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Goalsetting as a tool for  
involving people  
with learning disabilities in healthcare

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March 2002

This research was submitted  
in fulfilment of the requirements  
for the award of  
Ph.D.

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## **Abstract**

**Background:** This research was undertaken during a period of rapid change within the NHS including the deinstitutionalisation of care, and increased emphasis on partnership working. The main aim of the study was to examine collaborative goalsetting as a means of (a) involving people with learning disabilities in healthcare decision making and (b) measuring the impact of treatment interventions.

**Study Design:** Initially a qualitative approach was taken. Case study methods centred on the introduction of Goal Attainment Scaling (GAS) as an individualised measure of outcome within two acute specialist in-patient units. Views of co-operative care planning and evaluation were elicited from patients and clinicians through the use of GAS. A unique patient interview schedule was developed incorporating pictures as a supplementary method of establishing users' views. Following this a two-phase interview survey included views of care from eight practitioners and 10 managers and service commissioners. Finally a survey of 94 key stakeholders within Scottish learning disabilities services was undertaken.

**Findings:** Practitioners had difficulties implementing GAS. Twelve patients were selected for the GAS study by members of the multidisciplinary team. In total 16 goals were set and scaled and impact measured. Six patients participated in interviews, describing the users' view of the therapeutic process. The findings highlighted barriers to the inclusion of people with learning disabilities such as rapid discharge, extreme behaviour and severe learning disabilities. In all surveys outcome measurement was viewed as complex as well as open to manipulation. A consistent preference for individualised measures of outcome for people with learning disabilities emerged. The research indicated multiple perspectives on stakeholders' attitudes to partnership working, regarding, for example, power differentials, professional territorialism and interagency mistrust.

# 1. INTRODUCTION

In 1996, at the start of this research the NHS was driven by the internal market, which separated purchasers and providers of care. This was in order to address key resourcing challenges. This government led 'market' approach to service delivery heightened interest in resource utilisation resulting in examination of issues such as cost/benefit and concomitantly outcome measurement (Davies 1994). Around this time clinicians were being challenged as well to demonstrate that treatment was 'evidence based'. However, there was no significant groundswell of opinion calling for health service users to have a voice in health care decision-making. This was the case despite the NHS being publicly funded, emphasis on consumers in the 1990s, and an emerging disabilities rights movement advocating greater empowerment for disadvantaged groups, such as people with learning disabilities.

The work described in the following sections aimed to examine the relationship between the above policy issues and the practice-based reality of routine clinical care for adults with learning disabilities. It was considered a particularly opportune time to carry out such an investigation because of ongoing far reaching changes within learning disabilities services, away from traditional hospital care towards small scale multiagency community based provision. Therefore, the study was born into a period of volatility encompassing a demanding government health strategy, a requirement for clinicians to validate care, and the first hint of the users' agenda.

## 1.1 POLICY ISSUES

Following a political change of government, the 1997 White Paper *Designed to Care* set about dismantling the NHS internal market. The primary thrust in this policy was a move away from a competitive service culture towards one of co-operation and partnership. Furthermore partnerships were not only to be developed within professional relationships there was clear government direction for the involvement of patients in healthcare. This marked the beginning of seeking and listening to the users' voice within the NHS.

At a strategic level the drive towards a partnership approach has continued to evolve, for example the Scottish Executive published the Health Plan in 2000 (Scottish Executive 2000a), which signalled a further move towards developing multiagency partnerships for planning healthcare. The Scottish Executive also undertook a national strategic review of services for people with learning disabilities one of the key recommendations of which was greater attention to the coordination of services between Local Authorities and Health Boards (Scottish Executive 2000b). The review also formally heralded the closure of all hospitals for people with learning disabilities in Scotland by 2005, with subsequent implications for restructuring of healthcare delivery. Indeed government intentions had been clearly signalled previously through the Department of Health document (DoH 1998) *Signposts for Success*. The purpose of this publication was to promote good practice by clarifying the role of the NHS in providing services to people with learning disabilities in the community. In fact good practice was firmly linked to interventions being based on evidence of effectiveness whenever possible. This ethos was mirrored

by the emergence of clinical governance within the NHS whereby practitioners are held accountable for their own practice. Therefore recent policy trends have had a compounding effect on practitioners with requirement for careful reflection on efficacy of practice both at an individual level and within service provision

The 2000b service review also strongly championed the users' place within care partnerships by placing the users' perspective at the heart of the Scottish Strategy for people with learning disabilities (Scottish Executive 2000b). Moreover the requirement for effective partnership with users is now legally enshrined policy through the *Adults with Incapacity (Scotland) Act 2000*. In essence the Act requires inclusion of those lacking in capacity (such as people with learning disabilities) as much as reasonably possible. Indeed onus is firmly placed on professionals to find inventive and robust methods of achieving meaningful partnerships with users.

Thus throughout the lifespan of this study evolving government policy has reflected the key themes of partnership working, user involvement and clinical effectiveness.

## **1.2 NORMALISATION AND EMPOWERMENT WITHIN LEARNING DISABILITIES**

It is generally accepted that the most significant impact on services for people with learning disabilities over the past three decades has stemmed from the ideologies of normalisation and empowerment (Emerson et al 2001). The

normalisation movement evolved from Wolfsonberger's (1972) original principle of normalisation and was extended through the philosophy of social role valorisation (SRV) (Wolfsonberger 1983), which emphasised the importance of social inclusion. Currently many services for people with learning disabilities describe their aims in terms of O'Brien's Five Service Accomplishments (O'Brien 1987), which have been explicitly derived from normalisation/SRV.

The accomplishments are:

- Community Presence
- Choice
- Competence
- Respect
- Participation

The normalisation movement has been key in advocating access to 'ordinary living' for people with learning disabilities through the process of de-institutionalisation. Concurrently health practitioners were challenged to re-evaluate the effectiveness of their services and interventions in light of the changing lifestyles of those for whom they provide care.

The roots of the ideology of empowerment can be traced to the civil rights movement of the 1960s with emphasis placed on direct empowerment of people with learning disabilities in gaining control over their lives (Emerson et al 2001). Key components of empowerment are inclusion and the right to participate in decisions, which affect oneself. However at the point of service delivery inherent tensions have emerged regarding the right to self determination of users and the historical dominance of professionals and carers in the healthcare decision making process. Furthermore particular challenges remain regarding the meaningful inclusion of those with severe disabilities, and extreme behaviour, within therapeutic partnerships (Ramcharan & Grant 2001).

Thus the rationale for this study grew out of a desire to explore the multidimensional interplay of evolving government policy, learning disabilities ideology and frontline routine clinical practice.

### **1.3 STUDY RATIONALE**

The work discussed in this thesis had, as its initial focus, examination of the effect of collaborative goal setting on therapeutic interventions and outcomes for people with learning disabilities who required specialist healthcare. The research was designed as a study of the measurement of treatment outcomes and the evaluation of therapeutic processes within two in-patient multidisciplinary assessment and treatment units for people with learning disabilities at Woodlands Hospital, Aberdeen. An individualised criterion – referenced measure of outcome, Goal Attainment Scaling (GAS) (Kiresuk & Sherman 1968) was introduced to the multidisciplinary staff team of

Woodlands. Practitioners' and patients' views of the utility of this technique for promoting co-operative care planning and for evaluating the impact of interventions was elicited. The main concern of this first stage of the research was to discover how practitioner/patient expectations of health input was translated into a common agenda and subsequently how the impact of health interventions was jointly evaluated. The GAS study was therefore a crucial vehicle for the examination of these issues which are embedded within routine clinical practice. This provided the opportunity for investigating how practitioners grapple with key issues such as developing an evidence base for their practice, apply a client centred approach to care, and involve users as partners in decision making.

The area this study chose to examine was considered highly relevant and topical in light of the continuous barrage of policy directives previously described. It was important and timely to ask: What is happening to health teams as deinstitutionalisation accelerates? Who is involved in setting healthcare goals? How is intervention delivered and evaluated? Woodlands Hospital was considered a hospital particularly appropriate in focussing attention on these questions. The two units included were designed to offer admission for those requiring short term acute and specialist assessment and treatment at times of major breakdown in health status with the aim of a timely return of individuals to their community homes. Thus care planning required multiagency co-ordination with clear potential for involvement of individual patients and/or carers. An important aspect of this study was its practice based perspective. The underlying philosophy was to take a practitioner orientated



approach. It was very much designed from the perspective of a healthcare professional (the researcher) trying to make sense of the interplay between government policy and frontline routine clinical practice, and the subsequent impact on the service received by patients. The study was not therefore an attempt to examine the situation observed in relation to theoretical models of clinical practice, or management operational models. This study represents an attempt to understand the issues as they emerge directly from data provided by practitioners and service users. The approach adopted was underpinned by a commitment to grounded theory (Strauss & Corbin 1998). The emphasis on actual practice was important because of recognised difficulties in effecting changes to established health practice irrespective of practitioners' dissatisfaction with the status quo (Foy et al 2001). Thus the diffusion of strategic policy and ideology into grassroots practice was likely to fail if government directives were viewed as empty rhetoric, incompatible with work place realities. Thus it was vital to find out more about routine health decision making with and for people with learning disabilities. To what extent was treatment based on evidence? How was health improvement measured? Which professionals and agencies were involved in care planning? To what extent were users and carers involved in the therapeutic process? Was it in fact feasible to include users in health planning and evaluation? It was important to find out about the multiplicity of influences on front line clinical decision making so that methods could be considered for effective support of practitioners and users to achieve best possible health outcomes.

Indeed the author had become aware of complex and multifaceted issues impacting on decision making when conducting previous studies with children with learning disabilities. Thus prior work had centred on establishing intervention priorities when offering occupational therapy (Young et al 1992) and also the measuring of outcomes of jointly set treatment goals (Young et al 1995). The work had additional resonance with the researcher's own professional development, both in terms of personal responsibility for efficacy of practice, and the exploration of occupational therapy ethos of clinical practice. Reflections from these prior studies were incorporated within the design of the research described in this thesis through choice of evaluation tool (GAS) selection of a practice based approach, and strong focus on facilitation of user involvement.

While the original intention was to restrict the research to a clinical study of GAS, undertaking the research made it clear that it was necessary to have a wider remit. Significant difficulties were found in achieving the participation of health professionals in the implementation of the specific goal setting technique. On the other hand users achieved greater participation than foreseen. Therefore the work raised questions of fundamental importance regarding outcome measurement, teamworking and the ability of people with learning disabilities to make decisions about their healthcare.

Thus it was judged important to explore the different perceptions of a wider group of stakeholders. This was to include commissioners of service and managers from across a multiagency spectrum as well as practitioners and users

of front line services. This would capture multidimensional aspects of health care for people with learning disabilities and at the same time would lessen the dangers associated with views being considered in isolation. For example the presenting of user views alone has potential to ignore complex interactions amongst people with learning disabilities, their families, their services and their communities. It has been argued that individualistic views may establish a user view, but not the supporting or contributing tensions produced in interactions with other stakeholders who may affect life experiences (Ramcharan & Grant 2001). Thus a multidimensional research design was considered important both in enriching and validating findings and indeed in providing well supported conclusions. Therefore the final phase of the study entailed a Scottish survey of adult learning disabilities services focusing on determining the nature and extent of outcome measurement within care provision. The survey encompassed Health Boards, Local Authorities, NHS Trusts, and representation from non-statutory organisations and user organisations. The survey was viewed as important in helping to place the first phase of the work in Grampian within a national context.

This thesis provides a contribution to knowledge in terms of evidence about the role and utility of goalsetting as a way of involving users in health planning and evaluation. The extent to which co-operative goal planning exists within learning disabilities services is critically evaluated and the work analyses factors which hinder implementation of the technique. The study also seeks to discover whether tensions exist at the interface between top down government strategy and bottom up work practice. The strategic influence on routine

practice, for example in relation to consumer involvement, is likely to become apparent at the interface between (i) managers/practitioners, (ii) different professional groups, and (iii) professionals/users.

Knowledge of different perceptions and expectations in relation to health service delivery will be crucial in managing conflict and promoting effective partnerships.

#### **1.4 AIMS AND OBJECTIVES**

The overall aims of this work were to examine the collaborative setting and reviewing of treatment goals as a means of (i) involving people with learning disabilities in healthcare decision making and (ii) measuring the impact of health intervention. Within this overall context, the specific aims of the study were as follows:

- To determine the extent to which the process of goalsetting is used by healthcare professionals for people with learning disabilities.
- To discover the nature and extent of users' involvement in setting goals for their own care.
- To establish the relationship (if any) between individualised goal setting and outcome evaluation.
- To determine the utility of GAS as a measure of establishing expectations of therapeutic input and ultimate satisfaction with outcome.
- To evaluate GAS as a methodology/mechanism for partnership within health care.

## **Objectives**

To undertake a study using GAS as a means of examining health input and evaluation with people with learning disabilities and associated health problems/severe challenging behaviour.

To audit care outcomes for patients of Oak & Pine Units within Woodlands Hospital using goal attainment scaling.

To use pictures as a supplementary means of eliciting patient views of therapeutic input through developing interviews based upon analogue scales and photographs.

To undertake small scale interview surveys on the views of clinicians, managers and commissioners regarding health input and evaluation for people with learning disabilities.

To conduct a Scottish postal questionnaire survey of views of the nature, purpose and extent of goalplanning and its evaluation, as perceived by stakeholders (policymakers, commissioners, providers and user organisation).

To compare and contrast all views on care outcomes/user involvement.

The above aims and objectives form the core of work described in subsequent chapters of this thesis. A review of research literature relevant to the study aims is presented in Chapter 2, however as the literature is continually growing reference to recent work is found in the discussion. The method of achieving

the aims and objectives including the choice of research design and a discussion of methodology employed is described in Chapter 3. The findings of the research is presented in Chapter 4.

Finally an appraisal of research design and methods is given in Chapter 5, along with discussion of the key results of the study and their implications, and analysis of potential areas for future research, and conclusions.

## **2. LITERATURE REVIEW**

### **2.1 INTRODUCTION**

The review of literature presented here underpins the research reported. In this section the concept of therapeutic health outcomes, with particular reference to the effect of interventions for people with learning disabilities, is central to the literature. Four main themes were identified from publications:

- Outcome measurement within health services - particularly relating to clinical outcomes within routine practice.
- User involvement in healthcare - especially involvement of people with learning disabilities in therapeutic endeavours.
- Goal attainment scaling - as a method of promoting a partnership approach to health care decision making and evaluation.
- Goal setting as a treatment strategy within health services.

Much of the literature comprises theoretical and review papers with relatively few articles reporting on data-based studies. Additionally many of the empirical studies reported in respect of people with learning disabilities have been carried out on small samples (less than 20 subjects) and the majority of research designs are qualitative (Hayman and Huckle 1993, Glover et al 1994, Dagnan et al 1994, Young et al 1997). Speculation as to why so few large scale studies of this population can be found may relate to the devalued status of people with learning disabilities within society in the past. Historically this client group was cared for in large isolated institutions where they received

paternalistic patient care at best and custodial warehousing at worst (Sines 1995). It could be argued that these large captive patient groups might have provided an ideal study base for evaluating the effects of healthcare. Yet paradoxically it seems that the trigger for systematic evaluation has been the trend towards community care with resultant hospital closure, illustrated in the work of, for example Booth et al (1989), Lindsay et al (1994), Deb (1995).

Conventional research tools often were found to be inappropriate for use with those who had severe intellectual or communication limitations. Even in studies designed to explore the needs and views of people with learning disability difficulties relating to engagement and communication have often resulted in the exclusion of severely disabled people (Dagnan et al 1994, Simon and Roy 1996). Thus despite efforts to create a means of expression for those with severe disability, many still have no voice.

The most long established and developed body of research within health disciplines is perceived to lie in the field of medicine. Davies (1994) has pointed that indicators of mortality and morbidity have been used for generations to measure, track and report on health status. Doctors have subsequently attempted to use knowledge and insights to alter rates of death and disease, thus influencing patient outcomes. In comparison the research base within the remedial therapies is at a relatively rudimentary stage of development, particularly in respect of occupational therapy. For example, there are few standardised occupational therapy assessment procedures or even published observational tests (Eakin 1997). Published empirical research has



only recently started to appear with regularity in the UK, previously occupational therapy research studies were more evident in the USA and to a lesser extent in Canada. Currently in the UK, many aspects of occupational therapy input continue to be based on theory and beliefs about how interventions work, rather than on knowledge of what actually works (Bannigan 1997).

From a management perspective Davies (1994) had already highlighted the fundamental question in relation to health care delivery, viz., “What works?”. Health care purchasers needed to know the value they receive for cash invested not just in terms of total expenditure but also in relation to health benefits (Davies 1994). It has often been assumed that health service managers were primarily interested in outcome measurement as a method of rationing limited resources especially when health providers were required increasingly to justify resource utilisation (Orchard 1994). However, health managers faced the additional task of deciding what services could be substituted or eliminated to control costs while maintaining quality (Davies 1994). Clinicians and patients were involved in choosing treatments that would improve health and not just limit length of stay.

Thus the themes of cost, quality and effectiveness currently driving the outcomes agenda present difficult and highly complex choices and trade-offs. The recent political experiment with a health services internal market might be viewed as having contributed to this process.

However the demise of the market approach in favour of partnership and co-operation is likely to herald a new chapter in the measurement and interpretation of outcomes.

### **2.1.1 Literature Search Strategy**

Literature searches were performed using the following databases:

CINAHL	1982-2002
PsycINFO	1984-2002
EMBASE	1988-2002
ASSIA	1990-2002
MEDLINE	1996-2002

- Hand searching supplemented database searching
- The search was confined to English language reports
- Key terms employed were: setting goals/objectives; outcome measures; goal attainment scaling; client centred practice; learning disabilities; multidisciplinary teams

## **2.2 OUTCOME MEASUREMENT**

### **2.2.1 Evolution of Outcome Measures**

Health care practitioners always have been interested in the clinical outcomes of their intervention (Long 1995). The systematic recording of changes in patient health status related to specific intervention strategies is a long-established form of clinical evaluation within the National Health Service. Indeed Appleby (1994) refers back to Florence Nightingale's intention to

measure and quantify outcome through ideas of triage. However, patient outcomes such as performing day to day activities with minimal disruption, or broader health outcomes such as economic stability through paid employment have not necessarily been part of the outcomes agenda (Long 1995).

Historically the outcome of patient and practitioner have been to an extent entwined (Davies 1994), but past practice was often based on patient views which had been modified by professional perspectives and judgements (Dixon & Long 1995). In addition it was often assumed that health practitioners were appropriate patient advocates. Recent interest in patient outcomes has emerged in response to the growth of consumerism and the development of reliable and valid patient based instruments (Davies 1994). Indeed Gardner et al (1997) has noted that the shift in society from an industrial to a service economy resulted in quality being determined at the point of interaction with the customer whose desired outcomes were diverse and did not remain constant over time.

Hence it was argued that organisational success depended on firstly identifying customers' outcomes and then adapting the service accordingly. In the USA this concept was examined by the Council on Quality and Leadership In Supports For People With Disabilities (The Council) who, in 1991, decided to develop a new set of individualised outcome measures to enhance quality for users. This was in contrast to previous methods of measuring outcomes which focused on evaluating compliance with organisational process or standardised scales (Gardner et al 1997). Since 1991 The Council has been engaged in developing a national accreditation programme based on values such as age

appropriateness, least restriction, community participation and social integration. Council representatives conducted focus groups and individual meetings with people with disabilities (including learning disabilities) to identify the priority outcomes they expected from services and supports. The Council's 1993 Outcome Based Performance Measures was used in 447 interviews as part of accrediting 54 organisations in 16 states throughout the United States. Results of the interviews identified seven major factors (Identity, Autonomy, Affiliation, Attainment, Rights, Health and Safeguards) which form the basis of the Council 1997 Personal Outcome Measures.

The Council found the process of developing person-centred outcomes challenging in terms of staff training and development, organisational restructuring, systems analysis and defining methodology. However feasibility of measuring quality in terms of personal outcomes was demonstrated and the results considered superior to previous quality measures such as compliance with organisational process or standardised outcome scores. Gardner et al (1997) argued that 'In a time of decentralization, rapid change, and increased decision-making by self advocates, quality measurement systems must emphasize a concern for individuality, adaptability, and change rather than the earlier hall marks of quality, such as standardization, uniformity, predictability, and conformity'.

### **2.2.2 Outcome and Attributability**

Shanks and Frater (1993) define outcome as a result for which neither cause nor effect is specified. They further define health outcome as a result which is

manifest as a change in health status although causal factors may not have been established. In contrast health care outcome is viewed as at least partly attributable to specified health care even though the result is not necessarily manifest as change in health status. For example, it may be alteration in social or economic circumstances. Finally Shanks and Frater (1993) contend that health outcome of health care is attributable and responsive to health care with both cause and effect known and specified. However attributability is essentially viewed as a matter of degree because of the multiplicity of factors impacting on everyday living. Furthermore in the broader context of human life a good health outcome of health care may still leave a compromised way of life, for example in relation to employment (Shanks and Frater 1993).

Within research, confidence in attributability is established through the methodology of the randomised controlled trial (RCT) where selection bias is avoided by randomisation and confounding variables are controlled. However use of the RCT within routine clinical practice is often impractical and doubts have been raised about the validity of generalising results from controlled research into routine practice (Long 1995). Shanks and Frater (1993) propose observational inference as an alternative pragmatic clinical strategy whereby observed associations between process and outcome are tested for causal links; the rationale being that it is useful to know *how* someone feels and functions even if it is not known why.

### **2.2.3 The Use Of Outcome Measurement In Clinical Practice**

Outcome measurement has been defined by Davies (1994) as: ‘The assessment, at a point in time, of one or more of the variables defined as “outcomes” or the results of the interaction between a patient and a health care delivery system.’ Choice of measurement instruments and procedures must reflect the need to record whether desired outcomes are being achieved (Long 1995). Different methods are available for a wide variety of areas to be measured for example, measures of physiological parameters, descriptions of patient quality of life, standardised measures such as the Nottingham Health Profile and individualised measures such as goal attainment scaling or patient specified outcomes. Instrument selection should take into account the quality of the measurement procedure in terms of reliability, validity and responsiveness to change, and both ease of use and clinical utility within routine practice (Long 1995). Moreover it is important to include factors relating to patient desired outcomes when choosing measurement instruments rather than selection being dominated by the views of clinicians or researchers as discussed in following sections.

Outcomes can be monitored through repeated measurement over time in ways that permit causal inferences about what produced results. This information may subsequently be used in the process of clinical decision making, patient care management and service delivery to achieve optimal patient outcomes (Davies 1994). Choice of appropriate timescales and monitoring points is complex, particularly in the management of chronic health problems where input to a patient may be provided by acute, community and primary care

services at different stages in a disease process. Decisions will be required as to who takes responsibility for longer term outcomes (Long 1995).

Additional complications may arise in relation to outcomes data collection across operational boundaries and also in relation to the burden of data collection on clinicians. Long (1995) warns that unless these issues are resolved there is a danger that the focus will remain on short term outcomes to the detriment of high quality patient care.

#### **2.2.4 Outcome Measurement and Therapy**

Evaluation of health treatment has to date been dominated by measurement of medical outcome of care with little reporting of the contribution of nursing and the professions allied to medicine (Chesson et al 1996). However nurses are the biggest and the most expensive staff group in the NHS, consequently purchasers and managers have a keen interest in whether the actions they take in care delivery have a positive effect for patients (Bond 1991). Running parallel to this agenda is the nurses' own interest in pursuing professional recognition.

It has become widely accepted by most health professions that sharper focus on the cost/benefit of various approaches to care is required. However professional concern regarding interpretation of such information remains (McNab 1994). For example in a survey of physiotherapy and speech and language therapy managers, carried out in North East Thames in the early nineties, all respondents believed that outcome information should be provided

to purchasers but it was argued that therapists must be closely involved in the development of outcome information to influence resource allocation (McNab 1994). Wider knowledge of outcomes was perceived as having the potential to impact on clinical freedom, but therapists' own willingness to question current practice or use of resources was believed to be increasing. It was argued that fair allocation of resources was only achievable by purchasers and therapists working in partnership (McNab 1994).

A Scottish two-stage survey of occupational therapy and physiotherapy departments to establish the extent to which outcome measures were being used, identified that measurement instruments were a recent introduction to most therapy settings with the majority being applied from the early 1990s (Chesson et al 1996). Indeed the first stage of the survey revealed poor recognition of the term 'outcome measures' echoing similar findings in a parallel 1992 Canadian study (Cole et al 1995). Therapists' inconsistent understanding of the way in which terms were used and understood in relation to outcome measurement has also been reported by Austin and Clark (1993). In both the Scottish and Canadian studies low usage of standardised measures were reported (37% and 41% respectively). Subsequent high reliance on non standardised instruments is viewed with concern since use of unreliable tools is likely to 'seriously diminish the credibility of the profession' (Eakin 1989). In the Scottish study the majority of respondents regarded outcome measurement favourably, but issues were raised regarding pressure of time and technical problems such as poor sensitivity of measurement tools. Moreover little evidence was found regarding multi-disciplinary work on outcomes or



systematic involvement of patients in evaluating outcomes (Chesson et al 1996).

Enderby (1992) highlighted that the effects of treatment, especially complex clinical endeavours such as rehabilitation, have often defied measurement. It was argued that the medical model of illness concentrating on impairment was too narrow for use in therapy evaluation and that the broader International Classification of Impairments Diseases and Handicaps (ICIDH-WHO 1980) was more applicable. Enderby (1992) described impairments as dysfunction at the organic structural level which could be measured in laboratory or clinical settings. Disability was viewed as reflecting the effects of impairment at a personal level through disruption of function and activity. Handicaps were described as disadvantages experienced as a result of impairment and disability. A model for evaluating therapeutic input was devised based on setting goals which took into account the broad ICIDH agenda and measured outcome using a six point rating scale (Enderby 1992).

Emphasis was placed on identifying and measuring expected changes which had occurred as a result of intervention. Thus the focus of measurement was specifically related to treatment outcomes rather than treatment processes or treatment outputs. Enderby (1992) argued that this must be achieved by setting and evaluating precise goals in consultation with patients and carers. Enderby (1992) considered this approach to outcome measurement broad enough to encompass and address the complex issues of the rehabilitation process rather than restricting practitioners to treatment and evaluation of impairment only.

### 2.2.5 Outcome Measurement and Occupational Therapy

Many aspects of Occupational Therapy are based on theory and beliefs about *how* interventions work, rather than knowledge at *what* actually works (Bannigan 1997). Eakin (1997) argued that to achieve evidence based intervention, the balance must shift from custom and practice therapy towards that which has been demonstrated as being effective and beneficial for the user. In seeking to demonstrate effectiveness of interventions it is important that therapists are able to make informed choices regarding measurement instruments. Jeffrey (1993) described the development of a set of objective criteria for selecting instruments to measure the effectiveness of comprehensive rehabilitation within the occupational therapy service of West Lothian NHS Trust. Four main factors were considered important in choosing appropriate tools: the purpose of the measure; the content of the measure; the psychometric properties of the instrument; and the administrative aspects of the measure. After reviewing the literature a range of measures were divided into three categories:

1. Functional measures which focus on self-care and mobility.
2. Instruments which are concerned with task orientation, social interaction, rehabilitation and role functioning for those with mental health problems.
3. Comprehensive rehabilitation measures which evaluate an holistic approach and reflect users' perceptions of recovery.

As a result of the review, senior staff who had responsibility for leading the clinical specialities in the occupational therapy service, were encouraged to choose measures using the selection criteria provided. It was emphasised that choices be made in collaboration with multi-disciplinary directorates and clinical teams. Jeffrey (1993) argued that measures must have sound content criteria, have well researched psychometric properties and be easily and economically administered.

In Sweden, Soderback et al (1994) examined the evaluation methods used by therapists and the effects of therapy received by six outpatients. The general objective of occupational therapy was defined as the influencing of patient occupation and daily activities of living (ADL) towards an increase in health and personal satisfaction (Soderback et al 1994). It was argued that little scientific evidence existed of how this objective was being fulfilled or indeed what the content and effects of clinical practice were. The purpose of the study was to analyse the content and evaluate the quality of occupational therapy for six outpatients as reported by their respective therapists, who were associated with the Department of Rehabilitation and Physical Medicine, The Karolenska Institute. Three therapists had their main workplace at health centres, the others were consultants to primary health care teams and worked at Occupational Therapy Departments in regional hospitals. Each therapist selected one of their current patients as an example of patient work. Five of the patients were living in their own homes and the other was on the point of being discharged from hospital. Examples of patient diagnosis included cerebral infarct, multiple-sclerosis, lumbago and epicondylitis, congenital motor injury. An inductive

and interpretative research technique with special study protocols was developed and each therapist recorded patient involvement in therapy over a two to three month period. The completed protocols were subsequently interpreted by an independent occupational therapist and a physician. Treatment evaluation methods included; goal attainment scaling, single case experimental design and pre and post test results. At the end of the study function and ability had improved in four cases and quality of life in five out of six cases as demonstrated by their abilities in ADL. However results were dependent on interpretation of the study protocols consequently the contribution of the independent physician was considered crucial in reducing the risk of bias (Soderback et al 1994). The method was judged to be of clinical value by the researchers but the results cannot be generalised. The study is an interesting attempt at systematic evaluation of the effects of the multi-dimensional process of occupational therapy within routine clinical practice. Nevertheless the findings must be viewed with caution because of extremely low numbers and high risk of therapist bias.

A different approach was used in Trent Region UK where a steering group of three District occupational therapists and two facilitator/researchers used a variety of methods to develop an outcome measure which could be used in all fields in which occupational therapists work (Spreadbury 1995). For one year the researchers worked with 50 staff (occupational therapists and nurses) at seven pilot sites in both physical and mental health settings in Trent Region. The participation of clinical staff was gained by the researchers promising that outcome measurement would be easily integrated into existing patient

documentation and that therapists' objectives would guide the process.

These included:

- Improvement in patient care, and effectiveness and efficiency of services.
- Producing evidence of effectiveness in order to be accountable.

(Spreadbury 1995)

An individualised approach to outcome measurement was chosen because the diversity of users' needs could not be met by a standard package. Rather a unique package of therapy and care was required to meet each individual's requirements. A method was developed based on goal attainment or problem solving. This was linked to a binary system of measurement, viz., whether or not the expected outcomes had been achieved. This was then scored YES (+1) or NO (0). It was argued that this simple binary method could be used as a first step for staff new to measuring outcomes before progressing to more sophisticated measures. The result of the research was the publication of the Binary Individualised Outcome Measure which could be used by therapists to measure and audit the outcomes of planned intervention (Cook & Spreadbury 1995).

The feasibility of using individualised outcome measures within routine practice of occupational therapy was examined by Young et al (1997). The purpose of this study was to evaluate goal attainment scaling (GAS) both as a

tool for identifying and measuring the outcomes of therapy and as a method of promoting multi-professional team working. A pilot study was carried out at a residential special school near Aberdeen between January 1993 and December 1993. Teaching and residential care staff were invited to identify children's occupational therapy needs and to contribute to the process of goal selection. A therapeutic process for setting and scaling appropriate goals, planning treatment and evaluating results was developed by the research team. Eleven children identified as priority candidates were assessed in the time available, and eight of these were found to have needs which could be addressed through setting therapy goals. This resulted in 23 different goals being scaled and measured. The findings demonstrated it was possible to measure the impact of therapy in 21 out of the 23 goals which were scaled, and improvement in performance was shown in 20 out of the 21 goals measured. It was acknowledged that this study was small scale and based on a convenience sample and thus may not be generalisable (Young & Chesson 1997).

However it was intended as a pilot and it did demonstrate that it was feasible to use GAS in the context of occupational therapy for children with learning disabilities and emotional and behavioural problems.

From the preceding examples there appears to be growing recognition of the need to develop systematic use of outcome measurement in occupational therapy. It is by subjecting treatment to scrutiny regarding outcome that therapy may be more closely focused and thus users may be helped more effectively (Young & Chesson, 1997). Nevertheless it is important that the

drive towards systematic evaluation does not become an end in itself or simply a means of professional justification. A crucial factor in validating outcome measurement is establishing clarity around *whose outcomes* are being met, and for what purpose. A key dimension therefore is to consider service users' views.

## **2.3 USER INVOLVEMENT IN HEALTHCARE**

### **2.3.1 Patients as Partners**

In 1993, Rabbi Julia Neuberger voiced concerns about the imbalance of power within the relationships of health service users and health professionals. She concluded that unless user input to the measurement of clinical outcome became established it would be difficult to continue to take healthcare evaluation seriously (Neuberger 1993). In relation to evaluation of health outcomes, Shanks and Frater (1993) point to evidence of divergent views between the patient's perception of well-being and the clinician's objective assessment, and acknowledge the challenge of reconciling different perspectives on the same situation. Further complications arise when the views of patients, clinicians and informal carers differ, highlighting a need for some system of weighting or trade-off between them. Despite the difficulties associated with a more collaborative approach Long (1996) points to several recent policy initiatives supporting the move towards patient centred practice, for example in cancer and diabetes services. In addition Godfrey (1996) proposes that users are 'experts' in their own illness and that professionals should seek out users' perspectives to be used alongside professional opinion.

Yet the user perspective is heterogeneous and may lack consistency over time as the disease process and the user's "disease history" develops, and as different treatment options become known (Long 1996). Similarly the role of informal carers is multi-faceted and carer needs will change in relation to the course, severity and nature of the user's illness (Fairfield and Long 1996). The burden of caring is acknowledged as being essentially a subjective concept as perceived and experienced by the carer rather than being something which can be measured objectively. Fairfield and Long (1996) advocate the value of measuring the consequences of caring as perceived by each individual. Professional lack of awareness of the fluidity and complexity within the carer/cared-for relationship was highlighted in a recent study of outcomes in mental health (Godfrey 1996). Staff ideas of confidentiality prevented information sharing and collaborative management of the illness, despite ongoing surveillance of mood and behaviour being a major feature of the caring task for people with chronic mental health problems. Fairfield and Long (1996) point out the importance of recognising that the outcomes of carers and cared for people are interdependent.

Within health service evaluation, Long (1996) argues that incorporating user defined outcomes within research studies will make the findings more relevant to practice. But Dixon and Long (1995) warn that patient outcomes may lack credibility in relation to established research methodology which is weighted towards analysis of standardised quantitative measurement and psychometric properties, and which is dominated by clinical rather than patient definitions of effectiveness. In the past consumer involvement in the NHS Research and



Development programme has been unsatisfactory, although the National Consumer Council is now involved in addressing the issue (Needham 1996). Consumer involvement in the design of research studies should help to achieve outcomes considered important by patients and carers rather than the research agenda being solely driven by professionals (Needham 1996).

The shift towards a partnership approach within healthcare has been supported at government level in light of a recent white paper, *Designed to Care* (1997), which stated that achieving better services to patients was to be pursued by; ‘Involving patients to a greater extent in decisions about their own care and treatment; and providing patients with more information about their health and about the options for treatment when they are ill.’

However it has been argued that individual decision making in healthcare is complex and problematic in that:

‘patients facing serious or life threatening illnesses are often too anxious to think rationally and to cope with understanding the complexities of risk and probability; the poor communication skills of some practitioners may compound the difficulties, and some professionals may censor what patients are told; the timing of information giving is crucial, for example receiving a diagnosis of serious illness often results in no other information being retained by the patient; an individual user’s need for information may change over time’.

(Needham 1996 p36)

Needham (1996) also highlighted that traditional practitioner/patient power relationships have often reinforced the idea that the clinician knows best or that there is a 'best' plan of management. This paternalistic model is in direct contrast to the consumerist model in which the professional imparts information and the patient makes a decision alone. Views gathered from the Practice Skills Programme at Oxford University School of Medicine have indicated that patients prefer a partnership model in which discussion of the evidence along with support and information from the clinician assists the decision making process (Needham 1996).

### **2.3.2 Goals As A Mechanism For Partnership**

In moving towards greater patient involvement in healthcare one option is to ask the individual to identify goals they would like the intervention to achieve, and at a later date explore whether these *have* been achieved (Long 1996). However Smith-Dupre and Beck (1996) have argued that despite considerable research on patient satisfaction and compliance there was a dearth of knowledge about patient/practitioner goal setting within health care. To address this perceived information gap a study was designed based on two key assumptions. Firstly it was argued that a health care encounter was inherently based on relationships (like all social interactions), and secondly participants must facilitate mutual and individual accomplishment of goals as neither player could do this alone (Smith-Dupre and Beck 1996). The study was carried out on 53 patient contacts with a female family doctor aged early thirties in private practice in south west United States. Most patients were white women and children of middle or upper socio economic status and patient age range was

from 2 weeks - 69 years. The physician in the study was chosen as an exemplar of promoting equal partnership interaction. A communication student observer was present during consultations to collect field notes and audio tapes which formed the basis of data analysis. Results highlighted the importance of conversational pre-sequences in relation to devising mutually acceptable goals. The pre-sequences tended to be used in problem areas where they appeared to serve an alignment function, for example, to save face or to check out empathy or to gain permission to pursue a goal. The pre-sequences supported the view that patients rely on doctors to approve their goals. The doctor in the study was viewed by Smith-Dupre and Beck (1996) as empowering patients by creating a symmetrical rather than an asymmetrical power balance and by working with patients to mutually devise treatment goals. Furthermore it was proposed that goals should be seen reflexively rather than hierarchically. For example politeness or face saving interaction was not "optional extras" but was important in developing the healthcare relationship and in expressing and accomplishing medical goals (Smith-Dupre & Beck 1996).

Mutual goal setting, greater awareness of the user's perception, and the establishment of an equal, reciprocal and collaborative relationship between nurse and patient was also described as important by Kenny (1990) in relation to care of the elderly. It was argued that user involvement and empowerment was placed in jeopardy as a result of regimented, institutionalised inpatient geriatric care where dependency was encouraged by staff. Rather than nurses doing as little as safely possible for patients and taking time to discover what patients could do for themselves, it was suggested that language and social

control was often used to reinforce staff power in maintaining rigid ward routine. Kenny (1990) argued that patient control over aspects of their own life should be a right not a privilege. Indeed King's (1981) model of nursing care advocated user involvement in health care with reciprocity of nurse-patient interaction being an essential characteristic of intervention. Thus nurses' purposeful interaction with patients to establish mutually achievable goals was crucial in shifting the balance of power and lessening the danger of iatrogenic dependency (Kenny 1990).

### **2.3.3 Involvement of People with Learning Disabilities**

Basic human rights of self determination and autonomy are dependent on freedom of choice, and individual decisions and choices may be seen as a way of asserting personal identity (Jenkinson 1993). Intellectual disability results in significant impairments in qualities which are important in decision-making such as discretion, social competence and an understanding of self interest (Jenkinson 1993). Assumptions have also been made about the impaired ability of learning disabled people in other areas of functioning. Thus in the past people with learning disabilities have been denied the control over their own lives which others take for granted.

According to Jenkinson (1993) theories of decision making draw a distinction between the normative model which is concerned with how people make decisions in the ideal situation, and the descriptive model which is concerned with how and why people think and act as they do when deciding. People rarely make everyday decisions which conform to the normative model, rather

individual biases, emotional reactions, complexity of choices and uncertain or risky outcomes affect the decision making process (Jenkinson 1993). Complex, subtle and multifaceted choices are particularly vulnerable to the influence of others. For example the way issues are defined, questions phrased and confidence demonstrated in the decision maker's ability, will influence the decisions. This has implications for advocates and service providers when assisting people with learning disabilities to make decisions. Also some people with learning disabilities show characteristics of learned helplessness where perceived inability to affect outcomes results in passive behaviour. Such a person is unlikely to take responsibility for decision making. Inability to decide may also occur because of lack of awareness of preferences. Thus people with learning disabilities are likely to experience greater difficulty with decisions than the non-disabled population, but Jenkinson (1993) argues that they can be helped to improve with training and experience.

Communication of choices can be problematic for people with learning disabilities and staff will need to be sensitive and responsive to alternative communication styles such as body movements, facial expressions and gestures. Response bias to questioning can complicate matters further. Thus Jenkinson (1993) highlighted that people with learning disabilities must be assisted to identify personal preferences when making choices otherwise there is a danger that advocates and professionals might mistake lack of protest for informed consent, habitual behaviour for active choice and resignation to one's lot with a contented lifestyle.

One example of trying to overcome such dangers in healthcare was described in a UK study which focused on producing a rating scale for assessing clinicians' communication with people with profound learning disability (Kerr et al 1995). Effective communication by health professionals is important for this client group yet little systematic evidence of the abilities of health workers is known and few audit or educational measures available. The study population reported by Kerr et al (1995) was small comprising only eight clients (4 male, 4 female) who were resident in a hospital unit for people with profound learning disability (IQ less than 20). Four psychiatrists and four nurses were assessed completing three simple non-invasive clinical procedures; blood pressure, pulse and axillary temperature. Evaluation of videotaped consultations was carried out by three experienced speech and language therapists, using a previously designed scale for analysing intervention with people with mild learning disabilities. This resulted in the devising of a new scale for people with profound learning disabilities in which the interater reliability of the speech and language therapists was significant when measuring total scores, non verbal communication and verbal behaviour. Reliability was less significant for vocal behaviour, response behaviour and empathy. It was intended that the scale be used educationally to highlight individual practitioners' deficits or strengths (Kerr et al 1995).

The researchers highlighted the need for replication of the study in light of small numbers, but argued that the instrument showed promise as an educational and audit tool to improve healthcare for people with profound learning disability (Kerr et al 1995).

Choice is a fundamental aspect of empowerment and in the context of learning disability this places a responsibility on care givers to ensure that their own values and preferences do not unduly influence the options offered to users. Jenkinson (1993) raised concerns about staff who admit to making decisions without consulting users despite an awareness of the need for user involvement wherever possible. Care planning procedures which emphasise goals and objectives identified by staff at the expense of client choice and preferences are incongruent with the current partnership model of care. Even so, client choices may be viewed as counter productive to progress when service providers decide what's in the user's 'best interest', and where 'best interest' is defined as whatever leads to an independent 'normal' lifestyle. In addition the element of risk has often been cited as reason to exclude people with learning disabilities from making important life decisions. Despite everyone sometimes making bad decisions, implications may be more serious for those with learning disability who may not have a large repertoire of learned skills and behaviours and may be less aware of consequences. But without some exposure to risk they will be denied the opportunity of learning that some consequences of decisions have negative outcomes (Jenkinson 1993).

The promotion of equal power sharing between staff and users involves practical considerations such as mechanisms for risk analysis, identification of checks and balances for testing new ideas and methods of endorsing a course of action chosen by clients themselves which may not always be supported by professionals or carers (Sines 1995). The attitudinal change needed to alter power relationships has been proposed as the greatest challenge facing nurses

working with people with learning disability (Sines 1995). Yet this investment in change was considered crucial by Sines (1995) in achieving a more enlightened and equitable partnership for all.

In a UK study Hayman and Huckle (1993) reported on issues relating to risk management and the different perceptions of everyday hazards held by 20 adults with learning disabilities, their informal carers and day-care staff at their training centres. The term hazard was used to describe an action that was perceived as potentially leading to an adverse outcome. A hazard was seen as a risk if someone was prepared to consider taking it and a danger if not. But it was acknowledged that differences in the perception of hazards by adults, informal carers and staff could only be understood in relation to their own personal judgement of risks and dangers, and not in the factual properties of the hazard. Results showed that adults and informal carers within families generally agreed in categorising hazards but differences were found; for example in relation to independent living, work and sexual relationships. Socio-economic factors were linked to risk tolerance with less privileged families allowing greater adult autonomy. These adults appeared to be achieving more of their potential in everyday living skills. Staff at day care centres were more accepting of risks for adults with learning disabilities than were informal carers, leading to instances of misunderstanding and conflict between formal and informal carers.

Moreover Hayman & Huckle (1993) referred to recent criticism of normalisation theory as being a behavioural method of making adults with



learning disabilities conform to normal patterns of social behaviour, they advocated a better alternative as being based on autonomy, citizenship, rights and self advocacy. It was further argued that strategies should be developed which centred on the adults way of dealing with choices and which would unite formal and informal carers in jointly supporting the user in pursuing his or her decision. This model would require a realignment of power relationships within families and between formal and informal carers (Hayman & Huckle).

Intellectual disability should not be the sole criterion for judging an individual's ability to make decisions since competence might be demonstrated in some areas of functioning but not others (Jenkinson 1993). Investigation into the thoughts and feelings of people with learning disabilities carried out in Scotland identified the validity of self reported emotions (Lindsay et al 1994). Sixty seven people with mild or moderate learning disabilities who were being considered for moving from hospital to community placements were included in the study. Several self report assessments of personal emotion were administered and the responses assessed for convergent validity as an indication of consistency of personal feelings of emotion. A research worker asked the subjects every item on the tests after previous work had been done to ensure the subjects understood the procedures and that assessments had an acceptable level of internal reliability. The study showed an impressive degree of convergent validity in responses indicating that the self reporting of people with learning disabilities in relation to emotions may be extremely reliable and valid. In fact it was proposed that the self perception of emotions by people with learning disabilities is as reliable or more reliable than other populations within

the community (Lindsay et al 1994). Indeed evidence is beginning to emerge that it is possible to meaningfully survey people with learning disabilities about issues such as lifestyle, health and illness (Flynn 1986, Atkinson 1988, Hayman & Huckle 1993, Joy 1997).

#### **2.3.4 User Involvement in Occupational Therapy**

The client-centred approach used in occupational therapy is central to the profession's philosophy and the way in which therapists think about their clients (Mew & Fossey 1996). The term client-centred originated in psychotherapy and was first described by Rogers in 1951 as therapy directed by clients empowering them to resolve their own problems (Mew & Fossey 1996). Interpretation of the term within occupational therapy hinges on therapists being viewed as having knowledge of rehabilitation techniques and adaptive methods which clients are unlikely to know, yet clients are required to be active participants in therapy. Therefore client-centred occupational therapy describes a collaborative, interdependent partnership between the therapist and user (Mew & Fossey 1996). However despite the apparent importance and prominence of client-centred practice in occupational therapy there remains confusion as to the exact meaning and application of the concept in practice.

Clarification is required on whether it means:

- the therapist provides necessary information for the client to make decisions and direct the therapy, with the therapist subsequently working on the client's agenda

- the therapist and client collaborate to achieve mutually agreeable goals
- the therapist merely takes the client's views into consideration while making the decisions unilaterally

(Mew & Fossey 1996)

Thus a central issue emerges regarding who is “expert” - client or therapist. According to Fearing et al (1997) clients are the experts in identifying problems and issues within the context of their own lives and in deciding whether or not they want assistance in understanding and addressing them. Therapists are experts in assisting clients to problem solve so that lost momentum can be redirected into satisfactory experience and development (Fearing et al 1997). Enabling therapists and clients to co-operatively problem solve was addressed by Fearing et al (1997) through a process (The Occupational Performance Process Model) to be used as a guideline for practice in fostering client/therapist alliances.

The growing emphasis within healthcare on cost effectiveness, outcomes and accountability has raised concerns that competence is preferred to caring (Mew & Fossey 1996). Thus when therapists over emphasise technical competence and clinical protocols the danger emerges of neglecting issues perceived as important by clients. One way of reducing such danger is by introducing formal procedures for therapists to translate values about client-therapist co-operation into practice. In Canada this was addressed through the Guidelines for the *Client-centred Practice of Occupational Therapy* (Department of National Health and Welfare and Canadian Association of Occupational Therapists

1983; 1991). In addition The Canadian Occupational Performance Measure (Law et al 1990,1991) (COPM) was designed to help therapists implement the guidelines. The COPM is an individualised measure administered in an interview, with information obtained through client storytelling rather than responding to a checklist. Results provide client identified performance issues and state clients' perceptions of their performance and satisfaction. If the client does not perceive issues as important the process is stopped. If the client is viewed by the therapist as at substantial but unacknowledged risk to self or others the therapist acts to protect those involved.

An American study of the involvement of adult rehabilitation patients in setting occupational therapy goals found that therapists did not maximise patients' and families' potential for involvement (Northern et al 1995). Thirty registered occupational therapists practising in adult rehabilitation settings were audiotaped during an initial evaluation interview. Researchers reviewed the data generated and also interviewed each therapist. Both therapists and patients were kept blind to the study's specific purpose but were informed that initial evaluation processes were being studied. A patient participation evaluation form was developed for the study which identified 23 patient and family criteria compiled from standards which were generated by accreditation commissioners and health care professionals. Results showed that although the patients and families were involved in a goal setting process, a number of the criteria were not attempted, thus much potential for involvement was unrealised (Northern et al 1995). Important factors which influenced therapists' use of a partnership approach with patients included; the application of a specific theory or

technique, time constraints, patients' age and assumptions about the patient's cognitive status (Northern et al 1995).

There are considerable challenges for therapists being able to put client-centred practice into operation, both in terms of developing processes and systems for intervening in a congruent and organised fashion, and in supporting therapists to become comfortable with the concept of the client as expert.

### **2.3.5 User Satisfaction**

According to Williams (1994) the growth of consumer satisfaction surveys within the NHS can be traced back to the 1983 NHS Management inquiry which recommended that health planners should evaluate services by obtaining the experience and perceptions of patients and local communities. Williams (1994) further argued that this call for user involvement has been largely translated by Health Authorities into requests for the measurement of satisfaction. Enthusiasm for consumer surveys is also viewed as resulting from questionnaire surveys being relatively cheap and easy to conduct, qualitative data being regarded with mistrust, and quantitative data being perceived as useful for monitoring purposes (Williams 1994).

In the past public views on health were poorly regarded and passive patients were viewed as 'good' patients. More recently the growth of consumerism gave weight to the voice of the patient, and in today's climate of partnership in health care patient views have become more valued. Yet it is important that the methodological and conceptual difficulties of accurately gathering and analysing user data is recognised (Williams 1994). Assumptions that

meaningful information can be obtained through satisfaction surveys can be misleading (Bisset & Chesson 2000). A crucial issue relates to the style in which patients are consulted with more critical comments being elicited when people are allowed to express themselves in their own terms. Thus quantitative measures of satisfaction tend to be favourable while qualitative reports show greater levels of disquiet. A danger exists that poor questionnaires may at best be misleading and at worst act as a form of censorship imposed on patients (Williams 1994). An illusion of consumerism may misrepresent the true beliefs of service users by forcing them to express themselves in alien terms.

### **2.3.6 The Satisfaction Of People With Learning Disabilities**

Clients with learning disabilities often have difficulty in understanding questions, relating to past experience and forming and expressing views (Witts & Gibson 1997). Clients' ability to meaningfully respond is to an extent determined by the way in which they are consulted and by whom. For example audits and surveys carried out by service providing professionals will not result in independent assessment of users' views, but professional training in learning disability will hopefully alert staff to conflicts of interest to be flagged up (Witts & Gibson 1997). Various learning disability professionals have attempted to assess client opinions of health team interventions, and this is viewed as a starting point in demonstrating to providers the need to listen to users (Dagnan et al 1994, Simon & Roy 1996, Witts & Gibson 1997).

In terms of effective communication with people with learning disabilities questions need to be simply phrased, open ended and if necessary repeated in

different formats to enable client response. This will be further discussed in the forthcoming methods section. Awareness of the effects of acquiescence and other types of response bias is particularly important (Sigelman et al 1981, Witts & Gibson 1997). The use of photographs & pictures have been found to increase response rates and enable meaningful reply (Sigelman & Budd 1986, Dagnan et al 1994, Simon & Roy 1996, Witts & Gibson 1997, Joy et al 1998). Nevertheless few measures devised for assessing the satisfaction of people with learning disabilities have been tested for reliability (Witts & Gibson 1997).

Despite the methodological difficulties involved, a UK pilot study examined the satisfaction of people with learning disabilities with services received from a community psychology service (Dagnan et al 1994). Eleven people referred through community teams for people with learning disabilities were interviewed. These users had been seen by three members (2 male, 1 female) of the psychology department for more than five sessions on a face to face basis. The users were seven men and four women who had a mean age of 32 years ( $SD=17$ ) and who achieved a reasonable level of verbal ability (mean raw score of 76 on the British Picture Vocabulary Scale) (BPVS; Dunn et al 1982). A semi structured interview schedule was used and structured questions were asked in three different formats:

- either/or questions using two response pictures
- an analogue scale
- a three point personal questionnaire (which had an inherent response consistency and positional bias check).

Results showed all formats had a high degree of reliability although this must be placed in context of very small population numbers with subjects who had reasonable verbal ability. Therefore findings need to be interpreted with caution and may have no relevance for those with severe disability. The more sophisticated questionnaire techniques (analogue scale and personal questionnaire) gave more sensitive information, for example strength of feeling, and open questioning seemed important in gaining more detailed information, for example variation in topic themes (Dagnan et al 1994). It was recommended that methods be examined further to identify the degree of verbal ability needed to use the techniques.

In spite of problems associated with obtaining valid and reliable views from people with learning disabilities it is important that methodology is improved and study results are used to inform service planning. One example of audit results influencing practice was described by Simon and Roy (1996). A consumer audit was undertaken in Sandwell (England) to assess the views of users and carers regarding service operation and service provided by four community learning disability teams. Each team consisted of a community nurse and specialist social worker. A semi structured interview was used to collect data from 15 users and 11 carers who were drawn from the caseloads of the four teams. Previously quality standards had been draw up by the team members in consultation with health and social work managers.



Tangible effects of practice being influenced by the audit results were:

- a leaflet was produced to explain complaints procedures
- an additional quality standard was developed to consult users on choice of venue for meetings
- team members undertook to ensure that users and carers received copies of assessments and care plans
- team nurses were to offer care management for users with health needs to help with access to facilities like respite care

(Simon & Roy 1996)

It was recommended that regular consumer audit was needed to continuously tailor services to the needs of users and carers. The Sandwell audit also highlighted the need to improve the means of eliciting the views of people with severe learning disabilities as eight out of the fifteen users selected could not be interviewed due to the degree of their disabilities.

From the preceding review it may be argued that the growth of consumerism, the promotion of the partnership approach within healthcare delivery, and the concept of each individual taking more responsibility for their own health status has firmly established user involvement on the health agenda. Yet inequities, complexities and issues of control remain. Finding approaches, models and tools acceptable to all stakeholders is likely to prove challenging. One technique worthy of consideration is goal attainment scaling.

## **2.4 GOAL ATTAINMENT SCALING**

### **2.4.1 Historical Introduction**

Goal Attainment Scaling (GAS) was first described by Kiresuk and Sherman (1968) as a method for evaluating community mental health programmes. The technique was developed to overcome difficulties associated with demonstrating treatment effectiveness and justifying resource utilisation when conceptual models of mental health were many and varied (for example medical, educational, sociological, behavioural) and treatment modalities equally diverse. The GAS system, therefore was not bound to any theoretical orientation or particular type of treatment or outcome assessment tool; rather it was a set of procedures designed to evaluate change (Ottenbacher & Cusick 1993).

In the 1950s and early 1960s in the USA the medical model of care and the power of physicians was predominant, in contrast to scant recognition of the rights of patients or the role of health managers (Kiresuk 1994a). During the mid 1960s an emerging awareness of the need for social reform focused attention on issues such as civil rights, feminism and consumerism and heralded a new era of accountability. Kiresuk and Sherman (1968) were influenced by USA government encouragement of welfare and mental health organisations to relate their activities to clearly stated goals and then demonstrate progress towards them.

Kiresuk (1994b) viewed GAS as having roots in the ideology of academic psychology of the 1950s and 1960s, when the concept of intentionality was

perceived as one of the key philosophical underpinnings of human behaviour. Thus the essentially active nature of mental processes led to the study and measurement of goal orientated behaviour. Kiresuk (1994b) also believed the intellectual concept of prognosis to be compatible with goal setting evaluation. He proposed that a combination of the themes of intentionality and prognosis operating within several professional contexts (for example nursing, medical) led to goal setting becoming common within evaluation and quality control methodology. A central issue in relation to the evaluation of mental health services was perceived to be bridging of the gap between broadly stated intervention goals (which were viewed as statements of good intent) and the particular objectives of the treatment programme (Kiresuk & Sherman 1968). General methods of justifying mental health intervention based on demographic or public health measures made it difficult to permit direct attribution of a particular programme effect because of the numbers of uncontrollable influencing factors. On the other hand specific patient-therapist goals within a treatment contract could appear unsystematic and trivial (Kiresuk & Sherman 1968). The rationale of GAS was to reconcile these differences by developing a measurement procedure capable of both evaluating mental health programmes and being sensitive to the particular mental health needs of people on an individual basis (Seaberg & Gillespie 1977).

Kiresuk and Sherman's original study proposed a solution comprising a scaling technique and a basic evaluation design which had three steps:

1. Goal selection and scaling
2. Random assignment of the patient to one of the treatment modalities;  
and
3. A follow up of each patient with regard to the goals and scale values  
chosen at intake

(Kiresuk & Sherman 1968)

The scaling technique devised for the goals had the capacity to utilise any form of objectively determinable event, for example degree of change on psychometric testing or public record document or self rating scale. Goals could also be weighted to denote relative value of each as an indication of treatment success. However, equal weighting of goals was considered acceptable and regarded as likely to lose little information. No limitation was placed on the number of goals chosen for each patient by the goal selector or goal selection committee. Following goal selection and weighting, the patient was randomly assigned to one of the treatment programmes except where medical factors clearly indicated a particular treatment of choice. After a predetermined treatment period, follow up by an independent person took the form of joint review, with the patient, of progress towards the goals identified prior to treatment. Precise assignment of patient achievement to a corresponding numerical value on the goal attainment scale enabled a composite score to be computed in accordance with a statistical procedure

provided by Kiresuk and Sherman (1968). This computational method was proposed as a basis for comparing treatment outcomes with different patient types and different treatment modes. However Kiresuk and Sherman (1968) cautioned that:

‘the inspection of the goals actually chosen for each patient may be the only route to a full appreciation of the purposes and operational character of the entire program’.

#### **2.4.2 The Concept of Goal Attainment Scaling**

GAS is an individualised criterion - referenced measure akin to a behavioural objective in many respects. Both entail:

1. The selection of goals that are observable and repeatable;
2. The specification of the conditions under which performance is to be measured;
3. Criteria for success to be stated in measurable terms; and
4. Goals being achieved within time limits.

(Palisano, 1993)

However, GAS involves the specification of five possible outcomes as opposed to only one for the behavioural objective (achieved or not achieved) which, as Palisano (1993) has highlighted, has considerable advantages for measurement of qualitative change and low (and often difficult to discern) levels of achievement. The process of setting goals has been described by Glover et al (1994) as follows:

‘Briefly a number of individual goals are decided upon with each client. They are then broken down into five levels of outcome, ranging from “much less than expected” to “much more than expected”, with “expected level of outcome” at the review date as the middle-point. Each of the five levels has a corresponding number, ranging from minus two to plus two, with expected level of outcome assigned a zero. It is important that the goals are written in behavioural terms so that measurement is simple and unambiguous’.

Glover et al 1994

### **2.4.3 Dissemination of GAS**

Since 1968 GAS has been used in a number of specialities and by a wide range of health professionals including nurses (Stanley 1984), physiotherapists (Colt & Finch 1991; Squires et al 1991; Palisano et al 1993), psychologists (Glover et al 1994) and occupational therapists (Young et al 1995).

GAS became established in the USA from the early 1970s onwards partly due to the appeal of the individualised character of the method and partly as a result of major efforts by the Program Evaluation Project in Minneapolis, which was directed by Kiresuk. This initiative received substantial financial support from the National Institute of Mental Health much of which was devoted to promoting GAS as an evaluation tool and clinical aid (Seaberg & Gillespie 1977). In contrast very little reporting of GAS can be found in the United Kingdom prior to 1990 (MacKay et al 1993). Recently, however, there has been a steady growth in usage; as reflected in such studies of Squires et al 1991;

MacKay et al 1993; Glover et al 1994; Cheseldine 1995; Young et al 1995; Reid and Chesson 1998. These recent UK studies have tended to be small scale fewer than 20 subjects, with the research population often depicting unrepresentative groups within the range of the general population. For example, children with severe learning disabilities and associated emotional and behavioural difficulties, stroke patients in receipt of physiotherapy and who were not dysphasic, infants with motor delay. This reflects the flexibility of the GAS process which can accommodate the needs of small unrepresentative groups and can also accommodate heterogeneity within subjects despite generic labelling such as diagnostic categories or social grouping (MacKay et al 1993).

Over the years, various papers offering critical review of the GAS process have examined the credibility of the approach (Seaberg & Gillespie 1977, Cytrynbaum et al 1979, Greenhalgh and Long 1996, MacKay & Lundie 1998). In 1977, a critique by two researchers at the Centre for Social Welfare Research, University of Washington, Seattle concluded that the move towards developing an individualised general purpose measurement procedure was to be encouraged, but proposed further rigorous development of the technique (including a clear statement of limitations before it could be unreservedly recommended (Seaberg & Gillespie 1977). In 1979 mixed conclusions were reported from a critical review of 41 GAS studies which met minimal criteria of completeness of information, and quality of research (Cytrynbaum et al 1979). The usefulness of GAS as an evaluation technique was questioned because of serious procedural and methodological problems. But GAS was viewed as having potential to enhance educational and intervention functions within

service delivery, especially in mental health settings. The involvement of patients in the goal setting process was judged beneficial to therapeutic effectiveness (Cytrynbaum et al 1979). Notably a review of GAS appeared in *Outcomes Briefing*, a publication of the Nuffield Institute for Health, relating to the UK Clearing House on Health Outcomes (Greenhalgh and Long 1996). The authors concluded that once training had been provided GAS was feasible for use in routine practice and gave useful information about outcomes to both users and clinicians. The extent of user involvement in identifying goals and evaluating achievement was considered crucial for proper application of the method (Greenhalgh and Long 1996).

#### **2.4.4 Validity of GAS**

Critical evaluation of the GAS procedure is complicated by variation in application of the method over the years (Cytrynbaum et al 1979). For example, in the original study of Kiresuk and Sherman (1968), goals were set by a committee and patients randomly assigned to treatment modalities, but this process has not been uniformly replicated and indeed is not currently practised. The conceptual flexibility and individualised nature of GAS is undoubtedly a potential strength but ambiguity within the model allows variability of interpretation which can also be a weakness.

A central issue emerges in relation to whether the essence of GAS is to do with the ability of selectors to accurately predict future levels of functioning within a given time interval, or if it is the specification of a set of goals and subsequent measuring of progress towards these goals (Bailey & Simeonsson 1988). Thus



it becomes critical to delineate who identifies goal areas, how many goals are to be pursued, and how are descriptors to be agreed and pitched as scale referents (Seaberg and Gillespie 1977, Cytrynbaum et al 1979).

The procedure through which goals have been conceptualised has included selection by committees, intake screeners, the therapist and the client. All of these sources have potential advantages and disadvantages. Committees and screeners may appear impartial yet may choose goals perceived as irrelevant by therapist and/or client. Therapists are likely to have a greater understanding of the specific needs of the client yet inevitably will have professional and personal bias. While it is seen as important in today's healthcare climate for clients to have the right to determine their own aspirations and desires they may have difficulty in conceptualising or expressing goals because of confusion or limited mental or emotional capacity (Seaberg & Gillespie 1977). However it has been proposed that greater user involvement increases the content validity of GAS since the aim is to specify goals relevant to the particular individual (Carr 1979, Cook 1995, Greenhalgh & Long 1996). Indeed Greenhalgh and Long (1996) recommend the negotiation of goals between user and clinician to ensure that they represent the users' concerns and aspirations while mirroring the intended effects of intervention and suggest that the internal reliability of GAS scores is optimised when five point scales of outcome are used with a minimum of three goals.

There are no specific criteria for determining which client needs should be addressed through goal setting and scaling. General guidelines suggesting that

goals be relevant, meaningful, measurable, realistic, significant and feasible leave considerable scope for subjective interpretation (Seaberg & Gillespie 1977). The procedure for setting referents for expected levels of achievement (the goal attainment scale) also involves a high degree of subjectivity. This flexibility underpins the individualised nature of the technique and is potentially a major strength. Nevertheless a bias towards stating goals that are too easily attainable or unrealistically challenging could pervade the process. Ottenbacher and Cusick (1990) advise that information relating to expected level of performance is best collected from multiple sources such as the client, family members and other service providers to enhance the accuracy of the GAS score. Concerns regarding incongruence between clients' and clinicians' perceptions of goal attainment would be minimised according to Seaberg & Gillespie (1977) if clarification and consistency was achieved in how to identify problem areas for goal setting, and in selecting referents for the goal scale.

#### **2.4.5 Research Usage**

Evaluating the impact of intervention with heterogeneous groups is challenging for service providers and researchers when conventional methods of measurement using standardised tools are ineffective. In addition the use of a fixed battery of measurement tools irrespective of individual needs or characteristics is potentially unreasonable and wasteful. Under such circumstances the flexible, individualised nature of GAS has appeal but to date GAS has been used for clinical rather than research purposes. In the first instance difficulties in constructing a robust evaluation design hinge on GAS not being a standardised measure consequently no information on absolute level

of functioning is given (Gowland 1993, Greenhalgh & Long 1996, Seaberg & Gillespie 1977). For example, an individual may have a high GAS score, indicating significant change in outcome during treatment yet still have a low level of functioning compared with other users.

Furthermore Gowland (1993) raises the issue of evaluation being open to therapist bias where standardised methods are not available to support conclusions about overall impact of treatment. Flexibility of approach is acknowledged as important, but standardised testing is crucial where the intention is to compare measurements over time or to compare individual measurements or programmes at a single point. Standardised information is also necessary to support accurate communication between professionals. Therefore a combination of individualised and standardised evaluation methodologies is likely to produce optimum health care management of individuals (Gowland 1993). In terms of appropriate usage, Gowland (1993) cautions that GAS should not be used as an alternative to standardised measures when aiming to demonstrate the relative impact of intervention on *groups* of individuals. Finally, although Greenhalgh and Long (1996) state that GAS should not be applied where measures of absolute levels of functioning are required, they contend that the method is ideally suited to measuring the degree of change in outcome.

#### **2.4.6 Clinical Usage**

Collaborative goal setting between different professionals as a clinical strategy has been well documented (Bailey & Simeonsson 1988, Ottenbacher & Cusick

1990, Palisano 1993, MacKay et al 1993, Glover et al 1994, Young & Chesson 1997). Indeed teams have recognised the usefulness of an approach such as GAS in terms of helping to clarify topics and recommendations discussed at meetings, and in allowing systematic analysis of team ability to project client outcomes, as well as identifying factors linked to variability in goal attainment (Bailey & Simeonsson 1988). In fact Ottenbacher and Cusick (1990) contend that the most important aspect of GAS is that it is practice based and practitioner orientated.

Furthermore Cytrynbaum et al (1979) commented favourably on the use of GAS as a treatment or interventional strategy rather than the method being regarded purely as an evaluation strategy. The use of GAS was perceived as assisting staff become more focused in their therapeutic approach which was interpreted as an important educational aspect of the technique. In addition it was also reported that client participation in goal setting resulted in increased treatment effectiveness as measured by mean GAS scores (Cytrynbaum et al 1979).

Other benefits associated with the use of GAS within routine clinical practice are that the technique can be readily subsumed into ongoing clinical record keeping, the process can be continually adjusted to take account of new or changing needs and also it can be applied by all members of a care team, following introductory training, as advanced skills in testing procedures and quantitative analysis are not required (Cook 1995). In addition staff who used GAS at a day centre for people with learning disabilities reported that it assisted

them to sustain a high level of motivation and to view service users in a positive light (Glover et al 1994). It has also been proposed that communication and skill definition is improved when staff identify which user goals can be progressed by the whole team and which will be attained through the specific skills of a single discipline (Cook 1995).

The importance (though not the necessity) of adequate training of those who set and evaluate goals was emphasised in the original Kiresuk & Sherman (1968) GAS methodology. Although the technique was viewed as relatively simple, the process of goal selection and scaling has been described as difficult and highly subjective (Cytrynbaum et al 1979). In addition Cytrynbaum et al (1979) argued it was argued that factors such as socioeconomic status, sociopsychological functioning, therapist expertise and treatment modality attributes required consideration. Thus it was proposed that complex reasoning was required for implementing the GAS procedure which needed considerable clinical expertise and also specific training and experience (Cytrynbaum et al 1979).

The importance of staff training in the implementation of GAS has been emphasised not only in relation to the correct application of the technique but also in the developing of a reflective practitioner (Carr 1979, Ottenbacher & Cusick 1990, Glover et al 1994, Young & Chesson 1997). Staff from different backgrounds are likely to require varying degrees of training and support.

For example those familiar with behaviour theory and objective setting may find the technique has resonance while others might need significant help (MacKay et al 1993).

#### **2.4.7 GAS and People With Learning Disabilities**

The potential usefulness of GAS for people with learning disabilities began to be explored in the 1980s. Bailey and Simeonsson (1988) concluded that GAS may be readily applied to those people classified as severely or profoundly mentally retarded, and that the process can be implemented at minimum expense in terms of required staff time. The technique was chosen by the author of this thesis for a local pilot study of children with learning disabilities (Young et al 1995) in the light of MacKay et al (1993) advocating that it was an appropriate evaluation tool in the investigation of small scale services particularly where clients were a small specific group unrepresentative of the general population. MacKay et al (1993) further contended that the results of GAS complement data from conventional normed measures by creating a clearer context for understanding the results of such measures which are usually unreliable when applied to “extreme” populations, whether they be Olympic athletes or people with severe intellectual disabilities.

The fundamental principle of individualised outcome measures is that they define differently for each client the outcome of care. In contrast standardised measures describe a required outcome as standard for all clients (Cook 1995). The Council On Quality And Leadership In Supports For People With Disabilities has demonstrated in the United States of America the feasibility of

measuring quality in terms of personal outcomes rather than compliance with organisational process or attaining a score on a standardised outcome scale. Indeed Gardner et al (1997) argued that the current quality agenda for people with disabilities must place greater emphasis on individuality, adaptability and change with less regard for standardisation, predictability and conformity.

GAS is not a panacea and serious reservations have been raised regarding its appropriate use. This must be weighed against the strengths of the technique, namely; it is user centred, it can readily be applied within routine clinical practice, it can cope with unique needs and varied methodologies which otherwise seem to defy evaluation by more conventional methods. On balance it is proposed that GAS can usefully complement traditional measurement approaches particularly with regard to atypical client populations where standardised procedures either cannot be tolerated or do not tell the whole story. The next section explores more widely, factors associated with goalsetting in health services.

## **2.5 GOAL SETTING AS A TREATMENT STRATEGY**

### **2.5.1 Goals and Healthcare**

Goal setting is an established approach within healthcare being used either implicitly or explicitly in most health interventions. Yet Strecher et al (1995) have argued that there has been little systematic evaluation of goal setting as a strategy for health behaviour change. This is contrasted with industrial settings where for example the technique of Management by Objectives became popularised, widely discussed and applied from the late 1960s onwards. In

addition laboratory studies conducted mainly by psychologists (of whom Bandura is perhaps most widely known) focused on cognitive and behavioural elements of goal setting. Stretcher et al (1995) point to the lack of controlled studies examining the applicability of goal setting theory within routine clinical practice.

Goal setting theory asserts a positive linear relationship between degree of goal difficulty and level of performance. This suggests that higher achievement occurs when a person is set reasonably challenging goals as opposed to no goals or vague goals such as 'do your best'. However, Strecher et al (1995) argued that goals set in health behaviour programmes were often easy or unfocused, for example 'to stop smoking' rather than 'total abstinence from smoking for a period of 6 months'.

Goal setting theory also identifies three motivational mechanisms, viz., the technique encourages people to try harder, for longer periods of time with less distraction to the task in hand. Strecher et al (1995) highlighted that behaviour change goals would probably be more effective than physiological status goals. For example, with diabetic clients it would be preferable to get goals to increase consumption of high fibre foods rather than to improve blood glucose levels. It was argued that behaviours were more directly under the person's control and were more strongly related to effort, concentration, and persistence than were metabolic outcomes which could also be subject to other influences.



The importance of user involvement in goal setting has been highlighted by Reid and Chesson (1998) who proposed that ownership of goals would encourage greater motivation, therefore increasing the likelihood of goals being sustained. This small (five subjects) exploratory Scottish Study looked at the amount of congruence between physiotherapists and stroke patients goals over a four month period. Therapists and patients set goals independently of each other and it was found that staff goals related more to physical activity while patients goals focused on functional outcome. Findings showed that patients failed to reach expected levels on their self set goals more frequently than for therapist set goals.

Reid and Chesson (1998) point to the danger of patients being disheartened by low achievements, or having to confront a poor prognosis, but argued that it was preferable for these issues to be addressed when professional support was available in the hospital rather than at a later date in potentially more isolated circumstances within the community. Therapists' perceptions of patients being unrealistic were acknowledged but it was proposed these must be balanced against the fact that there was no 'absolute reality'. On the one hand professionals had more experience and knowledge of the condition but on the other patients knew about themselves, their social circumstances and their inner resources (Reid and Chesson 1998).

Co-operative goal setting between professionals and users has also been proposed by Squires et al (1991) as a pre-requisite for active patient commitment to treatment programmes. Interestingly Strecher et al (1995) have

pointed to empirical evidence suggesting that when goal difficulty was held constant there was no difference in the individual's commitment or performance irrespective of whether goals were assigned, set participatively or self set. For example letting patients choose their own health behaviour change goals from a selection including smoking cessation, weight reduction, exercise, alcohol reduction, seat belt use and breast self-examination did not enhance behaviour change over provider assigned goals. Since this finding runs counter to widespread clinical perception of the importance of patient participation in goal setting Strecher et al (1995) have called for healthcare research regarding the effect of who sets goals.

There is growing evidence of goal planning being used by health care professionals (including therapists) as a strategy for exploring the link between intervention and outcome (Maloney et al 1978, Stanley 1984, Fleming & Tosh 1985, Squires et al 1991, Palisano 1993, Joyce et al 1994, Rothery et al 1995, Young et al 1997). Indeed Squires et al (1991) have asserted that comparison of outcome with agreed goals rather than 'improvement' is essential for the satisfaction of all parties.

A recent multi-centre study of four adolescent in-patient units in the UK (Rothery et al 1995) presented a model of assessment in terms of defined treatment goals which were specified at the beginning of treatment. The goals centred on four areas of functioning; the remission of symptoms; improvement in significant relationships; facilitating accomplishment of age-appropriate maturational tasks; and improvements in intrapsychic functioning. In total 16

treatment goals were operationally defined for the study, and a statement of selected goals (which reflected treatment intent) was completed for each admission. Outcome was measured at discharge using a six point bipolar scale. An attempt was made to identify which treatment method was considered to have had a predominant role. For example patients with schizophrenia and affective disorders mainly received treatment with medication aimed at symptomatic improvement. Patients with anorexia nervosa or conduct disorders primarily received treatment aimed at improving relationships with patients and peers. On discharge, goals aimed at symptomatic improvement generally appeared to have attained relatively greater improvement when compared with goals concerning maturational tasks, improving relationships and intrapsychic changes. Goal ratings were compared between diagnosis and in relation to outcome but results were inconclusive. Strong emphasis was placed on a multi-disciplinary approach but there was no evidence of user involvement in goal planning. The clinical investigators in this study considered treatment goal definitions to be a meaningful approach to measuring psychiatric disturbance in adolescents and a useful measure of change in the in-patient population (Rothery et al 1995).

Within physiotherapy Squires et al (1991) have argued that reviewing progress by measuring goal achievement would enhance understanding for team members and would assist in the process of service planning, specification of working practice and quality. This UK study audited contract goal setting with elderly patients by 75 physiotherapists. A mobility index form was completed by each therapist on five patients for up to a year. The audit found that

objective goals could be set and progress easily mapped and understood by team members. Over the period of the evaluation it was noted that different functions improved at different times. This knowledge was judged useful in making quantitatively-based decisions about care management and discharge planning. In Canada, Joyce et al (1994) used goal setting as a means of evaluating the impact of physiotherapy on 16 patients with brain injury in a rehabilitation hospital. The study found it was feasible to set meaningful individualised goals and measure progress with this client group. The goal setting process was judged useful in sharpening clinical insight, structuring team meetings and providing valuable feedback to professionals and users throughout the rehabilitation course (Joyce et al 1994).

Goal planning has also been used as an education and training strategy in relation to meeting the needs of people with learning disabilities (Fleming & Tosh 1985, Bailey et al 1988, Glover et al 1994, Young et al 1997). Fleming and Tosh (1985) found that clear and accurate goals broken down into incremental steps could be usefully applied by nursing staff using a collaborative multi-disciplinary approach including the client. This British in-patient study placed strong emphasis on training and supporting staff to implement a taught goal planning strategy. Indeed an implementation timetable presented at the end of the training package resulted in all 42 trained staff commencing the goal planning method within two weeks of completion of training. The role of the ward manager was perceived to be crucial in keeping goal planning going after the initial weeks. Also the ability of clinical staff to acquire new skills and examine personal attitudes was found to be important.

The introduction of goal planning and evaluation methods into routine clinical practice raised wider issues. The researchers were aware that efforts to introduce change in staff behaviour often produced short lived results even when outcomes were successful. They attempted to overcome this problem by developing structure and accountability in the service and by continuous involvement of senior staff. Initially this strategy appeared successful but the researchers acknowledged the requirement for longer term follow up (Fleming & Tosh 1985).

Therefore as previously described, the potential for goal planning to act as a mechanism for enhanced multidisciplinary working has regularly emerged within the literature. However no research reports have been found which describe multidisciplinary team functioning within learning disabilities services in more detail.

### **2.5.2 Goal Setting and Self Evaluation**

Locke and Latham's (1990) theory of goal setting proposed that goals led to improved performance because they served as standards against which participants could self-evaluate. Therefore eliminating a 'tester' would have no effect on levels of achievement. American research to test this theory was carried out on a study population of psychology students of whom 72 were male and 67 female (White et al 1995). The study consisted of ten elements and the design involved a tester or no-tester method which was linked to five different conditions, viz., do-your-best, a standard, experimenter assigns goal, experimenter suggests goal, self set goal. Results supported Locke and

Latham's theory provided the goals were perceived as realistic by participants. However, when goals were viewed as too difficult or too easy it was concern over evaluation by an external examiner that was found to motivate performance (White et al 1995). Thus attainment levels were found not to relate solely to internal mechanisms.

In the UK Henderson et al (1989) systematically examined differences between 18 children with movement difficulties and 18 well co-ordinated children in relation to goal setting, self esteem and locus of control. It was found that children with movement difficulties were much less realistic in setting goals than well co-ordinated children. The bias of both groups of children was towards setting higher goals than were achieved and this tendency was exaggerated for children with movement difficulties. Of the two groups those with movement difficulties were also less likely to take responsibility for all types of outcome; for example they were more likely to attribute success or failure to persons other than themselves. The effect of experiencing long term failure (as was likely for those with movement difficulties) was highlighted as an issue by Henderson et al (1989). The researchers commented on previous evidence (Sears 1940) which reported that experiencing long term failure resulted in atypical goal setting of the pattern displayed by the study children with movement difficulties. In addition possible links to 'learned helplessness' theory were noted as worthy of further exploration (Henderson et al 1989). Therefore factors which result in unrealistic self evaluation may have a distorting effect on goal setting and attainment.

Interestingly goal setting was viewed by Trammel et al (1994) as a method of empowering students to have a say in influencing their own performance. This small American study described the use of self monitoring to increase completion of homework assignments for eight children with specific learning disabilities. Selection of students for the study related to past failure to complete assignments and parental interest in improving academic performance. Goal setting and self-graphing of data was an integral part of the methodology and appeared to support an increase in assignments completed on time and to a specified standard. The authors acknowledged that the study focused on academic achievement only, and recommended further investigation of whether self monitoring of goals would affect areas such as social, vocational or independent living skills (Trammel et al 1994).

Thus examination of goal setting as a strategy within healthcare has attracted the interest of a variety of professionals and has been viewed as relevant to a wide range of care groups. Yet, despite some evidence of beneficial effects regarding educational, analytical and communication functions of the approach, inconclusive research findings and a wide variation in the design of studies would support Strecher et al (1995) in the view that health service evaluation to date has been unsystematic.

## **2.6 OVERVIEW**

The concerns of Strecher et al (1995) regarding unsystematic health service evaluation particularly in relation to goal setting methodology, resonate with current opinion that healthcare should be evidence based. The concept of

evidence-based medicine is: ‘The conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients. (Sackett et al 1996). Moreover Evidence-based medicine is viewed as a life-long self-directed learning process in which:

- Clinically important information is identified by converting gaps in knowledge into answerable questions.
- Best evidence is tracked down with maximum efficiency.
- Evidence is critically appraised for its validity and usefulness.
- Results of critical appraisal are integrated with clinical expertise and applied in routine practice.
- Performance of clinicians is evaluated.

(Sackett et al 1996)

The central role of medicine in reviewing the nature of best evidence in relation to clinical decision making is acknowledged. However, Taylor (1997) claims that development and broadening of the evidence based process has resulted in the term evidence-based practice (EBP) becoming more appropriate.

### **2.6.1 Methodologies**

There has been a shift of emphasis within the NHS towards practice being based on research evidence as opposed to tradition and expert opinion (Bannigan 1997). Indeed the Government has committed itself to an evidence-based health service (NHS Executive 1996). Within medicine the ‘gold standard’ evidence of treatment effectiveness has long been viewed as



emanating from the randomised clinical trial (RCT). Despite the undoubted rigour of this methodology it is not always feasible or most appropriate, for example follow up studies may prove the best method of clarifying issues relating to prognosis (Sackett et al 1996). Sometimes evidence also comes from the basic sciences of medicine, for example genetics or immunology. Questions which do not lend themselves to RCTs may be answered adequately through non-experimental descriptive studies or comparative/case studies. Indeed the creative use of both qualitative and quantitative methods of evaluation is becoming more widely accepted although less emphasis is often placed by decision makers on non-randomised approaches, or expert opinion, on the basis that they lack reliability (Lloyd-Smith 1997).

### **2.6.2 Occupational Therapy and EBP**

Strong views have been published in the British Journal of Occupational Therapy (BJOT) regarding the role and function of research in occupational therapy. One opinion is that it is out of touch with the working therapist (Minns 1996), while others believe it to be a crucial means of increasing knowledge and justifying the clinical effectiveness of therapy (Chard 1996). Within occupational therapy there is common usage of the apprenticeship model of practice where a high value is placed on traditional scientific authority, adherence to standard procedures and expert opinion. It has been argued that this approach may result in clients receiving ineffective interventions or even harmful input, and that practitioners were likely to have closed minds (Bannigan 1997). Thus at practitioner level within the profession there exists tension regarding what constitutes best practice.

The Code of Ethics and Professional Conduct for Occupational Therapists (COT 2000) (The Code) states that Occupational Therapists have a duty to ensure that practice is based on research findings wherever possible. The delivery of high quality care is viewed as being based on accurate and current information which is acquired by therapists who are personally responsible for undertaking continued learning. All occupational therapists are required to contribute to the continued development of professional practice through critical evaluation of intervention, audit and research (COT 2000). The Code (COT 2000) also requires occupational therapists at all times to recognise and respect the autonomy of clients receiving their services. Each client is viewed as unique, with the right to make informed choices and decisions about their own health. The Code (COT 2000) further states that such choices exercised by clients should be respected even when in conflict with professional opinion. Thus for practitioners major issues emerge in relation to resolving potential conflicts between offering a client-centred approach to therapy and the implementing of evidence based practice. Sumsion (1997) urged therapists to carefully consider the impact on clients of the decision to implement intervention, regardless of the evidence on which it was based. Issues raised by Sumsion (1997) for consideration included the need to clarify who is the client. For example it could be an individual patient, or a carer, or both patient and carer, or it could be the follow up service. Different users may have different agendas. Clarification is also required regarding which type of evidence should take precedence. For example, should evidence showing follow-up care is best practice take precedence over evidence that the user has made an informed choice not to accept follow-up? These complex issues further impact upon the

traditional therapist power base where client rejection of elements of the care plan may engender feelings of failure for the therapist (Sumsion 1997).

In addition, within routine practice multi-dimensional factors continually interplay, for example cultural, economic, legal, physical, political and social. Practitioners cannot ignore political and economic factors in light of waiting lists and scarce resources, but it is the therapist's responsibility to ensure the client's voice is not lost as a result of external driving forces (Sumsion 1997).

### **Conclusion**

From the literature, three key themes emerge as driving an agenda which supports inclusion of people with a learning disability and their carers in a process of designing, implementing and evaluating the health care they receive.

Firstly, the growth of consumerism within society allied to government directives for a partnership approach within the NHS, has produced a momentum for promoting greater user involvement in health decision-making (Davies 1994, Long 1996, Fairfield & Long 1996, Sumsion 1997). This heralds a challenge to long established predominance of professional opinion within healthcare and begins to open a debate on who is "expert" - user or professional?

Secondly, there has been a re-examination of how disabled people are viewed within society, for example, Wolfensberger's (1972) principle of normalization significantly influenced the perceived value of people with learning disability. Effects of an increasingly vocal disability rights movement are starting to

impinge on political thinking and service delivery. Issues of inclusion, consultation and satisfaction are recurring themes in the literature (Kenny 1990, Hayman and Huckle 1993, Dagnan et al 1994, Sines 1995, Witts & Gibson 1997). Yet warnings remain that patient delineated outcomes lack credibility in relation to established research methodology which is weighted towards analysis of standardised quantitative measurement, and which is dominated by clinical rather than patient definitions of effectiveness (Dixon & Long 1995). Furthermore, past exclusion of groups such as those with learning disabilities was based on assumptions that impaired intellectual ability precluded meaningful involvement in health decision making (Jenkinson 1993). There is evidence that such assumptions are now being challenged (Flynn 1986, Atkinson 1988, Hayman & Huckle 1993) and that the new agenda is one of developing valid methods, approaches and tools for appropriate inclusion (Lindsay et al 1994, Williams 1994, Dagnan et al 1995, Simon & Roy 1996, Joy 1997).

Thirdly, evidence based practice combined with spiralling costs and a business approach to care delivery has resulted in greater accountability for health providers. The requirement for health professionals to clearly demonstrate treatment impact and to justify resource allocation is now firmly established (Leach 1996, Sackett et al 1996, Eakin 1997). This growing emphasis on cost effectiveness, outcomes and accountability has raised concerns that competence is preferred to caring. Indeed when there is over emphasis on technical competence and clinical protocols a danger emerges of neglecting issues perceived as important by healthcare users (Mew & Fossey 1996). Thus

recognition is growing of the need to develop methods, which will translate the ideology of patient inclusion and partnership into routine clinical practice in a manner which is more universally credible and acceptable.

The literature reviewed here underpins the development of the main research study in which particular emphasis is placed on:

- Examination of emerging issues in respect of establishing collaborative goal setting and outcome evaluation within routine clinical practice.
- Delineation of essential factors for promoting meaningful involvement of people with learning disabilities in healthcare decision making.

The literature reviewed helped to refine research questions and develop appropriate research methodology and research procedures.

### **3. METHODS**

#### **3.1 INTRODUCTION**

This research has drawn from a number of theories and concepts which underpin the work. Case study research was chosen as the predominant methodology due to a number of factors. The properties of case study research which resonate with this investigation are described by Yin (1994) who proposes that the case study is:

- empirical, i.e. it is based on observation rather than mainly theory, and it aims to illustrate how things take place and why
- an investigation of current event
- set with a real life context
- set within event and contextual boundaries that are not entirely clear
- a methodology that collects data from multiple sources of evidence, using a range of different methods

The case investigated in this work centred on the introduction of Goal Attainment Scaling within routine clinical practice in two acute and specialist units for people with learning disabilities in Aberdeen. Thus the GAS study provided the initial focus of the work, and the issues which emerged guided the subsequent course of the investigation. The conceptual framework of grounded theory (Strauss & Corbin 1998) was used for hypothesising from data. The methodology was therefore exploratory, descriptive and interpretive which has resonance with the ideographic nature of the work described in this thesis.

Another methodological influence within this study was that of practice-led research. The term practice-led (Gray & Malins 1995) refers to undertaking research through action and reflection on action. The approach is likely to be used by individuals working in the area of study, such as present researcher who is a healthcare professional studying frontline healthcare practice within learning disabilities services.

The study was developed to include quantitative elements where appropriate. For example interview surveys were used to gather indepth views of care evaluation from GAS study clinicians and from managers and commissioners within Grampian. Furthermore a postal questionnaire survey was considered the most appropriate method for surveying adult learning disabilities services across Scotland.

Throughout this investigation an important consideration has been the study population i.e. people with learning disabilities. This has had a significant impact on the selection of research methods (see literature review).

### **3.1.1 Research and people with learning disabilities**

There has been considerable interest in studying the needs and wishes of people with learning disabilities despite recognition that this is a challenging area for research as discussed earlier. Issues confronting the researcher are as follows:

- the meaningful involvement of people with impaired intellectual capacity

- difficulties associated with poor communicative ability
- tendencies towards a response bias
- lack of experience in expressing of views
- a power imbalance between professionals and users of services

### **3.1.2 Recent Approaches**

Recently researchers have been exploring new approaches for addressing these complex issues. Indeed, in 1998 the British Journal of Learning Disabilities devoted an issue to a series of papers on current research ethics within the learning disabilities field. This indicated that qualitative and participatory methods were predominant and indeed no papers had been submitted based on either survey methods or experimental research (Walmsley 1998). The editors concluded that qualitative researchers were at the forefront of addressing ethical questions within learning disabilities, but urged others involved in different research contexts to join the debate thus contributing to the development of knowledge (Walmsley 1998).

Ward and Simons (1998) point to an attitudinal shift away from traditional research methodology which was carried out *on* subjects to a model whereby people with learning disabilities are involved as participants in the research process. This change in approach has been reinforced by funders of research, for example the Joseph Rowntree Foundation and the National Lottery Charities Board (now the Community Fund). Both explicitly encourage the empowerment of learning disabled people through more active involvement in the research process. This might be achieved by contributing to choice of topic,



type of design or acting as research consultants. Indeed there is evidence of a small but growing number of projects where people with learning disabilities are working as co-researchers, or are involved in developing techniques for dissemination of findings (Ward & Simons 1998, Van Hove 1998).

Change in methodology has highlighted issues to be addressed regarding meaningful involvement of people with intellectual impairment in academic endeavours. Support is viewed as crucial in dealing with issues such as technical complexities, informed consent and confidentiality (Ward and Simon 1998). Consideration must also be given to expectations of participants that research relationships will continue beyond the duration of the project (Walmsley 1998, Van Hove 1998). Models which place the participants of research in control of the process as co-researchers have been considered to be new paradigm research (Kiernan 1999). This new methodology fundamentally alters the power balance in the research process, away from the researcher and towards the participants (Kiernan 1999). Indeed some proponents of new paradigm research argue that the role of research is one of assisting emancipation for people with learning disabilities with the researcher becoming an activist in supporting disabled people achieve change (Kiernan 1999). Yet doubts have been raised with regard to the validity and practicality of new paradigm research. Of particular note are issues to do with maintaining the researcher's ability to be objective, especially in relation to the influence of pressure groups. Indeed, difficulties in detaching the views of supporters from the research process raises serious questions of the validity of the method (Kiernan 1999).

In the study reported here additional issues had to be taken into account when selecting the research methods to be used. For example, because the study base was the acute admissions sector of service provision the study population was likely to be heterogeneous. Potentially including those with profound or multiple impairments whilst attempting to ensure meaningful involvement would present major challenges. Further dilemmas involved the possibility of individuals expressing behaviour or aspirations in ways which might appear to run counter to their best interest. Under these circumstances complex decisions may be required from staff or carers regarding overruling the user's apparent 'choice' by applying principles of beneficence (Kiernan 1999).

The continuing debate over models of research within learning disabilities highlights the ongoing problem of how to investigate the experiences of people with learning disabilities, their views and aspirations. There is recognition that in the past much traditional methodology failed to engage those with learning disabilities in the research process, and there is now an increasing desire to develop valid and robust models which will meaningfully involve people in studies which more accurately and powerfully affect policy and practice (Kiernan 1999).

The basic themes embodied in the first phase of the study centre on examining; (1) the partnership approach to healthcare evaluation involving clinicians, carers and users and (2) the collaborate setting of goals within routine clinical practice. This approach resonates with qualitative research being concerned with uncovering meanings as seen by those who are being researched, in their

natural settings, and with understanding their view of the environment rather than that of the researcher (Jones 1995).

However, until comparatively recently quantitative methods have been dominant in health services research. Jones (1995) argued that this had come about because clinical scientists had difficulty in accepting the research methodologies of the social sciences in which the generation of hypotheses often replaces testing of hypothesis and explanation and understanding replaces measurement and generalisability respectively. Thus perceived lack of scientific rigour allied to unfamiliar presentation and publication of results has resulted in qualitative research struggling to gain credibility within health studies (Jones 1995). Other more general reasons for poor acceptance of qualitative methods may include professional elitism, difficulties with the replication of studies and changes to the power balance within research (Kover 1982). For example, in qualitative research 'subjects' have more freedom to express their own views.

Although the two approaches have been presented as adversarial there are advantages in combining the methodologies to build up a wider picture (Pope and May 1995). Indeed choice of method and how it is used can be matched to what is being studied rather than reliance being placed on the professional or methodological learnings of the researcher (Pope & May 1995). For example in this study quantitative methods are used for surveying the views of large numbers of respondents over a large geographical sector. While qualitative methods are used for in depth investigation of beliefs about healthcare and elements of complex therapeutic phenomena.

As in this study Pope & May (1995) point to reliance within health service research on health care professionals acting as investigators, participants and peer reviewers. Yet irrespective of whichever research model individuals may prefer, researchers tend to hold views on people and society gained from their culture, from research and academic literature and from values and beliefs which are shaped by personal experience (Kiernan 1999). A recent survey of community health trusts highlighted a lack of basic research skills felt by many health professionals (Eldridge & South 1998). Interestingly however, some doctors and many nurses believed that the current NHS research strategy was unfavourable to qualitative studies and that this emphasis was incongruent with the therapeutic basis of their own work (Eldridge and South 1998).

Difficulties in translating research findings into changes in practice are well documented and can lead to feelings of frustration and powerlessness at clinical levels (Jones 1995, Pope & May 1995, Eldridge & South 1998). However it has been argued that momentum for change takes time to build up but can eventually lead to major policy reform (Kiernan 1999). Furthermore it has been proposed that there is particular merit in including a wide variety of health service views from the perspective of users, professionals and managers at times of reform or policy change (Pope & May 1995).

### **3.1.3 Research Rationale**

Ultimately the research rationale for the early part of the study evolved from a synthesis of factors highlighted in the literature. When selecting appropriate research methods for application with people with learning disabilities and with

multidisciplinary staff teams in the first phase of this study, the researcher took into account issues highlighted in the literature, many of which pointed to the use of qualitative methods (see sections on Evolution of Outcome Measures, User Involvement of People with Learning Disabilities, GAS and People with Learning Disabilities).

Thus it was considered important to apply methods such as:

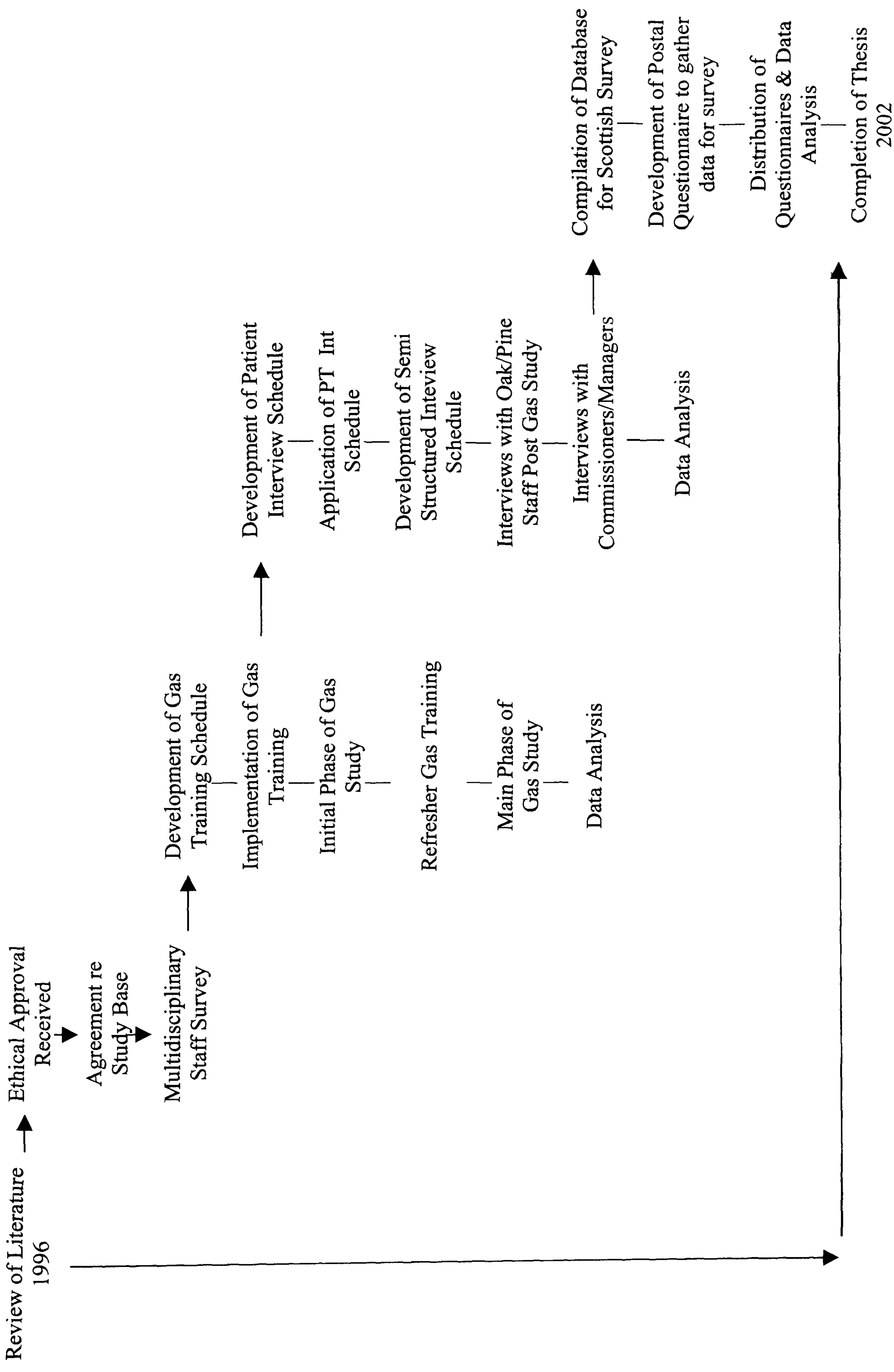
- individualised evaluation techniques
- relaxed, informal, unhurried interactional style with the learning disabilities population
- use of pictures to facilitate patient responses
- involvement of direct care staff in the implementation of the therapeutic study within routine practice
- conducting of individual interviews to gather more detailed and/or in depth information

However as identified in the literature it was also considered important to maintain a flexible approach whereby methods could be chosen to suit the elements under investigation rather than conforming to a predetermined set of evaluation tools. In fact qualitative methods used in the early phase of the work resulted in the raising of questions of fundamental importance regarding outcome measurement, teamworking and the ability of people with learning disabilities to make decisions regarding healthcare. This prompted broadening of the study to include; (i) investigation of managers and commissioners

perspectives on healthcare for people with learning disabilities, and (ii) a Scottish survey of adult learning disabilities services focussing on the nature and extent of outcome measurement within care provision. The latter stages of the research were carried out as a result of transfer of registration from M.Phil to PhD.

An overview of the research process is presented in figure 1.

**Figure 1 The Research Process**



### 3.2 RESEARCH STUDY BASE

The Clinical Services Manager at Woodlands Hospital gave outline support for the study early in 1996 ( Appendix 1) and ethical approval was granted in May 1996 by Grampian Health Board and the University of Aberdeen Joint Ethical Committee (Appendix 2).

Pine Admission Unit provides multidisciplinary in-patient assessment and treatment for up to 12 community based adults who in addition to having learning disabilities, are suspected of having psychiatric illness (Pine Admission Unit Operational Policy). Users exhibit a range of mental health problems, for example schizophrenia, depression, anxiety and phobia. Oak Challenging Behaviour Unit provides multidisciplinary in-patient assessment and treatment for up to 12 adults who normally live in the community and who in addition to having learning disabilities, present challenging behaviours which are not thought to indicate underlying psychiatric illness (Oak House Operational Policy). Challenging Behaviour refers to “behaviour of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to or use of ordinary community facilities.” (Emerson et al 1987).



Each multidisciplinary team comprises:

Consultant Psychiatrists (3)*	Occupational Therapist
Clinical Psychologist*	Speech and Language Therapist*
Clinical Psychology Assistant	Social Worker*
Qualified Nurses (8)	Physiotherapist *
Unqualified Nurses (8)	Dietitian*

\*Denotes Part-time input.

The two units were described in Grampian Healthcare Business Plan 1994/1997 as representing acute and specialist services for adults with learning disabilities in The Grampian Region. In November 1996 discussions with the Ward Managers of both units indicated they were willing to co-operate with the practical application of the study within their respective areas and further support for the work was obtained from the wider multidisciplinary teams at the team administrative meeting. The Consultant Psychiatrists who refer to the units gave formal support for the research to make use of everyday clinical material within the study.

### **3.2.1 Survey of Oak/Pine Multidisciplinary Team**

This study began in October 1996 by gathering views of staff regarding their the multidisciplinary team care planning process and desired therapeutic outcomes for patients. This preliminary data gathering was intended as a 'snapshot' of staff perceptions of care delivery with Oak & Pine prior to implementation of the GAS study. Emphasis was placed on the occupational

therapy contribution to team functioning because the researcher was an occupational therapist. This approach was considered more likely to be accepted by staff. It was considered important to obtain practitioners' views early in the study to obtain baseline data. It was decided to use questionnaires to collect data because standardised information was required from a relatively large study population (47), this being considered too many to be individually interviewed by a single researcher. Construction of questionnaires followed the strategy outlined by Chesson (1993), viz.,

- Efforts were made to devise unambiguous and easily understood questions so that there could be one schedule for all despite variation in amount of staff education/training, for example there were professionally qualified and unqualified staff.
- Instructions for using the forms were clear and simple and the layout was designed to be user friendly.
- Precoded questions were devised to promote straight forward efficient data analysis. There were specific sections for ranking items and for selecting options from a 'menu'.
- A covering letter was issued along with each form, briefly outlining the purpose of the survey and requesting a response within ten days. People were advised to leave blank any questions they considered difficult. Replies were anonymous and confidentiality was guaranteed.

There were a total of nine question areas, some of which had up to a maximum of twenty sub questions. The first four questions were brief and focused on

characteristics of the population linked to length of service, whether or not they possessed a professional qualification and whether or not their post was ward based. The remainder of the questions centred on perception of:

- the role of the occupational therapist
- priority areas for occupational therapy intervention
- provision/implementation of occupational therapy
- the multidisciplinary care planning process

The questionnaires were piloted at Strathmartine Hospital, Dundee and four were returned, one each from an occupational therapist, a dietitian, a speech and language therapist and a social worker. Despite prompting, no returns were received from nursing staff, therefore assistance was gained from Woodlands Hospital nurses who did not work in the study base. Returns were received from three trained and one untrained nurse and subsequent minor alterations were made to the original forms.

In January 1997 forty-seven questionnaires were distributed through the hospital internal mailing system to practitioners providing input to the two units. Addressed return envelopes were provided. The questionnaires were sent to the following staff disciplines: medical (4), psychology (3), professions allied to medicine (5), social workers (2), and nursing (33).

The questionnaires elicited information on a range of issues as described above. Thirty-four completed forms were returned within ten days with a further five

arriving within four weeks, giving a total response rate of 83%. Differing response rates were noted for non-nursing and nursing staff, this being 100% and 76% respectively. However it was recognised that within such a local population, the researcher was likely to be able to identify some respondents from unique personal information. This may have had an influence on responses. (See Appendix 3 for copy of schedule.) It was planned to repeat the survey at the end of a study of Goal Attainment Scaling to identify whether perceptions had changed as a result of personal experience of the process. However major staffing turnover, and staff difficulty with application of GAS made this unfeasible.

### **3.3 THE GOAL ATTAINMENT SCALING STUDY**

Goal Attainment Scaling (GAS) (Kiresuk & Sherman 1968) was selected as an appropriate tool for examining outcomes of routine health interventions for people with learning disabilities (see literature review section). In particular it was hoped that by implementing a study embedded in routine practice the researcher would discover the effect of GAS on:

- collaborative clinical practice
- user/carer involvement in healthcare planning
- the focusing of health input
- definition of health outcomes

In early March 1997 agreement was reached with Oak and Pine ward managers for primary nurses to attend training regarding GAS which would be co-

ordinated with shift patterns and planned leave. It was decided that two ninety minute sessions would be most suitable and these were scheduled for two consecutive Wednesday afternoons in late April 1997. This was when both nursing shifts overlapped. Negotiations with other disciplines regarding participation in training were completed by mid March and good multidisciplinary representation was achieved including occupational therapy, physiotherapy, speech and language therapy, psychology, psychiatry, social work and nursing. In total ten staff attended the two training sessions. The training objectives were:

- to teach GAS so that the concept was understood
- to achieve clarity of training so that participants were able to carry out a 'practice' goal with a selected patient
- to promote a collaborative approach to using GAS by encouraging involvement of users/carers/colleagues

The main aim of the training was that each participant would subsequently try one 'practice' goal and would return GAS data to the researcher in a predetermined format. The design of training took the form of face to face teaching of factual information; use of specific clinical examples to illustrate the relevance of the technique for the client group; interactive group exercises to develop insight into the description of goals in measurable performance terms; provision of handouts to reinforce key themes; guidance in the use of specifically devised checklists and record forms for accurate data recording. Where appropriate, record forms were piloted by staff in the day unit at

Woodlands Hospital. The training sessions were conducted as follows:

### **Session One**

- Introduction and overview of purpose of training.
- Definition of a 'goal'
- Brief description of GAS and provision of fact sheet handout.
- Group exercises in how to describe goals in performance terms, and provision of handouts from STEP manual and Bereweke Skills Teaching manual.
- Explanation of how to scale a goal using a variety of clinical examples chosen to resonate with the study base.

### **SESSION TWO**


- Brief recap of how to scale a goal with opportunity for participants to practice goal scaling.
- Explanation of how to record timeframe of goal, and scoring of outcome.
- Discussion of user involvement in GAS and provision of handout based on Sines (1995) paper.
- Introduction of the Patient Goal Form and reinforcement of the importance of user involvement in the process. In addition the form which had a distinctive border and pictorial representation of the goal concept provided a tangible record for the patient to keep (see figure 2). It was hoped this would act as a concrete prompt in future discussions about the treatment goal. Staff were instructed to use their own

discretion when offering assistance to complete the form. For example some patients might wish to write down their goal themselves and some might request that staff write it for them, others may elect to draw a picture of their goal, or cut and paste something appropriate from a magazine.

- Discussion of collaborative multidisciplinary approach to GAS and guidance on how to complete the Joint Goal Setting form which, in relation to patient/carer/staff, recorded who was involved, how much involvement there was and how useful involvement was felt to be.
- Introduction of a plan for participants to conduct a 'practice' goal with a selected patient. Provision of a GAS 'pack' containing all relevant checklists, record forms and examples. A short reference list was also included (see Appendix 4).
- Confidentiality and ethical issues for both staff and patients were discussed negotiated and agreed with participants. Closure.


Figure 2

The Patient Goal Form



My Name:

My Goal:



The form is enclosed in a large rectangular border. At the top center, there is a silhouette of a superhero with a cape, holding a shield. Below this, the text 'My Name:' is followed by a blank space for writing. Further down, the text 'My Goal:' is followed by a large blank space for writing. At the bottom center, there is a silhouette of a doctor in a white coat and glasses, holding a clipboard, and a patient sitting in a chair, leaning forward.



A request had been made that initial record forms for the 'practice' goal be returned to the researcher by 23 May 1997. Due to low response a letter was sent in early June to all participants asking those intending trying GAS to indicate thus. The letter generated very little response and there followed an unsettled period in both units with a number of staffing changes and long term sickness. Retraining was undertaken opportunistically with new staff including occupational therapy, clinical psychology, psychiatry and nursing. GAS participation remained very low and a decision was taken in February 1998 that if the situation remained unchanged at Easter a contingency plan would be effected. After Easter, no significant increase in use of GAS had been noted and so it was decided to try a more directive approach. The learning disabilities Clinical Services Management Group, key service managers and the Consultant Psychiatrists were approached for support in relaunching the GAS initiative on the understanding that selected staff participants would be required to complete the methodology with a minimum of two patients each. Support was forthcoming from all.

Key staff were identified for the second attempt to launch the GAS study, viz., four primary nurses, two occupational therapists, a speech and language therapist and a clinical psychologist. A date was agreed for one hour refresher training on 1 July 1998. This fast-track training comprised a recap of how to set and scale the goal, how to record data and guidelines for returning record forms to the researcher. User participation and a collaborative team approach to GAS was strongly reinforced. Ethical and confidentiality issues were also discussed and renegotiated. Each participant was provided with a new GAS

'pack' on the understanding that the technique would be tried with two patients per staff member over a four month period (01.08.98 - 30.11.98). The provision of an independent GAS mentor who would provide support for staff was offered but in the event not accepted. A short pre-trial questionnaire survey was conducted with those who attended refresher training prior to commencement of the relaunched study, to gauge perception of training and views on potential application of GAS.

### **3.4 DEVELOPMENT OF THE PATIENT INTERVIEW SCHEDULE**

The selection of GAS as the main investigation tool in this research relates to the most significant requirement of the methodology being that goals must be developed by all persons involved, for example client/clinician/carer. Indeed involvement of users in the GAS process is considered fundamental to valid application of the technique (Carr 1979, Cook 1995, Greehalgh & Long 1996). This inclusive approach chimes appropriately with current government emphasis on developing partnerships within health care, through such directives as the White Paper, *Designed to Care* (1997) and *Our National Health* (2000a). The partnership approach has also been embraced by the service user movement, although caution has been expressed regarding the willingness of established vested interest within the NHS to share power (Kenny 1990, Sines 1995, Needham 1996, Sang 1999). Yet including people with learning disabilities in research and evaluation demonstrates that their views are valued. Furthermore Dagnan & Ruddick (1995) has pointed out that there are many areas of their lives for which they are only valid informants. Thus it is timely to consider the development and application of appropriate tools for meaningful

inclusion of people with learning disabilities in their healthcare, and for presenting their views as valid.

There has been considerable interest in determining how to obtain meaningful responses to questions from people with learning disabilities and in establishing reliable and valid methods of interpreting replies (Sigelman et al 1981, Flynn 1985, Atkinson 1998, Booth et al 1989, Bull & Cullen 1993, Dagnan et al 1994 and Redworth 1998). Problems in obtaining meaningful responses are compounded when respondents have limited communicative abilities or poor or no speech; multiple handicaps; limited or no experience of the content of questions; and are anxious or unfamiliar with the process of interviewing (Booth et al 1989, Bull & Cullen 1993). Therefore although people with learning disabilities may be the only appropriate source of information it must be borne in mind that their ability to respond to questions is related to impaired intellectual capacity, presence of additional handicaps, and the mode of questioning (Flynn 1985).

Sigelman et al (1981) point to potential for response bias, particularly a tendency towards acquiescence which has been noted in relation to people with learning disabilities. These researchers highlight the importance of using open questions and avoidance of leading questions thus increasing the likelihood of obtaining valid answers. In addition there is evidence that people with learning disabilities need to be interviewed within a friendly and informal atmosphere in which questions are embedded in a conversational style (Atkinson 1988, Redworth 1998). Indeed Redworth (1998) has shown that an interviewee with

learning disabilities only became more open in expressing opinions after the tape recorder was switched off and the carer was no longer present.

Therefore when planning partnership endeavours with people with learning disabilities a variety of factors must be considered, viz.,

- Meaningful involvement of people with impaired intellectual capacity
- Difficulties associated with poor communicative ability
- Tendencies towards response bias
- Lack of experience in expressing views
- Power imbalance between professionals and users of service

Thus in this study it was considered crucial that additional attempts be made to elicit users' views which would be supplementary to the GAS process. This was to be achieved through development of patient interview schedule.

#### **3.4.1 Selection of Interview Tools**

Until recently most question formats for people with learning disabilities have been based on nominal data. Dagnan & Ruddick (1995) highlight the importance of discovering methods of recording ordinal or interval data, thus creating measurement suited to reporting strength of beliefs and attitudes and their change over time.

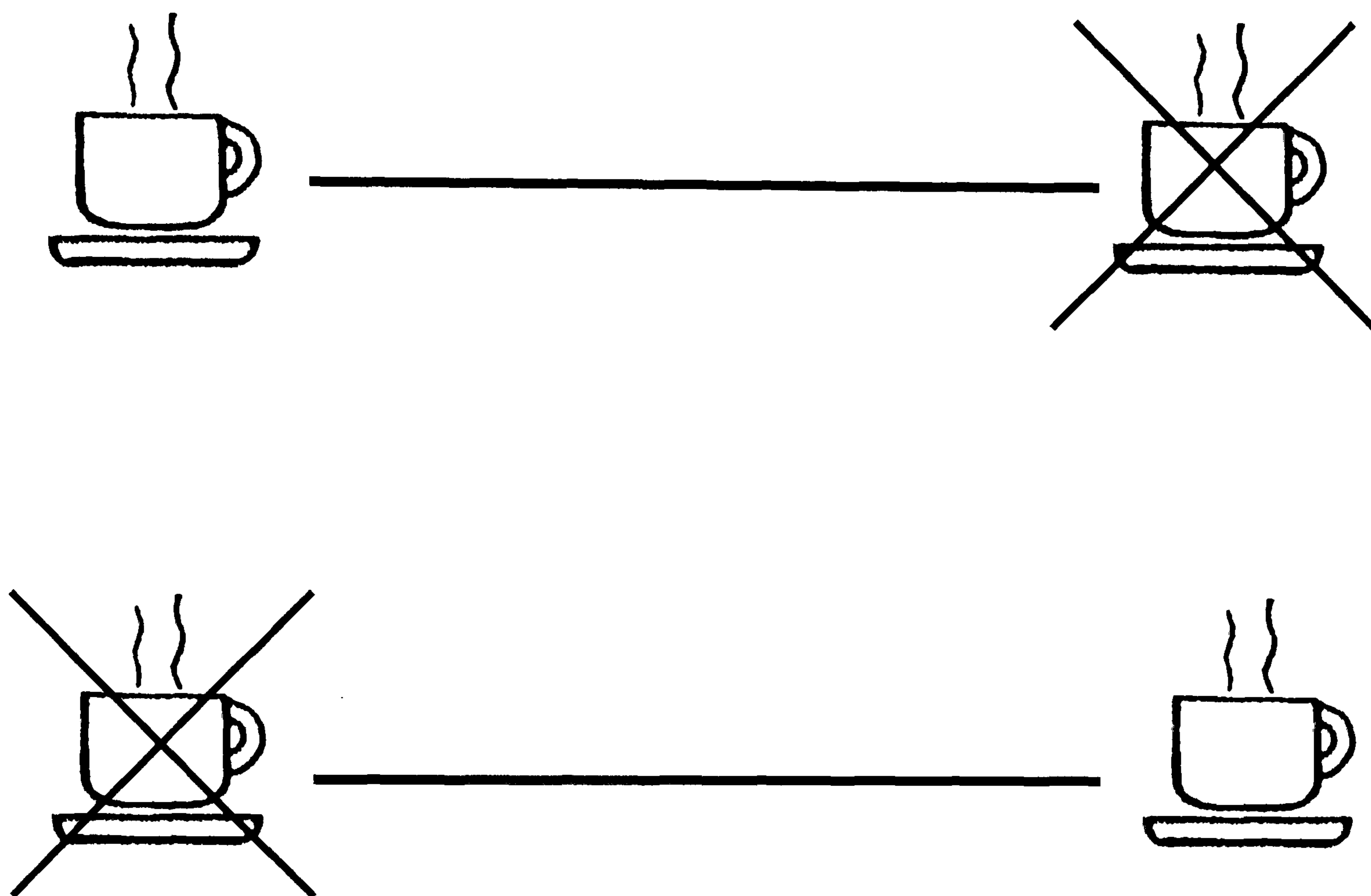
Dagnan & Ruddick (1995) described research which examined such structured questioning methods including the use of analogue scales which was selected for the following reasons:

- Evidence that some subjects with learning disabilities were consistently able to use the analogue scale.
- The analogue format is less dependent on higher receptive language ability than other structured question methods.
- The scale has an inbuilt control for response bias.
- Evidence to suggest that the analogue scale may be used with a good degree of reliability. However there was acknowledgement of the methodology being relatively sophisticated and there was lack of clarity about the level of ability needed to participate.

It was considered reasonable to attempt to use analogue scales as a tool for structured questioning within the present study despite uncertainty regarding its suitability for less able patients. In fact there were local concerns that some of the less able patients in Oak and Pine would be unable to tolerate – or meaningfully relate to – *any* structured attempts to gather views. It was indeed suggested that detailed observation of functioning with subsequent interpretation of behaviour might be the only way of eliciting views from some patients. That is, use of descriptive rather than tested and scored methodology. However this part of the study was considered exploratory and so it was decided worthwhile proceeding.

The analogue scale consisted of two pictorial anchors with a five inch line between them. For the present study pictorial symbols were selected from the Picture Communication Symbols (Mayer – Johnston 1989) because of the clarity and simplicity of the line drawings (copy of analogue scales Appendix 5). To ensure a consistent approach, the same symbol was used for both anchors with one crossed out to indicate the negative range of the question (see figure 3). The picture concept was to be explained to respondents as the symbols were meant to be informative and NOT a recognition test. Thus both visual and verbal cues were given with the intention of increasing the likelihood of patients' understanding. The line was divided into half-inch sections, which were scored from one to ten. The analogue question formats were repeated at the end of the interview to assess reliability. The positions of the pictures were reversed at the second presentation to control for position bias and scoring was corrected to allow for scale reversal (Dagnan & Ruddick 1995).

**Figure 3 Examples of Analogue Scale**



In addition it was decided to repeat the analogue scale procedure with a member of staff who knew the participant well in order to support reliability of responses. Using staff knowledge as a measure of validity implies that staff are better able to express what a person with learning disabilities wants or means than the individual himself/herself. March (1992) warns that this is an unwarranted assumption. Indeed there is evidence that asking staff about preferences of disabled people gives no indication of what the individual's own response would be (Sigelman & Budd 1986, March 1992). However if convergent staff/patient responses were obtained, this might be interpreted as strengthening perceived validity of responses. But if there was no agreement then there would be no indication of whose responses were more valid.

Two central concerns of this element of the research were to seek out suitable methods of inclusion for all people with learning disabilities, and to present their views as reliable. To this end an additional photographic interview format was devised to complement the analogue scale by providing a less sophisticated method of facilitating answers to questions. Thus it was hoped that a wide range of participants could be supported to engage in the interview and express their views. Moreover, the research literature suggests that reliability can only be established by the use of more than one question format (Stenfert Kroese et al 1998). A cautionary note has been sounded by Cardone (1999) who found that when used along with a personal questionnaire format, pictures did not help the interviewees' ability to respond appropriately. However it was suggested that clients' difficulties related in part to the forced choice of format of questioning in that study and it was recommended that future research take a more qualitative approach (Cardone 1999). Therefore despite limitations of pictures it was decided to use photographs in the GAS study because photography is a valued adult activity and generally thought to be interesting and pleasurable for participants (Booth et al 1989, March 1992, Anderson 1997, Wright 1999).

### **3.4.2 Pre Interview Preliminaries**

In order to further support the credibility of responses given by participants it was considered crucial to have a method of establishing communicative competence prior to interviewing. The British Picture Vocabulary Scale (BPVS) (Dunn et al 1982) was chosen as a simple measure of receptive vocabulary, which would resonate with the pictorial theme of the analogue



scale. The method requires the participant to indicate which of four pictures best illustrates a particular word. Although the BPVS is well established, caution has been urged in relation to interpreting and evaluating the scores of people with learning disabilities (Atkinson 1991, Howlin & Kendall 1991). Indeed the test has only been standardised up to aged 18 years, therefore when applying it with an adult population with learning disabilities more reliance may have to be placed on raw scores.

### **3.4.3 Obtaining Valid Consent**

Significant challenges exist in obtaining valid consent from people with intellectual disability for example Jenkinson (1993) points to the importance of assisting those with learning disabilities to identify personal preferences when making choices thus reducing the danger of lack of protest being mistaken for informed consent. In addition Guidance from the Medical Research Council on The Ethical Conduct of Research on the Mentally Incapacitated (MRC 1993) underscores the duty of researchers to explain to subjects potential advantages and disadvantages of participation. Thus while recognition is given to the argument that it can be important to gain knowledge which may be of benefit to mentally incapacitated people in general, (even though this can only be acquired by involving those who are unable to consent) the MRC counsels that it is crucial that safeguards are inbuilt for the protection of vulnerable people (MRC 1993). Examples of such safeguards would be that procedures involve negligible personal risk and that an independent person be present when seeking consent to ensure that consent is freely given and to gauge level of understanding. In this study a short consent form was developed to record

whether or not consent to interview was obtained (Appendix 6). It was considered appropriate to seek an independent witness nominated from within the nursing teams because such staff would be able to perform the dual role of patient supporter and independent witness. It was considered important to arrange all appointments with patients via the nursing team and in co-operation with the primary nurse, because the nurses knew the natural rhythm of the ward and the patient's daily routines and therefore could advise which times were likely to best suit the patient. The consent interview was held in a room on the ward where quietness and privacy could be assured. A flexible interview script was developed using clear unambiguous language and the researcher judged how to pace information giving and how much repetition was required depending on individual circumstance. Strenuous efforts were made to ensure the consent interview was as relaxed, unhurried and non-threatening as possible. Emphasis was placed on helping the patient to understand that the researcher was seeking assistance in a research endeavor and that the process was NOT intended as a test of patient competence. The researcher took the lead in giving explanation with the independent witness being available for patient reassurance and further clarification at the request of the patient. The final response was recorded on the consent form in a manner considered most meaningful for the patient who was asked whether self completion or completion by proxy was preferred. All patients were provided with a copy of a patient information sheet, which gave a brief written account of the study (Appendix 7).

#### **3.4.4 Data Collection**

In addition to preparation of specifically designed forms, processes and ongoing completion of field notes it was decided to tape record the analogue-scale interviews as a backup strategy which would enable cross checking of data if necessary for external validation. Tape recording would be discontinued if the patient requested so, or if it was obvious that an individual was anxious or uncomfortable with the procedure. In fact one individual refused permission for the interview to be tape-recorded and in another instance it proved difficult to analyse the content of the tape due to poor sound quality. A number of participants required reassurance and coaxing to feel comfortable in the context of the interview and it was judged inappropriate to introduce recording equipment under such circumstances. Therefore recording of interviews was abandoned.

#### **3.4.5 The Analogue Scale Interview**

Prior to interviewing, all elements of the schedule were piloted with three users of the Day Unit at Woodlands Hospital. Only minor revisions to the schedule were identified via the pilot.

Interviews were conducted in familiar settings around the hospital usually in a quiet area of the ward in which the patient was living at the time. Efforts were made to create a relaxed and friendly atmosphere and the interactions were unhurried. An interview script was developed for the analogue scales comprising open questions embedded in themes. Framing of questions was consistent although the same question was repeated using slightly different

language if this was considered necessary to reinforce understanding, for example “show me X”, “point to X”. Two introductory ‘practice’ questions were devised to familiarise respondents with the concept of analogue scaling. Neutral, universally recognisable topics were selected, viz., how much an individual liked coffee and how much they watched television. This was followed by a question about the weather, requiring a negative response. Then three questions relating to GAS were introduced using two concrete visual prompts to link the content of the questions to the GAS process. The first prompt was a photograph of the member of staff involved in jointly setting and working on the goal. The second was a visual representation of the goal recorded on a special form with a distinctive border (The Patient Goal Form Figure 2).

The three GAS related questions were as follows:

- Show me how much you talked to (STAFF) about (THE GOAL)... a lot, a bit, not much.

*Point to how much you talked to (STAFF) about (THE GOAL)*

- Show me how happy you feel about (THE GOAL).... a lot, a bit, not much.

*Point to how happy you feel about (THE GOAL).*

- Show me how hard you worked on (THE GOAL).... a lot, a bit, not much.

*Point to how hard you worked on (THE GOAL).*

\*Italics denotes alternative form of question.

Questions were asked in the order shown above. The entire schedule was then repeated with the pictorial anchors reversed on each scale for internal validity. Arrangements were subsequently made to repeat the analogue scale procedure with a member of staff who knew the patient well to provide external validity.

#### **3.4.6 The Photograph Interview**

The photograph interview replicated methodology for internal checking of validity outlined by March (1992), which involved asking questions for which there were factually correct answers. The presentation of pictures along with questions has been proposed as enhancing communication for the following reasons:

- pictures decrease the verbal loading of questions
- pictures reduce the need for the interviewee to make a verbal response
- pictures may reduce response bias (March 1992)

An important element of the photographic interview involved looking at an album containing pictures chosen to represent two themes. Ten pictures of ships/sea and ten pictures of animals were selected as being images likely to be easily recognisable to a wide range of respondents. Thus the album was designed to provide a non-threatening focus of attention on specific images. During interview participants were encouraged to look at pictures in the album one at a time and each individual was prompted by the researcher, “tell me what you see in the picture”. It was hoped this would give an indication of the meaning of the photographs for each individual. The pace of looking at and

talking about the pictures was determined by the level of interest shown by the participant. Once the activity was completed the interviewee was asked five questions in a pre-determined order. Two questions involved general knowledge and three were related to the content of the album.

An interview script was developed to ensure consistent framing of questions but the same question was repeated using slightly different language if this was considered necessary to re-enforce understanding. Response to questions took the form of a forced choice from two photographic options. Examples of questions are given below.

a) General Knowledge question

Here are some pictures I want you to look at them both.

- show me the picture of Woodlands  
(point to the picture of the hospital)  
(show me Oak ward/Pine ward)

The correct response was a photograph of the part of the hospital in which the participant lived. The incorrect response was a photograph of a residential bungalow of similar age and construction. (figure 4)

b) Interview related question

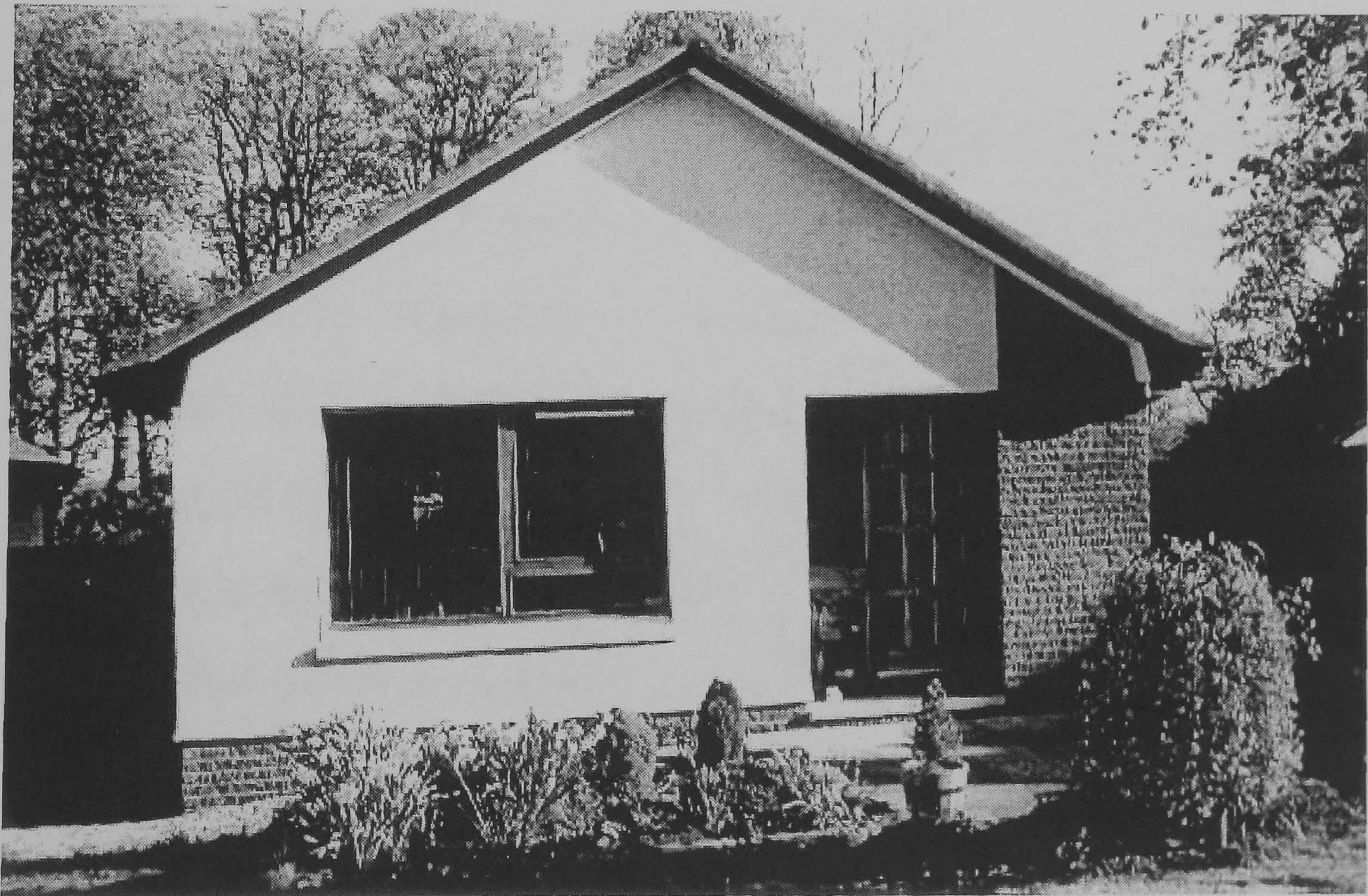
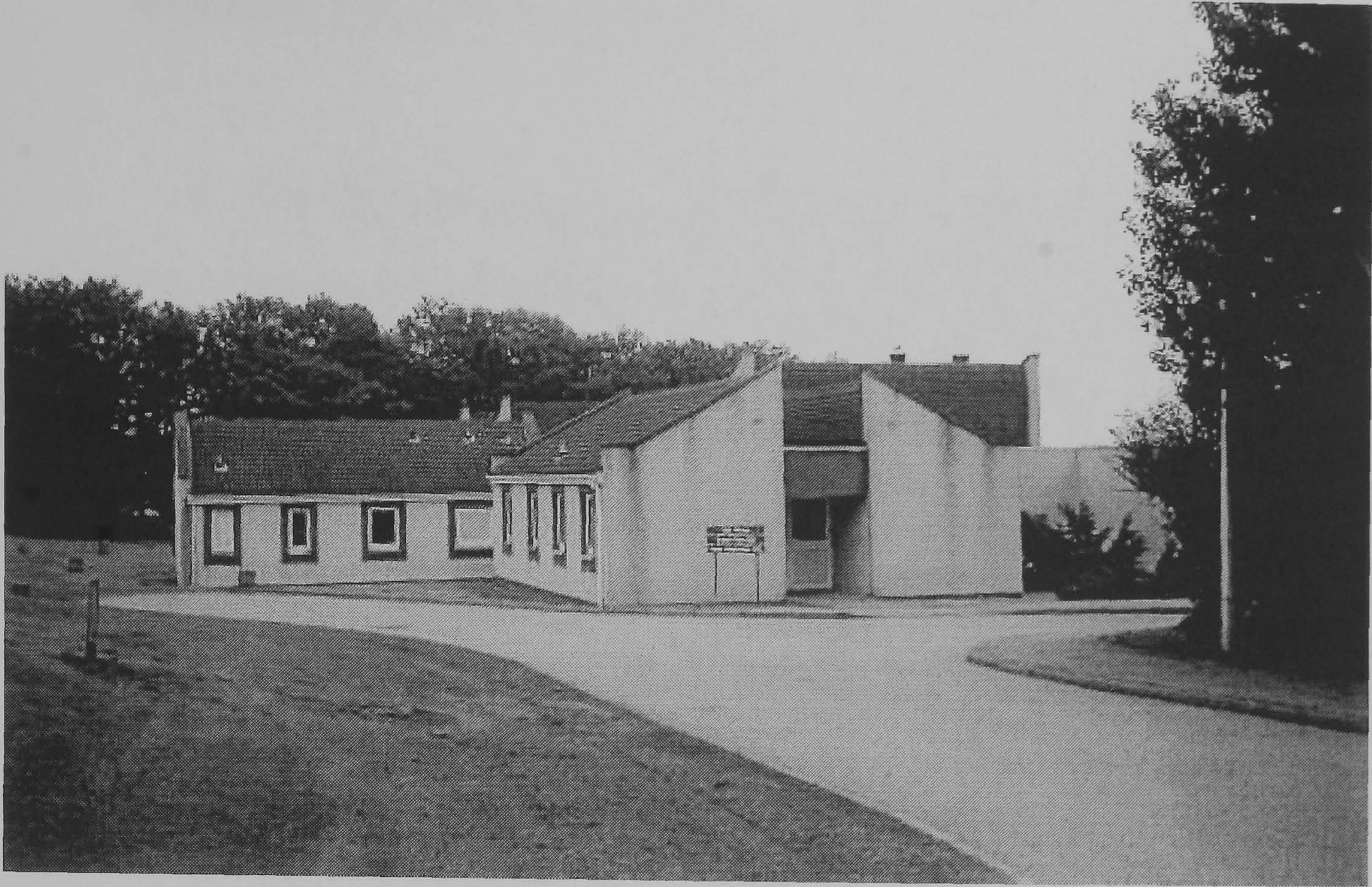
Here are some more pictures I want you to look at them both.

- show me the one that's the same as the pictures in the photo book

(Point to the one like the pictures in the photo book)

The correct response was a photograph of ships/sea. The incorrect response was a photograph of a car.

Figure 4      Photographs used on Photograph Interviews (Example)





### **3.4.7 Validation of Patients' responses**

Cross checking of responses was used as a method of establishing the validity of patients' responses to interview, viz.,

- The analogue scale was to be scrutinised for response bias by repeating the questions and reversing the position of the pictorial anchors.
- An external comparison of the analogue scale was to be made by a relevant practitioner judging how they consider the patient would have responded on the rating scale.
- A comparison was to be made of patient self reporting goal attainment on the analogue scale and staff team ratings of GAS outcome.
- Examination of patient responses to the photo interview was conducted regarding factually correct choices.

## **3.5 SEMI STRUCTURED INTERVIEW SURVEYS**

The final part of the first stage of the research comprised information gathering from staff who were involved in the implementation of the GAS study and from managers and commissioners of learning disabilities services. It was decided to collect data by conducting semi-structured interviews with individuals because in-depth information was required to address complex issues arising from the GAS study. This necessitated face to face discussion to elicit precise details or to probe for further clarification of stated opinions. However, there were issues which had the potential to influence responses, viz.,

- relative status of interviewer and interviewee

- perceived work roles of interviewer and interviewee within a local service which might result in concerns about the interviewer having a hidden agenda
- contextual issues in relation to the learning disabilities service going through a period of continuous and far reaching change. Thus there may be anxieties about an uncertain future or problems in relation to 'information giving fatigue'

In order to minimise the above factors, the interviews were designed to project an open and straight forward approach. The interviewer adopted a courteous and neutral manner and tried to eliminate cues which would lead the interviewee to respond in a particular way. Emphasis was placed on creating a comfortable ambience. For example the respondents had choice of interview location such as their own office, the researcher's office, or another suitable chosen venue. In addition the interviews were not audiotaped because it was felt that adopting an ordinary conversational style was less likely to inhibit responses. This was an important issue because of factors such as relative status and power differentials which required sensitive handling within practice based research. The interviewer ensured familiarity with the structure of the schedule and put emphasis on listening rather than talking, only using probes when necessary. Answers were written down on a pre-prepared schedule concentrating on key words and phrases. Additional notes were added immediately after the interview was completed and a finalised written account was completed within 24 hours.

### **3.5.1 Interviews with Oak/Pine staff after the GAS study**

In May 1999 letters inviting people to participate in the interview were sent to eight staff who had attended the GAS refresher training (four nurses, two occupational therapists, one speech and language therapist, one psychologist). The consultant psychiatrist who attended the original training was also contacted. Eleven questions were prepared covering (1) treatment evaluation and outcome, (2) the GAS process experienced in the study, (3) user involvement in healthcare, (see copy of schedule in Appendix 8). The questions were constructed using clear non-technical language. The schedule introduction explained the purpose of the interview and briefly outlined the current stage of progress within the context of the research timeframe. Confidentiality was assured. The initial two questions were designed to put individuals at ease, the main body of questions elicited specific views of the GAS process, and the final three questions were more generally linked to outcome measurement. These latter questions gathered data regarding personal preferences for care evaluation and allowed 'winding down'. The interviews lasted 30 minutes. During closure, staff were thanked for their support and assistance to date, and it was stated that a written summary of the findings of the GAS study would be provided for the ward multidisciplinary teams once data analysis was complete. Between 18 June 1999 and 7 July 1999 interviews were completed with all staff except one nurse who was on long term sick leave.

### **3.5.2 Interviews with Commissioners and Managers**

In July 1999 letters were sent to twelve commissioners and managers of learning disabilities services in Grampian briefly outlining the research, and inviting them to participate in the interview (two Health Board Commissioners, four Social Work Managers who had a joint commissioning/management role, two Managers of voluntary sector agencies and four NHS Managers). It was considered important to gather views on health evaluation from a wide variety of stakeholders because of government emphasis on a partnership approach to healthcare. It was also anticipated that gathering views from managers and commissioners would prove beneficial in helping to place findings from the GAS study within a wider context.

Twelve questions were prepared using a clear non technical language. Also prepared were brief written outlines of Oak and Pine Units and a definition of GAS including advantages/disadvantages of the technique. These were to be made available to interviewees as factual background information (See copy of schedule in Appendix 9).

The schedule introduction explained the purpose of the interview, gave a short account of the research including progress to date, and provided the interviewee with a written description of the study base. Confidentiality was assured. The initial two questions were designed to put people at ease by providing opportunities for individuals to describe personal experiences of service evaluation and outcome measurement. The main body of questions centred on partnerships with users, multidisciplinary and multiagency work practice, and

views on the type of health outcomes considered appropriate for people with learning disabilities. Views of GAS were specifically requested with a brief written account of the technique made available for reference. The final two questions asked about different priorities in relation to stakeholders' perceived outcomes agenda. During closure the interviewer thanked the interviewees for their participation and offered a final opportunity to add any comments not covered in the schedule. Between 26 July 1999 and 9 September 1999, ten 60 minute interviews were completed (one social work manager could not be contacted, and one social work manager nominated an alternate already included as a participant).

The interview surveys were designed to gather detailed views of care provision and evaluation for people with learning disabilities in Grampian. The final phase of the research was a broader Scottish questionnaire survey of adult learning disabilities services which was carried out to determine the nature, purpose and extent of goal planning and its evaluation in relation to this user group.

### **3.6 THE SCOTTISH SURVEY**

A postal questionnaire survey was selected as the appropriate method of gathering data from potentially large numbers of respondents across the widespread geographical area. It was envisaged the Scottish Survey would be important in placing the first stage of work in Grampian within a national context.

In light of government directives for a partnership approach to care delivery emphasis was placed on constructing a survey database which encompassed a wide range of stakeholders. This proved challenging due to fragmentation of learning disabilities services following reduction of traditional hospital based care and an exponential growth in smaller, interagency community based services. Furthermore because of data protection issues, problems arose in accessing potentially useful data sources such as mailing lists for learning disabilities organisations, for example, Enable, BILD, SHAS. In fact the survey database was developed from the following sources:

- Scottish Executive, Health Department (Information & Statistics)  
List of current inpatient learning disabilities locations in Scotland  
List of Health Board locations in Scotland
- Scottish Association of Health Councils (mailing list)
- Assistant Directors of Social Work, Learning Disabilities Sub Group  
members mailing list
- Scottish Executive, Social Work Statistical Liason Group (mailing list)
- Scottish Council of Voluntary Organisations  
Selected information from Health Education Board for Scotland (HEBS  
on CD)

Ultimately the Scottish survey encompassed Health Boards (15) Health Councils (15) NHS Trusts (28) Local Authorities (36) and representation from non-statutory organisations and user organisations (35).

*Design of the Questionnaire.* Construction of questionnaires followed strategy outlined by Chesson (1993), viz.,

- Efforts were made to devise unambiguous and easily understood questions, suitable for respondents from different professional backgrounds and varied employment backgrounds
- Instructions for using forms were clear and simple and the layout was designed to be user friendly
- As far as possible precoded questions were devised to promote efficient data analysis. There were specific sections for ranking items and for selecting options from a ‘menu’
- A covering letter to a personally named recipient was issued along with each form briefly outlining the purpose of the survey and requesting a response within ten days. Replies were numerically coded and confidentiality was guaranteed (see Appendix 10 for copy of schedule)

There were a total of seven question areas some of which had up to a maximum of ten sub questions. The questions centred on:

- Currently used evaluation methods in learning disabilities
- Views of outcome measurement
- Perceived appropriateness of specified methods of measuring health outcomes
- Extent and perceived effectiveness of user involvement in care

- Desired future methods of evaluation of care for people with learning disabilities

The questionnaire schedules were piloted by sending forms to seven individuals in different geographical areas of Scotland and from a variety of care organisations, viz., one health board, one health council, one voluntary agency, one social work employee with a strategic role, one social work employee with an operational role, two NHS trust employees (one clinical/one managerial). Only two postal responses were returned but three telephone contacts were received highlighting difficulties with the schedule. These centred on differences in language/jargon/labels used in different care agencies, and a requirement for more universal options to questions. In addition because the role of Health Councils was one of monitoring care rather than care provision a modified version of the schedule was required specifically for Health Council respondents (see Appendix 11). Therefore the schedule was re-designed to take account of pilot stage feedback and two forms were sent for final comment - one to a health council respondent and one to a social work respondent. Both were satisfied with the revised schedules.

In January 2001 the postal questionnaire was sent to 94 key stakeholders including a stratified sample of subjects from statutory organisations and a purposive sample of subjects from voluntary and user groups to ensure adequate representations. One follow up contact was made with non respondents. The final response rate was 76 (80%) yielding 73 usable forms.



### 3.7 DATA ANALYSIS

#### a) Analysis of patient's goals

Concerns have been consistently raised regarding the statistical procedures recommended by Kiresuk & Sherman (1968) to deal with GAS data obtained in practice. In fact serious reservations have been expressed regarding validity of data and computation of standard scores obtained by the conventional GAS procedure (Seaberg & Gillespie 1977, Cytrynbaum et al 1979, Mackay et al 1993). Therefore in this study analysis of goals has been carried out using the non parametric approach described by Mackay et al (1993) in which goal scores are treated as ordinal data. Thus in this study no standard scores were generated for individuals. However using the non-parametric approach means that no questionable assumptions have been made regarding numerical values used in calculation.

#### b) Analysis of patients' responses on analogue scales

Analysis was completed according to the method recommended by Dagnan & Ruddick (1995). The scale was divided into half inch sections, which were scored from one to ten. The analogue question formats were repeated at the end of the interview to assess reliability. The positions of the pictures were reversed at the second presentation to control for position bias and scoring was corrected to allow for scale reversal (Dagnan & Ruddick 1995).

#### c) Analysis of interview surveys

For both interview surveys categories were derived for the more quantitative data such as evaluation techniques described by respondents, and themes developed for narrative comment. Categories and themes were then agreed by the researcher and the university supervisory team and a

coding frame developed. All data were subsequently coded.

d) Analysis of postal questionnaire surveys

Data analysis of the Scottish survey was completed as follows:

(1) computer analysis of responses to closed questions using Excel

(ii) qualitative data analysis of open questions by identifying themes and developing a coding frame

Analysis of the Oak/Pine multidisciplinary staff team questionnaire was completed following hand collation of responses.

### 3.8 Overview of Methods

The variety of methods of data collection described in this section are shown in

Table 1. The findings of data analysis are presented in the next chapter.

**Table 1: Methods of data collection**

<b>Method</b>	<b>Participants</b>
Postal questionnaire survey (i)	Oak/Pine Multidisciplinary Staff
Goal Attainment Scaling Study	Oak/Pine Staff Oak/Pine Patients
Analogue Scales Interview	Patients involved in GAS study
Photographic Interview	Patients involved in GAS Study
Interview Survey (i)	Clinicians involved in GAS study
Interview Survey (ii)	Managers and commissioners of learning disabilities services within Grampian
Postal Questionnaire Survey (ii)	Respondents from adult learning disabilities services within Scotland

## **4. FINDINGS**

### **4.1 INTRODUCTION**

The results from this investigation will be presented in four main sections:

*Section One* outlines the findings of the survey of Oak and Pine staff expectations of the occupational therapy contribution to the team care plan and desired outcomes. Practitioners' views were obtained early in the study to provide baseline data regarding the study base.

*Section Two* provides results of the GAS study of co-operative care planning and outcome evaluation. Particular emphasis was placed on including patients' views of the therapeutic process and outcome of treatment.

*Section Three* presents the findings of the interviews with study base clinicians regarding GAS.

*Section Four* presents the findings of interviews with Grampian managers and commissioners regarding healthcare evaluation.

*Section Five* comprises results of the Scottish postal questionnaire survey, which elicited multiagency views of outcome measurement with people with learning disabilities.

## **4.2 SECTION ONE : SURVEY OF OAK & PINE MULTIDISCIPLINARY TEAMS**

This questionnaire survey was conducted during January 1997 with the aim of gaining a 'snapshot' of clinicians' perceptions of: the role of the occupational therapist; priority areas for occupational therapist intervention; provision/implementation of occupational therapy; and the multidisciplinary care planning process. Forty seven questionnaires were distributed to practitioners providing input to the two in-patients units. The questionnaires elicited quantitative data on the range of issues described above. Thirty-nine completed forms were returned giving a response rate of 83%. Differing response rates were noted for non-nursing and nursing staff, this being 100% and 76% respectively.

### **4.2.1 Summary of Results**

#### **Staffing Profile**

As can be seen from Table 2, the staff group was an experienced workforce with only four individuals having less than one year's learning disability experience (two trained nurses, two untrained nurses). The majority of respondents were ward based (28) rather than being departmentally based. Of the nursing respondents 48% were unqualified, and of the qualified nurses two were dual trained. One was a registered general nurse and one was a registered mental nurse in addition to being qualified in learning disability nursing. The remaining staff all had qualifications in a range of health professions or social work (Table 3).

**Table 2: Oak & Pine Staff Profile**

<b>Length Of Time Worked In NHS (In Years)</b>		<b>Length Of Time In Learning Disabilities (In Years)</b>	
< 1	4	< 1	4
1 - 5	11	1 - 5	13
6 - 10	10	6 - 10	13
11-15	2	11-15	3
16 - 20	9	16 - 20	4
21 - 25	1	21 - 25	1
> 25	2	> 25	1
<b>TOTAL</b>	<b>39</b>	<b>TOTAL</b>	<b>39</b>

**Table 3: Professional Qualifications Of Oak & Pine Staff**

<b>Qualification</b>	<b>No.</b>
<b>Nursing</b>	
Enrolled Nurse	4
Registered Nurse in Mental Handicap	9
<b>Medical</b>	
MB Ch B & MRC Psych	3
MB Ch B	1
<b>Psychology</b>	
MA Hons & 3 Yr Post Graduate training in clinical psychology	1
BSc Hons & Post Graduate training in clinical psychology	1
BSc Hons	1
<b>Professions Allied to Medicine</b>	
B Sc Nutrition and Dietetics	1
LCST	1
Grad Dip Physio	1
B Sc OT	2
<b>Social Work</b>	
MA Hons & Dip SW	1
DSW	1
<b>No Professional Qualification</b>	<b>12</b>
<b>TOTAL</b>	<b>39</b>

#### 4.2.2 Role of the occupational therapist

Additional data collected regarding views of the occupational therapists' contribution to Oak & Pine are not presented here and can be found in the appendices. (Perception of the occupational Therapist role in Oak & Pine – Appendix 12, Occupational therapy input ranked in order of perceived

importance – Appendix 13, Occupational therapy provision/implementation (Oak/Pine) – Appendix 14).

In fact the primary purpose of the staff survey was to gather baseline data regarding the multidisciplinary care planning processes which were established within Oak & Pine prior to the introduction of GAS. It was considered important to have a clear understanding of routine ward operational procedures at this stage in order to monitor the impact of introducing GAS.

#### **4.2.3 Multidisciplinary Care Planning**

There was no clear consensus regarding who might co-ordinate the care plan, as can be seen from Table 4. Most respondents (32) agreed that the team care plan should be decided by the team, although twelve also thought that individual professionals could make decisions unilaterally. Most respondents (33) agreed that the team care plan should be clearly recorded with all treatment aims shown, but 16 staff also agreed that only their own discipline's aims should be recorded in their own case notes. The greatest degree of team consensus concerned treatment being stated in a measurable way and evidence being available of attempts to involve patients meaningfully in health care.

**Table 4: Multidisciplinary Care Planning (Oak/Pine)**

Each patient's care plan should	n = 37*			
	Strongly Agree	Agree	Disagree	Strongly Disagree
Be co-ordinated by the Ward Manager	10	11	10	6
Be decided by each professional individually	5	7	9	16
Be co-ordinated by the Consultant	5	11	13	7+
Be decided by the MDT either through general agreement or majority vote	17	15	4	0+
Be written down clearly in one place with everyone's treatment aims shown	16	17	4	0
Be reviewed at agreed intervals by the ward manager	20	14	2	1
Be written down separately in each professional's own case notes showing only their own aims	6	10	11	10
Be reviewed by each professional as specified in their own treatment plan	11	16	6	4
Have the effects of treatment stated in a way which can be measured	15	19	3	0
Show evidence of trying to involve patients meaningfully in their healthcare	17	19	1	0

\* two respondents did not complete this section

+ one non-response to question

Table 5 shows perceptions of the required contribution from each discipline to different elements of the care plan. The attendance of all disciplines at clinical meetings was seen to be important. For other discrete activities, different disciplines were perceived to have key roles with some disciplines having little or no role. This held true even with activities where it might have been expected that everyone would have a contribution, for example management of behaviour, stabilising of mental state managing control and restraint. As might be expected within in-patient units the role of the nurse was perceived to be very significant.

In these particular units the occupational therapists were also ward based which may account in part for perceived high requirement for occupational therapy.

Thus the data gathered from surveying Oak & Pine multidisciplinary teams provided detailed information regarding the composition, skill mix, experience and training of the staff group. The findings also offered insight into staff perceptions of the care planning process, including required professional contributions *prior* to the introduction of GAS within Oak & Pine.

Thus it was hoped to achieve greater clarity regarding the impact of GAS. The results of implementing the GAS study are described in the next section.



**TABLE 5 : Perception Of The Required Contribution From Each Discipline To The Care Plan (Oak/Pine)**

	OT	SLT	SW	N	PSY	MED	OTH	n
Monday/Friday clinical team meetings	37	32	33	37	36	36	PT8 D7	37
Care planning/discharge planning meetings	38	34	36	39	36	39	PT4 D4 CN	39
Home visits	31	14	32	27	19	22	PT3 D2 CN1	39
Adaptive equipment eg rails, bath seat	37	0	5	25	0	1	PT5	39
Domestic skills	37	1	3	33	3	0	PT1	39
Developing mobility	30	0	1	30	1	5	PT25	39
Toileting programmes	26	1	0	37	20	4	0	39
Eating programmes	27	21	0	35	16	9	D15 PT3	39
Moving and handling guidelines	29	0	0	28	2	4	PT23	37
Communication Skills	22	37	2	29	25	5	0	39
Self care skills	33	3	3	36	8	2	PT2	39
Social skills	35	16	15	33	23	6	PT1 D1	39
Management of behaviour	20	12	8	37	36	30	0	39
Stabilising of mental state	13	7	10	33	29	38	0	39
Management of medication	1	0	1	38	7	39	0	39
Management of aggression - control and restraint	9	6	5	39	26	25	PT1	39
Leisure programmes	35	8	12	29	12	4	PT1	38
Community living programmes	33	15	33	29	24	14	PT2 D1	39
OTHER (Bowel management)	0	0	0	1	0	0	DI	1
OTHER (Dysphagia)	0	1	0	1	0	0	DI	1
OTHER (Pressure sores)	0	1	0	1	0	0	DI PT1	1

OT Nurse  
 SLT Psychology Staff  
 SW Psychiatrist/Registrar

OTH Other eg

PT Physio  
 D Dietitian  
 CN Community Nurse

## **4.3 SECTION TWO: THE GAS STUDY**

### **4.3.1 The patient participants**

Oak & Pine staff selected 12 patients to be involved in the GAS study based on the nature of each individuals needs and how identified needs were to be addressed. A profile of the 12 participants is shown in Table 6 demonstrating the diversity of personal characteristics and healthcare needs of those requiring acute in-patient admission. However the majority of patients included in the study by ward multidisciplinary teams were female (10:2). The complexity of individual care needs is further delineated in two case histories which illustrate in more depth the heterogenous nature of the participants. (See Appendices) Patient C (Appendix 15) was in-patient in Pine Unit, and Patient F (Appendix 16) was in-patient in Oak Unit.

The needs of Oak & Pine patients involved in the GAS study emerged as highly complex and wideranging. The process of setting and reviewing goals to meet individual needs is now described.

**Table 6 : Patient Participants in the GAS Study**

n=12

Patient	Gender	*Age	**Degree of LD	Primary Diagnosis	L.O.A. prior to GAS Trial (in months)	Other Significant Factors	Most Recent Reason for Referral to O.T.
A	F	36y 5m	Mod/Severe	Non specific. Admitted due to deterioration in health & emotional stability	2.5	Main carer unable to continue role due to poor health.	General functional assessment.
B	F	27y 4m	Mod/Mild	Challenging Behaviour.	65	None.	Functional assessment to inform community care plan prior to discharge.
C	M	27y 6m	Mild	Manic Depressive Illness.	1.5	Repeated hospital admissions following breakdown of community placements.	Assessment & development of daily living skills. Re-integration to community living when stable.
D	F	41y 7m	Mild	Manic Depression.	8	None.	Assessment of concentration levels during structured group activity. Confidence building.
E	F	59y 1m	Mild	Bipolar Mood Disorder.	12	None.	Functional assessment to inform care plan prior to community discharge.
F	F	44y 2m	Moderate	Challenging Behaviour.	56	Limited understanding of language.	Functional assessment to inform care plan prior to community discharge.
G	F	58y 5m	Moderate	Depression/Delusional Psychosis.	2.5	Has phases of refusing to eat or drink.	Assessment of daily living skills. Structuring of time - Exploration of leisure interests.
H	F	51y 11m	Moderate	Paranoid Psychosis.	9	Admitted under Sec 18 of Mental Health Act.	Functional assessment to inform care plan prior to community discharge.
I	M	38y 5m	Borderline	Depressive Episode & Anxiety State.	1	History of inappropriate sexual behaviour.	Assessment of domestic daily living skills, particularly cooking skills.
J	F	44y 7m	Mild/Mod	Hypomania	0.5	None.	Assessment of personal daily living skills with specific reference to transfers.
K	F	24y 5m	Severe	Autism, Epilepsy, Acute Challenging Behaviour.	35	Unable to tolerate structured activity.	Functional assessment, to assist with MDT strategies for constructively managing behaviour.
L	F	24y 9 m	Mild	Paranoid Personality Disorder. Challenging Behaviour.	6	Impaired vision & hearing. Previous admissions under sections of Mental Health Act.	Functional assessment. Development of domestic & community living skills.

\*Age: Age at onset of GAS Trial.

\*\* Degree of Learning Disability: ICD-10 Classification; 50-69 Mild, 35-49 Moderate, 20-34 Severe, Below 20 Profound.

L.O.A. prior to GAS Trial: Length of most recent admission prior to GAS trial.

## 4.3.2 The GAS Process

### 4.3.2.1 Collaborative involvement in goalsetting

Practitioners reported multidisciplinary staff involvement in the setting of all goals and the process was generally considered useful (Table 7). Notably instances in which there was named involvement of only one discipline were considered least useful.

**Table 7: Multidisciplinary team involvement in goal setting as perceived by staff**  
n=12

Patient	Involvement	Staff	Frequency	Usefulness (Range 1-5*)
A	YES	Nurse, Doctor	N,3 times, D once	5
B	YES	Nurse	<3 times	3
C	YES	Nurse, Doctor	Once	5
D	YES	Nurse, Doctor	Once	4
E	YES	Nurse, Doctor	<3 times	5
		Psychologist		
F (g1)	YES	Nurse, Doctor	<3 times	4
		Psychologist		
F (g2)	YES	Nurse	Once	2
**G	YES	Nurse, Therapist	<3 times	5
H	YES	Nurse, Therapist	Once	5
I	YES	Nurse, Therapist	<3 times	5
J	YES	Nurse, Therapist	Once	5
**K	YES	Nurse, Therapist,	<3 times	5
		Psychologist		
L	YES	Nurse, Doctor,	<4 times	5
		Therapist, Psychologist		

\* 1 = not useful, 5 = useful

\*\* same degree of involvement in all goals

Staff reported involvement of ten of the 12 patients during goalsetting, and the process was considered useful for all except one of those who were able to be engaged (Table 8). However, it is of major significance that there was no carer involvement in the GAS Study, apart from one carer being involved once in one goal.

**Table 8 : Patient involvement in goal setting as perceived by staff**

n=12

Patient	Involvement	Frequency	Usefulness (Range 1-5*)
B	YES	<3 times	4
C	YES	<3 times	4
D	YES	<3 times	4
E	YES	<3 times	3
**F	YES	<3 times	4
**G	YES	Once	4
H	YES	Once	4
I	YES	Once	3
J	YES	<3 times	4
A	YES	Not indicated	1
**K	NO	-	-
L	NO	-	-

\* Range 1 = not useful, 5 = useful

\*\* same degree of involvement in all goals

The meaningful involvement of patients in the GAS process was to be reinforced through the introduction of the pictorial patient goal form (Figure 2) which was intended to serve as a concrete prompt. The goal form was acceptable to eight of the participants and rejected by one (Table 9). A quarter of the participants were not offered the form due to staff doubts regarding the relevance of the prompt for individuals.

It is noteworthy that despite emphasis on the participatory nature of GAS during staff training, the goal for patient L was practitioner focused rather than collaborative. Therefore there was evidence of practitioners' preference for setting goals from a unilateral professional perspective rather than in partnership with users.

**Table 9: Acceptability of the Patient Goal Form**

n=12

<b>Patient</b>	<b>Response to Patient Goal Form</b>
B	Form was accepted
C	Form was accepted when staff were prompted by researcher to offer it
D	Form was accepted
F	Form was accepted and used for both goals as the focus remained the same
G	Three forms were accepted - one for each goal
H	Form was accepted
I	Form was accepted
J	Form was accepted
E	Patient did not accept the form
A	Form not offered, therapist judged it to be not meaningful for patient
K	Forms not offered for either goal, staff judged forms would be unacceptable to patient
L	No patient involvement in developing the goal, therefore form not relevant

#### **4.3.2.2 *The Goals and GAS Scores***

16 goals were set and scaled and therapeutic focus reflected the wide variety of care needs including; personal activities of daily living, community living skills, management of emotions and behaviour, therapeutic engagement and physical performance (Table 10). Variation in timescales related to type of goal, and patient potential for improvement. It proved possible to measure the impact of intervention for all goals.

**Table 10: Patient Goals and GAS Scores**

Patient	Type of Goal	Timescale of Goal (in weeks)	Raw GAS Scores **	
			Initial	Attained
A	Self care - showering	4	-1	+2
B	Selecting a healthy diet	12	-1	0
C	Self medication	4	-1	+1
D	Snack cookery	23*	-2	+2
E	Self care - showering	10	-1	0
F	g1 Use of public transport	14	-1	+1
	g2 Further developing use of public transport	12	-1	-1
G	g1 Developing eating skills	4	-1	+2
	g2 Self care - showering	4	-1	0
	g3 Mobility and transfer skills	6	-1	0
H	Anger management	10	-1	0
I	Anxiety management	6	-1	+2
J	Engagement in activities	6	-1	0
K	g1 Making tea	6	-1	+2
	g2 Management of aggression	4	-1	+1
L	Engagement in therapy	12	-1	+1

\* Original timescale was 16 wks, delayed due to discharge occurring whilst therapist on holiday NB: goal measured in community setting

\*\*GAS Scores  
 - 2 much less than expected outcome  
 - 1 less than expected outcome  
 0 expected outcome  
 +1 better than expected outcome  
 +2 much better than expected outcome

Qualitative analysis of GAS scores shows that targets were exceeded in nine instances and met in six instances (Table 11). Scores remained at baseline for one goal. This analysis suggests a tendency towards underestimating patient potential by staff.

**Table 11: Analysis of Patient GAS Scores**

				n=12				
Patient	Raw attained Scores			Qualitative Analysis				
	g1	g2	g3	A	B	C	D	E
A	+2			1				
B	0				1			
C	+1			1				
D	+2			1				
E	0				1			
F	+1	-1		1			1	
G	+2	0	0	1	2			
H	0				1			
I	+2			1				
J	0				1			
K	+2	+1		2				
L	+1			1				

- Key g1-g3 : goals set for each individual  
 A : targets exceeded  
 B : targets met  
 C : targets not met but beyond baseline  
 D : scores remaining at baseline  
 E : scores regressed from baseline



### 4.3.2.3 Patient Views of GAS

Patient views of the GAS process were reported in interviews using analogue scales and photographs. Consent to interview regarding the GAS study was obtained from six of the 12 patients (Table 12). Of the remaining six participants in the study only one individual refused consent for interview. There was a lack of access to three potential participants due to rapid discharge, which was an interesting feature of conducting practice based research. Finally consent was not obtained from two patients because of difficulties in individuals' tolerance of engagement.

**Table 12: Patient consent for Interview (GAS Study)**

			n=12
<b>Patient</b>	<b>Consent Obtained</b>	<b>Remarks</b>	
B	YES	Completed all elements of schedule	
C	YES	Completed all elements of schedule	
F	YES	Completed all elements of schedule for one goal only	
G	YES	Completed all elements of schedule for three goals	
H	YES	Completed all elements of schedule	
I	YES	Completed all elements of schedule	
E	NO	Patient refused consent	
K	NO	Researcher advised by MDT not to seek consent, believed distressing for patient	
L	NO	No patient involvement in goal, interview not relevant	
A	NO	Discharged and left area before consent obtained	
J	NO	Discharged and left area before consent obtained	
D	NO	Discharge and delay in measuring goal made follow-up inappropriate	

The six participants who gave consent completed the British Picture Vocabulary Scale (BPVS) prior to interview. This highlighted significant variation in individuals' understanding of language (Table 13). Yet despite

variable participant abilities and varying levels of sophistication in the two modes of questioning, all six participants completed both the analogue scales and the photograph interview.

**Table 13 : Patient Scores on the British Picture Vocabulary Scale\***

Patient	Date of Assessment	Age at Assessment	Raw Score (Range 0-150)	Age Equivalent (in years & months)	Confidence Intervals ** (in years & months)
B	08.09.97	27y 10m	65	7-0	6-6 to 7-6
C	05.08.97	27y 7m	74	8-0	7-5 to 8-7
F	30.12.98	44y 6m	38	4-3	3-10 to 4-8
G	09.12.98	58y 10m	35	4-0	3-6 to 4-5
H	30.12.98	52y 2m	60	6-5	5-11 to 7-10
I	11.12.98	38y 8m	128	15-9	14-10 to 16-8

n=6

\* The BPVS is designed for people 2½ -18 years. The test measures understanding of standard english.

\*\* Confidence levels on the BPVS are 68%.

#### 4.3.2.4 *Self reported patient responses to the analogue scales*

All participants were able to complete the analogue scale by indicating a specific point on the line for each question on both presentations. With regard to interpretation of responses a variety of factors emerged as follows:

- I. *Internal validation of scale.* When scrutinising for response bias there was evidence of participants giving the same response to all questions, viz., participants F & H only used a very narrow band at the positive end of the scale. However, both individuals immediately noted the reversal of the pictorial anchor on the second presentation and adjusted their responses accordingly within the same narrow band.

II. *Congruence between self-commentary and given responses.* A number of individuals verbalised their reasons when responding to questions which allowed the researcher to compare self commentary and given responses. Reluctance to record a negative response on the scale was noted for C, F & H resulting in incongruency between commentary and the scale response. Subsequently during external comparison of the analogue scale a nurse spontaneously commented that F would have known that a negative response was correct but would have had difficulty in marking the scale negatively. However incongruence was not solely linked to negative response questions (instances of more than three point difference in response to two presentations were judged incongruent). Participant C was incongruent twice, and his self commentary indicated that he had a poor grasp of correct usage of the rating scale. Participant I was very ambivalent regarding one question resulting in him giving totally opposing responses to the two presentations. On the other hand participant B was incongruent three times but made comments to indicate that she had changed her mind on the second presentation or had interpreted the question from a slightly different perspective. Participant G also gave incongruent responses thrice but did not provide much commentary: thus it was not possible to note reasons for divergent responses.

III. *Patients' Mental State.* During interview C complained of experiencing free floating anxiety although he clearly stated that he wished to continue with the interviewing. The interview was

punctuated by episodes of C carrying out relaxation techniques to help calm himself down. In addition although C listened attentively to explanation of the rating scale he occasionally ascribed his own meaning to pictorial anchors, for example suggesting that one might represent anger and another sadness.

During external comparison of the analogue scale staff reported that G held unusual mental beliefs. Indeed G was perceived by staff as being physically capable of reaching her goals, and her current poor performance was viewed as a manifestation of her mental state rather than reduced functional ability. Therefore a nurse reasoned that validating G's responses was highly complex because of perceived discrepancies between physical capabilities and mental construct.

IV. *Power relationships.* The researcher had explained to participants that their assistance was required in a research endeavour and that the interview schedule was designed to gather views rather than to evaluate participant performance. However individuals were aware that the researcher also worked in another part of the hospital, and that arrangements for carrying out interviews had been made via the ward staff team. This may have influenced participants' perception of the researcher's role. Indeed C became highly agitated during BPVS implementation, repeatedly asking for clarification of the researcher's designation and finally demanding to know whether his performance would be reported back to the ward staff team. Calmness was only

restored when the confidential nature of the procedure was re-enforced and he accepted this.

#### **4.3.2.5 *Validation by external comparison of the analogue scale***

In general external comparison highlighted overall congruence between self completion and staff reporting of likely patient responses. However in addition to the difficulties with negative questions previously described, divergent staff/participant responses were also noted in relation to:

*Participant B.* Divergent views emerged regarding (i) goal attainment and (ii) effort expended on achieving the goal. The staff view indicated that B would have rated both factors very positively. In fact B rated both negatively, and her body language concurred with verbal commentary and scale response to denote negative goal attainment and effort.

*Participant C.* Divergent views were given regarding participant involvement in goal setting. The staff view indicated that C would have rated this positively. In fact, on the first presentation C rated involvement as being poor even though this response did not concur with his own verbal commentary. On the second presentation C's rating denoted much more involvement in goal setting.

*Participant G.* Divergent views emerged regarding (i) goal attainment and (ii) effort expended on achieving the goal. The staff view indicated that G had made some progress towards attaining her goal relating to showering, yet G rated herself as having NOT attained this goal at all. Interestingly G rated herself as having expended virtually no effort on her goal relating to mobility and transfer skills which may be significant when considering staff comments about G's poor mobility being perceived as linked to mental rather than physical factors.

*Participant I.* Divergent views were given on one of the introductory questions and also regarding involvement in goal setting. The staff respondent viewed I's dislike to coffee as being much more intense than he himself reported. In relation to involvement in goal setting I's comments indicated that he was very ambivalent thus he gave two opposite responses. This differed from the staff view, which indicated that he would have consistently rated himself as very involved.

#### **4.3.2.6 Overall comparison of staff views and patient views**

Generally staff and patient views of patient involvement in goalsetting were congruent (Table 14). However greater variation of views emerged when comparing attained GAS scores (reported by staff) and patients' self reported performance on the analogues scales (Table 15). Congruence was noted for I, C & F (goal one). But G's self reported performance was not congruent with

staff rating of goal attainment, particularly in relation to satisfaction with goal one. Interestingly both B & H attained the expected outcome for their goal but B rated low satisfaction with this outcome whilst H rated high satisfaction. Arguably respective levels of effort may have influenced satisfaction.

**Table 14: Staff & patient perceptions of patient involvement in goal setting: Comparison**

			n=6
Patient Goals	Staff perceptions of patient involvement (Range 1-5*)	Patient self perceptions of involvement**	
B	4	HIGH	
C	4	MEDIUM	
F	g1	4	HIGH
	g2	4	not possible to obtain
G	g1	4	HIGH
	g2	4	HIGH
	g3	4	MEDIUM
H	4	HIGH	
I	3	MEDIUM	

\* Range 1 = not useful, 5 = useful

\*\* See appendix 17 for details of patient self perceptions

**Table 15: Attained GAS scores & patients' self-reported performance: comparison**

				n=6
Patient Goals	Attained GAS Score*	Self-rated Satisfaction	Self-rated Effort **	
B	0	LOW	LOW	
C	+1	HIGH	HIGH	
F	g 1	+1	HIGH	HIGH
	g 2	-1	Not possible to obtain	Not possible to obtain
G	g 1	+2	LOW	HIGH
	g 2	0	LOW	MEDIUM
	g 3	0	LOW	LOW
H	0	HIGH	HIGH	
I	+2	HIGH	HIGH	

\*GAS scores: + 2 = much better than expected  
+ 1 = better than expected  
0 = expected outcome  
- 1 = less than expected  
- 2 = much less than expected

\*\* see appendix 17 for details of patient self perceptions

#### **4.3.2.7 *Patient Responses to the Photographic Interviews***

All six participants were able to respond to the five forced choice questions by selecting one of two photographs presented. Furthermore all individuals consistently made factually correct answers to all questions by choosing the appropriate picture, apart from C on one occasion. This error was linked to unusual external factors which resulted in ambiguity in relation to a specific question. Thus confused circumstances impacted upon the only incorrect response given. In fact despite the less sophisticated nature of the photograph interview format it was impressive that responses were virtually universally correct. Moreover despite variable patient ability levels all became very actively engaged and appeared to enjoy the photograph interview.

#### **4.3.2.8 *Overview of the GAS Study***

Despite staff having greater than anticipated difficulty in clinical application of GAS it did prove feasible to collaborately set and evaluate treatment goals with in-patients receiving acute and specialist care. Furthermore interviewing patients yielded additional data which described the therapeutic process and outcome of the treatment from the users' viewpoint rather than the professionals' view. It is of significance that there was virtually no carer involvement in the GAS study. Professionals' views of care provision and care evaluation with people with learning disabilities are presented in the next section.



#### **4.4 SECTION THREE : FINDINGS OF SEMI-STRUCTURED INTERVIEWS WITH OAK & PINE MULTIDISCIPLINARY TEAMS**

##### **4.4.1 Multidisciplinary Staff Characteristics**

All eight multidisciplinary team members approached were willing to be interviewed. Seven of the eight had attended the 'refresher' GAS training and one individual had participated in the original training only. Three staff were primary nurses, two were occupational therapists and there was one each speech and language therapist, clinical psychologist and consultant psychiatrist. Over half of these staff (5/8) worked exclusively on either Oak or Pine; the clinical psychologist worked 60 per cent of her full time post on Oak (remainder in community); the speech and language therapist worked 50 per cent of her full time post in both Oak and Pine (remainder in community); and the consultant psychiatrist provided part time input into both wards dependent on which of his patients had been admitted at any given point in time. All staff were trained practitioners, experienced in working with people with learning disabilities.

##### **4.4.2 Introduction**

This results section reports on eight main themes which emerged during the interviews: (1) generalised negative perceptions of outcome measurement in health care; (2) different perceptions of outcome measurement dependent on professional role; (3) delineation of currently used outcome evaluation techniques; (4) desired future methods of outcome measurement in health care; (5) views of the purpose of measuring outcomes of health care; (6) attitudes regarding patient involvement in outcome measurement; (7) attitudes

regarding carer involvement in care planning and health evaluation; (8) views of GAS as a method of outcome measurement for the study population. These key areas are considered below.

#### **4.4.3 Negative Perceptions Of Outcome Measurement**

Half of the staff interviewed (4/8) highlighted negative aspects of healthcare outcome measurement. There were beliefs that outcome measurement was narrowly focused, rigid and mechanistic, viz., “sometimes outcome measurement doesn’t show the true picture - it’s hard to show up changes in reality - it can look OK on paper, but prove impossible to evaluate (SZ) ..... it definitely shows measurable things but I worry about losing the whole picture ..... (it’s) difficult to measure sometimes because it’s multifactorial with many different disciplines involved (VZ) ..... it has to be done but it is difficult ..... there are too many purists (ZZ) ..... an awful lot of time is spent putting things on paper (UZ)”. The dangers of focusing on the wrong things or irrelevant things were highlighted and there were reservations about the appropriateness and sensitivity of measurement tools. For example, “only major incidents are recorded, not the everyday things (SZ) ..... it’s easier in situations where things are more concrete, harder in communication situations because at least two people are involved with wide variability of cues and complexities (ZZ)”. However these fears were counterbalanced by dissatisfaction with aspects of current practice whereby unfocussed and unsystematic evaluation resulted in lack of clarity regarding achievements. For example, two therapists said “(I) tend to set broad aims but (my) recording

process is not specific enough and sometimes (I) lose track ..... (I) write copious treatment notes - it's all there - but I can't easily pick out the changes (YZ) ..... we do measure all the time but implicitly rather than explicitly (XZ)".

Interestingly, a nurse and a therapist commented on poor undergraduate training regarding precise delineation of outcomes and their measurement.

#### **4.4.4 Different Perceptions Of Outcome Measurement Dependent On Professional Role**

Ward based, direct care staff such as nurses tended to have a narrower, more symptom specific approach to evaluating health outcomes. For example, the monitoring of eating and sleeping patterns, and the review of activity levels. A ward therapist said she examined "task orientated things". The psychologist said "most of my work is behavioural". The psychiatrist described his role slightly differently. He said his approach was broad and holistic and he talked of looking for outcomes in relation to for example, "social cohesion at home", and "reduced behavioural manifestations". Five of the eight staff commented on the usefulness of feedback from colleagues in relation to monitoring outcomes, with such feedback being sought primarily from within the ward team. The psychiatrist was the only professional to name external colleagues (General Practitioners) as a potential source of information regarding outcomes.

#### **4.4.5 Delineation Of Currently Used Evaluation Techniques**

The majority of staff (5/8) described longitudinal evaluation of care plans and treatment records as a commonly used evaluation technique. Three nurses, a therapist and a psychologist quoted this methodology. Two other well-used evaluation techniques were; (i) observation of patient performance (described by two therapists, a nurse and a psychiatrist) and (ii) feedback/discussions with team colleagues and other professionals (described by a nurse, a therapist, a psychologist and a psychiatrist). Less frequently used evaluation methods were the eliciting of the patient's view of progress, used by a therapist and a psychologist; and the evaluation of the patient's ability to sustain relevant relationships, used by a therapist and a psychiatrist. Only one professional, a therapist, sought carers' views of progress as an evaluation technique.

#### **4.4.6 Desired Future Methods Of Outcome Measurement In Healthcare**

Over half the staff interviewed (5/8) comprising two nurses, two therapists and a psychologist stated a preference for clinical outcome measures in the future. For example "maybe some way of monitoring care plans more specifically (YZ) ..... measuring the difference between baseline information and current functioning (WZ) ..... Continual assessment of planned care as opposed to audit of service such as discharge rates (TZ)". Two staff, a therapist and a psychiatrist expressed a desire for quality of life measures to be used, viz., "we must avoid looking at the symptoms and try to get at the underlying things ..... it's often about altering the support package so that people are optimally functional and reasonably stable (VZ)". One nurse advocated

follow up interviews with users as the evaluation method of choice, viz., “what worked well for them ..... what hadn’t been addressed”.

Three team members, two nurses and a therapist, expressed a dislike for “number crunching” measures such as bed occupancy rates or discharge rates. One nurse raised the issue of commonly agreed measurement currency, viz., “the principles of measurement should be the same at ward level and management level - we shouldn’t be measuring different things”. A therapist pointed to the dangers of externally imposed measures, viz., “there’s a danger of imposed measurements being unsuitable and may be devaluing what is being worked for by the team”. Finally a psychiatrist commented on the complexities involved in trying to measure outcomes for this client group because of “the multifactorial nature of patient problems and the large amount of professionals often involved in the care package”.

#### **4.4.7 The Purpose Of Measuring Outcomes Of Healthcare**

Half of the team members interviewed (4/8) commented that outcomes evaluation was necessary to inform continuous adjustment to the care plan. Thus there was implicit recognition that outcome measurement should lead to improved patient care through the process of clinical reasoning, viz., “we need to know that things are better (VZ) ..... it (outcome measurement) should be a routine part of our work (WZ)”. However only one person, a nurse (TZ), explicitly stated “we must have outcomes to plan beneficial care in an ongoing way”.

There emerged a strong undercurrent of fear and protectionism regarding outcome measurement. For example a therapist (XZ) said, “there is fear about how to demonstrate outcomes to others, but we must”. One team member commented that a problem was “outcome measurement is perceived as a threat to professional competence ..... the problem is when people take things personally rather than realising it is the intervention that is being evaluated ..... they think it’s their fault ..... there’s a fear of failure” (WZ).

Three team members felt the need to protect themselves both professionally and legally. For example a nurse (UZ) commented on the amount of time taken “covering yourself legally rather than getting on with things ..... if it’s not on paper then it hasn’t been done”. Two therapists raised the issue of professional justification which was viewed by one individual as necessary to prevent a belief that “anybody can do it” (YZ). However even within the health team there were perceptions of some disciplines being able to present themselves as being very specific and very sure of their recommendations, while others felt a lack of credibility in some of their functioning and in how their contribution was valued by colleagues. For example, a therapist said “(we) undersell ourselves, don’t market ourselves, are reluctant to state clearly what we have done and what effect we think it has had ..... we have a lack of standardised or very established tools, so there’s a perceived lack of credibility in some of what we do and how it’s valued by others”. In addition two staff expressed concerns that in the future, funding might depend on demonstrating achievements with greater clarity, viz., “we will have to prove our impact on people’s lives (YZ) ..... in the pendulum of approaches, things like the GAS

approach are currently favoured by funding agencies ..... (we must have) proof of outcomes ..... proof of good use of time” (VZ). Finally one therapist (ZZ) raised the prospect of outcome measurement potentially resulting in inappropriate withdrawal of service, viz., “I tried it for six weeks and it’s not working - so that’s my input finished”.

#### **4.4.8 Attitudes Regarding Patient Involvement In Outcome Measurement**

Of the six team members who implemented GAS three (two nurses and a psychologist) reported that patient involvement was not achieved either because the nature of the goal itself centred on working towards engaging the patient in a therapeutic alliance, or the patient’s limited level of understanding prevented meaningful involvement. The other three staff (two therapists and a nurse) reported that it was possible to partially involve patients in care planning and evaluation. The overriding factor which made meaningful involvement problematic was perceived to be limited levels of patient understanding. In fact this was highlighted by all six team members. The other key area of difficulty cited by three of the six staff (two therapists and a psychologist) was problems with communication. In addition a nurse (UZ) commented that the unstable mental state of some patients restricted their involvement. Interestingly no team members felt that the GAS technique itself adversely affected the process of involving patients in care planning.

There were differing views regarding whether the therapeutic relationships had been changed by greater patient involvement, in particular there appeared to be a distinction between the two wards. Intervention on Oak tended to be

‘slower stream’ because of the nature of patients needs in relation to severe challenging behaviour. Thus Oak staff reported little change to therapeutic relationships, either because patients were very resistant to engagement, or because relationships had already been strongly established over an extended period. Conversely on Pine where there were different patient needs and a faster treatment throughput, it was reported by a nurse and a therapist that patient involvement effected greater awareness of work process and work progress, viz., “they (the patients) could see the reason why they were being asked to do things ..... they could see you were trying to help them” (UZ). Interestingly the therapist (XY) commented that there had been no screening out of those patients the team felt may not have been able to cope with GAS.

Overall differing attitudes to patient involvement emerged. For example, a nurse (UZ) advocated follow up patient interviews as the preferred method of establishing outcomes, focusing on “what worked well for them ..... what hadn’t been addressed”. However a therapist (YZ) had reservations, viz., “some patients might say yes to anything ..... or might respond inaccurately depending on their mood which constantly changes”. Finally patient involvement was identified by a nurse (SZ) as a method of “getting everyone on board”. (SZ) further proposed that if commitment wavered, it could be reinforced through a reminder “you set this up too”.

#### **4.4.9 Attitudes Regarding Carer Involvement In Care Planning And Health Evaluation**

There was virtually no carer involvement in the GAS trial, the one exception



being a carer who was consulted once in relation to a specific goal. This consultation was rated by staff as highly useful.

Generally the Oak and Pine teams appeared ambivalent regarding carer involvement in health planning and evaluation. Despite all eight respondents initially indicating that a partnership approach was important and necessary, all staff went on to highlight difficulties in working together with carers.

Perceived areas of difficulty included:

- Clashes of philosophy of care. For example, a nurse (SZ) said “some agencies reject the behavioural model on principle ..... it can get black and white rather than us talking it through”. A therapist (YZ) said “the importance of client choice can be taken too literally and carers can have an over idealistic view of what the clients can cope with ..... sometimes agencies have to experience the consequences of ignoring advice, but then if the care breaks down it’s the client who suffers - especially if carers leave it too late to ask for support and there’s a readmission”.
- Breakdown of patient/carers relationships. For example where relationship breakdown had been a major precipitating factor in admission some partnerships were viewed as unachievable, viz., “they don’t want them (the patient) back” (YZ).
- Complexity of partnership relationships. A therapist (XZ) said, “the relationship stuff is very complex ..... depends on ward staff attitudes ..... depends on carer knowledge and degree of involvement”. A nurse

said “sometimes it’s more to do with people ..... an awful lot of it is a personality thing” (SZ).

- Knowledge of the patient. There was evidence of differences in the respect afforded to family carers as opposed to paid carers. A nurse (SZ) felt it was easier to develop relationships with families “because they do know their relative in an in depth way”. Building relationships with paid carers was at times viewed as harder because of a perception that knowledge of the patient was superficial.
- Mixed agendas. For example potential conflict of interest in relation to patient needs and carer needs. One nurse (TZ) asked, “who are we giving most treatment to - the patients or the carers?”.

There were contrasting perceptions of the level of carer involvement achieved within Oak and within Pine at the time of interview. Some team members viewed staff/carers relationships as rudimentary, viz., ... carers are not involved in developing the care plan (UZ)”. Conversely some staff felt the situation was much more variable, viz., “people (carers) can be as involved as they want ..... the team is guided by carer preferences although (the team) will try to encourage involvement sensitively where possible” (WZ). Variability in perception of carer involvement was also present in relation to collaborative care planning as there emerged clear differences in mode of operation between Pine & Oak and also differences within Oak itself. Because of Pine’s acute admission function there was a perception that carers often were struggling to support patients immediately prior to admission. Thus at the point of admission carers were viewed as in need of respite from caring, viz., “it’s over

to you (the team) now” (VZ). Pine staff, a nurse and a therapist reported initial high carer involvement, through information giving regarding patient functioning, which contributed to the initial baseline assessment. From that point onward, carer involvement was reported by a therapist to be “hit or miss - ranging from good to abysmal”. There was a reported resurgence of carer involvement around the point of discharge. On Oak contact with carers was generally perceived to be greater, especially with carers of acute admissions patients “because there is more of a general recognition that assessment and problem solving is required - to sort out specific difficulties”(TZ). Interestingly a nurse (TZ) reported less involvement in care planning by carers of long term Oak patients, “because they regard Oak as their relative’s home and seek more social contact with staff”.

In relation to patient needs, there was staff recognition that it was inappropriate to expect carers to be involved in dealing with extreme challenging behaviour.

Finally there emerged issues regarding what constitutes true multi-agency partnership, including carer input. At a strategic level one team member pointed to imbalance within partnerships, with social work being viewed as less committed than health, viz., “the buck stops with us (healthcare professionals) ..... some others from social work are puppets ..... they have been told there’s no money, so can’t negotiate honestly” (VZ). In addition some players were viewed as driven by political agendas rather than concern for the well being of individual patients, viz., “some others are too remote

from the reality of people's lives ..... they are driven by their own goals and are not interested in the person and their well being" (VZ).

Regarding individual care planning, complex factors affected partnerships. For example, the ward teams reported some difficulties when attempting to engage carers in order to pass on established effective care regimes. A nurse (UZ) said, "there's no point in hastily handing over programmes that others can't do or won't implement because it just won't work ..... it can take a while to get common ground ..... we have to try to meet halfway - chip away at things ..... offer long term support". The process of building meaningful relationships was viewed by a therapist (XY) as a means of encouraging the ward team to be more reflective, viz., "If you keep it internal then your views are not challenged and you can get a false sense of security.

It helps to question yourself more - this is not watering down your recommendations, it's being realistic".

#### **4.4.10 Views of GAS As A Method Of Outcome Measurement For The Study Population**

Of the eight staff who participated in the "refresher" GAS training, seven had used it in the GAS trial. Of these seven individuals, one team member was on long term leave at the time the interviews were conducted, thus it was not possible to gather her views. Eight team members were interviewed in total, one having attended the original GAS training only.

Of the eight staff interviewed, seven indicated that the GAS approach was consistent with their own professional training. For example, two occupational therapists commented on similarities between GAS and activity analysis, and three nurses found the basis of GAS to be similar to the goal setting approach in nurse training. However both therapists and nurses felt that the GAS technique encouraged those using it to be more focused, viz., “it actually **made** you think about it (the goal) more (UZ) ..... can’t get away with putting down the same old chestnuts (XZ) ..... must show (the outcome) is observable (XY)”. The one individual who found the GAS approach different from their own professional perspective commented, “I am used to a global approach ..... (I’m) not trained to approach things in a mathematical way ..... but I can see the sense of it and would be prepared to delegate it to other individuals” (VZ). Of the eight staff interviewed, the two who had not used GAS identified the main factors for lack of usage as follows. One individual (VZ) perceived the GAS approach to be too different from the usual method of working and considered the discipline of changing to another workstyle too great a commitment. However, this individual also commented “this may be my own anxiety about the problem” (of applying outcome measurements in a detailed systematic fashion) “maybe (the GAS technique) would feed in to overall evaluation more effectively than I think”. However overall VZ considered that correct application of GAS would require too great a time commitment and said it was “difficult to make room for it personally”. The other individual (ZZ) considered the GAS technique unsuitable for use with their patients on the wards at the time of the trial. Interestingly ZZ also had reservations about using GAS with patients who had mental health problems,

which was notable bearing in mind the method was originally developed for use by community mental health teams.

Of the six respondents who did use GAS, two primary nurses (TZ, SZ) participated in the process as part of the clinical team, and four individuals (UZ, WZ, XZ, YZ) used the methodology both uni-professionally and from a multidisciplinary perspective. Decisions regarding application of the technique were reportedly based on whether the nature of patient needs would be best addressed through an individual or team approach.

Generally the Oak and Pine teams appeared unconvinced that GAS could usefully contribute to the care planning and evaluation process and only two staff (XZ, YZ) indicated they would be prepared to use the methodology again. Both pointed to the value of discussing specific goals with colleagues and patients. In fact the Pine therapist reported that the GAS study was the only time Pine staff had planned care together in an integrated way. The remaining four staff (SZ, TZ, UZ, WZ) said they were unlikely to use GAS again for the following reasons.

- SZ rejected the concept of scaling and felt it was better to have just one outcome
- UZ perceived difficulties in trying to integrate the GAS technique into the routine nursing care planning process and thought there would be “problems getting the whole staff team on board with it”
- WZ found it difficult to apply routinely because of “problems in

translating Oak patients' needs into GAS measureable terms". In addition WZ expressed a preference for other work styles, "probably won't use it again because I've got my own "toolkit" .... would only use it again if pushed by the team". Finally WZ commented on the timing of introducing new methodology into the team, viz., "Oak has already developed another method of working ..... GAS would just confuse systems already in place

- TZ was ambivalent about future GAS usage and said "Oak doesn't have a set format for *multidisciplinary* goal setting .... so GAS might be potentially useful for this type of work .... would certainly consider it along with any other models for multidisciplinary outcome measurement".

In relation to GAS having an effect on team communication four Oak staff felt that the methodology made no difference to the communication process on Oak. All considered that this was because Oak communication channels were already well established and working effectively. In contrast two Pine staff (UZ, XZ) felt that using GAS had improved communication, but only for those directly involved in the GAS study. One individual (UZ) commented that limited communication regarding the specifics of care planning was the norm on Pine, "they (others in the team) are not interested in the details, they just want the overview". The other individual (YZ) felt that ward communication in general had been marginally improved through seeking specific feedback from colleagues on patient achievements regarding their goals. However XZ added that prompting was required, viz., "you had to

guide their thinking quite a bit”, for example by asking specific questions. Even then, awareness of GAS was considered very variable, “some people carry on regardless in their own way, no matter what” (XZ). Interestingly XZ also commented on increased ward communication identifying congruence between goals identified by staff and by patients, viz., “the staff team came up with their views on goals first. Then the patients were asked or facilitated to identify their goals, *without* being told what staff thought. It was interesting that they (the patients) came up with the same things the staff team had identified”. Finally a therapist commented, “I valued the team working, sitting down together and being more aware of what different professionals can offer ..... sharing the clinical reasoning makes staff more inclined to buy in ..... this kind of system (GAS) makes it more difficult for staff to go their own way” XZ.

#### **4.4.11 Overview**

The Oak & Pine practitioners were found to be ambivalent regarding the value of outcome measurement within routine clinical practice, and also regarding the development of healthcare partnerships with users and carers. Insights gained from these interviews with clinicians informed the survey of Grampian managers and commissioners.

The content of the interviews with Grampian professionals was focussed on the same issues explored in the survey of clinicians to effect a comparison of views. The findings of the interviews with managers and commissioners are reported next.



## **4.5 SECTION FOUR: FINDINGS OF SEMI-STRUCTURED INTERVIEWS WITH SERVICE MANAGERS & COMMISSIONERS**

### **4.5.1 Interview Respondents**

A total of ten individuals were interviewed. This included four health service managers, two social work managers/commissioners, two voluntary agency managers and two health board commissioners. All those interviewed were involved in the learning disabilities service sector in Grampian, apart from one health board commissioner whose role was more generally linked with acute health services. All respondents readily gave consent to be interviewed when approached, and appointments for completion of the schedule were arranged without difficulty. Interviews were of approximately 60 minutes' duration and took place either in the researcher's office or the interviewee's office depending on preference.

### **4.5.2 Introduction**

Here, the eight major aspects of care delivery which emerged during the interviews are reported. Main views expressed related to: (1) outcome measurement in general; (2) current service evaluation techniques; (3) attitudes regarding user involvement in care planning and service delivery; (4) perceptions of power relationships within care provision; (5) evaluation of health care within Oak and Pine; (6) perceptions of the type of service desired by Oak and Pine patients; (7) views of the type of health interventions which should be provided by the Oak and Pine teams; (8) supporting carers of Oak and Pine patients.

### 4.5.3 Views of Outcome Measurement

There emerged a range of views on the role of outcome measurement in the NHS. Two health service managers reported positively on the use of medical audit and clinical outcome measures, particularly where a multidisciplinary approach was developed. However complex factors were perceived to exist within this methodology, viz., ‘outcome measurement doesn’t interfere with clinical care, whatever shows up should help to improve or adjust or develop care’ (BB) ‘outcome measurement is a target, it shouldn’t be used for whipping us, the rationale for exceptions should be acknowledged and reasons accepted if valid’ (KB). Differences in implementation of measures were identified, viz., ‘compliance was variable in areas where patients could speak up for themselves regarding whether they wished to take part. This begs the question as to whether compliance was freely achieved in areas where they couldn’t and staff just implemented procedures. Also some of the achievements came down to level of staff commitment to the concept, this was variable’ (KB) More generally two health service managers pointed to perceived issues for staff, ‘fear of failure can be an issue for staff’ (KB)... ‘it’s not too difficult, folk don’t like it (outcome measurement) because there’s lots of effort involved and it’s very time consuming’ (QB)... ‘I’ve no concerns about outcome measurement if it’s truly tailored to patient needs, rather than for professional justification’ (KB).

Two voluntary agency managers preferred person centered quality of life measures viewed from the users perspective, viz., ‘this is much better than measuring what staff are doing .... we must beware of targets becoming an end

in themselves - bean counting' (RB) One individual expressed concerns about "being swamped by bureaucracy and there are dangers of the tail wagging the dog..... the approach is important, it needs to be, so how does the system work around here, rather than applying a formula' (NB).

Limited availability of measurement instruments. Three commissioners commented on the lack of sensitivity of the available tools particularly within such areas as mental health and learning disabilities (see box 1).

**Box 1: Lack of measurement instruments**

'currently outcome measurement is more developed in acute services, much less so in mental health and learning disabilities - currently Quality Network is considered a mechanism to start from'. (LB)

'Outcome measures are complex in the NHS, they would be linked to evidence based practice. Evidence should be used wherever possible but there are large areas where it's difficult to get, especially in people based services where there can be issues regarding needs and wants.' (MB)

'They (measures) are crude, limited and lack sophistication, what's missing is good measures of co-morbidity. Within the acute sector commissioning outcomes may be different in different units, but case mix complicates things, we only have crude indicators, no validated detailed measures are available. Also there are major problems with quality of data - incomplete data or poor quality of coding.' (SB)

Problems regarding instrument selection. Issues emerged regarding selection of measurement tools, viz., ‘I understand the pressures at the coalface but the Health Board is very prey to he who shouts loudest. We must have data on effectiveness of interventions leading to greater health gain’ (SB) ‘It’s very important to select the right tool to avoid the potential of disadvantaging patients. The hospital team has a major role in identifying appropriate tools. The suitability and validity of the tools should be examined jointly by commissioners and providers. The proof of the worth of outcome measurement is that it shows improvement for the patient, rather than becomes an end in itself through masses of paperwork or complex processes’ (LB) A health service manager and a social work manager/commissioner commented on complex causal factors and joint ownership of measures. ‘Much more work is needed on finding suitable outcomes and it must be collective, all parties must get onboard in determining meaningful outcome measures - commissioners are crucial to the thing. Also much stuff is not straightforward cause and effect,. sometimes hospital admission is more to do with society’s tolerance levels, rather than a person’s illness or condition. Sometimes in learning disabilities we can’t influence outcomes, for example if challenging behaviour is linked to environmental factors and there’s resistance to changing these’ (OB) ‘I have concerns about stand alone approaches, for example health only. There should be joined-up thinking. I worry that we’ll still do it separately in learning disabilities because we’re all busy looking after our own corner. There are resource implications in this because we’ll be competing for a limited pot of money’ (TB)

Preferred future outcome measurement in Learning Disabilities. A variety of views emerged with the majority (6/10) pointing to the importance of a joint approach to outcome evaluation. Viz., 'there should be agreement that outcome measures are multiagency from the word go, this will enable us to tie others into an agreed plan and therefore to effect budget commitments' (OB)..... 'we need measures which show evidence of joint working to create care packages' (LB).... 'What's really important is that we must do it together, if we do it in isolation there will be continual conflict' (TB). Half of respondents (5/10) stated a preference for person centred individualised measures for example, 'the Quality Network Stuff'. A social work and health service manager advocated a broad approach to evaluation, viz., 'we should use a whole variety of tools and compare and contrast along the whole spectrum of provision' (BB).... 'We need a comprehensive holistic approach across the board' (TB). A voluntary sector manager said, 'we should try to use the same measures as for the whole population, rather than special learning disabilities measures' (NB) A commissioner wanted to see, 'strong guidance and lots of training around interpretation of results - to avoid an over simplistic approach' (SB) Finally one manager said 'the ultimate outcome is all hospitals closed and people carefully integrated into the community and mainstream healthcare' (TB) This individual added, 'That's a dream.'

Views of whether there is a common approach to achieving outcomes for users. Four respondents (two commissioners and two health service managers) expressed doubts regarding there being a common agenda used by both frontline staff and managers/commissioners for achieving outcomes for users. (See box 2).

Despite reservations about the way some middle-managers carried out their role half of those interviewed (5/10) identified functional managers as being crucial to the development of a partnership approach to health outcomes for users, viz., 'the team leader acts as a bridge between top down management views and bottom up issues generated by the ward team' (KB) 'passing requirements down through relevant managers leads to acceptable standards of patient care' (BB). 'My managers connect to frontline teams and the team ethos voice comes up through the senior' (TB)

The use of policies, procedures, standards and strategy statements were also identified as methods of promoting a common approach to user outcomes. Other techniques included staff training, staff supervision, staff appraisal and the use of individualised care planning systems.

## **Box: 2 Mixed agendas for achieving outcomes**

‘It’s hopeless,... we get stymied. There’s a need to discuss things with senior managers and operational people as well - but often this doesn’t happen and we only talk to senior managers. We *must* get copies of plans and minutes of development agreements to clinical people as well, to keep everyone informed. Sometimes we give money for a particular development and then find it doesn’t go to the area it’s supposed to’ (SB)...

‘I’m very aware of problems with personal or mixed agendas - things can be spoiled by individual managers not passing information or by passing misleading information’ (QB)....

‘(We must) try to develop more effective communication systems with people at the sharp end by going and talking to them. Work will be enhanced if we’re all on the same wavelength - it has been very “arms length” between managers and frontline staff todate’ (OB).

### **4.5.4 Currently Used Evaluation Techniques**

A wide variety of evaluation approaches was reported. The majority of interviewees, (7/10) highlighted the importance of ‘quality measures’ and all seven referred to a specific individualised person centred methodology, viz., Quality Network Service Review. Two of the seven also considered individual staff supervision systems to be an important model of quality monitoring. Other quality measures reported once each were service audit, personal research study and a specific quality assurance technique designed for social work.

Table 16 shows other evaluation methodologies as described by the interviewees. These include statutory and legal requirements, business methods, staff appraisal and health improvement measures.

**Table 16: Evaluation techniques described by interviewees in interview schedule**

Evaluation Technique	n = 10			
	Commissioners	SW Mgrs/Coms	Health Mgrs	Vol Mgrs
Activity based measures eg bed occupancy	✓✓	✓	✓	
Statutory registration & inspection requirements.		✓✓	✓	✓
Contract monitoring.	✓	✓✓		✓
National/business initiatives eg Best Value, EFQM*.		✓		✓
Formal review of service projects			✓✓	✓
Health improvement measures eg clin. audit, clin outcome, screening tools	✓		✓✓	✓
Annual appraisal of staff.			✓	✓

\*EFQM - European Foundation of Quality Management

Perceived effectiveness of current techniques. Perceived effectiveness of various evaluation methods was variable. The activity based measures were described by a commissioner as, ‘not particularly effective, just high level stats showing trends....., the quarterly dialogue with trust representative makes it a bit more meaningful.’ A health service manager had reservations about the use of clinical outcome measures which were felt to be ‘effective in the



short term but I've concerns about maintaining gains long term... the framework is OK but the paperwork can be too complex and make it seem a much more heady concept than it actually is (KB)'. In addition a health service manager described the use of standardised questionnaires completed by service users as ineffective because, 'we wanted to demonstrate clear health benefits but didn't really show this because we were picking up a lot of folk with chronic problems... the approach helped us to get the right focus, that is to pick up on problems which were important to users, but more work was needed on how to evaluate if input was truly effective... also the service was very costly so there were issues regarding cost versus quality of life' (OB). Another health service manager cautioned that even when healthcare outcomes were achieved 'there are big problems with people getting stuck (in hospital) therefore in terms of the total package of returning people to the community the impact is disappointing' (QB).

A social work manager commented on problems with feedback from evaluation which 'took a long time and generated lengthy reports of questionable value... the most positive thing about it was that the process impacted on staff performance' (MB).

A commissioner and a health service manager commented that effectiveness was more readily identified if it was possible to use validated tools or standardised processes and protocols because comparative judgements could be made with more confidence. However, a social work manager cautioned, 'we have problems in evaluating things that are more emotional ... there is substantial room for improvement .... we are not skilled at personal elements

in measurement' (TB). A health service manager made positive comments about local evaluations which 'affect services to patients directly for example in developing or refining care planning systems so that there is a continual evolution of service' (BB)

Half of respondents (two voluntary services, one social work and two health service managers) regarded Quality Network Service Review as an effective form of care evaluation, viz., 'it's looking at service from the individual patient's viewpoint' (OB) ... it resonates with (our service) being a value based service' (RB) ... 'it's most meaningful because it's based on information that comes from the point of view of the user' (NB) ... 'it's a good structure for developing things, for example releasing staff to evaluate other areas' (KB).

*The Impact of Evaluation on Policy and Commissioning.* Four commissioners pointed to multiple factors which affected the commissioning process. For example, 'outcome measurement results should underpin evidence based practice but it's no more than one of the factors influencing policy and it's not the overriding factor even though we might like it to be... this is because of politics with a large and small P... also practicalities such as geography and distance come into play' (SB)... 'The regular meetings are where decisions are made regarding changing of commissioning. For example, are targets going to be amended because the process has slowed right down, or is a big effort going to be made to put extra impetus in regarding specific care groups to guarantee reaching projections?' (LB)... 'There is substantial room for

improvement but the commissioning process is beginning to be more systematic for example through the approved provider list' (TB).... 'and the development of action plans' (MB). Three managers (two health service and one voluntary sector) expressed reservations about the impact of evaluation, viz., 'the impact on policy is questionable, getting things to shift in complex organisations is difficult, not an exact science .... any impact is likely to take approximately eighteen months to show through, for example an effect on personal relationships' (NB) .... 'Evaluation methods have a very variable influence on policy, some projects are perceived to have worked well and can also be rolled out well to other areas, but I don't think we're very good at evaluation' (QB).

Two health managers and a voluntary sector manager pointed to the importance of joint ownership, viz., 'it is important that staff themselves take onboard issues and ownership of clinical outcome rather than top down direction' (KB) '(methodology) can influence policy because we do it together, health service, social work and health board, it is crucial that the commissioners are onboard..... trying to develop services with patients at the heart of things is gaining credibility, for example the Quality Network can act as a "kite mark" of good practice' (OB) 'Useful evaluation must be in the hands of the people doing the work, ownership is needed' (NB). Finally a commissioner commented, 'I can't understand why people are threatened by external evaluation because it's generally a win/win situation. If it's good it will attract more resource, if it's poor it often needs additional resource to make it better (SB).

#### 4.5.5 Attitudes regarding user involvement in care planning and service delivery

The majority of interviewees (7/10) reported user involvement in their service area and the remaining three respondents indicated that involvement was variable. A wide range of methods of involvement were identified including the following:

- participation in individual care planning meetings which would personally affect the client (sometimes this was achieved via carers);
- participation in practical management of the household, for example, which food to buy;
- participation (at various levels) in staff selection;
- the use of focus groups or consultation with various groups of service users;
- involvement via training, for example the Open University patterns for living courses which has themes such as inclusion, fairness and equity and relationships;
- involvement in service planning via social work locality planning groups;
- involvement at a strategic level for example, developing the Grampian Learning Disabilities Strategy document 'Choices for our Future'.

Generally it was considered important to use a variety of consultation tools, viz., 'the combination of *all* these methods builds up a body of effectiveness' (MB)... 'Learning Disabilities Services are becoming more skilled at working

in partnership, we're developing skills and confidence, hot issues regarding managing change such as hospital closure have forced us to confront this' (TB). However significant ambivalence emerged regarding the extent and effectiveness of user involvement locally. A major concern for six of the ten respondents centred on the danger of tokenism, viz., 'we must avoid lip service and tokenism' (TB)..... involvement must be dependent on level of ability to avoid tokenism' (RB). Two voluntary service managers clearly stated that it was not appropriate to involve users in service management, viz., 'this smacks of tokenism or PC' (NB). In addition a majority of respondents (8/10) pointed to flaws in the partnership process, viz., 'we all try to be client focused but still tend to be service focused, professionals can get in the way because they all think they're doing the right thing but this can prevent them acknowledging others' contributions' (OB)..... 'effectiveness is limited because you tend to get the views of those willing to be on groups and who have strong feelings' (MB) Difficulties emerged regarding personal agendas and emotive interpersonal dynamics, viz., 'there are concerns about patients having unrealistic dreams heading to unrealistic expectations of what staff can offer' (KB), 'the involvement of people may falsely raise expectations which are unlikely to be met' (SB), 'emotive issues need to be handled with care, for example when to withdraw treatment, and sometimes we *use* people who get caught up in the politics' (QB).

Three respondents (two health managers and a commissioner) pointed to a lack of tools and techniques for inclusion, viz., 'recently there's more of a move to trying to involve patients in care planning but we need more creative

methods of meaningful and valid methodology'(KB)... 'there are problems with communication and levels of understanding, and also issues around certain types of information leading to mental distress for some people (BB)..... who do you involve? users or carers or interest group representative or a tax payer representative?' (SB).

Interestingly at commissioner level there were differing views of organisational commitment to partnership, viz., 'the Health Board strongly supports inclusion by financing methods of supporting users to be involved, and trying to introduce methods whereby involvement is meaningful' (LB)..... 'there is reluctance of the Health Board to back this (user involvement) because of extra costs and a lack of tools' (SB).

#### **4.5.6 Perceptions of power relationships within care provision**

The ten respondents unanimously acknowledged different priorities of stakeholders in relation to the outcomes agendas. For example, 'It comes down to getting the balance right, everybody has to recognise the different perspectives. Clinicians are right to promote "care", but if it costs four times as much it is the best use of resources?' (LB)..... 'The management role should be one of facilitation as there is not even a homogenous view within the different groups, for example, different parents see it differently. Commissioners want value for money' (OB)..... 'The government level is demanding particular standards but frontline staff might think these are rubbish' (MB).

Problems were identified in relation to reconciling different perspectives, viz., ‘we should be constantly trying to create an agreed agenda by trying to reach consensus *prior* to commissioning, but we don’t do it effectively, that’s where we go wrong’ (TB).... ‘The needs of the person are often forgotten about in the midst of various professionals’ protectionism - when people say this is a professional imperative, they mean we know best’ (QB). A commissioner suggested the scenario was even more complex for commissioners, viz., ‘patients/carers/clinicians want to demonstrate that the service is effective. It’s more complex for commissioners who are seeking areas to *disinvest* in as well as invest. It’s a more hard-nosed approach - what will be discontinued, or left to wither on the vine while money is routed elsewhere?’ (SB).

A wide range of views emerged in relation to which outcome agenda takes priority. A commissioner, a voluntary and a health manager stated that the user’s perspective should be dominant but in reality was not. However a different health manager cautioned that users ‘must be helped to take account of reality - but this should not be used as an excuse by professionals to control service priorities and service delivery’.

The majority of interviewees (6/10) thought that the clinicians’ agenda was predominant, viz., ‘the clinicians win on a moral basis, their outcomes help them win the argument’ (SB)... ‘I suspect in the long run the power lies with the clinical staff. They have the most information and can withdraw co-operation’ (NB) However strong undercurrents of unease emerged regarding medical dominance, viz., ‘The medical power base is very strong and that’s

OK, they should hold sway as long as the opinion is objective - but sometimes this is suspect' (QB)..... 'The clinicians' agenda tends to take priority, but increasingly this is being challenged. We have to resolve the cultural issue of medical dominance' (TB). Conversely a health manager said, 'I hope the clinical view would take priority but currently there are problems regarding health needs, defined by clinicians, being acknowledged by social care staff, senior health managers and the health board' (BB).

Two respondents (a health and social work manager) considered that managers' views prevail, viz., 'in the event of conflict managers views would take priority - in the end of the day we're doing *this*' (MB). Finally a health and a voluntary agency manager pointed to the importance of financial control, viz., 'the money agenda takes priority' (BB)... 'Generally money brings power, therefore the commissioners - the health board - holds the control at present' (RB).

#### **4.5.7 Evaluation of Healthcare Within Oak And Pine**

*Views of appropriate health outcomes for patients in Oak/Pine.* Seven of the ten respondents felt that an important outcome was treatment intervention which achieved good control of underlying symptoms, both physical and psychiatric. Two of the seven further stated that this type of outcome measurement was 'the same as for everyone' (KB,RB) (in the general population).



Control of symptoms was closely linked to patients suitability for discharge and indeed two commissioners viewed the care team's agreement on patients being 'fit for discharge' as an outcome measure in itself. In total four of the ten interviewees, three commissioners and a voluntary sector manager, viewed the resuming of an ordinary lifestyle in an appropriate community setting as a suitable outcome measure. A social work manager felt that the transfer to home of successful coping strategies for minimising the condition was a valid measure of outcome; and a health service manager stressed that outcomes must be multidisciplinary and multiagency.

Two commissioners pointed to the use of re-admission rates as measures of outcome but one of these individuals cautioned 'it would be vital to determine the cause of re-admission, for example re-admission due to cyclical mental health problems would be valid - failure of a social care package would be worrying' (LB).

Finally a commissioner suggested methods such as periodic user satisfaction surveys, monitoring of suicide rates/prison admission rates, and views of community staff, viz., 'how responsive have they found the units to be and how good is the communication' (SB).

Seven of the ten respondents stated a preference for the use of individualised measures with people with learning disabilities, viz., 'I am sympathetic to this (individualised) approach' (NB)... 'there are dangers with specific standard measures because they may not be meaningful to the individual' (OB)... 'the

more rigid the tools, the less likely to encourage creativity in staff' (KB)..... 'standardisation in learning disabilities equates to institutionalisation, I have worries about the lowest common denominator' (QB). Three managers (two voluntary sector, one health service) were generally open minded about the selection of measurement tools in healthcare evaluation, 'nothing's perfect' (RB) 'it's OK to try the range of measures' (BB). However, one individual cautioned, 'outcome measures in psychiatry with this care group (learning disabilities) is very subjective, there are problems in selecting appropriate standardised tools, often it comes down to trial and error' (BB). Two commissioners cautioned that robust evaluation of measurement techniques was important, viz., 'individualised measures would be acceptable if used in conjunction with other tools to balance out the drawbacks, quantitative and qualitative methods should be used in a complementary way' (TB)... 'if no standardised tools are available for the client group then anything is better than nothing, but there must be a thorough check that no standardised tools are available as they would be first preference. The individualised approach would be OK but we should try to build in some sort of independent external check, for example external audit or peer review. Also any change must be clinically significant - the goals must be meaningful' (SB).

#### **4.5.8 Perceptions of the types of service desired by Oak and Pine Patients**

Tensions emerged between the professional's perceived duty of clinical care and the user's right to self determination. For example a health manager said 'they (patients) don't need subjective healthcare which gives the professional view priority and indulges in professional territorialism. We tend to do things

to people rather than with them and we have problems with being risk averse. Behaviours tend to act as blockers to moving people on, for example, they did that last week so can't be considered for the community for at least a year' (QB).

This viewpoint was not shared by all, and a different health manager said, 'sometimes patients' wants are linked to an unbalanced mental state and therefore not seen as appropriate by professionals. They need a consistent approach, routines, firm, but friendly handling from an experienced and skilled staffgroup' (BB).

A commissioner and a health service manager pointed to patients' need for respect, viz., 'users and carers want to be treated as equals, they should be thought of as clients, they're not receiving a charitable service, we should be thinking if they had the budget what would they buy? (SB)...

Six of the ten respondents perceived the patients to want intervention which would alleviate their condition, viz., 'help and support to get better' (MB) ... 'attention to physical needs and looking at epilepsy and other organic things' (NB) ... 'at least to have symptom relief from mental health problems and a stabilising regime' (QB) ... ' a service that can change with them throughout the course of their illness, a flexible service that responds to them as individuals' (TB).

Four respondents (two commissioners a health and a social work manager)

point to the importance of emotional support. For example, ‘it’s about stabilising a situation and providing familiar faces to give intensive support through the development of bonds between patients and staff (LB) ... ‘they (patients) also want kindness, tolerance and understanding’ (SB) ... ‘they (patients) want a homely environment with warm and caring staff groups who provide reassurance and deal with things in a professional but friendly manner’ (BB) ‘(they want) support, reassurance and lots of input from staff (MB).

Three interviewees (two health and one social work manager) raised the issue of providing sanctuary, viz., ‘(they need) time and space and rest away from stress, but not only this or we’re missing the point, it must be therapeutic and leading onto a better lifestyle’ (OB) ..., ‘there’s a need for sanctuary because people settle down very quickly (on admission) – there must be a comfort zone despite the drawbacks of institutionalised care delivery’ (KB).

#### **4.5.9 Views of the types of health intervention which should be provided by the Oak and Pine teams**

Half of the respondents (two commissioners and three health managers) emphasised that interventions should be from a multidisciplinary and multiagency perspective. For example ‘there needs to be effective integration with care management regarding the funding of appropriate community packages to prevent recurrence of problems on discharge .... (there needs to be) close working between the hospital team and the community team’ (LB)..... ‘I would like to see much better real multidisciplinary involvement,

the dominance of medical power can stifle creative healthcare initiatives' (QB)... '(there should be) setting up of a therapeutic regime as soon as possible with a programme to take it forward including planned handover to other agencies at appropriate points' (OB). This partnership approach was linked to returning inpatients to appropriate community setting as smoothly and effectively as possible (mentioned by four of the five individuals). Four interviewees, two health managers, a social work manager and a commissioner felt that interventions should be comprehensive, viz., 'the whole gamut of health interventions, - learning disabilities, psychiatric, behavioural and social problems (BB) ..... 'physical stuff, ADL skills, counselling, complementary therapies' (OB)... 'provision of different modes of treatment, drug therapy, behaviour therapy, talking therapy' (MB).

Interestingly, two voluntary sector managers had sharply divergent views in relation to appropriate health interventions. One queried the validity of "learning disabilities" health care per se (box 3,1). The other pointed to the importance of specialist health input for people with learning disabilities (box 3,2). Another area of concern highlighted by a health and a voluntary agency manager related to the relevance of health interventions for challenging behaviour (box 3, 3 and 4). Behaviour management and counselling was described as 'the middle ground', and it was stated that hospital may not be the best place for this type of provision.

Finally, four individuals, (two commissioners, a health and a social work manager) pointed to the importance of a speedy response for those who presented with acute problems.

**Box 3: Ambivalence regarding health interventions**

1. 'learning disabilities clients should have access to ordinary general health services backed up by support from carers, .... learning disabilities clients with psychiatric problems should have input from general psychiatry rather than learning disabilities psychiatry as in Pine' (RB).
2. (Pine patients need) 'basic health checks to detect underlying causes which can get missed in the learning disabilities population.... and treatment of psychiatric problems (in Pine) (NB).
3. 'I have concerns about the appropriateness of health interventions for *functional* challenging behaviour - *are* they health interventions? should they be addressed in their own environment - we're still using the hospitals as the bin for those we can't manage' (NB).
4. 'I've more concerns about the evaluation of challenging behaviour outcomes - it's crucial to involve users because their needs might be different from professionals' views' (OB).

**4.5.10 Supporting carers of Oak/Pine patients**

All ten respondents perceived families/carers as also requiring support for themselves, viz., 'families and carers need to be well informed and part of the process, I have worries about a tendency for families to get shut out by

hospital teams who give the message - it's over to us now' (NB)... 'carers need a lot of support in coping with the person coming back out into the community to pick up the threads of their life' (TB)... 'Families need support from somewhere, the current setup and funding system makes us look at individuals rather than the whole family dynamic' (OB).

More than half of those interviewed (6/10) considered that carer support was a joint responsibility of health and social work staff, viz.,

- 'It's the responsibility of everyone and must be collective, it shouldn't be adversarial, there should be consistency of support from a variety of perspectives (RB)'.....
- 'It's not black and white it needs to be done with the full back up of the clinical team' (OB)....
- 'It's not clear cut, it must be done and there should be negotiation as to who can best do it. When I was a social worker and part of such a team often there was no difference between what I was doing and what the community nurses were doing' (NB)....
- 'We must not have demarcation, this will only harm the patients. Carers should have support from hospital teams as well a social workers - depends on the type of support needed. Also we must consider how good is the social work service available - often it's not as good as social work would like' (SB)

A health manager and a social work manager felt that carers needed different input at different times, For example, support from the hospital team if passing information about reasons for admission/progress/outcome future management; from both health and social workers when decision making about the future of the family; from social workers if families need input for themselves such as respite arrangements' A commissioner commented, 'primarily the hospital team is there for the patients, but it's crucial that health staff can give support to carers and families when needed. This should not be to the detriment of patient care - getting the balance is key' (LB). This individual added, 'health care professionals have more credibility with carers than social workers or care-manager's.

The above highlights that although carer support was unanimously viewed as important the reality of delivering appropriate input is highly complex. Challenging issues have been identified in relation to professional territorialism, multiagency co-ordination and a diversity of carer and user needs.

#### **4.5.11 Overview**

Thus a comprehensive body of knowledge began to emerge, built up layer upon layer from the findings of both interview surveys and the GAS study. There was resonance in the ambivalence expressed both by clinicians and by managers and commissioners regarding the value of outcome measurement.



Furthermore, collective doubts were expressed by all professionals interviewed regarding the effective development of care partnerships with users and carers.

Therefore, a broader investigation of the nature and extent of outcome measurement within care provision for people with learning disabilities in Scotland was undertaken in order to set the findings of the Grampian research within a national context. The results of the Scottish questionnaire survey of adult learning disabilities services are presented in the next section.

## 4.6 SECTION FIVE: FINDINGS OF THE SCOTTISH SURVEY OF CARE EVALUATION FOR PEOPLE WITH LEARNING DISABILITIES

### 4.6.1 Response Rate

A postal questionnaire was sent to 94 key stakeholders as described in the methods section. Seventy six forms (80%) were returned. This yielded 73 useable forms. There was a high response rate from all organisational groupings apart from non-statutory agencies such as Enable, Choices, Ark, Sense. (Table 17). There were no apparent trends in responses from the different types of non-statutory organisations.

**Table 17: Scottish Survey Response Rate By Respondents**

<b>Respondents</b>	<b>Nos. Received</b>	<b>%</b>
NHS Trusts (n=19)	17	89
Local Authorities (n=27)	24	89
Health Councils (n=15)	12	80
Health Boards (n=13)	10	77
Non Statutory Agencies (n=20)	13	65

### 4.6.2 Views of Outcome Measurement

Views of outcome measurement were overwhelmingly positive as shown in Table 18. In fact all respondents from non-statutory organisations consistently disagreed with all of the statements shown in Table 18. However three respondents, one each from Health Councils, Local Authorities (LAs) and NHS Trusts (Trusts) agreed that outcome measurement was too difficult. One LA respondent agreed that outcome measurement takes up too much time and approximately 18% (13/73) did not know whether the approach was too time consuming. All of the non

statutory and all of the Trust respondents disagreed that outcome measures get in the way of care but three (LAs), two Health Council and one Health Board respondent was unsure of whether the service user might be disadvantaged because of outcome measurement.

**Table 18 : Views of Outcome Measurement (Scottish Survey)**

Aspects of outcome measurement	Disagreed	Agreed	Don't know	No Response	Total
Outcome measurement is too difficult	62	3	6	2	73
Outcome measurement takes up too much time	56	1	13	3	73
Outcome measurement gets in the way of care to the detriment of the service user	64	-	6	3	73

Interestingly some respondents spontaneously wrote their own comments about outcome measurement directly onto the forms. These were reported as follows:

- Outcomes within learning disabilities are difficult but are also valuable (Health Board)
- There is an issue re complexity of outcome measures (LA)
- Outcome measurement is confusing at times (Non-Statutory Agency)
- Outcome measurement needs investment (Non-Statutory Agency)
- Outcome measurement is often subjective/outcome measurement is used to justify our existence! (Non-Statutory Agency)

Specific Outcome Measures. Only 23 (31%) respondents reported that specific outcome measures were used with nearly half describing care planning and reviewing as a specific methodology (Table 19). However one non-statutory respondent stated that care planning and reviewing was used in their organisation but that they did not consider this to be *specific* outcome measurement. In addition a LA respondent stated ‘depends on what is meant by outcome measures’.

**Table 19: Reported specific outcome measures used with people with learning disabilities (Scottish Survey)**

<b>Outcome Measures</b>	<b>Reported Use</b>	
Use of care planning and reviewing	11	(48%)
Standardised measures or formal published tools	7	(30%)
Quality service network review	2	(9%)
Use of national quality indicators as guide and measures	2	(9%)
Use of outcomes specified in service contracts	2	(9%)

n=23

Nevertheless some reference was made to particular tools, viz., Care Programme Approach (one Trust), Person Centred Planning (one Trust & one non-statutory), Goalsetting (one LA, one Health Council, one non-statutory). Reported examples of standardised or published tools in use included, Health of the Nation Outcome Scales (Learning Disabilities); Assessment of Motor and Process Skills; Berewecke Charting; Personal Outcome Measures (The Council on Quality & Leadership in supports for people with Disabilities USA). Reported examples of national quality indicators used for monitoring included CSBS Generic Standards, and SHAS indicators. Finally eleven respondents (15%) stated that specific measures for people with learning disabilities were currently being developed.

### 4.6.3 User involvement in the care process

The overwhelming majority of respondents 67 (92%) reported user involvement in care services. In fact only four individuals, (two Health Council, one LA, one Health Board) stated that no steps were taken to involve users. Analysis of involvement was completed by developing a coding frame which the following issues emerged. Nearly half of respondents reported involvement through user forums (Table 20). User involvement in staff training or selection of care providers was primarily reported by LA respondents. Reported involvement in service planning or involvement through contract specification came mainly from Health Board and Local Authority forms.

**Table 20: Reported types of user involvement with care services (Scottish Survey)**  
n=67

<b>Description of Involvement</b>	<b>Reported Involvement</b>	
User forums/residents' councils/tenants' meetings	30	(45%)
Involvement in own care planning	19	(28%)
Use of advocacy	18	(27%)
Involvement in service planning	14	(21%)
Stakeholder or national consultation conferences	12	(18%)
Interviews/surveys/structure questioning	10	(15%)
Recruitment or training of staff/selection of care providers	6	(9%)
User involvement specified in service contract	2	(1%)

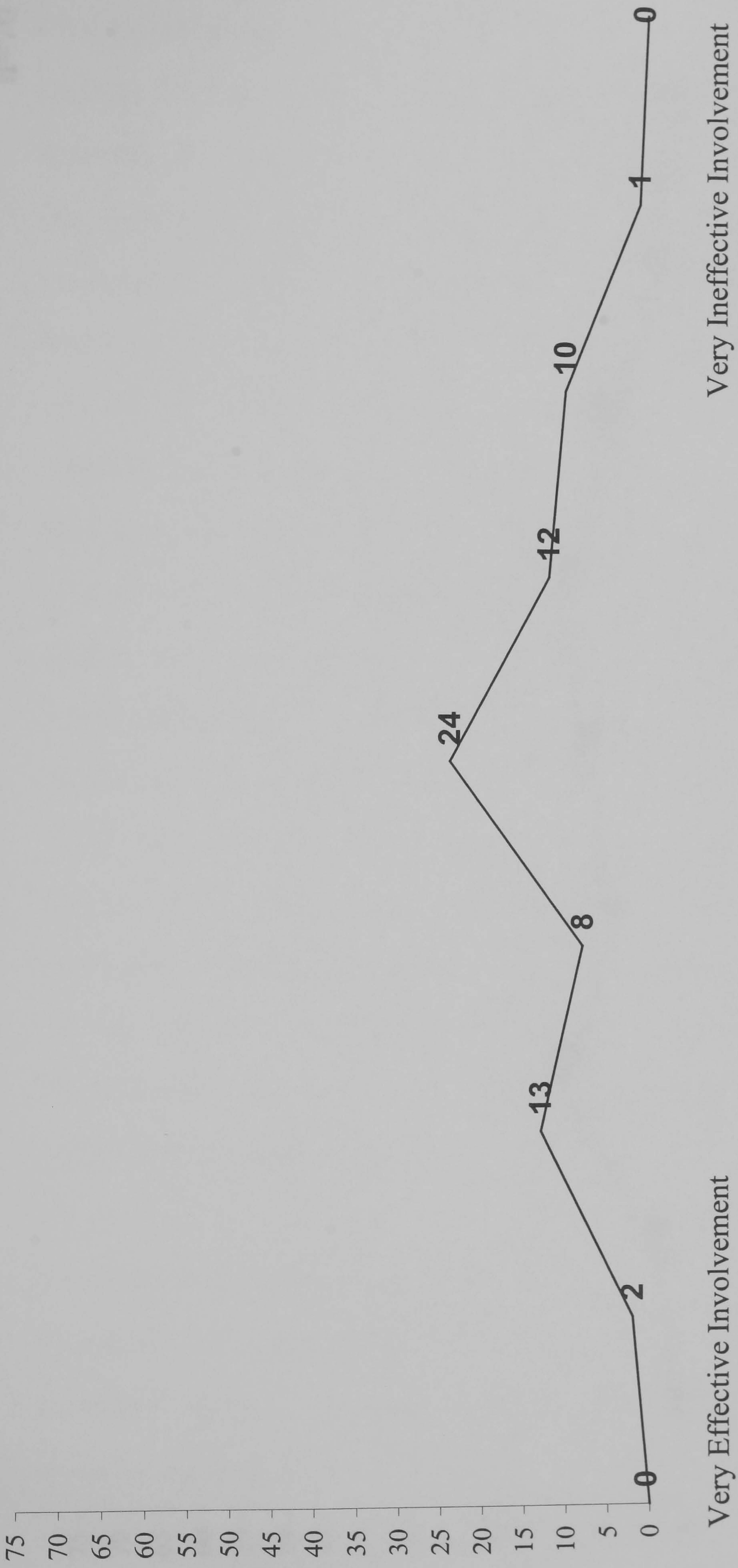
Reported effectiveness of user involvement. The majority of all respondents judged effectiveness of user involvement to be around the mid/higher range of an effectiveness scale as shown in figure 5. The greatest variation in individuals' views of effectiveness were within Health Council and LA respondents. The complexity of user involvement was reflected by a LA

respondent who wrote spontaneously on the form ‘there is still difficulty in getting a balance between supporting the service user group, and enabling them to make an independent contribution to planning services’.

Staff awareness of expectations of user involvement. Staff awareness of what managers and commissioners expect of them regarding user outcomes was rated as being more variable on the scale (figure 6). There were two clusters of responses, approximately one third indicating higher awareness and approximately one third lower awareness. Variation of views within different categories of respondents is shown as follows. Health Trust individuals reported both the highest level of staff awareness and also low levels of awareness. Overall LA respondents reported lowest staff awareness. Interestingly a Health Council respondent marked the scale high on staff awareness but spontaneously added the following comment regarding general hospital services; ‘nurses (were) observed to require training in communicating/understanding behaviours, and that people with learning disabilities may not know how to ask for assistance in eating/drinking/general care/reassurance. Nurses generally mean well but are not aware of how to accommodate needs’.

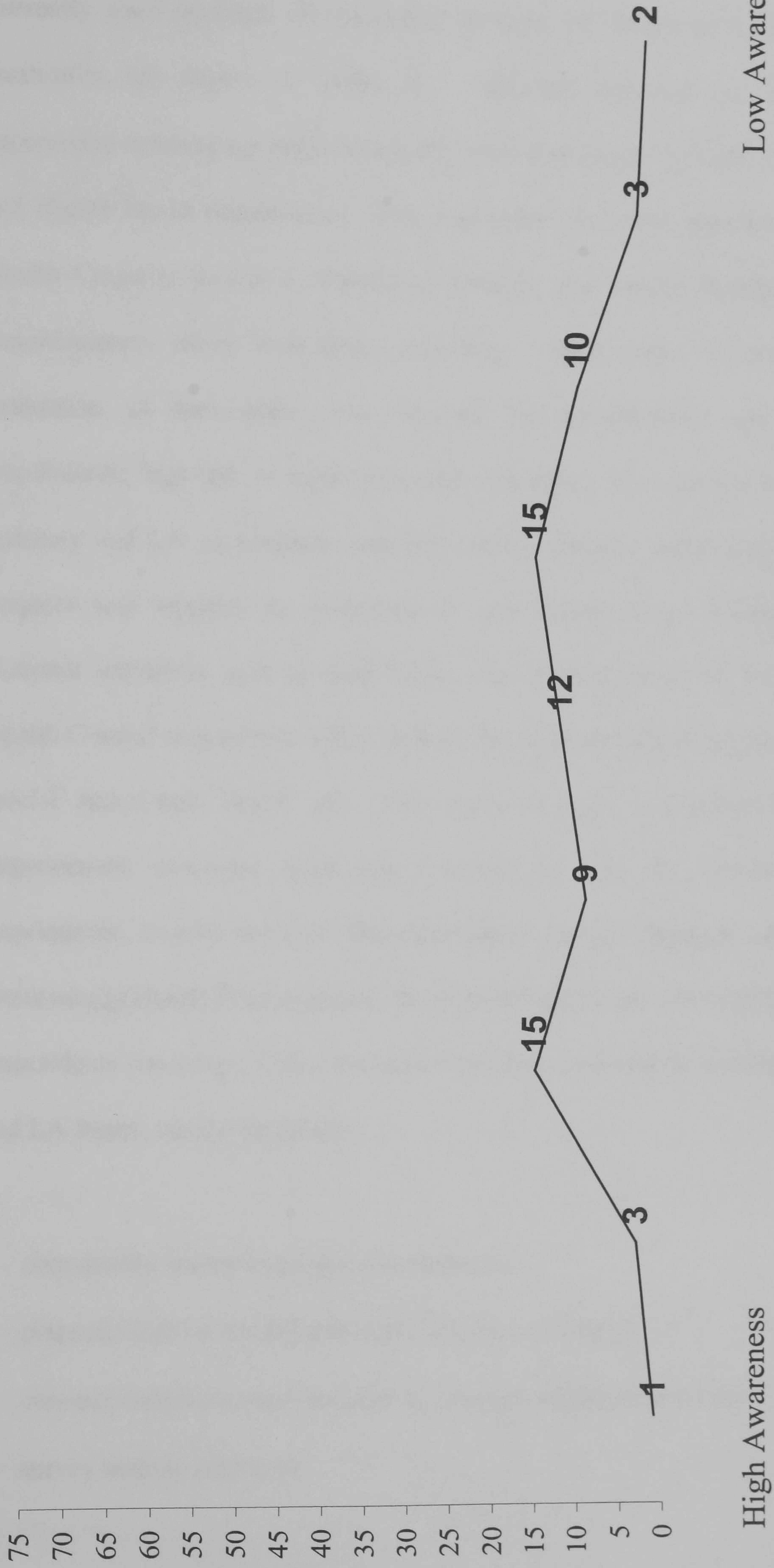
**Figure 5 Stakeholders' reported effectiveness of user involvement in care services**

n=70



**Figure 6 Stakeholders' reported staff awareness of what managers & commissioners expect of them regarding user outcomes**

n=70





#### 4.6.4 Current evaluation methods

Currently used methods of evaluating services for people with learning disabilities are shown in Table 21. Although reported use of staff supervision systems was high overall there was low usage by Health Council and Health Board respondents. This may reflect their non provider roles, Health Councils having a ‘watchdog’ function and Health Boards being commissioners rather than direct providers. High usage of long term evaluation of care plans was reported by non-statutory and Trust respondents; high use of registration and inspection was reported by non-statutory and LA respondents; and high use of formally reviewing service projects was reported by non-statutory and Health Board respondents. National initiatives such as Best Value were reported less by Trust and Health Council respondents which reflects this methodology being more of a ‘social’ rather than ‘health’ tool. Conversely, as might be expected, health improvement measures were less reported by LA and non-statutory respondents. Overall there was less reporting of ‘quality’ measures although interestingly Health Trust respondents reported highest use and Health Board respondents low usage. Other evaluation methods, reported on non-statutory and LA forms, are shown below:

- own quality framework (one non-statutory)
- planned visits by locality manager (one non-statutory)
- contract compliance and monitoring (one non-statutory one LA)
- survey activity (one LA)

- service development plans (one LA)
- internal QA audits, eg. buildings or safety inspections (one non-statutory)

**Table 21: Reported methods of evaluating services for people with learning disabilities (Scottish Survey)**

Methods	n=73	
	Reported Use of Methods	
Staff appraisal/staff supervision systems	62	(85%)
Eliciting the client/carer view of progress	61	(83%)
Longterm evaluation of care plans/progress records by staff	56	(77%)
Statutory registration and inspection	52	(71%)
Formal review of service projects	52	(71%)
Actively based measures, e.g. bed occupancy	47	(64%)
National initiatives e.g. best value	45	(62%)
'Quality' measures e.g. quality service network review	33	(45%)
Health improvement measures e.g. clinical audit	31	(42%)
Other methods	7	(1%)

Fifty-one respondents (70%) stated that evaluation methods effected changes to policy and practice, although there was less reported change from health council and health board respondents.

*Evaluation methods effecting changes to policy and practice.* Of those reporting changes 32 (63%) of individuals described particular evaluation approaches which had altered practice and policy. For example 14 respondents pointed to local reviews and audits, such as audit of health check lists or health assessment instruments; nine respondents stated that eliciting client views had changed practice; and three respondents said that government policy directives resulted in changes.

*Resulting changes.* The remaining 19 respondents (37%) indicated *how* particular evaluation methods had effected change. For example nine respondents described how user views effected changes to policy and practice, either at strategic level where user views were felt to be instrumental in shaping plans to ‘fit’ with user aspirations or needs. Or at care planning level through for example changes to activities provided, or changes in types of services individuals might access. Five respondents described how statutory registration and inspection had led to reviews of staffing, changes to recording systems and improvements to fabric of buildings. Five respondents highlighted how national and local directives had effected change by promoting alterations to service shape and delivery. Finally, one example was given of how an audit of incidents of restraint had changed practice. From this, new policy was developed including particular methods of restraint to be used.

#### **4.6.5 Reported appropriateness of outcome measures**

Strong support emerged for individualised methods of outcome and goal setting with users (Table 22). Indeed over half of respondents indicated on a ranking scale, that these approaches were very appropriate for use with people with learning disabilities. A Health Trust respondent ranked standardised methods towards the appropriate end of the scale (4) *provided* instruments were standardised for use with people with learning disabilities. A different Trust respondent suggested satisfaction surveys be targeted towards carers rather than users and were this to be so, ranked appropriateness of the method around the mid-point of the scale.

Respondents gave little credibility to measures of hospital admission and discharge rates. Other appropriate measures suggested by respondents were:

- combination of different methods, (one LA respondent scored at 5)
- mental health rating scales, (one non-statutory respondent scored at 4)
- evidence produced at regular intervals in line with specified outcome measure (one health board respondent scored at 5)

**Table 22: Reported appropriateness of methods for measuring health outcomes for people with learning disabilities (Scottish Survey)**

n=73

Methods	Reported appropriateness on 1-5 scale, 1=approp, 5=very approp					nr*	Total
	5	4	3	2	1		
Setting and reviewing goals with users	41 (57%)	19 (26%)	4 (5%)	1 (1%)	-	8 (11%)	73 (100%)
Individual methods	40 (55%)	15 (20%)	5 (7%)	2 (3%)	1 (1%)	10 (14%)	73 (100%)
User satisfaction surveys	15 (20%)	21 (29%)	18 (25%)	7 (9%)	2 (3%)	10 (14%)	73 (100%)
Standardised methods	7 (9%)	12 (16%)	22 (30%)	12 (16%)	5 (7%)	15 (20%)	73 (100%)
Hospital admission/discharge rates	3 (4%)	5 (7%)	19 (26%)	14 (19%)	17 (23%)	15 (20%)	73 (100%)

\* nr=non response

#### 4.6.6 Preferred future evaluation methods

Fifty respondents (68%) representing all sectors surveyed described the types of outcome measures they would wish to see introduced for people with learning disabilities in the future.

Of those stating a preference, 32 (64%) made reference to implementation of specific tools or approaches. For example, SHAS quality indicators, Health of the Nation Outcome Scales, (Learning Disabilities), O'Brien's 5 Accomplishments, Goalsetting, Satisfaction Surveys, Quality of Life Measures and Service Measures. Issues emerged regarding what was perceived to effect *meaningful* measures of outcome, with low credibility afforded to 'number crunching' approaches such as admission/discharge rates or financial activity. More valued were quality of life measures. For example, employment rates or evidence of social inclusion or empowerment. One LA respondent particularly valued the ability of users to take on 'adult' roles including risk taking. This point has resonance with 17 (34%) of respondents who supported user involvement in developing and evaluating measurement approaches - with some outcomes being user defined. For example a LA respondent said 'outcome measures would need to be owned by staff and service users - not set by others as it won't be valued and won't work!'

The complexity of measurement within learning disabilities services was acknowledged by 10 (20%) respondents from provider organisations. Flexibility of tools and approaches was considered important in being able to

respond to the differing range of needs and abilities within the spectrum of learning disabilities, and problems with communication were viewed as compounding factors. Indeed it was considered necessary to have a mix of quantitative instruments and tools in different formats. Outcomes were also viewed as multidimensional with measurement possible at service level, at individual user level and at the interface between agencies. This raised questions of resource management with one LA respondent advocating provision of extra resource to ‘support, implement, monitor and review.... This should not be additional work for already hard pressed staff’. A warning from another LA respondent highlighted that outcome measurement must ‘not (be) achieved through lots of additional beaurocracy and form filling’. Indeed a Health Council respondent asked ‘would/could outcome measurement be yet another beaurocratic paper exercise which had little real impact on people with learning disabilities. Is there a better way forward?’. Yet despite concerns regarding complexity of information management, complexity of care needs, and doubts regarding validity of outcomes only one Health Trust respondent commented on the importance of education and training of staff regarding outcome measurement.

Issues emerged regarding the appropriateness of the medical model within learning disabilities and how it ‘fits’ with outcome measurement. A LA respondent said ‘the more medical orientated models are not (appropriate) ..... people with learning disabilities are not ill’. However another LA respondent advocated closer working between community learning disabilities nurses and GPs, ‘to increase their knowledge base of people with

learning disabilities'. Thus recognising the importance of the interface between service users and primary care. Two Health Trust respondents also wished for 'better access to generic services' and 'accessing specialist services *only* where mainstream is not appropriate'. But a Health Council respondent stated that 'referral on to specialist care should be a requirement when involving people with known medical problems ..... poor attitudes amongst professionals should be identified to ensure that appropriate care is given without compromise'.

Thus, effective introduction of outcome measurement within learning disabilities was viewed as highly complex, multidimensional and potentially resource intensive. However, only one LA and one Health Trust respondent advocated an integrated approach to tackling this challenging remit. Specifically the trust respondent proposed, 'a joint health and social service paper to state that one system must be used across all services - may be incorporated within community care assessments, and goalsetting from that original document. Joint ownership of the community care assessment would be required, therefore it would make sense to have health/social teams together in one building, having one filing system'.

#### **4.6.7 Conclusion**

From the findings of the survey a gap emerged between rhetoric and reality. In principle, outcome measurement was viewed positively by respondents. However, in practice, concerns were expressed regarding spiralling bureaucracy, over-simplistic approaches to complex care needs, doubts



regarding validity of outcomes, and fears of measurement being open to manipulation. In addition, effective involvement of users in the care evaluation process was viewed as variable.

Finally, across all stakeholders, a clear preference was uncovered for individualised measures of outcomes with people with learning difficulties.

#### **4.7 OVERVIEW OF FINDINGS**

The findings reported here build up a complex and multifaceted body of knowledge. New insights have been gained through placing the realities of the GAS study at the heart of the investigation and comparing empirical results with views of investigation held by front line clinical teams, local managers and commissioners and national survey participants. Main results of the study are as follows.

- a) Clinical staff had greater than anticipated difficulty in implementing goalsetting methodology, and establishing the GAS study required two attempts
- b) Oak and Pine staff selected 12 patients to be involved in the GAS study based on the nature of each individual's needs and how identified needs were to be addressed
- c) Sixteen goals were scaled and it proved possible to measure impact of intervention for all of them. Targets were exceeded in nine instances and met in six instances. Scores remained at baseline for one goal

- d) Consent for interview was obtained from half of the 12 patients involved in the GAS study. The six who gave consent were able to complete all elements of the patient interview schedule. This yielded additional data which described the therapeutic process and outcome of treatment from the patient's view point rather than the professional's view.
- e) Limited levels of patient understanding were identified by staff as the main factor inhibiting patient involvement in GAS. Of the six multidisciplinary team members who implemented GAS, three reported that it was possible to partially involve patients in care planning and evaluation, and three reported involvement was not achieved.
- f) Despite emphasis being placed on achieving a collaborative approach to goalsetting during GAS training, there was no carer involvement in 15 of the 16 goals which were set.
- g) Half the Oak and Pine staff who were interviewed expressed negative perceptions of outcome measurement in healthcare. More specifically the majority of respondents were unconvinced that GAS could usefully contribute to the local care planning and evaluation process.

- h) The majority of managers and commissioners who were interviewed expressed a preference for individualised measures of outcome for use with people with learning disabilities. General concerns were expressed regarding lack of appropriate measurement tools, and lack of collective stakeholder ownership of measurement approaches regarding such clients.
- i) The ten managers and commissioners unanimously acknowledged complex relationships with stakeholders regarding outcomes agendas especially in relation to differences in power. The majority of respondents thought that the clinicians' agenda was in fact predominant although there were differing opinions as to whether this was appropriate. Three individuals felt that the user's perspective should be dominant but in reality was not.
- j) Despite fragmentation within care provision, an 80% response rate was achieved in the Scottish survey of adult learning disabilities services, yielding 73 usable forms.
- k) More than half of respondents in the Scottish survey indicated that goalsetting with users and individualised methods of outcome measurement were very appropriate for use with people with learning disabilities.

- 1) The overwhelming majority of Scottish survey respondents, 67 (92%) reported user involvement in care services. Effectiveness of user involvement was judged to be variable when rated on an effectiveness scale.

The tensions and apparent contradictions revealed in the findings of the research are explored in more depth in the discussion which follows this section.

## **5. DISCUSSION**

### **5.1 INTRODUCTION**

The studies described in this thesis set out to examine the delivery and evaluation of healthcare for adults with learning disabilities in Scotland. Particular emphasis was placed on (i) the systematic exploration of healthcare within the realities of routine practice, and (ii) the delineation of the contributions of key stakeholders within the care process, viz., users, carers, practitioners, managers and commissioners. The study theme became increasingly topical around the millennium as clinical governance and partnership with service users emerged as dominant features of NHS strategy.

Within the context of an ever changing NHS, this study addressed a number of issues related to collective determining of appropriate clinical interventions, and the meaningful involvement of people with learning disabilities in that process. More specifically the study aimed to examine collaborative goalsetting (GAS) as a means of achieving effective care partnerships within routine practice; to examine the effect of using an individualised measure of outcome (GAS) as a means of enhancing the clinical evidence base; to determine the feasibility of gathering views of people with learning disabilities regarding care using a pictorial approach; to compare the views of users, practitioners, managers and commissioners regarding healthcare provision and evaluation; to discover views of care provision and evaluation for people with learning disabilities within Scotland; and to determine the relationship among government directives, NHS strategy and the realities of routine care delivery.

The study is discussed here as follows. Firstly, study design and methods are appraised. Secondly, key issues emerging from study findings are highlighted and explored including:

- The study ethos which pre-dated government policy and directives
- The inclusion of a group of participants not normally involved in research
- Consent and interpretation of user responses
- Measurement of outcomes and the emerging preference for individualised measures
- Multiple perspectives within the study
- The research focus in relation to therapy research
- Transferability.

Finally, implications of the research are highlighted and conclusions drawn.

## **5.2 APPRAISAL OF RESEARCH DESIGN AND METHOD**

The study design was firmly embedded within the realities of routine healthcare with examination of practice based issues and patient/practitioner relationships being of primary interest.

*The GAS Study.* The nature of the GAS study attempted to complement the routine care planning and service delivery within the study base of Oak and Pine Units, with minimum disruption to established ward policy and

procedures. It was considered important that no external research constraints were placed on clinical decision making. Thus participants in the GAS study were selected for inclusion by the multi-disciplinary clinical teams with no influence from the researcher. However, despite obtaining good clinical team representation within initial GAS training, application of the approach was poor during the first year of the study. Indeed there remained a modest number of patient participants and limited setting and reviewing of goals even after refresher GAS training and a shift to a directive approach within the GAS study.

However, the ethos of applied research is concerned with emerging realities from practice within the field. Thus exploration of multidisciplinary resistance to implementation of GAS added to the richness of the study. Indeed completion of the GAS study was of twofold interest. Firstly individualised outcome measurement data was collected in respect of the interventions of clinical teams within acute and specialist units for people with learning disabilities. Secondly, the *process* of applying GAS in this area provided a focus for gathering of views of healthcare evaluation from a range of key stakeholders, viz., users, practitioners, managers and commissioners. Thus a comprehensive body of in-depth knowledge was built up, layer upon layer, from the GAS study. With regard to technical limitations of GAS, concerns were acknowledged relating to the statistical procedures recommended to deal with the data obtained in practice. Thus in the GAS study raw scores were analysed using a non-parametric coding frame (MacKay et al 1993), consequently no standardised scoring was generated for participants. Indeed as

found by MacKay & Lundie (1998) the *process* of applying GAS in this study was considered as valuable as the determination of outcomes, although the outcomes were part of the process. Thus the importance of GAS in creating a structure for problem definition, planning, evaluation and discussion was considered as significant as the choice of statistical approach to data analysis.

*User Involvement.* Despite well known difficulties in gathering valid and reliable views from people with learning disabilities, it was considered crucial that patients were given a voice within this study. Including their views presents users as valued participants in research. In addition the patients' responses provided the only source of information which reflected users' perspectives of healthcare. Although interviews were planned and semi-structured, participant involvement was achieved by deliberately adopting a relaxed, unhurried, informal, flexible approach to interview. It is acknowledged that this 'softer' style of interaction raises issues of validation, however there is evidence that a less formal approach to structured questioning yields more meaningful data (Atkinson 1988, Redworth 1998).

*Semi-Structured Interviews.* Because of the practice based nature of the research a number of practitioners and managers interviewed regarding healthcare evaluation were known to the researcher. Issues of assuring confidentiality and respecting professional roles required careful consideration and sensitive handling. For example, it was decided that data recording during interview be achieved by noting key phrases on prepared forms and subsequently writing up in full within 24 hours. This was considered preferable



to tape recording which, was felt to be potentially more threatening for participants. It was important interviewees were comfortable with the interview process thus enabling confidence in expressing honest opinions. Validation of responses was subsequently achieved through verifying of written findings by participants. This was important to achieve objectivity and to minimise researcher bias. Satisfaction was expressed by participants regarding level of confidentiality.

*Research Tools & Approaches.* The multidimensional nature of the research was underpinned through the use of a variety of techniques and approaches. For example, quantitative methods were most suitable for the Scottish survey, and qualitative analysis of staff interview data was more appropriate. In addition an exploratory approach was developed using pictures and photographs for interviewing users. Thus only by judicious and creative use of a range of research approaches was it possible to build up an in-depth and comprehensive body of knowledge within the study.

### **5.2.1 Applied Research**

This practice based study uncovered issues which have resonance with participant observer research. For example potential conflicts of interest became evident for the researcher when balancing personal agendas linked to roles of healthcare professional, healthcare manager and independent researcher. For example, sensitive judgement was required when reporting on findings to the study base clinical teams, and to the service management team,

yet also safeguarding participant confidentiality. In this context clarity of thought was imperative.

Furthermore the complex interplay of the researcher's employment role and research role is likely to have caused confusion for others. Thus the researcher's work colleagues may have had concerns with issues of trust both at clinical and managerial levels. Moreover there may have been issues of political mistrust during interviews with multiagency managers and commissioners of services in relation to the dual role of the researcher, viz., independent researcher and healthcare worker. However managers and commissioners responses were comprehensive, open and wide-ranging. Furthermore interview findings were readily validated by participants.

There was clear evidence of mistrust of the research process by one patient (participant C). This patient was obviously unconvinced of the researcher's independent status and clearly perceived the role as part of clinical team functioning despite assurances to the contrary. Other patients may also have had worries about confidentiality, which were not so overtly displayed. In addition lack of patient validation of interview content is acknowledged as a weakness of the research.

Furthermore the dual role of ward staff as patient supporter and independent witness is likely to have additionally complicated research relationships and power differentials. The researcher viewed the inclusion of ward staff as being supportive in providing a means of patient reassurance, and by enabling

practical arrangements such as advising on patient availability. However, ward staff may also have introduced bias.

The nature of applied research uncovered tensions between strategic direction and routine care. For example, the requirement for clinicians to practise from an evidence base is allied to government policy of ensuring quality of health care through clinical governance. From the GAS study there was evidence of implicit staff recognition that outcome measurement could lead to improved patient care through the process of clinical reasoning enhancing the evidence base. For example a nurse said ‘we must have outcomes to plan beneficial care in an ongoing way’. Yet half the Oak and Pine staff who were interviewed also expressed negative perceptions of outcome measurement and application of GAS was in fact limited.

The practice based approach also highlighted considerable staff difficulties in applying goal setting routine care. In fact joint goal setting with users and the focusing of attention on user outcomes appeared particularly problematic in this study. This conflicts with well established use of ‘treatment goals’ within the health service generally. Thus even allowing for barriers to inclusion of people with learning disabilities, it is of interest that application of apparently fundamental health care methodology was found to be so problematic in practice.

The key issues, which emerged from the study are now discussed.

## 5.3 DISCUSSION OF KEY ISSUES

### 5.3.1 Study Ethos

The basic tenets which underpin this research relate to issues of partnership working; of valuing and empowering users; of agreeing care outcomes with users; and of evaluating impact of care interventions jointly. These issues have become increasingly topical as reflected by a range of recent policies, strategies and legislation. For example the *Adults with Incapacity (Scotland) Act (2000)* has placed a legal requirement on obtaining the meaningful involvement of people with learning disabilities wherever possible. Moreover greater social inclusion is now demanded through political and health service directives, viz., *Our National Health: A plan for action, a plan for change* (Scottish Executive Health Department 2000a) and *The same as you?* (Scottish Executive 2000b). In addition recent introduction of clinical governance within the NHS requires practitioner accountability for effectiveness of care, and user involvement in health decision making.

However it is important to recognise the work of this study commenced prior to the gathering momentum described above, which has resulted in major shifts within policy making and strategic focus. Consequently this research is coming

to fruition at a time which places it in the forefront of health evaluation with people with learning disabilities.

### **5.3.2 The inclusion of people with learning disabilities in research**

As previously reported a major component of this research was concerned with examination of meaningful involvement of people with learning disabilities in the planning and evaluation of their healthcare. Indeed the main investigation tool (GAS) was selected because of the requirement that goals be developed by all persons involved to ensure validity, for example client/clinician/carer (Carr 1979, Cook 1995, Greenhalgh & Long 1996 and Turnbull 1998). However, when planning a partnership approach with people with learning disabilities a variety of factors required consideration, viz.,

- The need to achieve meaningful involvement
- Difficulties associated with the poor communicative abilities of people with learning disabilities
- Tendencies towards response bias
- Lack of experience of people with learning disabilities in expressing their views
- The power imbalance between professionals and users of services.

Therefore, it was considered important to supplement the GAS process with additional patient interviews to ensure a voice for users. This was viewed as necessary because patient delineated outcomes continue to lack credibility within health care (Dixon & Long 1995). Yet evidence suggests that the self

reports of people with learning disabilities are indeed valuable (Lindsay et al 1994, Murray & Lakani 1998, Raitasuo et al 1999). Indeed this study is important in adding to the knowledge base within learning disabilities where few studies have reported on outcomes of care for in patients with additional psychiatric symptoms or behavioural disorders (Deb 1995, Raitasuo et al 1999, Gaylor 2000). In addition, even within the small amount of literature available concerns have been raised in relation to participant recruitment problems and exclusion criteria (Gaylor 2000). Thus, the GAS study adds new perspectives both in relation to examination of routine clinical practice and care provision with no external research influence on participant selection and no exclusion criteria; and also new understanding stems from the central place given to establishing the users view of healthcare.

The study highlighted the feasibility of using collaborative goal setting to jointly plan and evaluate health care for in-patients with learning disabilities and additional complex care needs within routine clinical practice. This was achieved despite the heterogeneous nature of the study population and despite the challenges of meaningfully involving people with learning disabilities in care decision making. In fact it proved achievable to measure the impact of intervention for all goals which were set and scaled. In addition the tools and approaches used to interview patients were found to be appropriate in that all participants were able to complete all elements of the interview process, viz., the consent procedure, the BPVS, the analogue scales and the photograph interviews. Moreover, responses were reliable in that once consent was given smooth engagement in the interview was achieved, and inconsistent replies

were justified by self commentary and/or body language denoting either ambivalence to questions, change of mind or fluctuation in mental state.

The GAS study also brought into focus a number of barriers to the inclusion of people with learning disabilities as research partners in evaluating healthcare. The first issue relates to the heterogeneous nature of the study population from which one participant with severe disabilities and extreme behaviour could not be interviewed because of safety risks. This highlights poorly developed support mechanisms within routine clinical care for helping those with more profound disabilities or very challenging behaviour to express views.

Secondly, the nature of the routine practice was found to mitigate against patient inclusion in giving views of healthcare. In fact three of the 12 potential participants were excluded from the patient interviews because of rapid discharge from the units. Thus negating planned attempts to gather user views.

Thirdly, there emerged practitioner ambivalence regarding involvement of people with learning disabilities in healthcare. Staff indicated that user involvement was essentially desirable but also expressed strong reservations regarding achieving meaningful involvement in practice. Valid reasons were given for lack of inclusion, for example difficulties with communication or problems with levels of understanding. Yet, arguably some of the difficulties in establishing partnerships may have been due in part to ambivalence regarding power sharing with power imbalance between healthcare professionals and users of service a recurring theme in the literature (Kenny 1990, Jenkinson

1993, Neuberger 1993, Sines 1995, Needham 1996, Sang 1999).

Fourthly, awareness of power differentials in the health services is not solely an issue for professionals. Evidence points to the importance of recognising users' perspectives on power imbalances within healthcare relationships (Goble 1999, Arscott et al 1999, Fovargue et al 2000). Indeed in the GAS study (despite having been given assurances of confidentiality) participant C became acutely distressed by fears that his interview performance would be evaluated by the researcher and fed back to the ward team.

Fifthly, one patient refused consent for interview, highlighting that although inclusion may be offered users retain the right to decline involvement.

Sixthly, the engagement of study participants in giving views of their healthcare was only achieved through significant investment of time, careful planning and a sensitive and flexible approach to interviewing. Whether or not such resources might be achievable within routine care is arguable.

Thus emerged a body of knowledge related to the inclusion of a group of participants not normally involved in research. Issues of participant consent and interpretation of responses are discussed in the next section.

### **5.3.3 Patient consent**

An important facet of this research was establishing the feasibility of meaningful involvement of people with learning disabilities in routine healthcare planning and evaluation. That it did prove feasible to engage six



people with learning disabilities in a structured interview, despite individuals having additional health problems which had precipitated admission to specialist treatment units for those with mental health problems or severe challenging behaviour, is indeed worthy of note. The main issues emerging from the inclusion of users in the study are discussed below.

Careful consideration was given to the possibility of response bias, and problems associated with different levels of understanding of participants who had a wide range of abilities and co-existing health problems. The specific strategies for enabling engagement and minimising bias included introducing a patient supporter when seeking consent, promoting a relaxed, unhurried, no-pressure approach and describing the interview process through pictorial examples.

In fact six of the seven patients who were asked to participate gave consent. When judging whether agreement to participate was indeed informed consent, various factors emerged. First, it is important to highlight that one patient felt supported enough to refuse consent, which clearly indicates choice. This is of interest in that actually many 'ordinary' health consumers have a tendency to comply with requests made by professionals in healthcare settings. In addition, a different participant refused permission for tape recording of the interview, yet was happy to contribute once the recording machine was removed - again denoting active choice. Second, all participants who consented went on to complete all elements of the interview process, viz., BPVS, analogue scales and photograph interview. If consent had been false it is likely problems of

engagement and compliance would have emerged. Third, the use of nursing staff as patient supporter and independent witness raised complex issues. On the one hand staff with in-depth knowledge of participants were well placed to judge whether consent had indeed been freely given. In addition, the nurses were considered to be an important source of support for users in that the presence of known and trusted staff might arguably have assisted the participants to be confident about reaching a decision. But on the other hand, staff may also have introduced bias. Additionally, participants may have perceived the presence of two professionals (the researcher and the nurse) as intimidating, thus increasing the likelihood of acquiescence.

Therefore, a degree of subjectivity is acknowledged in accepting user consent as valid in this research, despite strenuous efforts to achieve detailed planning, sensitive personal interaction and objectivity of interpretations. Indeed the considerable challenges, which emerged in the study regarding obtaining valid, consent from those with complex needs or severe disabilities are mirrored in the literature (Morris et al 1993, Wong et al 1999). Thus, a yawning gap remains between the rhetoric of user involvement and empowerment, and the realities of meaningful engagement of people with learning disabilities.

#### **5.3.4 Interpretation of responses**

In this study, great care was taken to validate the responses given by participants. This was considered important in strengthening the position of people with learning disabilities whose opinions are often perceived as lacking credibility. Indeed there has been considerable interest in determining how to obtain meaningful responses to questions from people with learning disabilities

and in establishing reliable and valid methods of interpreting replies (Sigelman et al 1981, Flynn 1985, Atkinson 1988, Booth et al 1989, Bull & Cullen 1993, Dagnan et al 1994, Redworth 1998). Within the GAS, study users' responses to interview were reliable in that once consent was given smooth engagement in the interview was achieved, and inconsistent replies were justified by self commentary and/or body language denoting either ambivalent to questions, change mind or fluctuation in mental state.

However, evidence of response bias also emerged, particularly in instances of reluctance to give a negative response. For example, an individual stated that a negative response was correct but insisted on making a positive response on the analogue scale. This has resonance with warnings in the literature regarding dangers of habitual behaviour (such as acquiescence or other bias) being mistaken for active choice (Jenkinson 1993). Furthermore, the obtaining of additional data from staff to supplement patient self report data on the analogue scales did reveal some inconsistency of opinion. However, differences in responses was *not* interpreted as an indication of invalid patient responses. Indeed, it has been argued that individuals with learning disabilities can offer more accurate insights into the effects of services on their lives than information obtained from others (Stenfert-Kroese et al 1998).

With regard to the two modes of questioning, the more sophisticated technique of analogue scales gave more sensitive information, for example, regarding strength of feeling, but responses were clouded by inconsistencies described above. The photograph interview appeared meaningful to all participants in

that correct responses were virtually universal. However, this mode of questioning was dominated by the researcher's agenda rather than seeking personal opinion from users. Caution is also needed in that the literature suggests that a pictorial approach does not overcome all the problems associated with obtaining the views of people with learning disabilities. Indeed the GAS study clearly demonstrated that although a pictorial approach enabled user responsiveness the use of pictures did not eliminate tendencies towards acquiescence.

Finally, an interesting dilemma emerged in the study regarding tensions between user empowerment and the validation of user views. It was considered important that the communicative competence of users was clearly established prior to interview. This was viewed as crucial in strengthening credibility and presenting views as valued. Therefore, all users were first assessed using BPVS (Dunn et al 1982). Thereby emerged the dilemma. On the one hand, application of systematic testing was deemed appropriate, both in terms of robust research design and to enhance credibility of people with learning disabilities. On the other hand, testing of people with learning disabilities prior to interview implied that they needed to be 'checked out' before responses could be accepted as reliable which was clearly not empowering. In fact, these highly complex and potentially contradictory themes reflect current debate within the learning disabilities arena. Power imbalance between healthcare professionals and service users has been a recurring theme in the literature (Kenny 1990, Jenkinson 1993, Neuberger 1993, Sines 1995, Needham 1996, Sang 1999). Furthermore, recent evidence has pointed to the importance of

recognising users' perceptions of power imbalances within healthcare relationships (Goble 1999, Arscott et al 1999, Fovargue et al 2000). Therefore the issues emerging in this research regarding meaningful user inclusion in healthcare decision making serve to underscore the considerable and complex challenges fundamental to effective and valid partnerships with people with learning disabilities.

### 5.3.5 Measurement of outcomes

Those responsible for commissioning and providing healthcare have looked to outcome measurement as one method of deciding how to effectively target health resources (Shanks & Frater 1993, Davies 1994, Long 1995). Indeed, outcome measurement has been viewed as potentially helpful when making difficult and highly complex healthcare choices involving trade-offs between cost, quality of care and treatment effectiveness (Davies 1994).

Yet, in the present study, outcome measurement was viewed by practitioners and managers as complex and open to manipulation. There were recurring fears of becoming swamped by bureaucracy, of 'the wrong things' or 'the easy things' being measured, and of targets becoming an end in themselves. Interestingly, these concerns emerged consistently in interviews with clinicians, in interviews with managers and commissioners and in the postal survey of views of outcome measurement. Concerns were also raised regarding lack of appropriate tools and methods of measuring outcomes for people with learning disabilities. There was particular disregard for crude 'number crunching' measures such as bed occupancy rates, with clinical outcomes or individualised outcomes generally finding more favour.

Yet, despite such assertions, the majority of staff who participated in the GAS study remained unconvinced that GAS could usefully contribute to the local care planning and evaluation process. Indeed a strong undercurrent of professional resistance to outcome measurement emerged in the GAS study, which was linked to fear of failure. In addition, there were worries that

outcome measurement might be used for professional justification rather than to enhance or develop patient care. The uncovering of staff resistance in the research is of considerable importance highlighting 'emotional loading' of outcome measurement. Thus, whilst there was implicit recognition that outcome measurement should improve quality of care (and therefore was clinically valid), there was also rejection of the approach due to fear of failure and protectionism. This has major implications for supporting staff to feel comfortable with implementing changes within routine practice.

Clear tensions emerged between evaluation methods regarded as meaningful by frontline staff, such as individualised or 'quality' approaches, and methods perceived as more scientifically credible. For example, a commissioner and health manager pointed to effectiveness being more readily identifiable where validated or standardised processes were used, because comparative judgements could be made with more confidence. However, the research also uncovered a consistent preference, across all groups of study participants, for individualised measures of outcome for use with people with learning disabilities. Indeed the majority of GAS study practitioners preferred individualised clinical outcomes; half of the managers and commissioners who were interviewed stated a preference for person centred individualised outcomes; and the majority of survey respondents pointed to appropriateness of individualised methods. This emerging preference for individualised measures is of considerable interest in denoting acceptance of the credibility of 'softer' measures with learning disabilities as opposed to required adherence to 'harder' standardised or quantitative methodologies.

Finally, research findings cast doubts on the impact of evaluation methods such as outcome measurement within the commissioning and policy making process. In this study, commissioners pointed to a multiplicity of factors which influence health resource utilisation, with the significance of political and geographical issues strongly emphasised as being as influential in decision making as outcomes information.

### **5.3.6 Multiple perspectives within the study**

The eliciting of multiple perspectives on care provision for people with learning disabilities and additional complex health needs is in fact rare. Indeed, the work presented here offers a unique insight into the considerable challenges involved in obtaining meaningful engagement of a wide variety of stakeholders within different elements of the research process. However, only by extensive and in depth consultation was it possible to build, layer by layer, a robust and comprehensive understanding of pertinent issues.

It is worthy of note that engagement of users, practitioners, managers and commissioners was achieved despite the previously described problems of meaningful user involvement and despite issues of inter professional and interagency trust. In addition, high response rates both in interviews and in the survey underscores that engagement was achieved both locally in Grampian and nationally within Scotland. Indeed, the move towards community based care for people with learning disabilities has resulted in fragmentation of service provision.



Thus, challenges were encountered in developing a reliably representative data base from which to survey views of outcome measurement across Scotland.

The 80% response rate is therefore a considerable achievement.

The notable exception within this research is the failure to achieve involvement of carers. Lack of carer inclusion in the GAS study is regarded as significant, raising important issues worthy of separate in-depth study. The failure to achieve carers' involvement in this work is of considerable regret, in that a major focus of the study design was a desire to effect the inclusion of views of *all* stakeholders regarding planning and evaluation of care for people with learning disabilities. Thus, the exclusion of the carer's voice diminishes the richness of the findings.

The multidimensional nature of this research has generated knowledge of convergent stakeholder's views; for example preference for individualised measures previously described. In addition, there emerged collective ambivalence regarding the extent and effectiveness of user inclusion in the care process. In principle, the involvement of people with learning disabilities in care was viewed as desirable by all. However there remained recurring concerns in relation to lack of appropriate tools and approaches for inclusion and worries regarding the danger of tokenism.

The multidimensional nature of the research elicited knowledge of perceived effectiveness of multiagency partnerships. In fact joint ownership of care approaches and methods of evaluation was viewed universally as important.

But complex stakeholder relationships, particularly in relation to power differentials, was reported as placing restrictions on work place effectiveness. For example, multiagency partnerships were viewed as flawed by practitioners where there was perceived lack of commitment from co-workers, either due to limited provider resources, or where others were suspected of following a prescribed political agenda rather than focussing on legitimate user needs. Problems were also reported by managers when attempting to reconcile different professional perspectives, with fears of user requirements being ignored in the midst of various professionals' protectionism.

Therefore this study has brought into focus implications with regard to building of trust within both interpersonal and interagency relationships if partnership working is truly to become a reality.

### **5.3.7 Therapy Research**

The professions allied to medicine (PAMS) have the same responsibilities as other health workers for ensuring quality of care through basing clinical decisions on research evidence wherever possible. Responsibility for allocation of health resources including funding of research and development (R & D) lies with the government. Thereby exists a clear link between quality of care and effective access to R & D infrastructure. However, in the past, the PAM's, workforce is viewed as often having been marginalised, not knowing how to access information, identify own R & D needs, or inform policy decisions which affect them (Plant & Hossing-Rangecroft 2001). The barriers to effective accessing of research information by PAMs have been described as

lack of time for reading/applying research in the workplace; lack of knowledge and/or skills; and poor support systems (Plant & Hossing-Rangecroft 2001).

However in the future there will be a new state registration body for PAMs, namely The Council for Health Professions. This has major implications for the therapy professions in that future regulation and registration is to be strongly linked to continuing professional development (The Council for Professions Supplementary to Medicine 2000). Thus the embracing of R & D activities to underpin clinical practice will become central to professional survival. There are growing signs of a PAM's recognition that a shift in practice is required. For example, NHS Executive Funding was obtained for a one year project to increase effectiveness of PAM's R & D within Northern and Yorkshire region of England (Plant & Hossing-Rangecroft 2001). This denotes both growing confidence within the therapy professions in relation to R & D and recognition by funders of the importance of supporting PAMs to develop their research base. Indeed the publication of Meeting the Challenge: A Strategy for the Allied Health Profession (DH 2000) firmly places R & D on the agenda for all therapy professionals.

Occupational Therapy Research. The work described in this thesis is a contribution to the body of knowledge within occupational therapy research. Occupational therapy only became a graduate profession in 1992 and to date has a modest research capacity. The research activity within occupational therapy may be best illustrated in relation to the following context. In the second version of the Register of Therapy Researchers (Joint Therapies

Research Group 1999) 89 (51%) of occupational therapists on this voluntary database possessed a taught masters degree, and 32 (18%) a research degree, PhD, M.Phil. or equivalent (Ilott & White 2001). In addition the College of Occupational Therapists' library, which contains the national collection of unpublished research and work based reports, held approximately 400 dissertations (Carr 1999) from a population of 21,006 state registered occupational therapists (CPSM 2000). Furthermore, reservations about the relevance of research to occupational therapy were expressed within the profession as recently as 1996 (Minns 1996).

However, the College of Occupational Therapists grasped the research nettle and have provided strong professional leadership in driving forward a strategic vision of R & D within occupational therapy. The first professional R & D strategy was published in 1997, and building on this work there is now the 2001 College of Occupational Therapists' Research & Development Strategic Vision & Action plan (Ilott & White 2001). The College has now unequivocally stated, 'research is central to the practice of occupational therapy'.

However this statement is arguably more aspirational than factual at present. Indeed the preliminary findings of a scoping study of R & D in Scotland, Wales and Northern Ireland conducted by Creek (2001) confirmed a poorly developed research base in the Celtic nations (Ilott & White 2001). It was highlighted that, 'although there is much interest and some evolving centres with research leaders, there is limited capability and confidence within the workforce either to use or to undertake research' (Ilott & White 2001). Therefore, the College of

Occupational Therapists' strategy is crucial in pointing the way forward for all occupational therapists. In practical terms action is proposed at two levels. First, all occupational therapists are expected to accept personal responsibility for offering the most effective service; and second, the College will promote the need for national co-ordinated investment in allied health professions research. Key elements of note from the strategy are a strong commitment to user involvement at all levels and stages of the research process, and a move towards developing an evaluative culture within the workplace.

Thus, a major professional and practice based shift has been signalled within occupational therapy during the past five years. Indeed, the strategic vision has only very recently come to fruition through publication in June 2001. That the study described in this thesis has such strong resonance with leading edge professional thinking demonstrates a sound grasp of key issues prior to strategic guidance becoming available. Themes of partnership working, user involvement, evaluation of input and taking responsibility for therapy offered are prominent in both the strategy and this research. Moreover, with reference to Bannigan's (1997) assertion that occupational therapists know more about *how* interventions work rather than *what* actually works, this study has begun to clarify efficacy of input through measurement of jointly determined outcomes of care.

### **5.3.8 Transferability**

The research was constrained by virtue of a single researcher, which placed limits on the scope of the work. Furthermore, the findings of the small

exploratory GAS study cannot be generalised because of low numbers. However, the limited numbers of participants did permit issues to be explored in greater depth. The GAS study also uncovered issues, which are of interest in relation to conducting practice-based research and eliciting user views within routine healthcare.

Yet, the problems of conducting small scale research with limited resources resulted in inability to explore all of the emerging issues. For example, the failure to achieve carer involvement in this work is of considerable regret as discussed previously.

Furthermore, there were issues in relation to technical limitations of the research tools. For example, the BPVS was applied to give an indication of the communicative competence of patients interviewed in the GAS study. However, the BPVS is only standardised up to the age 18 years. Therefore, more reliance must be placed on raw scores for the adult participants in this study. Limitations associated with GAS have been discussed previously with particular concerns highlighted regarding statistical procedures for analysis of raw data. Thus, no standardised GAS scoring was generated in this study. In fact, a major focus of this investigation centred on the collaborative process of GAS and the subsequent impact on partnership working. This qualitative approach has therefore resulted in the limited scope to make comparative judgements about the GAS outcomes generated within the research.

#### 5.4 AREAS FOR FURTHER RESEARCH

Finally what does this study reveal about areas for future research? Priority issues are as follows.

*Carer inclusion in healthcare planning and evaluation.* Despite the emphasis currently placed on partnership working there was a dearth of carer inclusion revealed in this research which gives cause for concern. It is important to discover whether this is representative of current practice. The issue needs to be explored from the perspective of the nature of acute and specialist in-patient care, whether this mitigates against practitioner/carers partnerships, and consequently what effect this might have on aftercare. It would be useful to compare practitioner/carers relationships within in-patient and community based settings. Knowledge of the factors which promote effective joint working could prove instrumental to achievement of optimum healthcare strategies in the community in the longer term.

*Development of tools and approaches for inclusion.* Paucity of instruments and methodologies for meaningful involvement of people with learning disabilities has been a recurring theme in this research. This was reported in the literature, highlighted in staff interviews and recorded in the postal survey. The tools and methods used in the GAS study were found to be appropriate in that engagement of users was achieved. However, interpretation of responses proved problematic particularly in relation to response bias. As reported in other studies, difficulties were compounded in relation to involvement of those with severe learning disabilities and/or extreme behaviour. In fact there must

be rigorous examination of the feasibility of meaningful involvement of those with very complex needs to determine whether the rhetoric of inclusion for all is indeed realistic.

*Empowerment of staff to practise from an evidence base.* This research uncovered deep distrust of evaluation techniques such as outcome measurement by frontline staff engaged in routine care. This was evident despite dissatisfaction with current practice and despite implicit recognition that structured evaluation enhances quality of care. The development of models for practitioner engagement is urgently required as evidence based practice is unlikely to be embraced by staff until they have claimed ownership of health evaluation. There needs to be new understanding of how to offer staff education, which achieves changes to practice. There must be development of staff support systems for building clinical confidence and allaying fears. There must be processes for investment in a 'no blame' culture in which user outcomes are viewed as evidence of treatment efficacy rather than indicators of staff competency.

*Staff ambivalence to partnership working.* Throughout this research practitioners, managers and commissioners have made statements supporting the principle of a partnership approach to care. Users have demonstrated partnership by consenting to be part of the research process. However, on closer examination it became apparent that actual implementation of collaborative working by staff was rudimentary. In fact, a therapist reported the GAS study was the only occasion in which she had collectively planned care



with multidisciplinary team colleagues. Furthermore staff facilitation of user involvement in the GAS study was limited and carer inclusion virtually non-existent. In addition, clinicians, managers and commissioners all reported problems in relation to joint working, with issues of power differentials, clashes of ideology and lack of tools for inclusion coming to the fore. Therefore, a stark contrast emerged between strategic directives for joined up working and user empowerment, and the realities of frontline practice uncovered in this study. For government policy to be effectively translated into routine practice these issues require urgent attention.

## **5.5 CONCLUSION**

The work reported has extended previous research looking at the use of collaborative goalsetting within care evaluation and the meaningful involvement of people with learning disabilities in partnership working. The investigation has also yielded new findings about measuring the impact of care and the barriers to user inclusion in that process. A significant contribution to knowledge has been made regarding:

- The uncovering of staff difficulties in setting healthcare goals
- The discovery of an emerging preference for individualised measures of outcome within learning disabilities
- The definition of multiple perspectives on stakeholders attitudes to partnership working
- The identifying of significant discrepancies between government directives and frontline practice

Empirical findings from this research also complemented those from a review of the literature highlighting a lack of tools and approaches for inclusion of people with learning disabilities; problems with interpretation of user responses; and staff resistance to changing established practice.

A core component of this work was the examination of healthcare for people with learning disabilities within routine clinical practice. The GAS study was inventive in capturing multidimensional views of treatment, from key stakeholders, with minimum external research influence on established clinical processes within acute and specialist units. A new unique interview process was developed to gather user views. The study was original in placing the realities of the GAS trial at the heart of the investigation and comparing empirical findings with views of care evaluation held by frontline clinical teams, local managers and commissioners and national survey participants. This multifaceted approach provided valuable insights into divergence of strategic rhetoric and clinical reality, which has far reaching implications.

*Implications for NHS policy.* This research has shown that meaningful inclusion of users in learning disabilities services had major resource implications. Interviewing users in the study required considerable investment of time and effort in obtaining consent, developing appropriate interview tools and interpreting the validity of responses. This raises issues in relation to the practicality of user inclusion within routine care, particularly for those with severe or very complex needs.

Both extra resources and a major education initiative will be required for meaningful involvement of people with learning disabilities to truly become embedded in routine care.

*Implications for the therapy professions.* Within PAMs national hierarchies there is growing awareness of the importance of evidence based practice in relation to professional development and credibility, as discussed earlier. Yet this study uncovered difficulties with implementation of structured evaluation methods such as outcome measurement by frontline practitioners. Indeed strategic directives alone are unlikely to be enough in achieving a shift in practice within the therapy professions. Clearly there are issues of increased support for research education, and development of critical appraisal methodologies, both at undergraduate and postgraduate levels.

*Implications for staff.* This research revealed staff ambivalence to partnership working, particularly regarding user inclusion, and strong resistance to changing established patterns of working. To achieve harmony between staff practice and government directives a major attitudinal shift in values, power relationships and appraisal of clinical intervention will be required. Undoubtedly staff education, training and support is of key importance, but on its own may not be enough. For example, GAS training was well received in this study but did not effect changes in practitioners' behaviour. Arguably change will only emerge when staff are enabled to be confident in renouncing their fears and embracing personal responsibility for the care they provide.

Finally there are implications for research with people with learning disabilities, especially in relation to the conundrum of participant empowerment versus respondent credibility. This study has thrown into sharp relief the dichotomy of valuing and empowering people with learning disabilities through presenting their voice as scientifically valid. Significant challenges remain in relation to resolution of this issue.

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RDD1495

GRAMPIAN HEALTHCARE  
NATIONAL HEALTH SERVICE TRUST

*Services for People with a Mental Handicap*

10th April 1996

Mrs A Young  
Therapy Services Manager  
c/o Aspen Day Unit  
Woodlands Hospital  
Cults  
ABERDEEN

Dear Mrs Young

**M. Phil Study**

---

Further to the extensive dialogue you and I have had over your undertaking the above I write now to give you my formal support. In the study I understand you will be making use of a certain amount of everyday clinical material and I am agreeable to this.

On a less formal basis, can I offer you every encouragement in carrying the study through to a successful conclusion.

Yours sincerely

Dr R D Drummond  
Consultant Psychiatrist

---

Woodlands Hospital, Gargton Road, Cults, Aberdeen AB1 9PB  
Tel: (01224) 663131 Fax: (01224) 663131 Ext: 51607



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AND  
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Tel: (0224) 273005  
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Our Ref: LC\IAA

12th June 1996

Ms Anita Young  
Therapy Services Manager  
Woodlands Hospital  
Craigton Road  
Cults  
ABERDEEN, AB15 9PR

Dear Ms Young

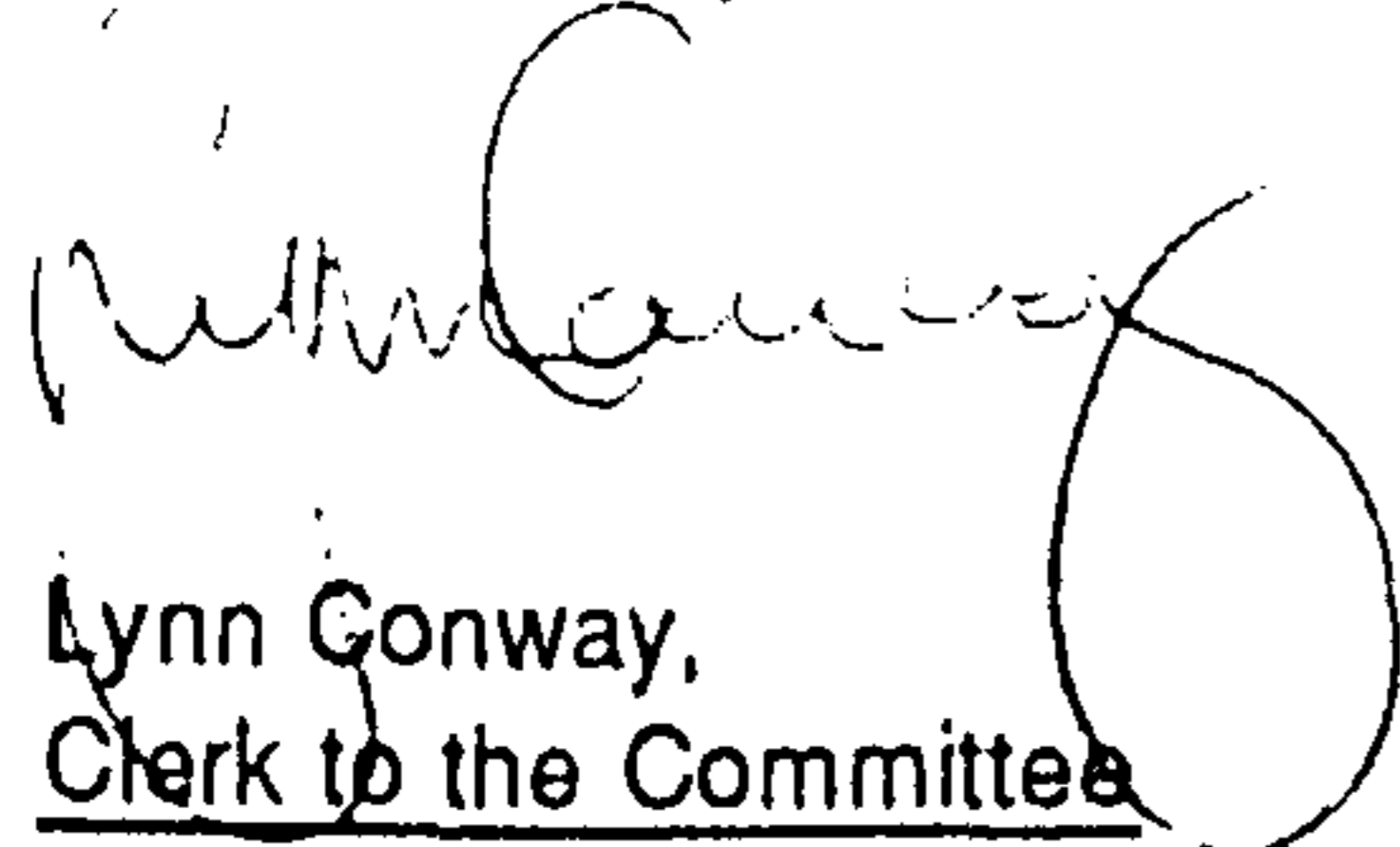
**The effect of goal attainment scaling on expectations of therapeutic input and ultimate satisfaction with outcome**

The above project was considered at the Joint Ethical Committee meeting of 30th May 1996, and I am pleased to confirm that ethical approval for this project has now been granted, subject to the patients being informed how long the interview should last. The Committee would like a copy of the letter from the Consultant Psychiatrists for our files.

With regards to medical indemnity, I enclose a form which should be completed and returned to either: (i) Dr J Hern, Clinical Director, Aberdeen Royal Hospitals NHS Trust, Foresterhill House, Ashgrove Road West, Aberdeen, (ii) Dr R Scorgie, Medical Director, Grampian Healthcare NHS Trust, Westholme, Woodend Hospital, Aberdeen, or (iii) Clinical Director, Moray Health Services NHS Trust, 317 High Street, Elgin, as appropriate, if you wish one of the above Trusts to accept liability for medical indemnity for this project. Where drugs are received from a drug company for use in a trial, these must be stored in the Pharmacy Department for reasons of good practice.

We would be very glad to receive, in due course, copies of any publications arising from this research. Thank you for bringing this study to the Committee's attention.

Yours sincerely,



Lynn Conway,  
Clerk to the Committee

Clerk to the Committee

Ms Lynn Conway  
Dept of Public Health Medicine  
Grampian Health Board  
Summerfield House  
2 Eday Road  
Aberdeen, AB15 6RE

Tel: (0224) 663456 Ext.75225  
Fax: (0224) 404014

Project No:96\142

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Please quote project number in all correspondence

**CONFIDENTIAL**

**OAK/PINE MULTIDISCIPLINARY TEAM (MDT)  
QUESTIONNAIRE**

**PLEASE ANSWER ALL THE QUESTIONS**

**Q1** How long have you worked in the NHS approximately \_\_\_\_\_ years

**Q2** How long have you worked with people with learning disability? approximately \_\_\_\_\_ years

**Q3** a) Do you have a professional qualification? YES/NO  
 b) If YES please state \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**Q4** a) Is your post based on the ward? YES/NO  
 b) If YES circle which ward PINE/OAK

**For the following question please circle the number that best represents your opinion on the statement given;**

**(1 = Strongly Agree, 2 = Agree, 3 = Disagree, 4 = Strongly disagree)**

<b>Q5</b> I think it's the OT's job to;	<b>Agree</b>		<b>Disagree</b>	
Help patients develop self care skills eg dressing/bathing/eating	1	2	3	4
Advise on coping strategies, eg using a raised toilet seat for independent toileting	1	2	3	4
Provide activities to occupy patients	1	2	3	4
Help patients develop domestic skills eg cookery/laundry	1	2	3	4
Make tasks achievable by teaching different ways of doing things	1	2	3	4

	Agree		Disagree	
Help patients decide what they need to do to live the kind of life they wish	1	2	3	4
Encourage patients to do what the team thinks is best	1	2	3	4
Help patients work out what is realistically possible for them to do	1	2	3	4
Enable patients to pay attention to tasks and join in activities	1	2	3	4
Help patients cooperate with others, control behaviour which upsets other people and/or tolerate other people	1	2	3	4
Help patients use community resources eg public transport/swimming pools	1	2	3	4
Give carers something in writing to help them understand and work with the patients	1	2	3	4
Other (please state) .....	1	2	3	4

**Q6** If OT was restricted, how do you think the input listed below should be ranked in order of importance from 1 to 6?

(1 = Most Important, 6 = Least Important)

- Developing specific skills, eg bathing \_\_\_\_\_
- Providing activities to occupy patients \_\_\_\_\_
- Teaching coping strategies, eg survival cookery \_\_\_\_\_
- Providing written OT guidelines for colleagues/carers \_\_\_\_\_
- Promoting constructive use of leisure time \_\_\_\_\_
- Helping patients make choices about lifestyle \_\_\_\_\_

**Q7** Please identify all the staff you feel should be involved with the activities listed below by ticking the relevant boxes (✓)

OT Occupational Therapist      N Nurse      OTHER eg Physio  
 SLT Speech and Language Therapist      PSY Psychology Staff      Dietetics  
 SW Social Worker      Med Psychiatrist/Registrar

	OT	SLT	SW	N	PSY	MED	OTHER please state
Monday/Friday Clinical Team Meetings							
Care Planning/Discharge Planning Meetings							
Home Visits							
Adaptive Equipment eg rails, bath seat							
Domestic Skills							
Developing Mobility							
Toileting Programmes							
Eating Programmes							
Moving and Handling Guidelines							
Communication Skills							
Self Care Skills							
Social Skills							
Management of Behaviour							
Stabilising Of Mental State							
Management of Medication							
Management of Aggression - control and restraint							
Leisure Programmes							
Community Living Programmes							
Other (Please State)							



For the following questions please circle the number that best represents your opinion on the statements given;

(1 = Strongly Agree, 2 = Agree, 3 = Disagree, 4 = Strongly disagree)

Q8 I think each patient's multidisciplinary care plan should .....

	Agree		Disagree	
Be coordinated by the Ward Manager	1	2	3	4
Be decided by each professional individually	1	2	3	4
Be coordinated by the Consultant	1	2	3	4
Be decided by the MDT either through general agreement or majority vote	1	2	3	4
Be written down clearly in one place with everyone's treatment aims shown	1	2	3	4
Be reviewed at agreed intervals by the ward manager	1	2	3	4
Be written down separately in each professional's own case notes showing only their own aims	1	2	3	4
Be reviewed by each professional as specified in their own treatment plan	1	2	3	4
Have the effects of treatment stated in a way which can be measured at the end of the programme	1	2	3	4
Show evidence of trying to involve patients meaningfully in their healthcare	1	2	3	4
Other (please state)				
.....	1	2	3	4

Q9 Please indicate your opinion of the following;

	Agree		Disagree	
I feel we have adequate OT input to Oak/Pine	1	2	3	4
I think the OT should decide which patients get OT	1	2	3	4
I think the MDT should decide which patients get OT	1	2	3	4
I think the Consultant should decide which patients get OT	1	2	3	4
I think all Oak/Pine patients should be offered OT	1	2	3	4
I feel OT does not benefit some Oak/Pine patients	1	2	3	4
I think nurses and therapists should work together in an integrated way	1	2	3	4

	Agree		Disagree	
	1	2	3	4
I feel it is important to be as involved as possible in the total care of each patient	1	2	3	4
I do not feel I should have to carry out OT recommendations in the absence of the OT	1	2	3	4
I do not have time to carry out OT recommendations	1	2	3	4
I feel competent to carry out OT recommendations	1	2	3	4
Carrying out OT recommendations interferes with my own objectives	1	2	3	4
I do not always understand why the OT advises certain things	1	2	3	4
I do not feel able to ask the OT all the questions I would like	1	2	3	4
I do not feel at ease when working alongside the OT	1	2	3	4
I enjoy working with the OT	1	2	3	4
Therapy techniques do not encourage normalisation	1	2	3	4
Normalisation is important in the treatment of Oak/Pine patients	1	2	3	4
Sometimes it's hard to fit normalisation principles in with the needs of Oak/Pine patients	1	2	3	4
Oak/Pine patients need to be treated the same way as any other member of society	1	2	3	4

Please return to Anita Young in the envelope provided by \_\_\_\_\_

Thank You

## GOAL ATTAINMENT SCALING FACTSHEET

### Goal Attainment Scaling is:

- Based on setting a number of goals for each patient and then measuring progress on a five point scale.
- A tool for evaluating clinical input therefore offers a means of improving clinical service.
- Suitable for use with patients who have a wide variety of different needs, such as those with learning disabilities.
- Patient centred so its important that work is focused on issues that are meaningful and relevant for each individual. This avoids goals being chosen just because they may be easy to implement or achieve.
- Not linked to any one theory or treatment model so decisions about care plans and treatment are left to those directly involved in each care episode. The technique does not dictate what input is offered it is simply a set of procedures designed to evaluate change.
- About working together to achieve mutually planned outcomes so it is important that patients, carers and staff are jointly involved in choosing and describing goals wherever possible.
- A method which focuses on patient gain rather than staff competence. Although it is recognised that staff experience, skills and training will have an impact on the process, GAS is not a method of judging staff performance.

# EXAMPLE.

## DESCRIPTION OF GOAL

Staff Code . . . . . SSCX . . . . . Timescale . . . . . 3 months . . . . . Key  
 Patient Pilot No . . . . . PP43 . . . . . Date Set . . . . . 2.1.97 . . . . . I = INITIAL PERFORMANCE  
 Goal No . . . . . 1 . . . . . Date Ended . . . . . 27.3.97 . . . . . A = ATTAINED LEVEL

SCALE	DESCRIPTION	Developing Social Skill.
-2 Worst Expected Outcome	Will eat a snack in hospital dining room when supported by 2 staff.	
-1 Less Than Expected Outcome	Will eat a snack in hospital dining room when supported by 1 member of staff	I
0 Expected Outcome	Will eat a snack in a public cafe when supported by 1 member of staff	
+1 More Than Expected Outcome	Will eat a snack in a public cafe accompanied by another resident & 1 member of staff	A.
+2 Best Expected Outcome	Will eat a snack in a public cafe when accompanied by a companion.	

## MEASURING RESULTS OF GOAL ATTAINMENT SCALING

Measurement is achieved by recording initial performance and achieved outcome.

Use the Description Of Goal Form and indicate initial performance at the end of the first session by recording I on the form at the appropriate scale point.

Indicate achieved level by measuring the outcome at the end of the last session and recording A on the form at the appropriate scale point.

# GOAL ATTAINMENT SCALING PRACTICE

Dear \_\_\_\_\_

Thank you for the copy of the goal attainment scale you recently sent me.

Date set		Date ended	
----------	--	------------	--

The patient pilot number for this goal is:	
The goal number is:	

Thank you for sending me / please send me the completed Joint Goal Setting form.

I will be in touch again around the time you plan to measure the goal.

Meantime I'll give you a call to find out whether the patient goal form was accepted, or not, by your patient.

**THANK YOU VERY MUCH.**

Yours sincerely

**ANITA YOUNG**  
Head Occupational Therapist.

# MEASURING THE GOAL ATTAINMENT SCALE

Dear \_\_\_\_\_

The goal you set for patient number \_\_\_\_\_ is due to be measured soon.

Please circle the initial performance level as measured at the end of the first session (dated \_\_\_\_\_).

-2	-1	0	+1	+2
----	----	---	----	----

Please circle the attained level as measured at the end of the last session (dated \_\_\_\_\_).

-2	-1	0	+1	+2
----	----	---	----	----

If you wish to add any comments please do so in the space below.

Please return this form to me when measurement is complete.

**THANK YOU FOR YOUR HELP.**

**ANITA YOUNG**  
Head Occupational Therapist.



My Name:

My Goal:





## **GUIDELINES FOR USING THE PATIENT'S GOAL FORM**

The difficulties involved in obtaining informed views, choices and decisions from patients with learning disabilities, in relation to health planning are acknowledged. The challenge for staff is to find ways of addressing the issues.

The purpose of the patient's goal form is to provide something tangible which the patient can keep as his/her own record of agreements.

In addition it is hoped the form will act as a concrete prompt in any discussions about the treatment goal.

Please use your own judgement in deciding the type of assistance to offer patients in completing their form. For example, some may wish to write down their goal themselves and some may request that staff write it down for them. Others may elect to draw a picture of their goal.

## User Involvement In Care Planning

A modified summary of points from:

Sines D(1995) Impaired autonomy - the challenge of caring *Journal of Clinical Nursing*, 4, 109 - 115

Sines argues that modern healthcare for people with learning disabilities must begin with a basic re-examination of the nurse/client relationship and an adjustment to the balance of power that is perceived to exist between staff and client.

- Recently there has been increased public demand for professionals to develop a partnership with clients which will result in shared action plans for care.
- O'Brien's Accomplishment Framework (1987) offers a new partnership for care for clients with learning disabilities. According to O'Brien all professionals should measure the effectiveness of their interventions against five areas that enhance quality of life;
  - ◆ choice
  - ◆ relationships
  - ◆ dignity and esteem
  - ◆ participation and integration
  - ◆ competence
- New systems of negotiated care or life planning are needed to respond to O'Brien's theory. Some examples are; the individual programme planning process, care management, Shared Action Planning and the case management approach. Each of these systems depends on goal planning as a basic principle.
- Imogene King's model for nursing is also based on the principles of goal realisation. In King's theory, the joint planning and achievement of goals is essential to the process of nursing.
- Sines suggests that nurses can empower their clients using advocacy to assist them take an active role in determining their future - this will include clients making decisions about their health status and the provision of care. (Advocacy is defined as the process of acting for, or on behalf of other people who are unable to do so themselves.)
- The promotion of equal power sharing between staff and client will involve a number of practical considerations, one of which is the calculation of risk, and the endorsing of actions chosen by clients themselves, (which may not always be supported by professional carers).
- Sines states that attitudinal change is seen as the greatest challenge facing the nursing profession today. He views investment in change as a way of achieving a more enlightened and equitable partnership for all.

# JOINT GOAL SETTING

---

1 Staff Code \_\_\_\_\_

2 Patient Pilot Number \_\_\_\_\_

For Question 3, 4 and 5 please circle as appropriate.

3 When choosing and describing goals was there;

a) Patient Involvement Yes/No (if no go to Q4)

b) If YES how much  
 Once  
 Up to 3 occasions  
 4 or more occasions

c) Regarding the goals did you find patient involvement useful/not useful.  
 (please indicate on the scale below)

Useful	Not Useful

4 When choosing and describing goals was there;

a) Carer involvement Yes/No (if no go to Q5)

b) If YES how much  
 Once  
 Up to 3 occasions  
 4 or more occasions

c) Regarding the goals did you find carer involvement useful/not useful.  
 (please indicate on the scale below)

Useful	Not Useful

5 When choosing and describing goals was there;

a) Involvement of staff colleagues Yes/No (if no stop here)

b) If YES circle who was involved (please circle as many as apply)

Nurse / Doctor / Therapist / Psychologist / Social Worker

c) How much involvement  
 Once  
 Up to 3 occasions  
 4 or more occasions

d) Regarding the goals did you find involvement of colleagues useful/not useful.  
 (please indicate on the scale below)

Useful	Not Useful

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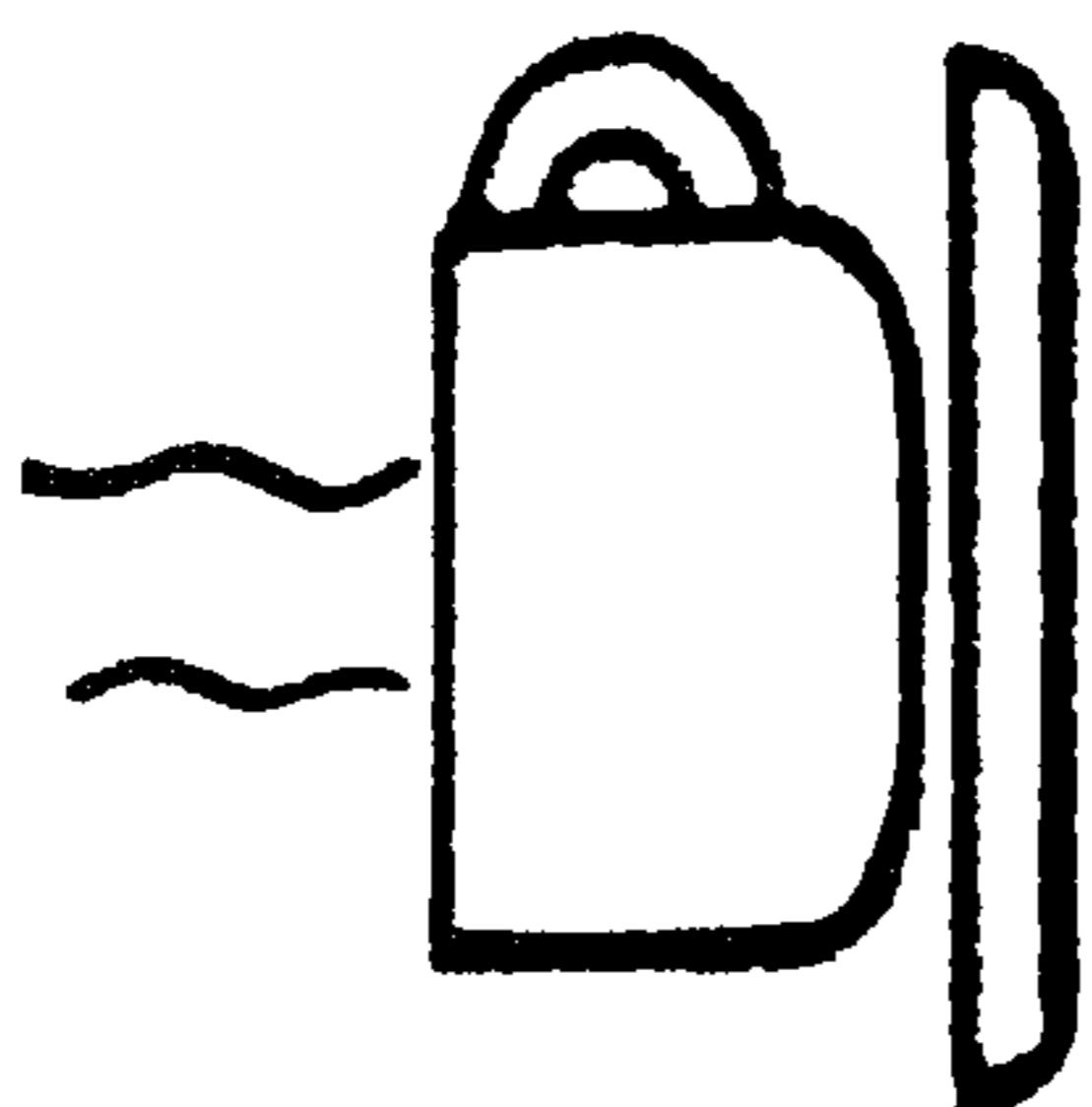
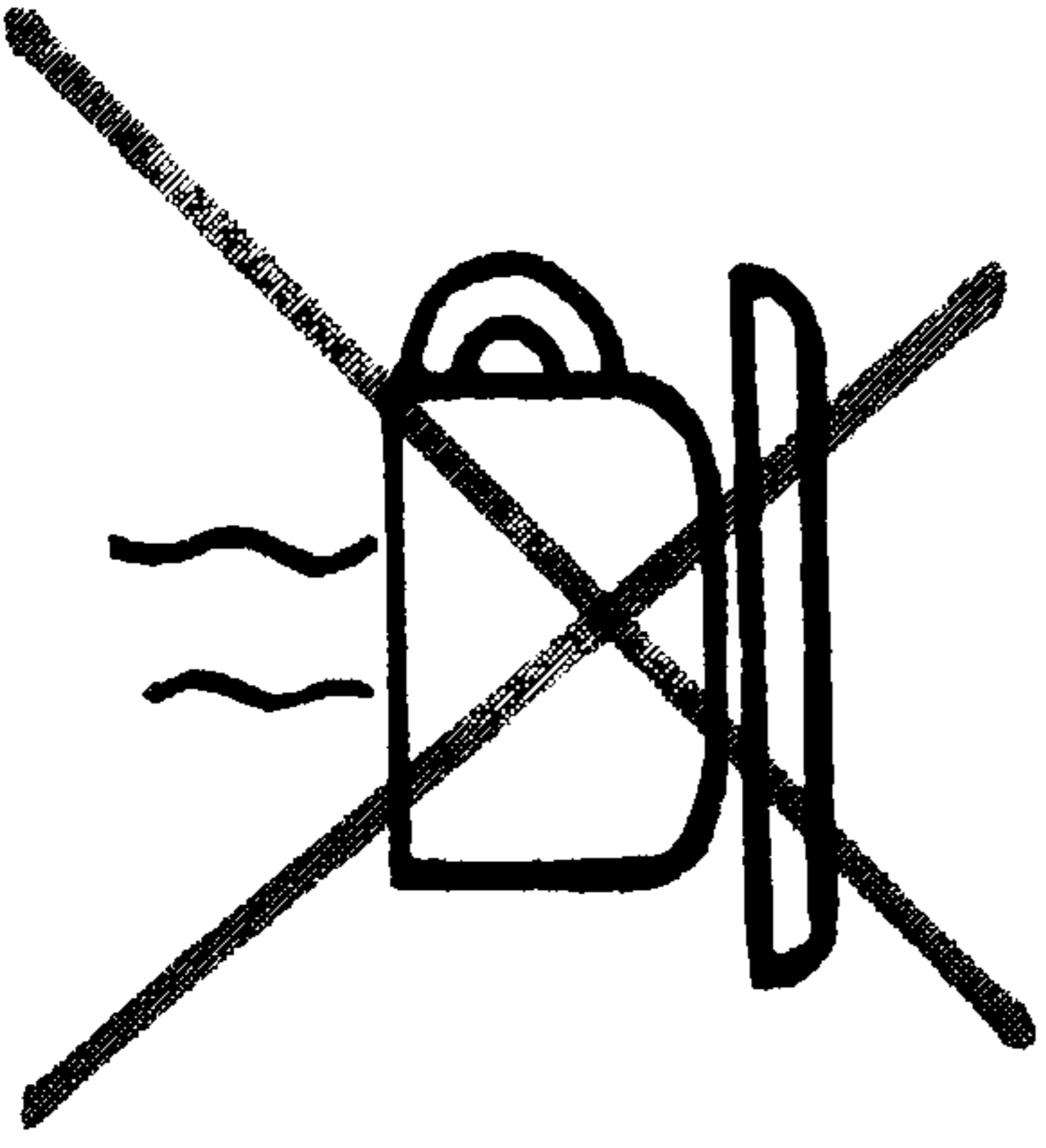
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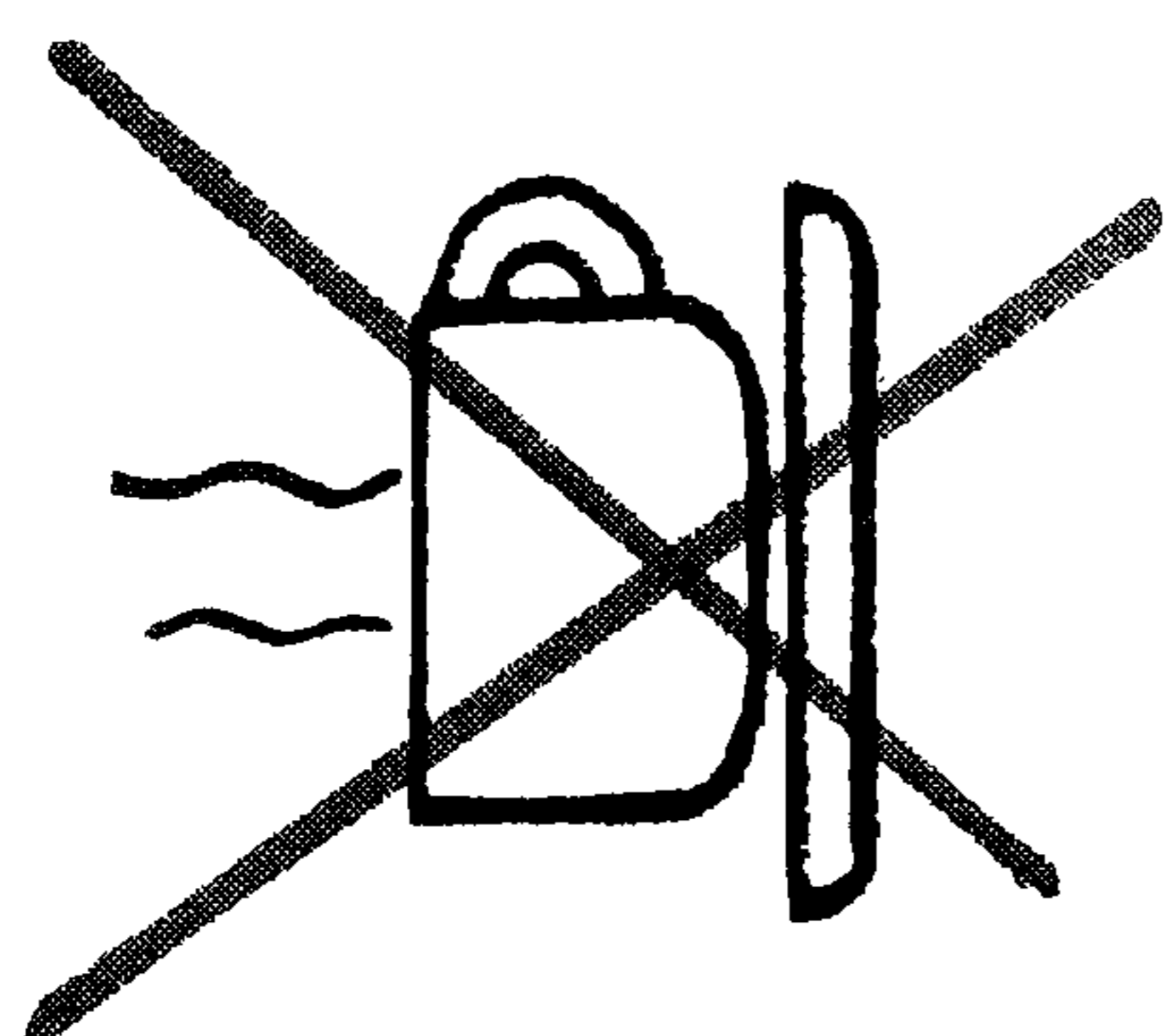
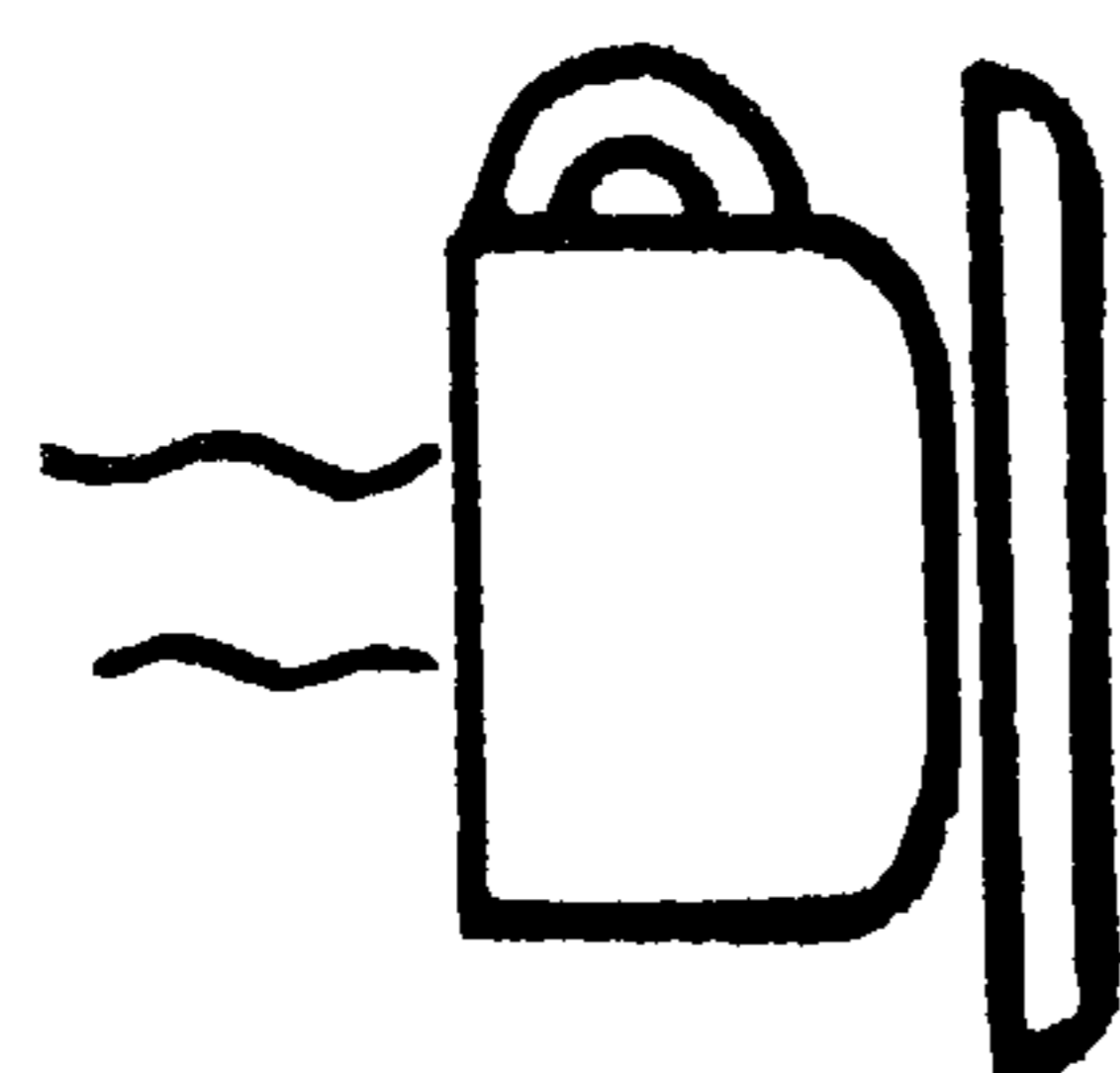
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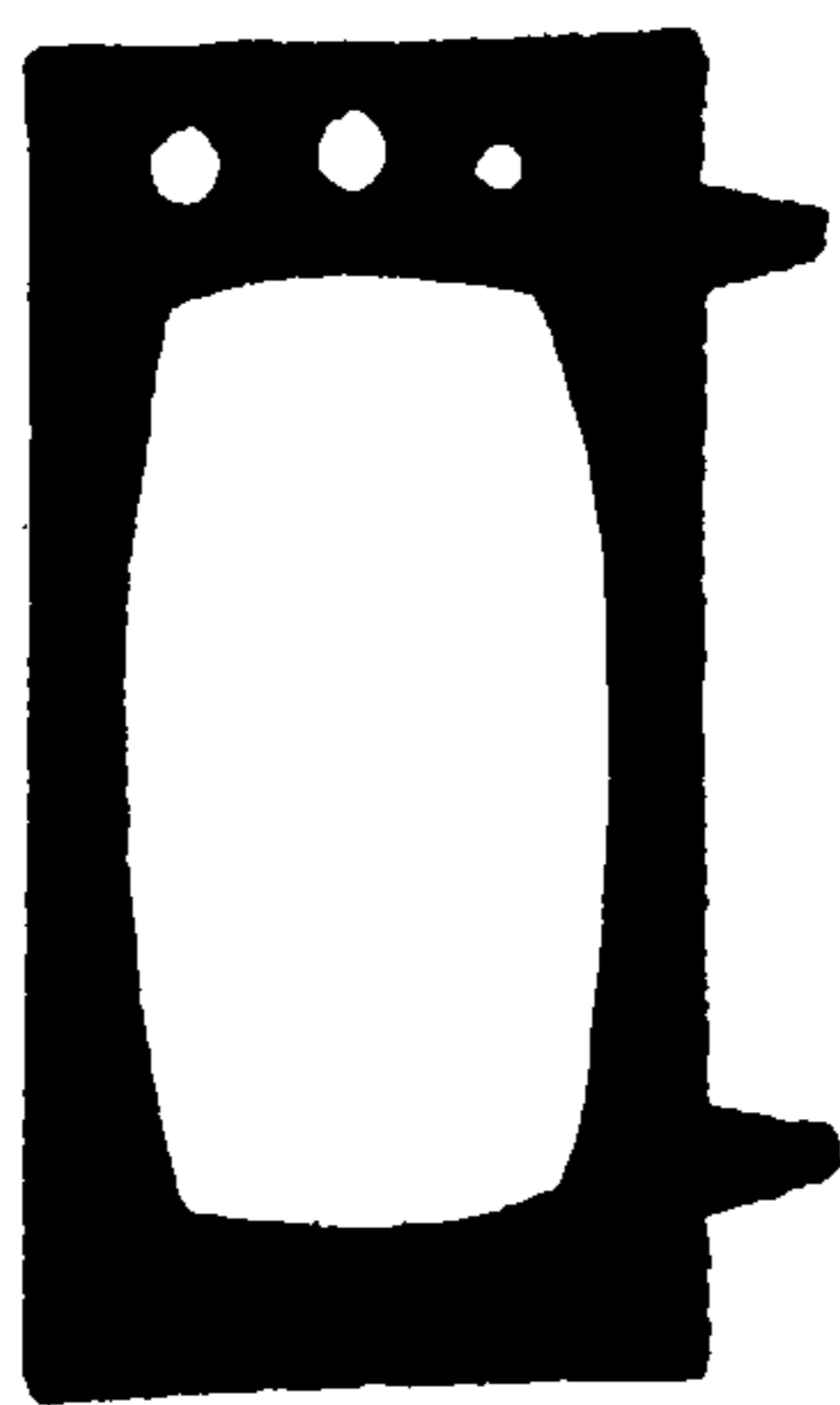
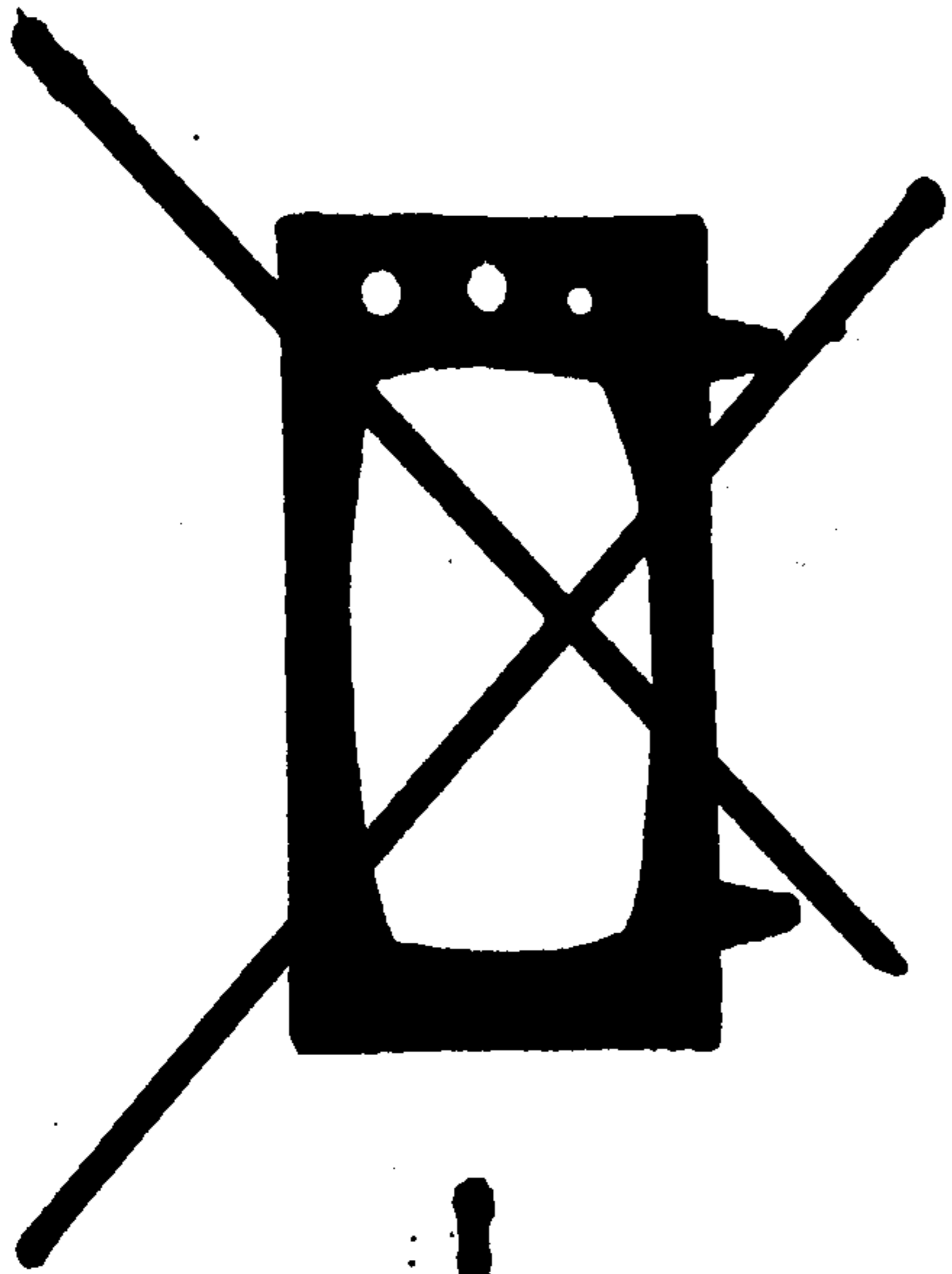
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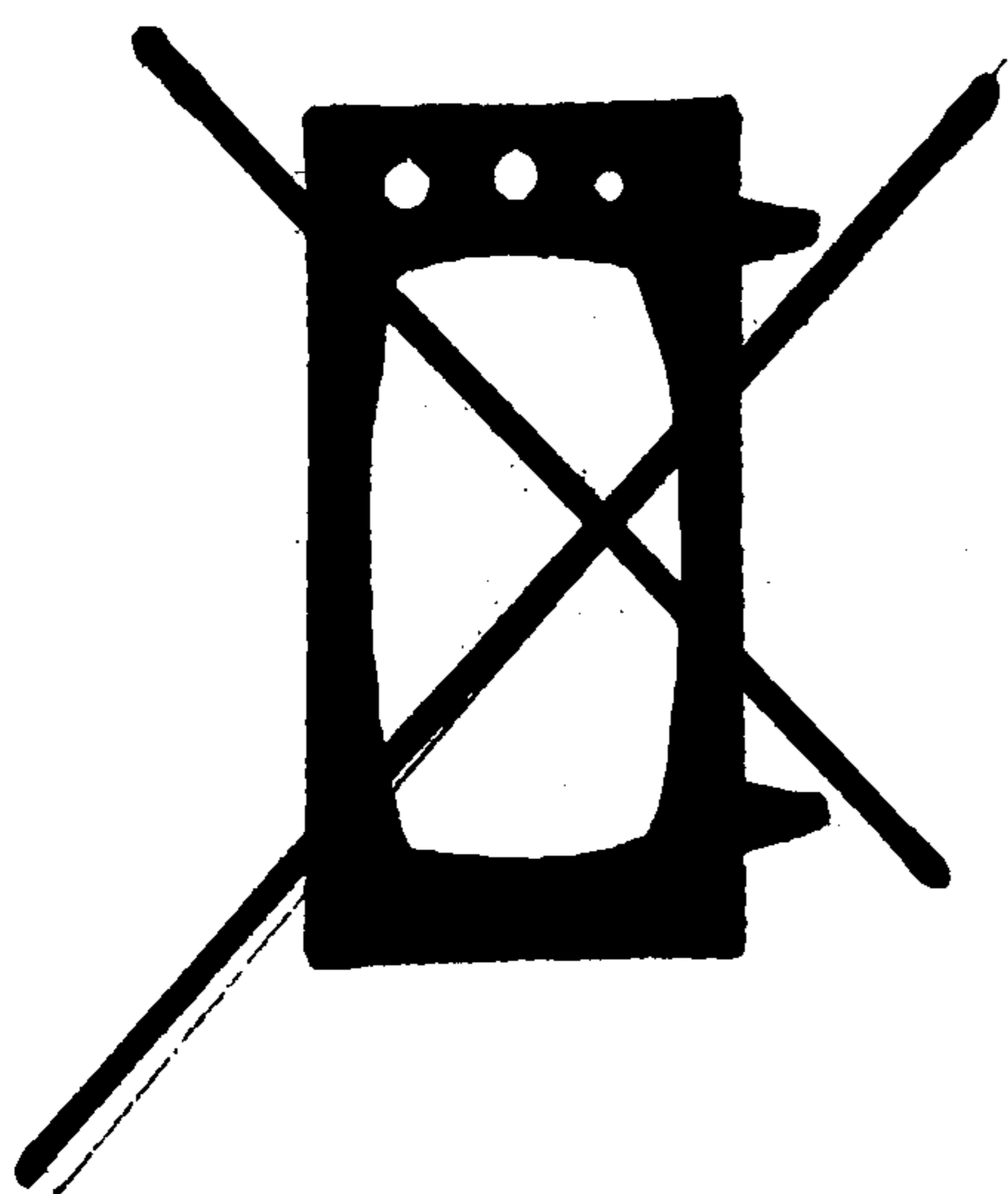
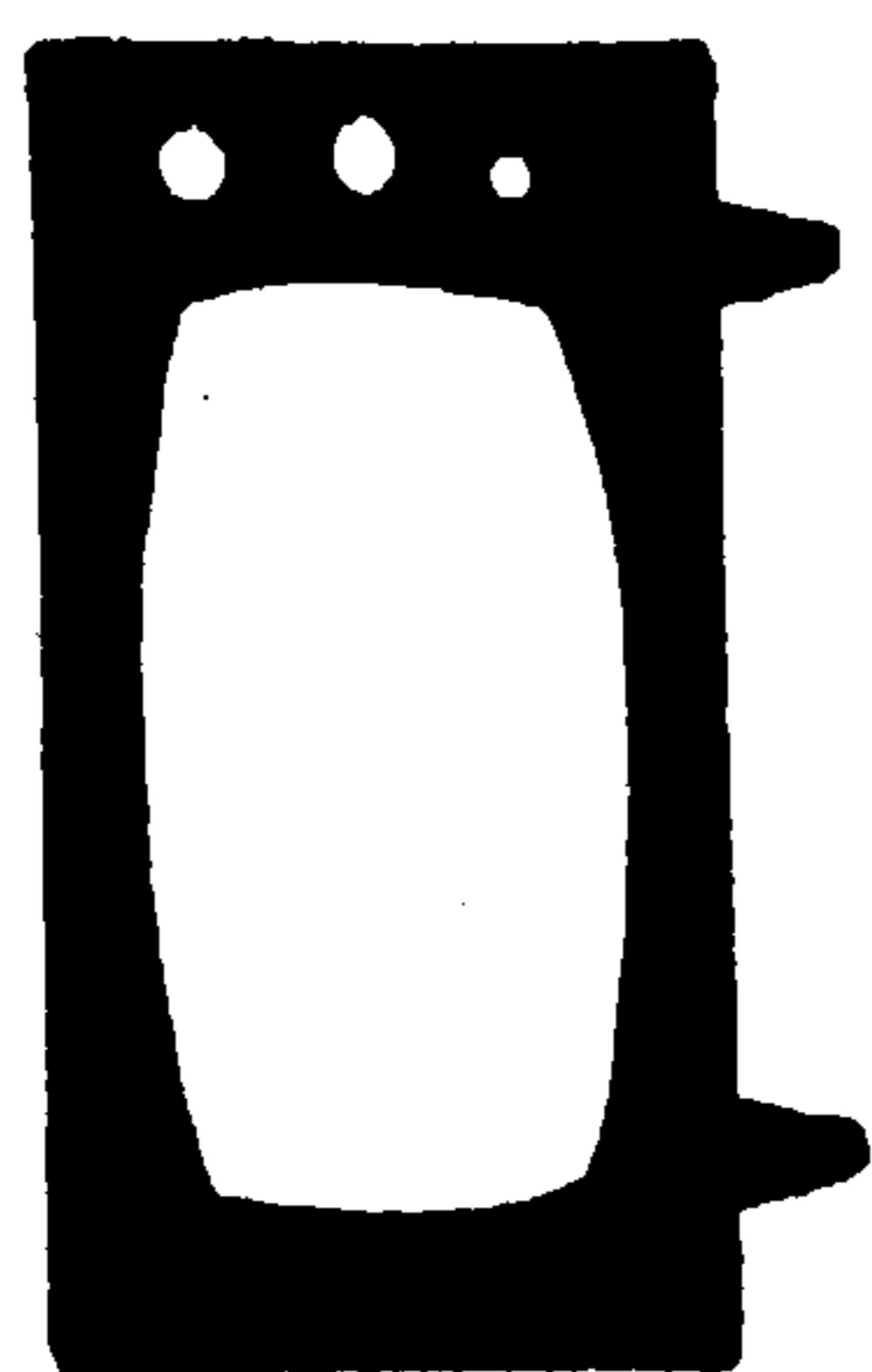
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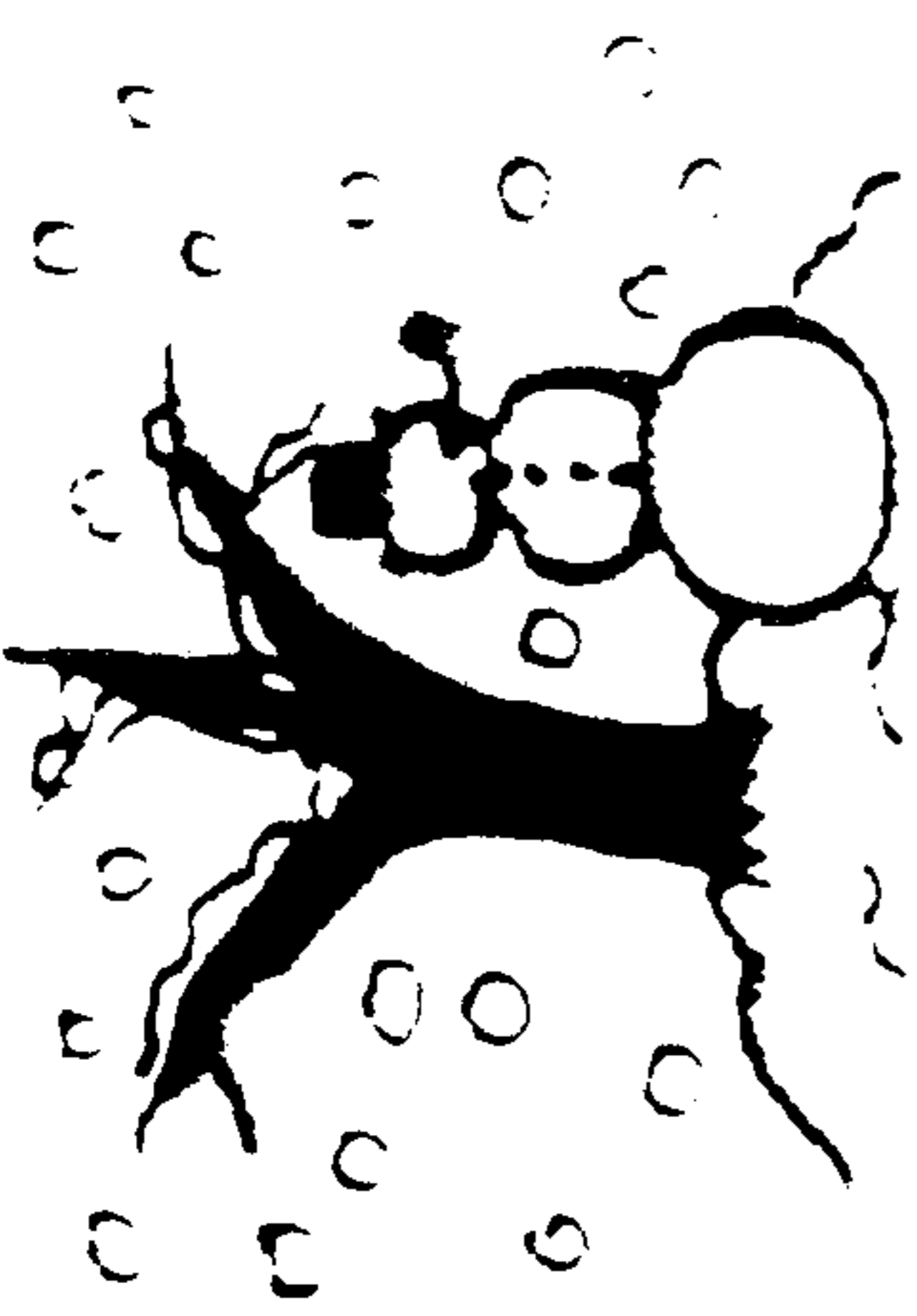
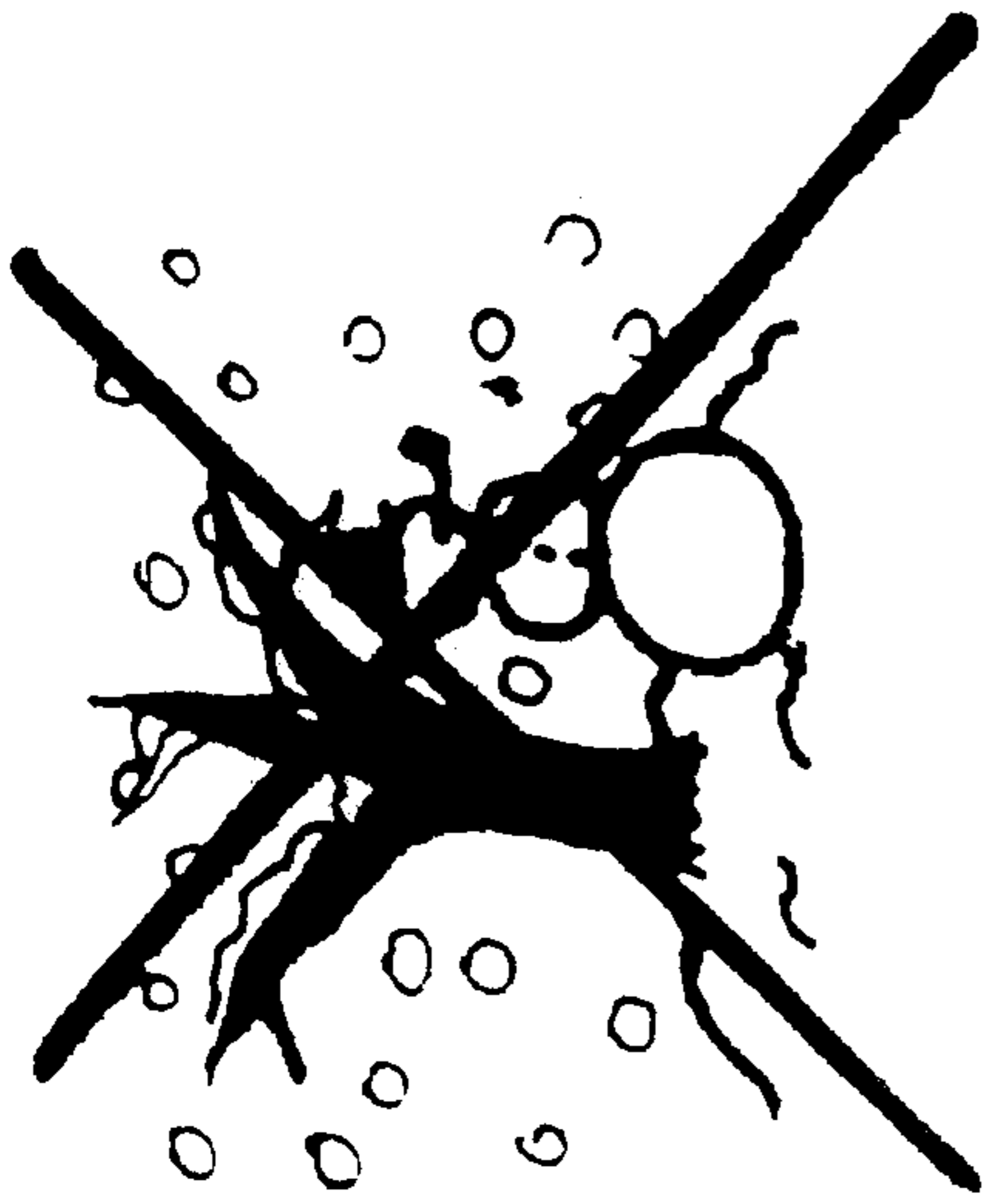


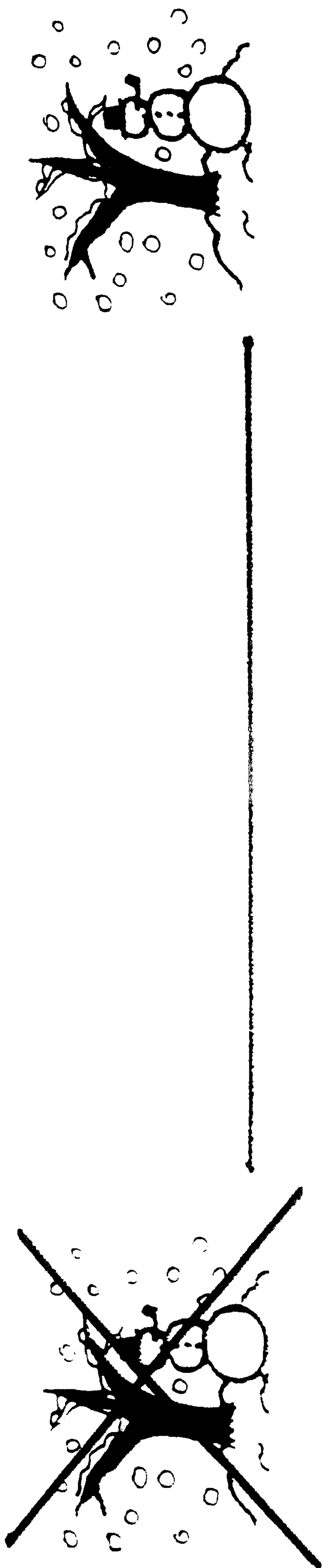


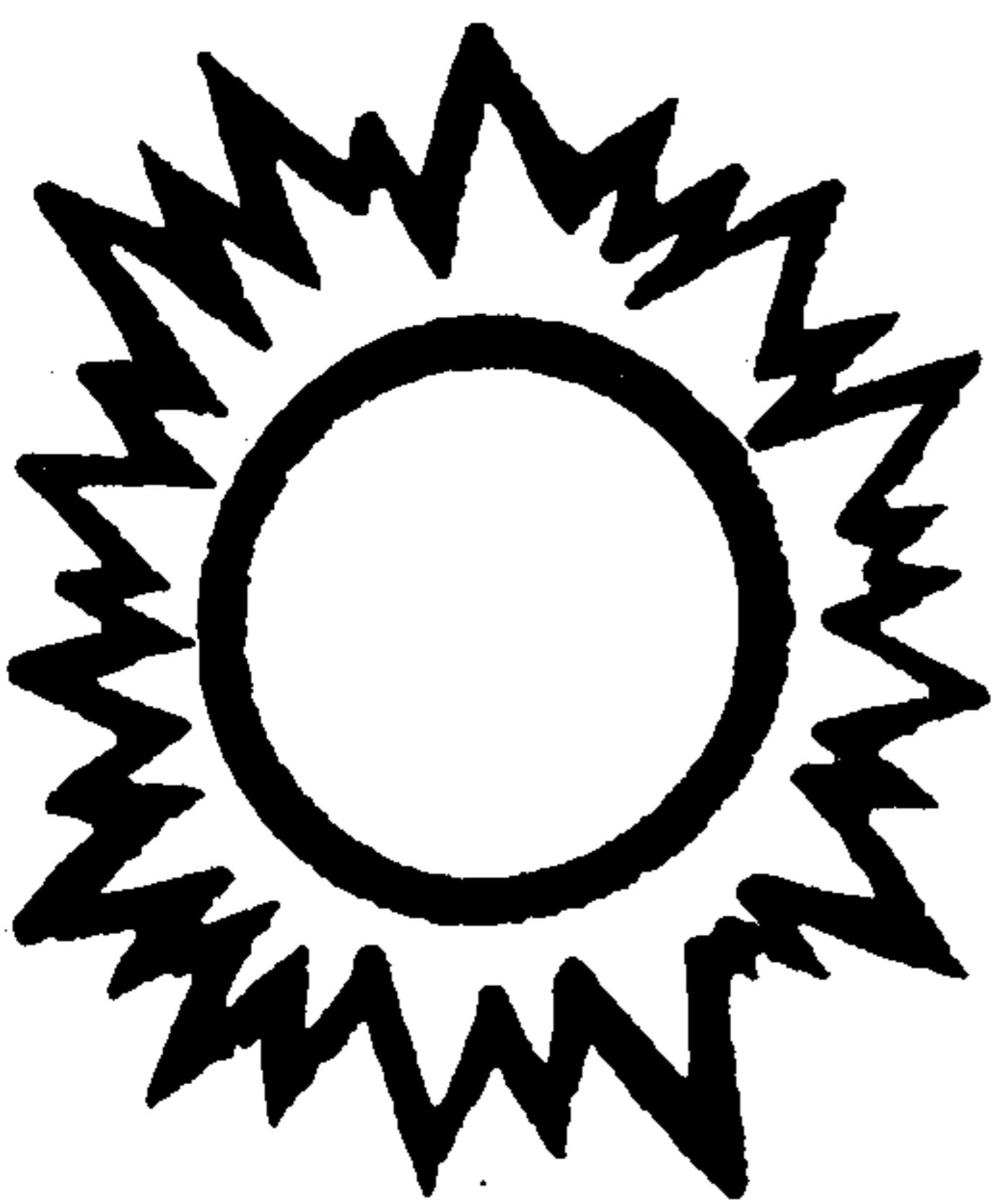
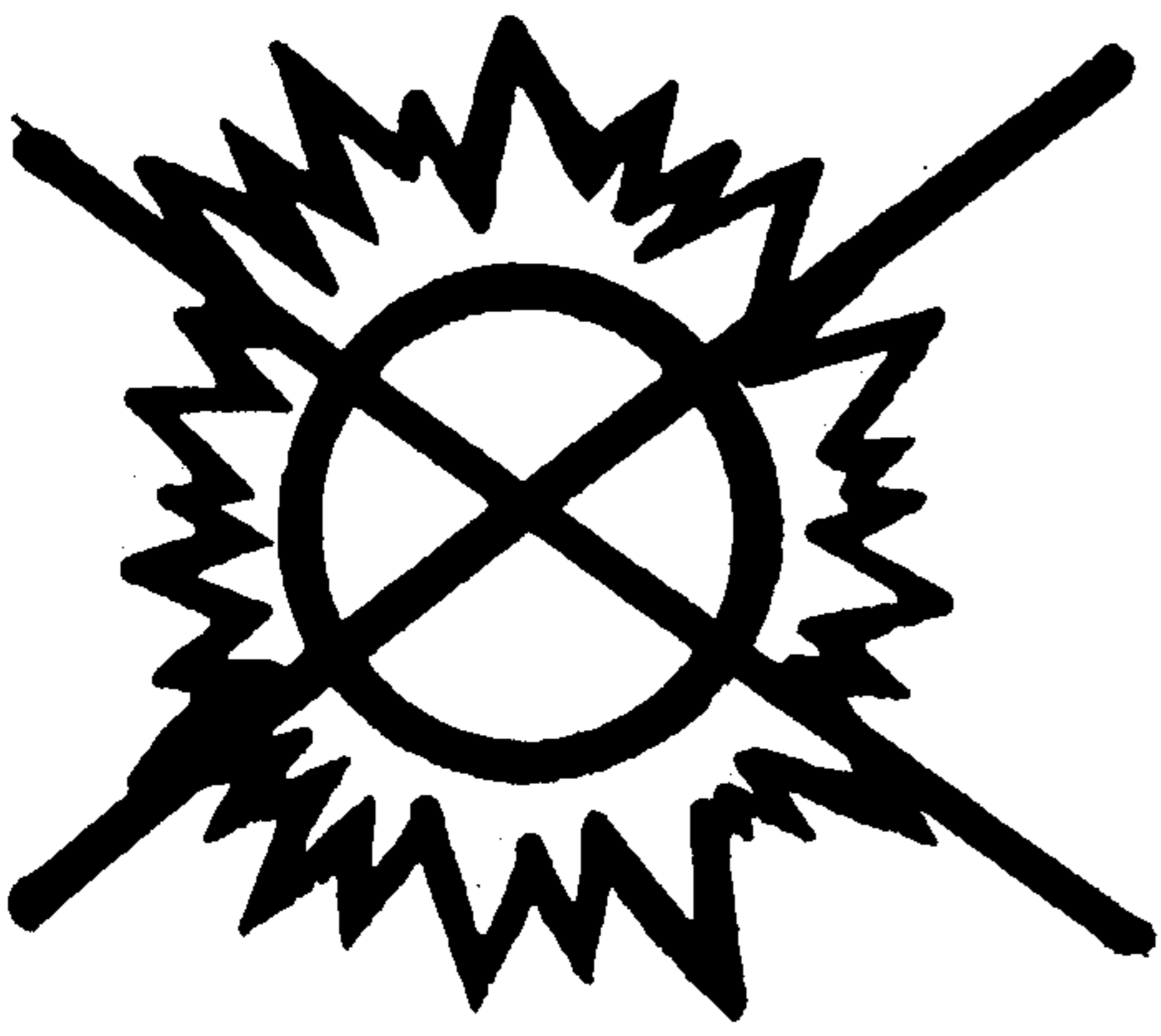


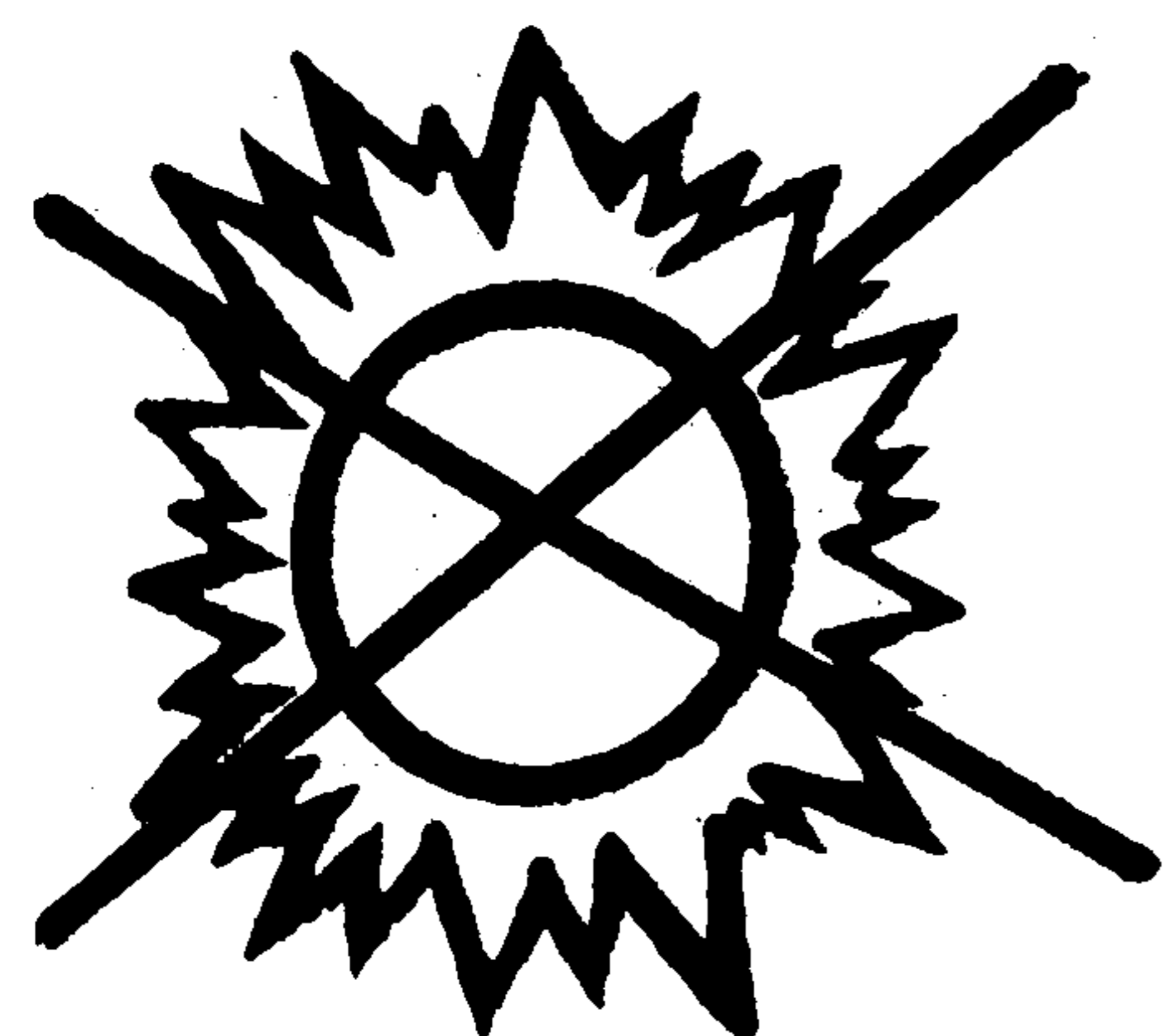
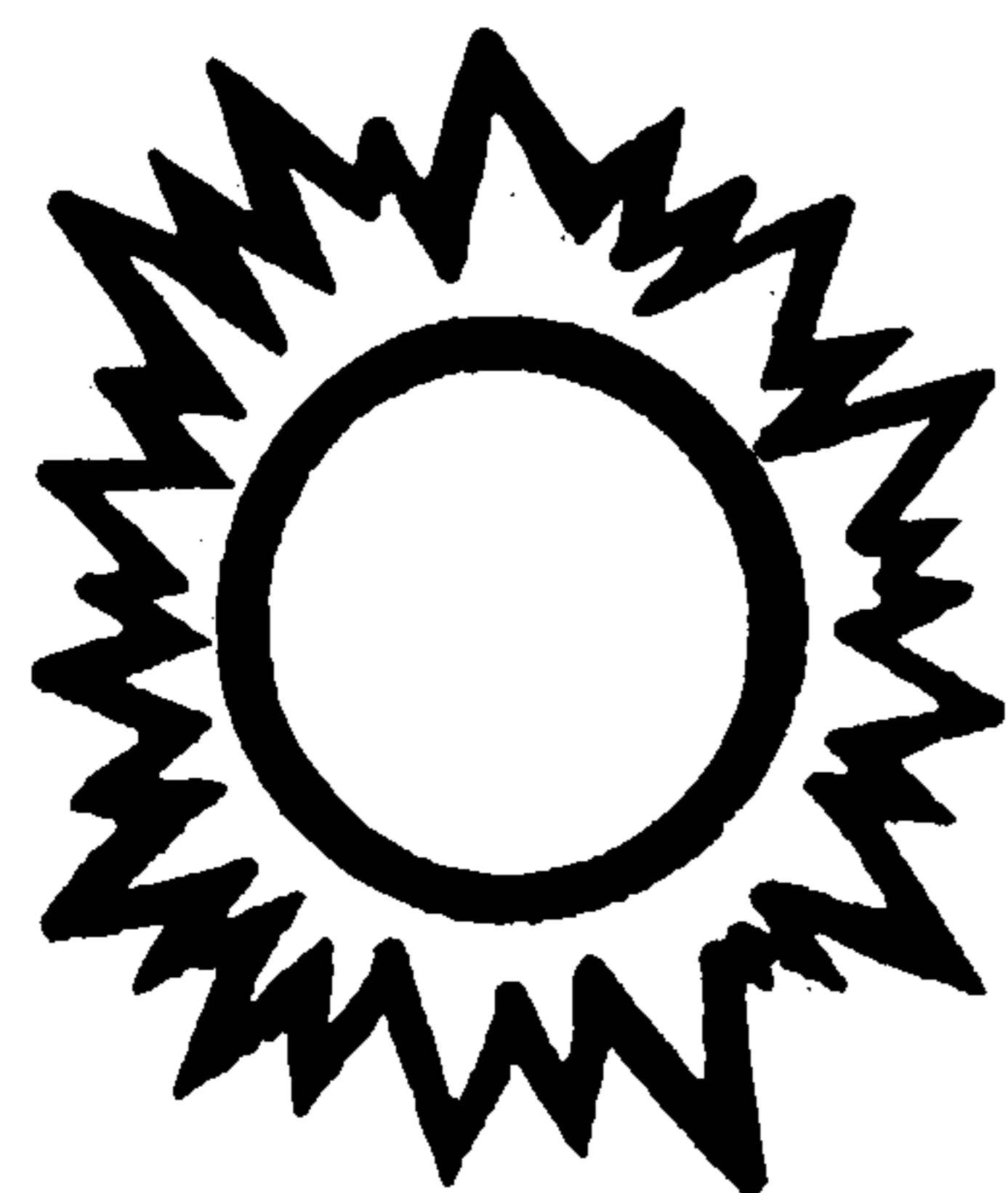


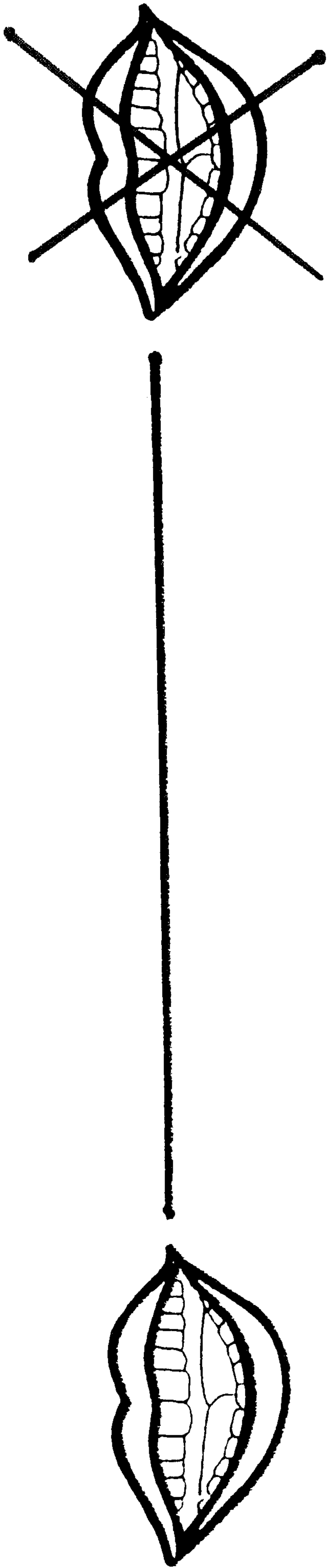


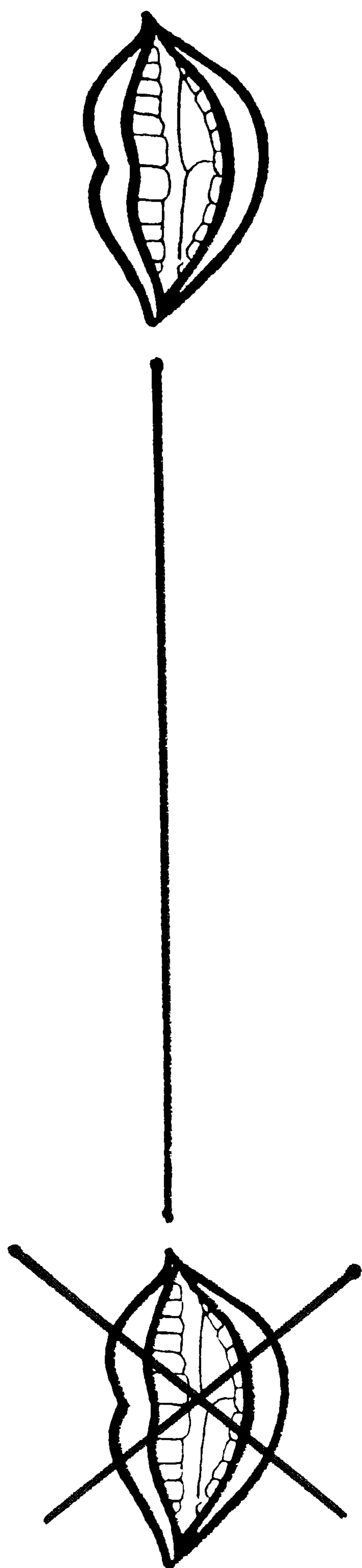


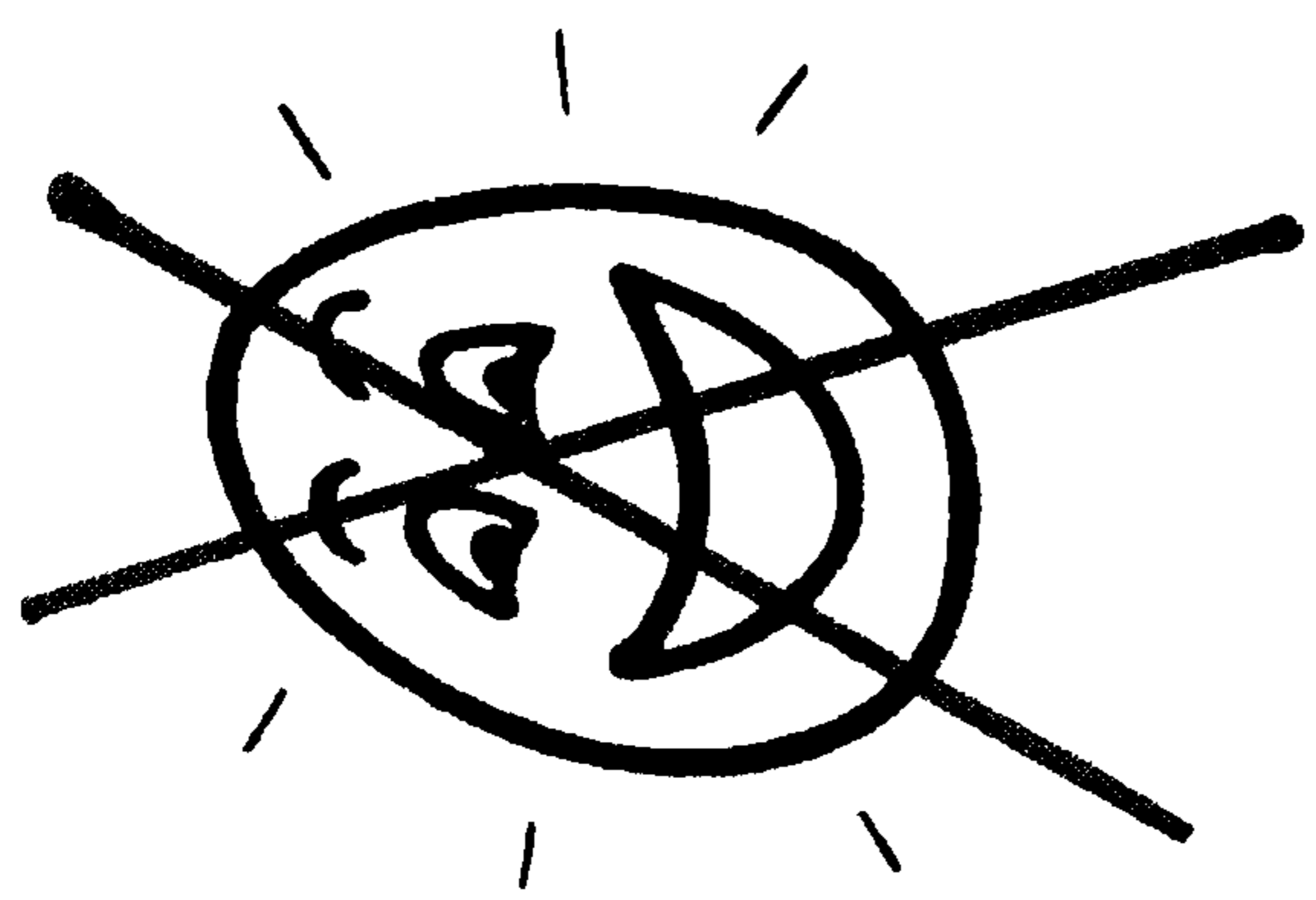


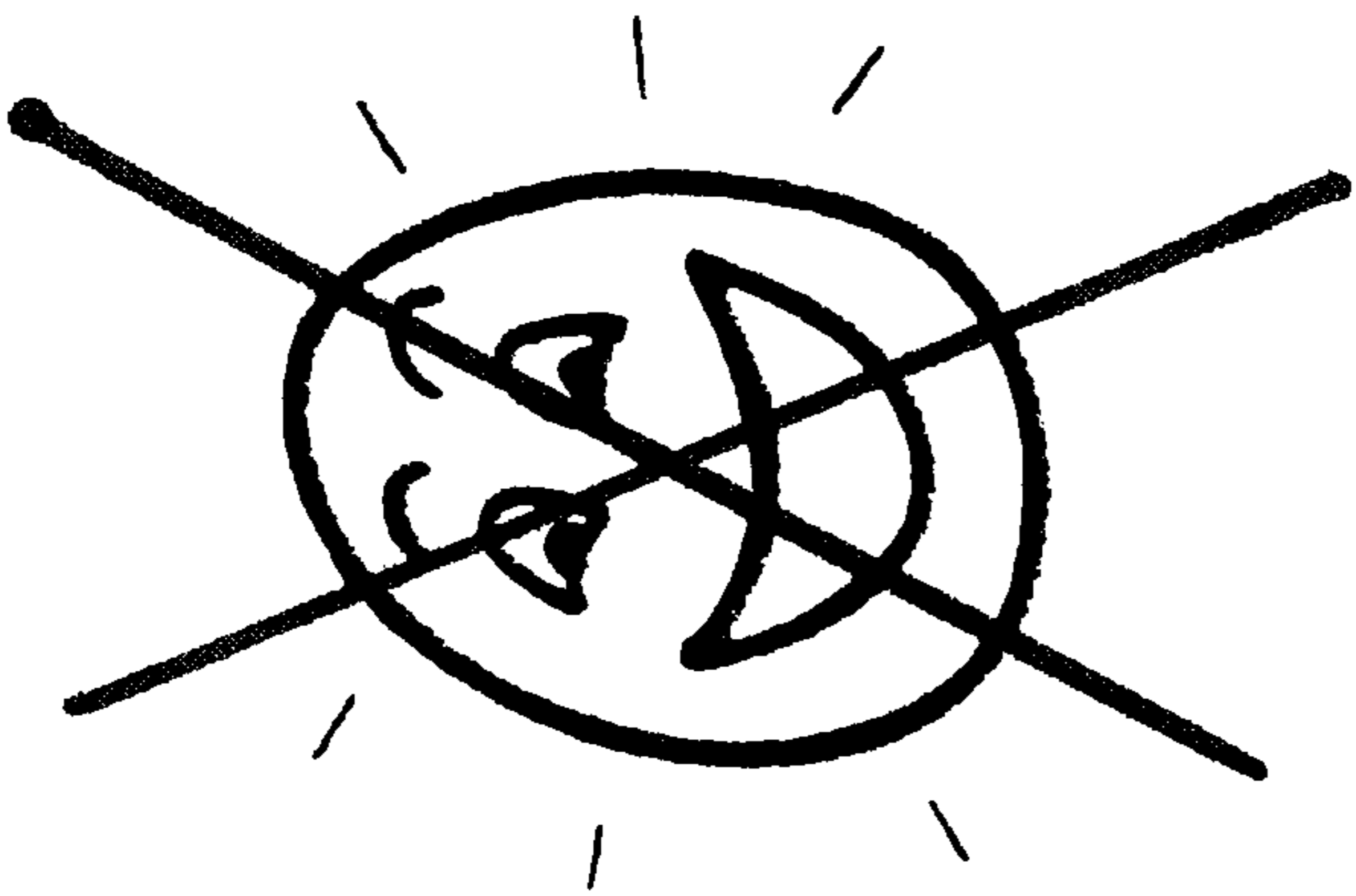
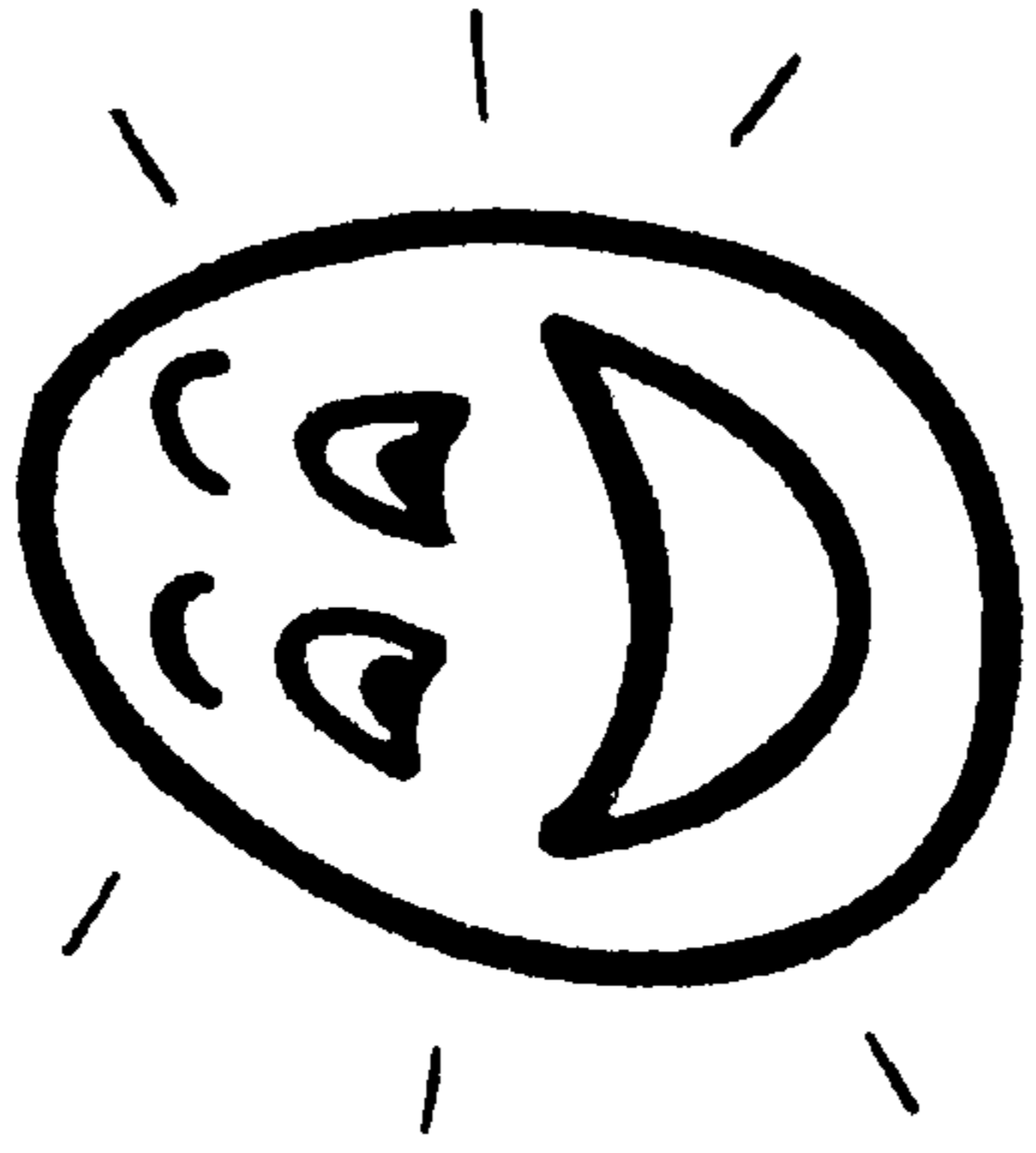




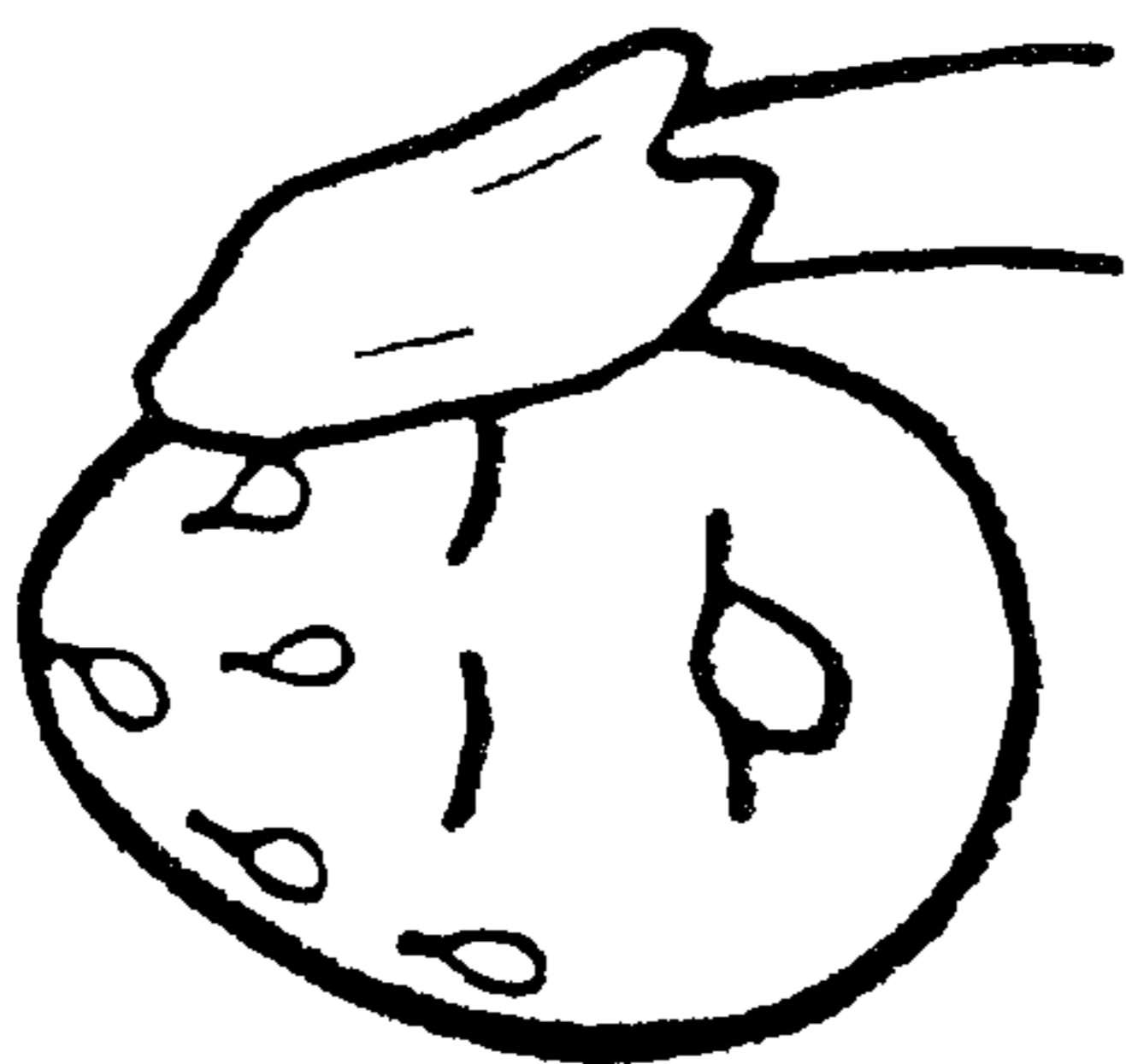


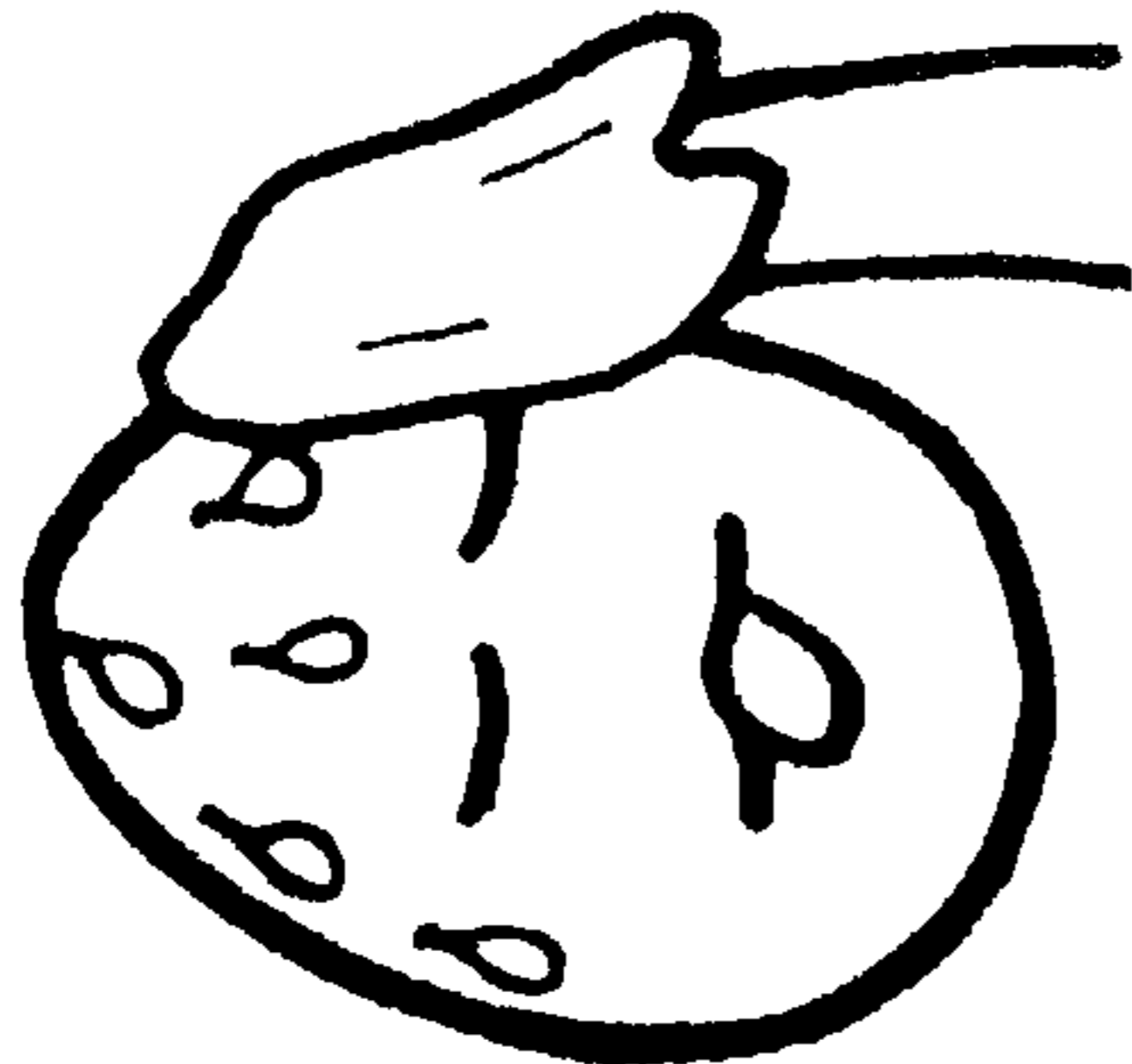












**CONSENT FORM**

Name Of Patient .....

I have read, or listened to the "Therapy Project" information sheet, and I have had a chance to talk to Anita Young about it. I am willing to talk to her, and for our talk to be recorded. I understand I can stop the meeting whenever I want to and that I will still have my therapy as usual.

Signed .....

Agreed verbally or by gesture .....

Agreement/signature witnessed by  
.....

Designation .....

Additional information:  
.....  
.....  
.....  
.....  
.....

## PATIENT INFORMATION SHEET

### THERAPY PROJECT

Anita Young is an Occupational Therapist who works at Woodlands Hospital. She wants to find out what people in Oak and Pine think about the therapy they get. She would like to talk to some people about this and to tape what they say. What she is told may help in the planning of health services for people in Oak and Pine. Those who talk to her will not be named in any reports. Those who decide they don't want to talk will still have their therapy as usual.

Anita Young, Occupational Therapist

Tel: 01224-663131 ext 51538

**SEMI STRUCTURED INTERVIEW WITH OAK/PINE  
STAFF POST GAS TRIAL**

1 I'd like to start off by asking, How do YOU tell if you think your treatment approach is working?

2 Some people think that Outcome measurement is too difficult and that it gets in the way of patient care.

Do you agree/disagree with any of that?

**SEMI STRUCTURED INTERVIEW WITH OAK/PINE  
STAFF POST GAS TRIAL**

- 3 Do you think that the GAS approach is consistent with the way you were trained to go about your work, or does the concept cause you any problems?

Ask to expand on similarities/differences.

- 4 Did you actually manage to use GAS at all over the past few months?

if YES

if NO

Did you use it on your own/  
or part of the clinical team?

What were the main  
factors in not Using it?

\* only for those who used GAS

**SEMI STRUCTURED INTERVIEW WITH OAK/PINE  
STAFF POST GAS TRIAL**

\* 5 What did you think of GAS as a tool for using within routine practice?

eg did it affect:           relationships with patients  
                                  evaluation of input  
                                  treatment effectiveness  
                                  other?

Would you use it again?

\* 6 Did you find that using GAS had any effect on communication within the clinical team?





**SEMI STRUCTURED INTERVIEW WITH OAK/PINE  
STAFF POST GAS TRIAL**

- 9 Presently there is much emphasis on “the partnership approach” within the health service. What are your thoughts on having more involvement of patients/families/carers in the healthcare process, eg in relation to where it may be appropriate/inappropriate.
- What are the barriers?
  - What are the drawbacks?
  - What are the advantages?
- 10 In the future if there was a government directive which said outcome measurements must be used in the health service, what would you like to see being used in Pine/Oak?

**SEMI STRUCTURED INTERVIEW WITH OAK/PINE  
STAFF POST GAS TRIAL**

- 11 On balance, do you support or reject outcome measurement.

## SEMI STRUCTURED INTERVIEW WITH COMMISSIONERS/MANAGERS

---

(Short background introduction will be given re Oak/Pine)

1 Presently in our society there is much emphasis on quantifying work efficiency and work effectiveness (eg management by objectives).

What techniques have you used to try to evaluate the services

– delivered by your workforce?

– Commissioned by you?

How effective did you feel that they were?

How did evaluation influence subsequent policy/commissioning?

## SEMI STRUCTURED INTERVIEW WITH COMMISSIONERS/MANAGERS

---

- 2     There is growing awareness of outcome measurement within the health service. What are your views on outcome measures and their role in the NHS?  
If you have used specific techniques, how accurate did you think the measures were?

Did some measures work better in particular areas?

How consistent were different methods?

- 3     Some people think that outcome measurement is too difficult and that it gets in the way of patient care.

Do you agree/disagree with any of that?

## SEMI STRUCTURED INTERVIEW WITH COMMISSIONERS/MANAGERS

---

- 4 Currently we hear a lot about “the partnership approach” within health services. Does your service take any steps to involve users at present?
- What methods
  - How effective are they
  - Are there areas where you feel user involvement is particularly appropriate/inappropriate?



**SEMI STRUCTURED INTERVIEW WITH  
COMMISSIONERS/MANAGERS**

---

- 7 What kinds of service do you think patients want and need from the health teams in Oak/Pine?

Why do you think this?

- 8 Do you think families/carers should receive support from Oak/Pine Teams or is this the responsibility of Social Work?

Why do you think this?

## SEMI STRUCTURED INTERVIEW WITH COMMISSIONERS/MANAGERS

---

- 9 What type of health outcomes do you consider appropriate for patients in Oak/Pine?

Explore thoughts on standardised/individualised measures.

(Link to GAS) - ? acceptance of individualised methodology and quant/qual data.

- 10 Do you think the different stakeholders may have different priorities in relation to outcomes agendas? Eg throughput v/s “care”.



**SEMI STRUCTURED INTERVIEW WITH  
COMMISSIONERS/MANAGERS**

---

11 In the event of differences, do you think any one of these stakeholders' agendas might take priority?

12 In the future if there was a government directive that OM must be used in the health service, what would you like to see being introduced in learning disabilities?

## GOAL ATTAINMENT SCALING

- Is an individualised criterion referenced measure similar to a behavioural objective, but which specifies five possible levels of outcome rather than just one (achieved/not achieved).

### Advantages

- Flexible enough to cope with heterogeneous populations.
- Useful for measuring low or difficult to discern levels of change/achievement.
- Can be applied when conventional methods of measurement using standardised tools are ineffective or can't be tolerated.
- Ideally suited to measuring degree of change in outcome.
- Is inclusive of the user's perspective.

### Disadvantages

- Open to therapist bias.
- NOT a standardised measure therefore no information is given on absolute levels of functioning.
- Cannot be used to compare measurements over time, or to compare groups of individuals or programmes at a single point.

### Research Study Base

Pine Admission Unit provides multidisciplinary in-patient assessment and treatment for up to 12 community based adults who in addition to having learning disabilities, are suspected of having psychiatric illness (Pine Admission Unit Operational Policy). Users exhibit a range of mental health problems, for example schizophrenia, depression, anxiety, phobia.

Oak Challenging Behaviour Unit provides multidisciplinary in-patient assessment and treatment for up to 12 adults who normally live in the community and who in addition to having learning disabilities, present challenging behaviours which are not thought to indicate underlying psychiatric illness (Oak House Operational Policy). Challenging Behaviour refers to “behaviour of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or delay access to or use of ordinary community facilities.” (Emerson et al 1987).

Each multidisciplinary team comprises:

Consultant Psychiatrists (3)*	Occupational Therapist
Clinical Psychologist*	Speech and Language Therapist*
Clinical Psychology Assistant	Social Worker*
Qualified Nurses (8)	Physiotherapist *
Unqualified Nurses (8)	Dietician*

\*Denotes Part-time input.

CONFIDENTIAL

<b>OUTCOME MEASUREMENT: CARE PROVISION FOR PEOPLE WITH LEARNING DISABILITIES</b>
--

*Please answer all questions*

**Q1. Currently much emphasis is placed on quantifying work efficiency and the effectiveness of care. Does your organisation use any of the following methods to try to evaluate services for people with learning disabilities?  
Please tick as many as apply [ ✓ ]**

- |  |     |
|--|-----|
| Activity based measures, eg bed occupancy                    | [ ] |
| Eliciting the client/carer view of progress                  | [ ] |
| National initiatives, eg best value                          | [ ] |
| "Quality" measures, eg quality service network review        | [ ] |
| Statutory registration and inspection                        | [ ] |
| Staff appraisal/staff supervision systems                    | [ ] |
| Long term evaluation of care plans/progress records by staff | [ ] |
| Health improvement measures, eg clinical audit               | [ ] |
| Formal review of service projects                            | [ ] |
| Other (please specify)                                       | [ ] |

**(b) In relation to the above are you aware of particular evaluation methods resulting in changes to practice or policy? Yes/No (please circle)**

If Yes please give details.

**Q2. There is growing awareness of outcome measurement within the health service. In your service have you used specific outcome measures for people with learning disabilities?**

Yes/No (please circle)

If Yes please list below measures used:

(please turn over)

**Q3. Please indicate your view in relation to the following statements (please circle)**

Outcome measurement is too difficult Agree / Disagree / Don't know

Outcome measurement takes up too much time Agree / Disagree / Don't know

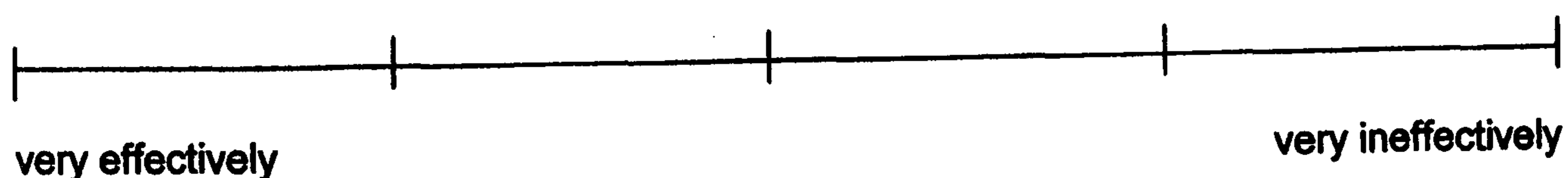
Outcome measurement gets in the way of care to the detriment of the service user Agree / Disagree / Don't know

**Q4. Currently there is much emphasis on partnership within care services. Does your service take any steps to involve users at present? Yes/No (please circle)**

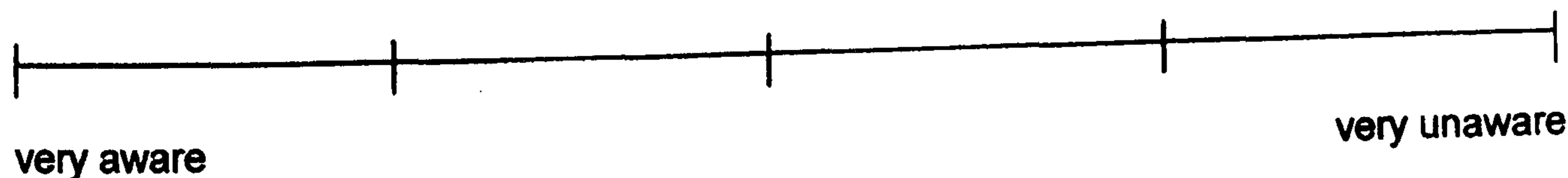
**If Yes**

(a) What has been done?

(b) On the scale below please indicate by a cross how you think your service involves users.



**Q5. In your opinion to what extent are front-line staff eg nurses, care workers, aware of what managers and commissioners expect of them regarding user outcomes? (Please indicate on scale by cross).**



**Q6. Of the methods listed below for measuring health outcomes please rank the appropriateness of each one, for people with learning disabilities, using a 1-5 scale. (1=not appropriate 5=very appropriate) Please circle.**

Standardised methods	1	2	3	4	5
User satisfaction surveys	1	2	3	4	5
Individualised methods	1	2	3	4	5
Hospital admission/discharge rates	1	2	3	4	5
Setting and reviewing goals with users	1	2	3	4	5
Other (please state)	1	2	3	4	5

**Q7. If there was an NHS/local authority directive that outcome measurement must be used, what you would like to see introduced within learning disabilities, and if possible give reasons for your answer.**

**Thank You for your help**

CONFIDENTIAL

<b>OUTCOME MEASUREMENT: CARE PROVISION FOR PEOPLE WITH LEARNING DISABILITIES</b>
--

*Please answer all questions*

**Q1. Currently much emphasis is placed on quantifying work efficiency and the effectiveness of care. Have you observed healthcare organisations eg Trusts, using any of the following methods to try to evaluate their services for people with learning disabilities?**

**Please tick as many as apply [ ✓ ]**

Activity based measures, eg bed occupancy	[ ]
Eliciting the client/carer view of progress	[ ]
National initiatives, eg best value	[ ]
"Quality" measures, eg quality service network review	[ ]
Statutory registration and inspection	[ ]
Staff appraisal/staff supervision systems	[ ]
Long term evaluation of care plans/progress records by staff	[ ]
Health improvement measures, eg clinical audit	[ ]
Formal review of service projects	[ ]
Other (please specify)	[ ]

**(b) In relation to the above are you aware of particular evaluation methods resulting in healthcare providers changing their practice and policy? Yes/No (please circle)**

If Yes please give details.

**Q2. There is growing awareness of outcome measurement within the health service. Have you observed healthcare providers using specific outcome measures for people with learning disabilities?**

Yes/No (please circle)

If Yes please list below measures used:

(please turn over)

**Q3. Please indicate your view in relation to the following statements (please circle)**

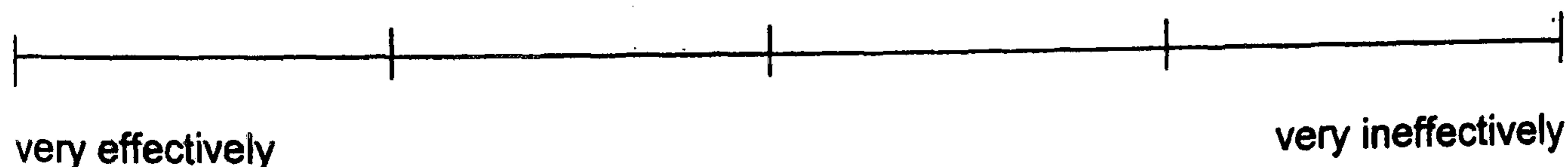
- |  |                               |
|--|-------------------------------|
| Outcome measurement is too difficult   | Agree / Disagree / Don't know |
| Outcome measurement takes up too much time                                       | Agree / Disagree / Don't know |
| Outcome measurement gets in the way of care to the detriment of the service user | Agree / Disagree / Don't know |

**Q4. Currently there is much emphasis on partnership within care services. Does your service take any steps to involve users with learning disabilities in communicating their views of healthcare provision. Yes/No (please circle)**

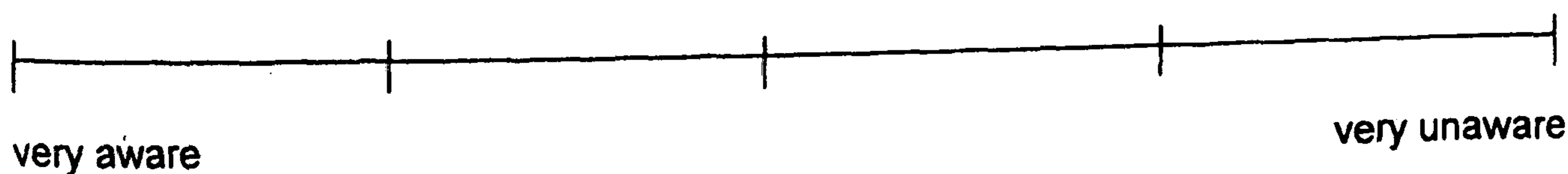
**If Yes**

(a) What has been done?

(b) On the scale below please indicate by a cross how you think your service involves users.



**Q5. In your opinion to what extent are front-line staff eg nurses, care workers, aware of the potential for involving users in developing care outcomes? (Please indicate on scale by cross).**





**Q6. Of the methods listed below for measuring health outcomes please rank the appropriateness of each one, for people with learning disabilities, using a 1-5 scale. (1=not appropriate 5=very appropriate) Please circle.**

Standardised methods	1	2	3	4	5
User satisfaction surveys	1	2	3	4	5
Individualised methods	1	2	3	4	5
Hospital admission/discharge rates	1	2	3	4	5
Setting and reviewing goals with users	1	2	3	4	5
Other (please state)	1	2	3	4	5

**Q7. If there was an NHS/local authority directive that outcome measurement must be used, what you would like to see introduced within learning disabilities, and if possible give reasons for your answer.**

**Thank You for your help**

**Perception Of The Occupational Therapist Role in Oak /Pine**

n=39

<b>The Occupational Therapist's Role is</b>	<b>Strongly Agree</b>	<b>Agree</b>	<b>Disagree</b>	<b>Strongly Disagree</b>	
To help patients develop self care skills eg dressing/bathing/eating	15	21	1	2	
To advise on coping strategies, eg using a raised toilet seat for independent toileting	20	14	5	0	
To provide activities to occupy patients	6	22	10	1	
To help patients develop domestic skills eg cookery/laundry	21	14	3	1	
To make tasks achievable by teaching different ways of doing things	20	17	2	0	
To help patients decide what they need to do to live the kind of life they wish	4	24	8	1	**
To encourage patients to do what the team thinks is best	3	21	11	3	*
To help patients work out what is realistically possible for them to do	15	23	1	0	
To enable patients to pay attention to tasks and join in activities	11	24	4	0	
To help patients co-operate with others, control behaviour which upsets other people and/or tolerate other people	4	19	13	2	*
To help patients use community resources eg public transport/swimming pools	13	21	5	0	
To give carers something in writing to help them understand and work with the patients	15	20	2	0	**

\* one non response

\*\* two non responses

**Occupational Therapy Input Ranked In Order Of Perceived Importance***n=37\**

TYPE OF INPUT	RANKING					
	(1= most important 6= least important)					
	1	2	3	4	5	6
Developing specific skills eg bathing	10	17	5	3	1	1
Providing activities to occupy patients	1	1	5	7	5	18
Teaching coping strategies eg survival cookery	9	12	10	6	0	0
Providing written guidelines for colleagues/carers	11	2	7	7	8	2
Promoting constructive use of leisure time	2	2	5	7	12	9
Helping patients make choices about lifestyle	4	3	5	7	11	7
	37	37	37	37	37	37

\* 2 no information

Occupational Therapy Provision/Implementation (Oak/Pine)

	Strongly Agree	Agree	Disagree	Strongly Disagree	n
There is adequate occupational therapy input to Oak/Pine	22	12	4	0	38
The occupational therapist should decide which patients get occupational therapy	13	19	13	4	38
The MDT should decide which patients get occupational therapy	9	14	12	3	39
The Consultant should decide which patients get occupational therapy	0	5	24	10	39
All Oak/Pine patients should be offered occupational therapy	14	10	13	2	39
Occupational therapy does not benefit some Oak/Pine patients	3	16	13	5	37
Nurses and therapists should work together in an integrated way	36	6	0	0	39
It is important to be as involved as possible in the total care of each patient	23	13	2	0	38
Others should not have to carry out occupational therapy recommendations in the absence of the occupational therapist	2	3	23	8	36
There is not enough time to carry out occupational therapy recommendations	0	7	19	9	35
I feel competent to carry out occupational therapy recommendations	7	22	5	0	34
Carrying out occupational therapy recommendations interferes with my own objectives	1	0	20	12	33
I do not always understand why the occupational therapist advises certain things	0	4	22	9	35
I do not feel able to ask the occupational therapist all the questions I would like	0	0	16	20	36
Working alongside the occupational therapist promotes feelings of unease	0	0	12	24	36
Working with the occupational therapist is enjoyable	24	12	0	0	36
Therapy techniques do not encourage normalisation	0	1	19	17	37
Normalisation is important in the treatment of Oak/Pine patients	18	18	3	0	39
Sometimes it's hard to fit normalisation principles in with the needs of Oak/pine patients	11	19	7	1	38
Oak/Pine patients need to be treated the same way as any other member of society	16	9	9	2	36

**Case History - Patient C****Social Background**

C is male and he was born on the first of January 1970. He spent his early childhood years with his brother in a children's home in Wales. The boy's father was born in Pakistan and their mother in Scotland. There were two other siblings but none of the children were able to stay with their mother because of her own learning disabilities. 'C' and his brother were adopted by a family who followed an unconventional lifestyle travelling around Europe and Asia in a converted bus. The adoptive parents had two children of their own but added another four adopted children from a variety of ethnic backgrounds to the family. For a time they spent part of the year in Orkney, part in France and part travelling.

C had a turbulent relationship with his adoptive mother and eventually problems with behaviour led to him being admitted to Ladysbridge Hospital, Banff in April 1981. C remained in the boys' unit at this large hospital for people with learning disabilities from age 11 to 15 years. Occasionally he returned home to Orkney for holidays but he was unable to sustain a return to living permanently with his adoptive family. In 1986 at age 16, he moved to a Rudolph Steiner placement near Aberdeen. In 1990 he moved again to what was to be the first of many supported community accommodation placements. Over the years C's adoptive family have kept in touch by letter, telephone and occasional visits. They currently live in New Zealand.

**Personal Interests**

C has a strong interest in religious ideology and currently has links to a Roman Catholic Church. His social interests have been met in the past through attendance at

day centre type establishments for people with learning disabilities. He also enjoys swimming although he needs support to pursue this activity. He has no record of employment.

### **Healthcare History**

C has been known to specialist learning disabilities health services since his original admission to hospital in 1981. Over the years he has required input from a wide variety of healthcare professionals both within hospital and when living in the community. Intensity of health support has fluctuated dependent on the stability of his mental health, emotional state and behavioural competence. His mental illness was only fully recognised five years ago (1995) and in retrospect it seems likely that unrecognised psychiatric problems had led to his placements breaking down in the past rather than just behavioural difficulties.

A recurring theme in the casenotes is that he presents as more able than he actually is. He has mild learning disabilities and is described as giving the impression of having good verbal skills, while in fact his understanding is limited. There can be problems with others having unrealistic expectations of his performance. Over time 'C's' functional performance has tended to fluctuate significantly depending on his mental state and mood. Some of his carers have found this difficult to accept.

C's primary psychiatric diagnosis is manic depressive illness. Over the years he has had psychotic episodes and there have been incidents of parasuicidal attempts. When his anxiety state is high there is a tendency to refuse medication leading to further deterioration of his mental health. There have been times when he has been admitted to

hospital under sections of the Mental Health Act. On one occasion C complained to the Health Board about being detained in hospital stating that he wished to be out in the community to live his own life and pursue aspirations of becoming a catholic priest. Community residential placements have repeatedly broken down due to Cs' difficulty in sustaining relationships with other tenants. Single tenancy has been considered and indeed commissioned but despite showing initial enthusiasm for this option C's anxiety about the arrangements for living alone reached the point where an emergency hospital admission was required the day before he was due to move in. The placement was subsequently abandoned.

C's most recent community placement was with a mental health care provider. This was felt to be appropriate due to C's dual diagnosis of learning disabilities and mental health problems. The specialist community learning disabilities health team continued to provide ongoing support to both C and the provider staff group. In this way it was hoped that the full range of C's needs could be effectively met. However, C has once more required hospital admission and the mental health staff have indicated that they cannot provide the level of support C needs in the longer term. They have advised that an alternative placement be sought. The care manager has decided that C requires a more structured environment with higher staffing levels than provided in the mental health placement. Meantime C remains in the learning disabilities admission unit.

**Case History – Patient F****Social Background**

F is female and was born on 19<sup>th</sup> June 1954. She lived with her parents as one of three surviving siblings, all of whom had learning disabilities. Another child had died in infancy at the Royal Scottish National Hospital in Larbert. The parents were perceived to have ongoing problems in coping with their family and casenotes refer to a deprived social background. As a child F attended a local special education facility which could support her moderate learning disabilities. She came to the attention of Child Health Services in 1966 because of disturbed behaviour at school of recent onset. Behaviour at this time was thought to be reactive rather than indicative of personality disorder.

In 1970 F started attending a local authority day centre in Aberdeen. She has required much ongoing support to sustain this placement which has been characterised by difficult relationships with peers resulting in violent incidents. It has been proposed that low self-esteem was a major contributing factor in her inability to sustain relationships. By 1983 the level of violence at the day centre had escalated to the point where there were major concerns for safety. Various services and professionals were involved in supporting F, her family and the day centre staff and many coping strategies were tried including tranquillising medication. A recurring theme in the casenotes is the importance F places on family relationships. Significantly it has been reported that the relationship between home and the day centre was poor.



In 1989 F's father died and her mother faced increasing pressure in coping alone. At this point F started to receive periods of respite care at a local authority residential hostel, this being linked to her mother's failing health. In November 1990 F became resident at the hostel due to her mother's admission to hospital and subsequent transfer to residential care for the elderly. Despite the break up of the family unit at this point, F maintained regular and close contact with her mother and sisters.

Over the next few years F continued to live at the hostel and attend the day centre, although in both settings poor relationships with peers and instances of violence continued. In 1992 F demonstrated a degree of insight into her problems by contacting her doctor on her own to request help. At this point hostel staff were having difficulty in controlling violent outbursts leaving them feeling threatened and frightened. F presented as being very distressed around this time and specialist health support was provided mainly through the Consultant Psychiatrist in Learning Disabilities and the clinical psychology service.

### **Healthcare History**

While living with her family, F received intermittent specialist health interventions for a variety of reasons including suspected epilepsy (never conclusively diagnosed), obesity and challenging behaviour. Over the years the consultant psychiatrist in learning disabilities prescribed medication to be used as "a first aid measure" in dealing with what was viewed as essentially behaviour arising out of F's living and other circumstances. Support was also provided by the clinical psychology service.

In December 1993 F was admitted to Oak House which was part of the new specialist learning disabilities assessment and treatment services in Grampian. The goal of admission was to help F control her behaviour extremes. The Oak multidisciplinary team identified a crucial factor in that F appeared to have a greater understanding of language than was actually the case. Many of F's outbursts were thought to stem from simple misunderstandings. The team viewed F as being essentially a shy person who reacted violently to noisy environments and people milling around. During 1994 F made good progress in Oak and it was felt that a major contributing factor in this was that the team were able to gain the trust and support of F's family. Her family remained very important to F who visited her mother in the residential home weekly and also had regular contact with her sisters. By early 1995 planning for discharge commenced. A service design was drawn up by the Oak team to inform the development of appropriate supported community accommodation and detailed handling of behaviour guidelines were prepared for new carers.

Major difficulties arose in obtaining a suitable community placement. As time passed F became disillusioned because she had worked hard controlling her behaviour and felt very disappointed by the lack of forthcoming accommodation. Repeated attempts were made by members of the health team, care management and day centre staff to highlight the urgent requirement for a suitable placement. At this point, Advocacy became involved and this added a useful dimension to her quest for accommodation. None of these approaches had the desired result.

Eventually in April 1997 the Consultant Psychiatrist made contact with the Mental Welfare Commission expressing concern at the situation and pointing out that F's

wellbeing was affected by lack of a suitable placement. This course of action highlighted once more the seriousness of the matter to senior officers within the social services and Grampian Health Board. Early in 1998 F was linked to a new build project in Aberdeen. Timescales remained vague at this point but it was anticipated that the project would take around a year to come to fruition. Additionally in February 1998 F's low mood was causing concern and it was suspected that the death of her mother the previous summer had left F with feelings of unresolved grief. Bereavement counselling commenced and although considerable time was required to build up a therapeutic relationships F eventually made good progress.

The development of F's supported community placement continued over the next year with major input from the Oak multidisciplinary team. The service design was updated and a very detailed and structured careplan was passed on to new carers. The new staff were encouraged to spend time in Oak getting to know F before she moved and the ward team provided extensive training for all carers. In June 1999 F was discharged to her new home, the support staffing of which she shared with another women well know to her. Oak staff provided backup as and when required during the immediate post discharge period and at a point deemed appropriate specialist health support transferred to the community learning disabilities health team. In December 1999 F was reported to be happy in her new home and coping well.

**Participants' self rated satisfaction/effort (on analogues scales)**

The raw scores from the two presentations of the analogues scale were aggregated , then averaged. Scores were then banded as follows:

0 up to 4	=	high satisfaction
Over 4, up to 7	=	medium satisfaction
Over 7 up to 10	=	low satisfaction