on what has or hasn't worked regarding:

participatory planning,
needs assessment and outcome measurement methodologies,
health/social service/ housing relations,
county-based systems,
unified local mental health management and funding
"core services agencies,"
service contracting, performance contracts, etc.
family and consumer involvement in planning and policy,
targeted vs. integrated services,
and case management

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22 October, 1990

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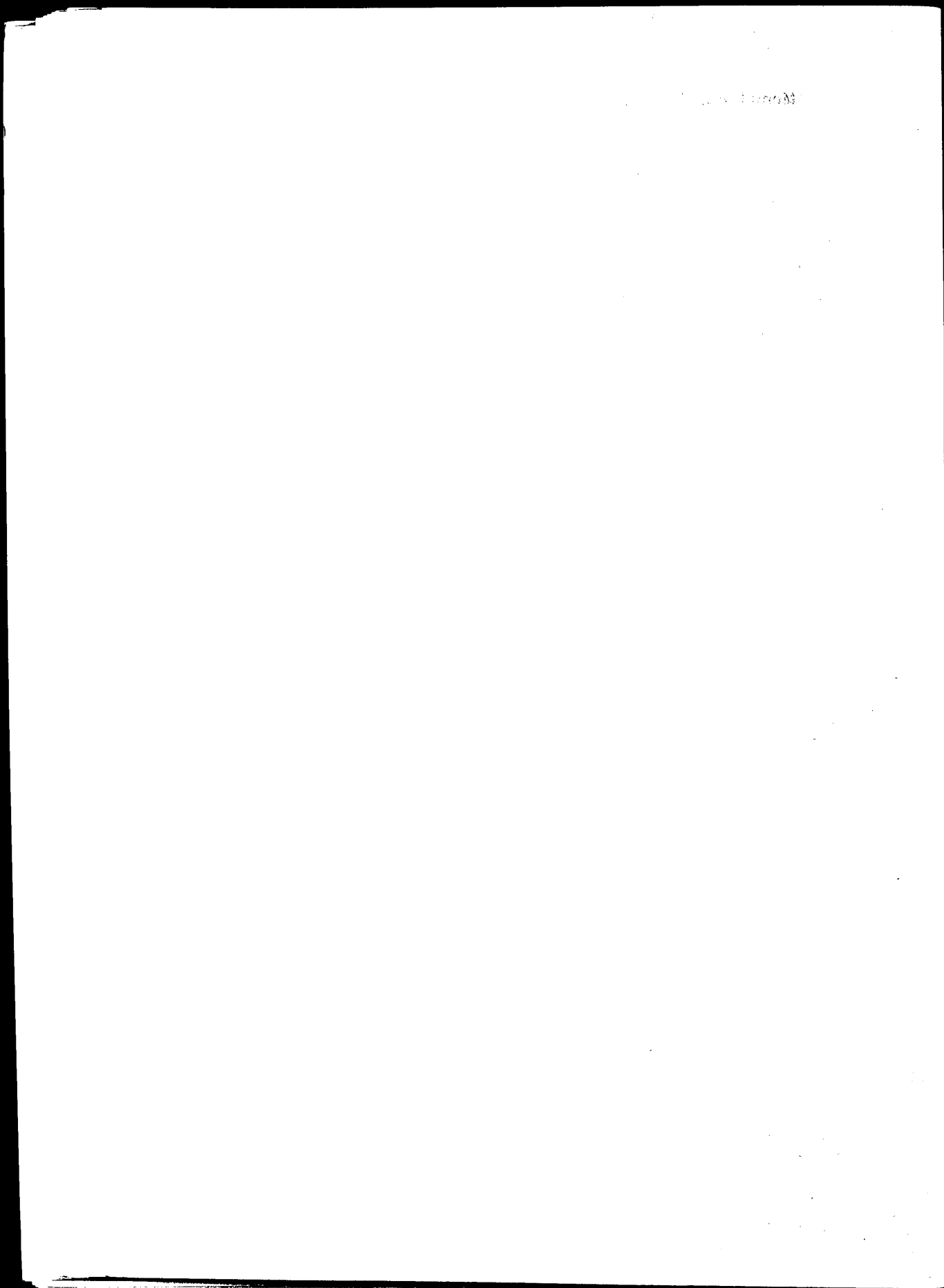
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[The page contains extremely faint and illegible text, likely bleed-through from the reverse side of the document. The text is too light to transcribe accurately.]

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