Revalorisation: what experiences, resources and supports contribute to successful social reinclusion and a return to valued social status for people with severe and enduring mental illness

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REVALORISATION: WHAT EXPERIENCES, RESOURCES AND SUPPORTS CONTRIBUTE TO SUCCESSFUL SOCIAL REINCLUSION AND A RETURN TO VALUED SOCIAL STATUS FOR PEOPLE WITH SEVERE AND ENDURING MENTAL ILLNESS.

A thesis submitted in partial fulfilment of the requirements of the Open University for the degree of Doctor of Clinical Psychology

JUNE 2000

SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY COLLEGE
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ACKNOWLEDGEMENTS

Many people helped in the development and execution of this project, some over many years. I wish to thank my CMHT colleagues for contextualising this work by dedicating time and commitment to developing an SRV based mental health service and helping to develop the Support Needs Questionnaire with Peter Lindley and me.

I should also like to thank the four people I interviewed in the qualitative study for their humanity, extreme honesty, candour and humour. It was a privilege and an honour to be allowed so deeply into your experience. I have gained much from this.

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ABSTRACT

Background: Social Role Valorisation (SRV) is a social science meta-theory about social devaluation. Its innovative technologies are designed to promote valorisation (normalisation). SRV had a major impact on learning disability services in the 1980’s but has had limited exposure in mental health. Its effect on policy is evident however.

SRV has developed reliable, valid ecological assessments of normalisation in service environments. Life-style Planning operationalises normalisation goals for individuals. Its reliability and validity are unknown. Life-style Planning has two goal domains designed to ensure universal basic needs are met and address unique individual needs arising from primary disabilities. SRV also identifies revalorisation needs, to compensate for prior devaluation. In a previous study an instrument designed to assess universal basic and unique individual needs was standardised on a representative population of people with severe and enduring mental illness.

Aims: To validate the goal domains of the assessment instrument and develop an understanding of the user perspective on SRV and revalorisation.

Design and participants: Factor analysis was used to explore the underlying structure of the assessment instrument. In a second, qualitative study, “expert” mental health user/survivors were interviewed and their transcripts analysed using Interpretative Phenomenological Analysis.
Results: The instrument’s factor structure matched its design intentions and supported the validity of its goal domains. The qualitative results compared favourably with similar studies from the user, empowerment and recovery literatures. Participants painted a graphic picture of devaluation and revalorisation and illuminated what is required to promote “psychological revalorisation”. This took the form of a return from a false identification of themselves, based on the internalisation of ignorance and social prejudice stemming from societal fear and blame, to a new identification with a class of proud and empowered mentally ill people.

Implications. The discussion considers revalorising adaptations to psychological therapies for people with significant devaluation histories.
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Kristiansen (1998), a leading Social Role Valorisation (SRV) scholar, describes revalorisation as one of three types of need. *Basic universal needs* are the same for all people of the same age, gender and society. *Unique individual needs* derive from real impairments (e.g. severe and enduring mental illness) and needs arising from peoples' experiences of help or hindrance. *Revalorisation needs* arise from being perceived as a member of a devalued "class". Kristiansen (1998) refers to revalorisation as 'having one's identity and status strengthened and defended, often at a "class" level' (p.4), to "compensate" for historically unmet need. It is the very crux of valorisation.

1.1 *Social devaluation despite clinical effectiveness*

Empirical evidence supports a growing consensus about which treatments are effective for people with severe and enduring mental illness (e.g. Shepherd, 1998). These treatments, like family interventions in schizophrenia, can be difficult to implement partly due to resistance to change in services (Fadden, 1998). However, even when effective treatments are implemented, service users may continue to find themselves encumbered with secondary handicaps resulting from reduced status, social exclusion and the effects of social devaluation on their identity and status (Sainsbury Centre for Mental Health, 1998).
1.2 The influence of SRV

Although SRV (Wolfensberger, 1983) is not well known in mental health services, it is widely known in services for people with learning disabilities (Knapp, Cambridge, Thomason, Beecham, Allen & Darton 1992; Flynn, 1999). At a superficial level SRV’s principles resemble those of empirically based best practice in mental health (Kendrick, 1997). Their influence is easily found when reading between the lines of public policy; particularly in the social exclusion and equality agendas of current government thinking. The author of a recent MIND report on “Creating Accepting Communities” almost uses, but noticeably refrains from quoting SRV in their guiding principles for social inclusion (Dunn, 1999).

1.3 The challenge of SRV

A closer examination reveals SRV to be paradigmatically different from traditional practices in psychiatry. It is an amalgam of theory, a novel construal of the purpose of human services and little promulgated but respectable empiricism. SRV principles offer much to the problems of implementing evidence based practice. It has produced practical technologies to reduce secondary handicaps and exclusion resulting from devaluation.

SRV is concordant with strategies on reducing social exclusion (SCMH, 1998), stigma and discrimination, and ensuring positive imagery and accurate reporting (Sayce, 1998) but is rarely cited. SRV may offer much ‘but (be) too controversial to acknowledge explicitly’ (Wainwright, 1994). SRV goes beyond current concerns
about effects such as social exclusion, stigmatisation and discrimination, to identify a universal process involving all society in maintaining the “problem” of devaluation. This may be the root of its lack of open appeal.

1.4 SRV

SRV reformulates the “Principle of Normalisation” (Wolfensberger, 1972). It is promoted as a universal empirical social science meta theory about social devaluation (Wolfensberger, 1980). Normalisation identifies society’s responses to people who are or have become “different” on some socially valued dimension, in the form of negative attitudes such as stereotyping. Wolfensberger (1972) suggests this creates social devaluation which leads to common outcomes or “wounds” (Figure 1) that people bear because they are “viewed as different” by society. The wounds occur in a context of a descending spiral into fulfilling the negative expectations of society (Wolfensberger, 1972).

SRV is centrally concerned with identifying the features of social devaluation as a societal process. Devaluation is seen to have profound implications for “classes” of people perceived negatively by society because of their difference. For the mentally ill this difference is based on impairments in behaviour, feeling or thought. The second concern of SRV is to “reverse”, or “minimise” devaluation through practices, systems and societal action on behalf of devalued people and those at risk of devaluation. This amounts to “revalorisation” (Wolfensberger, 1983).
Figure 1. Historical stereotypes and the “wounds” (Jenkins, 1999: with permission).

- People may be REJECTED.
- People may be FORCED INTO DEVALUED ROLES.
- These devalued roles include:
  - Being ‘other’ or ‘alien’
  - Sub-human or Non-human
  - Menace or Object of Dread
  - Sinners
  - Object of Ridicule
  - Object of Pity
  - Burden of Charity
  - Child Role
  - Sick or Diseased Organism
  - Death Related Roles
- People may be PLACED CLOSE TO IMAGES THAT CARRY NEGATIVE MESSAGES. This can include accommodation, clothing, carers and many other factors. This includes image transfer between people with different or similar impairments by being PLACED TOGETHER WITH SUCH OTHERS WHO ARE DEVALUED [CONGREGATION].
- They may be SCAPEGOATED AND BLAMED FOR THE PROBLEM.
- They may be PHYSICALLY OR SOCIALLY PLACED AT A DISTANCE. [SEgregated]
- They may experience LOSS OF CONTROL OVER THEIR LIVES.
- And experience DISCONTINUITY WITH PLACES AND OBJECTS.
- And SOCIAL AND RELATIONSHIP DISCONTINUITIES.
- Which lead to IMPOVERISHMENT OF EXPERIENCE.
- Then LOSS OF NATURAL RELATIONSHIPS AND THE GAINING OF ARTIFICIAL RELATIONSHIPS.
- DEINDIVIDUALISATION occurs with regimentation and mass management.
- They may be SEEN IN TERMS OF THEIR DISABILITY.
- People may end up poor or at least unable to use their money and so experience INVOLUNTARY MATERIAL POVERTY.
- They may also suffer LOSS OF AUTONOMY AND RIGHTS.
- Additionally people may get cut off from knowledge of and participation in the religious, spiritual, and moral worlds. This is LOSS OF SPIRITUAL FULFILLMENT.
- It is possible that they will have an AWARENESS OF BEING A SOURCE OF ANGUISH to loved ones or to others.
- They may end up with A SENSE OF WORTHLESSNESS, DISLIKE OF SELF OR DESPAIR.
- And may experience justified RESENTMENT OR HATRED OF PRIVILEGED CITIZENS.
- All of the above is likely to lead to WASTED LIVES.
- And finally people may be at risk of being treated so badly that they are at risk of BRUTALISATION, VIOLATION AND EVEN EARLY DEATH.
- It is not required that people who are devalued will necessarily suffer all of the above wounds, but each devalued person is likely to suffer more of each category than a valued person would.

These issues clearly emerged in MIND’s “Not Just Sticks and Stones” survey (Read & Baker, 1996). For people with severe and enduring mental illness these wounds are ever present (Perkins & Repper, 1996). They include functional impairments: concentration problems, fluctuating mental state, thinking difficulties, unusual ideas, painful feelings and unusual experiences related to a primary disorder. They also include secondary “handicaps” resulting from devaluation: social exclusion, segregation, congregation with other devalued people and distancing from valued people (Wolfensberger, 1972). The psychological effects of wounding are like
institutionalisation (Goffman, 1976) and depersonalisation (Breakwell, 1986). These processes chart the loss and change, and often unhelpful treatment experiences, that form many service users' experience of gradually eroding lifestyles (Erickson, Beiser, Lacong, Fleming, & Liw, 1989) and devalued personal identification (Haywood & Bright, 1997).

Wounding may also be conceptualised as causing "secondary" or "induced" psychopathology. This may be compounded when the effects of wounding are perceived by clinicians as integral to illness rather than as acquired.

For Wolfensberger (1972) social devaluation also operates in services because of their part in society's response to difference. For example, there is a history of mental health practitioners holding similar negative attitudes towards mentally ill people as lay persons (Calicchia, 1981). Normalisation emphasises developing, sustaining and enhancing culturally valued roles as the effective means to protect against wounding. In SRV the highest order purpose of human services therefore becomes securing and maintaining the highest possible social status for people.

SRV clearly distinguishes needs from means. The means used in SRV derived services are designed to meet needs by enhancing competency, image or reputation. Service systems are most likely to achieve their higher purpose when all service efforts are organised within a coherent hierarchical model of functioning as described in Figure 2. Practice is defined as 'the use of culturally valued means to establish, maintain and/or enhance culturally valued experiences, behaviour and expectations'
The use of culturally valued means includes age, gender, ethnicity and religious appropriateness.

**Figure 2.** The hierarchical structure of SRV *(adapted from Wolfensberger, 1983)*

<table>
<thead>
<tr>
<th>Physical Settings</th>
<th>Relationships &amp; Groupings</th>
<th>Activities, Programs, &amp; Other Uses of Time</th>
<th>Language, &amp; Other Symbols &amp; Images</th>
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<td>Enhancing</td>
<td>Enhancing</td>
<td>Enhancing</td>
<td>Enhancing</td>
<td>Physical</td>
<td>Enhancing</td>
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<td>Harmony</td>
<td>Juxtaposition</td>
<td>Service</td>
<td>Personal</td>
<td>Accessibility</td>
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<td></td>
<td>to Other Programs</td>
<td>Workers</td>
<td>Appearance</td>
<td>to Clients</td>
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<td>Real &amp; Urgent</td>
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<td>Internal &amp;</td>
<td>Enhancing</td>
<td>Enhancing</td>
<td>Personal</td>
<td>Size &amp;</td>
<td>Relationships</td>
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<td>Separation of Program Functions</td>
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<td>History</td>
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<td>Program Funding</td>
<td>Challenging</td>
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SRV brings to the clinical tradition the insight that how people are "perceived" also determines their treatment *(Flynn, 1980)*. This operates at the individual, social and service system, and societal levels.
1.5 **SRV's recurrent themes**

Wolfensberger (1972) identified seven core themes contributing to normalisation:

- The role of unconsciousness in institutionalisation
- The importance of roles and role expectancy/circularity
- The developmental model
- The power of imitation
- The dynamics of social imagery
- Physical and social integration
- The “conservatism” corollary

Recently continuity, individuality and meeting unique individual needs through effective services (Kristiansen, 1998; Jenkins, 1999) have been added. The themes underpin SRV derived practice and bind services into a coherent model designed to exploit every opportunity for creating, maintaining and enhancing valued social roles for service users.

1.6 **The conservatism corollary**

This is the most relevant theme for this dissertation. The key aspect is recognising that devalued people require special attention paid to their experiences of helplessness and hopelessness (Kristiansen, 1998). The means to revalorisation is extra vigilance (*positive compensation*) when making life decisions or using services, so that such
people are no longer exposed to devaluing imagery, association or activity and become associated with valuing imagery, association and activities (Jenkins, 1999). Such helplessness, hopelessness and entrapment are cited as important issues in the psychological treatment of the affective component of schizophrenia (Birchwood & Iqbal, 1998).

People exposed to extensive devaluation develop "devaluation histories" which often bear individual "signatures". The evidence for this is extensive. Many devaluing experiences are known to be linked to onset of severe mental illness (Brown & Harris, 1978; Ambelas, 1987; Falloon & Fadden, 1993). Onset itself can also be traumatising (McGorry, Chanes, McCentury, Van Reil, McKenzie & Singh, 1991) and pre-existing devaluation plays a significant role in determining the extent of residual disability after onset (Wing & Morris; Perkins & Repper, 1996). Early intervention protects against these experiences, reducing disability and social isolation (Erickson et al, 1989; Thornicroft & Breakey, 1991), but is rarely implemented (SCMH, 1998).

In mental health services separating what is a direct effect of illness and what is secondary, i.e. caused by devaluation, can be a difficult clinical task. The conservatism corollary addresses this by alerting us to the question of how to assess and subsequently meet "revalorisation" needs. Although considered at the "class" level, SRV has little to say about psychological revalorisation. However recently themes resonant of accounting for revalorisation needs have emerged in the psychological literature. Adapted clinical practices resulting from a recognition of the special needs of people with severe and enduring mental illness have been reported. These include therapy based on collaborative partnership (Fowler, Garety & Kuipers, 1998),
empirical enquiry (Chadwick, Lowe, Horn & Higson, 1994) and lengthy engagement in therapy for psychosis allowing trust to develop based on experience rather than reputation (Birchwood, 1998). Most reports however describe poor availability of effective treatments for people with psychosis (Jackson & Farmer, 1998; Fadden, 1998; Shepherd, 1998).

1.7 Measuring “normalisation”

Devaluation and revalorisation can be measured using PASS (Program Analysis of Service Systems) (Wolfensberger & Glenn, 1975) and PASSING (PASS-Implementation of Normalisation Goals) (Wolfensberger & Thomas, 1983) which take an ecological approach (Flynn, Guirguis, Wolfensberger & Cocks, 1999).

Both instruments measure normalisation from the user perspective. They use the wounds (Figure 1), the hierarchical organisation of SRV (Figure 2), and the recurrent themes to rate services. Ratings are conducted by trained independent teams.

PASS and PASSING are the fullest operationalisations of Normalisation and SRV respectively. They have been subject to rational redesigns based on factor analysis (Flynn et al, 1999). Their factor structures matched the theory (Appendix 1).

1.8 SRV services

Societal methodologies attempt to reduce stigma and discrimination through academic and public involvement in service design, development, evaluation, education and use
PASS and PASSING training is offered to purchasers and service managers. Service evaluation is used for “class” interventions and in context setting for local destigmatisation (revalorisation) campaigns. An example of a local values framework resulting from a “class” intervention that took place in the locality of the present research is in Appendix 2 (Turner-Crowson, 1977).

Social interventions structure experience to enable active individualisation, continuity of natural supports, e.g. “Circles of Support” (O’Brien & O’Brien, 1991), use of generic community health resources and valued local facilities, comprehensiveness, preserving individual rights, social inclusion and positive imagery.

Individual revalorisation involves naturalistic assessment: such as “Getting to Know You” (Brost & Johnson, 1982, Thomas & Rose, 1986). Personal development strategies designed using “Life-style Planning” (O’Brien, 1987a) are then used to bring about normalisation through client achievement in the “5 Service Accomplishments”. These are based on the recurrent themes. They are: Community Presence (physical integration), Community Participation (social integration), Choice and Control, Social Roles and Respect, and Competence and Skills. With each accomplishment, their associated wounds and potentially revalorising experiences are identified (O’Brien, 1987b).

SRV advocates using familiar and trusted means firmly rooted in universal human values. Such services should be culturally indistinguishable from “ordinary life”
except for taking additional support to people and the use of evidence based treatments where required and in privacy. Attendance at “clinics” is minimised and treatment is provided in the least stigmatising and familiar setting, e.g. a GP practice. Work schemes take place in real workplaces alongside fellow employees rather than in sheltered workshops.

1.9 SRV implementation

SRV has been ubiquitous in UK learning disability services for 20 years (Knapp, et al, 1992). There has also been explicit implementation in elders’ services (Thomas, Holt, Illingworth, Maddocks & Robinson, 1990) but it remains little implemented in mental health.

As a new paradigm SRV has elicited strong views amongst mental health professionals. Wainwright (1986) described it as a “useful generative framework”. In response Clifford (1986) suggested SRV theorists were denying mental illness. It was criticised for valuing roles not people (Szivos & Griffiths, 1990) and for not being a theory (Rapley, 1990). Wolfensberger, the main developer of SRV, has documented its “misunderstandings” since 1983.

The author finds considerable relevance in SRV for people with enduring mental illness. However because of the controversy that surrounds SRV and the general ignorance of its empirical base it is important to evaluate it empirically and to develop well researched instruments for assessing need as conceptualised by SRV. The empirical base is easily accessible in the general social science and mental health
literatures. The evidence relates to the recurrent themes and service “components” like “ordinary housing” (Braisby, Echlin, Hill & Smith, 1988) or “place-and-train” employment (Bond, 1998) derived from them. There are well advanced examples in mental health, but no comprehensive SRV service implementations are reported.

1.10 SRV’s empirical base

The evidence for the relevance, outcomes and relative effectiveness of SRV derived services over traditional best practice is patchy but impressive. In some areas service components and technological processes have a solid empirical base. They reduce social devaluation and improve mental health as much if not more than some of the best traditional services (Davis, 1998). A comprehensive evaluation of the power of SRV based services requires more comprehensive implementation. A brief review of the evidence is presented below.

The recurrent themes are supported in the general psychological literature and the mental health literature. For example, Wolfensberger (1972) begins his critique of institutions by asserting the importance of unconscious processes in forming defensive institutional practices that contribute to “wounding”. His assertions were based on early theoretical psychoanalytic work of the same period (e.g. Menzies-Lythe, 1970). Since then the empirical evidence has confirmed his earlier assertions (Apte, 1968; Carter & Evans, 1978; Lamb, 1979; Bennett & Morris, 1983).

Wolfensberger (1972) cites various stereotypic roles that are ascribed to “different” groups and “put on to them” as a result of a process that may begin at birth,
the time of acquisition or the onset of primary impairments. Evidence for the effects of role expectancies and role circularity comes from accepted social learning theory (Hodgson, 1984). It is also known that severely mentally ill people are particularly vulnerable to social environmental demands (Perkins & Repper, 1998). Commentators have repeatedly called for service environments to maintain the valued cultural mores of normal society (Wing & Brown, 1970; Leff, 1991; Perkins & Repper, 1996; Birchwood, 1998; Fadden, 1998).

Today, the developmental assumption might be referred to as "Life Long Learning". A good example is using culturally valued learning environments for adults. In SRV terms these are colleges of higher education or the workplace not service facilities. Recent random controlled trials put this to the test for people with mental illness. Bond (1998) summarises the results of "Place and Train" work schemes when compared with traditional "Train and Place" schemes. SRV derived "Place and Train" was more successful (Shepherd, 1998; Bond, 1998). Sheltered employment was found to reduce peoples' employment chances (Bond, 1998). The availability of work options was more important than the characteristics of the people served (Gervey & Bedell, 1994).

Social learning theory (Bandura, 1977) has demonstrated the power of imitation. The dynamics of social imagery however is more problematic and relatively unexplored. Wainwright (1998) has summarised the evidence. For example, advertising is more effective in creating "charity giving" when it induces guilt, sympathy and pity. Posters illustrating equal rights for devalued groups produces an almost opposite effect (Eayrs & Ellis, 1990). Such findings may change in time.
Wainwright (1998) counsels caution in accepting some of Wolfensberger's (1972) ideas about negative image transfer but concludes there is enough support for further research.

Physical and social integration are now bywords in the social inclusion agenda and form necessary if not sufficient conditions for social inclusion. It is known that traditional community services have a greater impact on physical integration than social integration (Knapp et al, 1992). Social networks take time to develop (Anderson, Dayson, Wills, Gooch, Margolius, O’Driscoll & Leff, 1993), but the networks of people living in the smallest, most normalising, group housing become the most extensive (Anderson et al, 1993). Service users want normalised accommodation and prefer independent living with visiting support. (Tanzman, 1993).

A variety of SRV related themes also contribute to service user satisfaction (Dansereau, Dutreau, Ely & Flynn, 1990; Knapp et al, 1992; Anderson et al, 1993) and quality of life. These include: proximity/accessibility of housing to local amenities (Flynn, 1985) and small numbers of people in any dwelling (Hull & Thomson, 1981).

High quality, small homes in middle income communities with good local facilities, conscious staff avoidance of overprotection (Golden, 1982), where attention is paid to culturally normative lifestyle support are the most effective in achieving social inclusion (Cournos, 1987).

SRV derived de-institutionalisation schemes have been compared to modern rehabilitation and traditional methods. SRV schemes scored as well if not better on
levels of normalisation and mental health improvements (Carson, Dowling, Glynn & Oliver, 1994; Cullen, Carson, Holloway, Towey, Jumbo, Smellie & Glynn, 1997).

Outcome studies place SRV derived services equal to or in some instances ahead of traditional best practice. The evidence for increased integration resulting from culturally valued employment is strongest with accommodation a close second. The importance of the conservatism corollary stands out. What is particularly good for people generally is also good for people with severe and enduring mental illness.

In summary, the recurrent themes are obviously relevant. The evidence for their validity is also persuasive but more work is required on imagery. The main service systems arising from SRV, “Ordinary Housing” and “Place and Train” employment are effective. The universal and specific mental health literatures concur producing clear evidence of what reduces devaluation and enhances the status of mentally ill people as a “class”. Unfortunately much of this remains overlooked or is disregarded through clinical myth and prejudice (Shepherd, 1998).

1.11 Quantitative study

SRV can be criticised for an imbalance between “systems” level interventions based on PASS/PASSING; and qualitative and quantitative research (McGill & Emerson, 1992). For example, paying attention to developing valid, reliable assessment procedures/instruments for individuals has been considered devaluing in itself (Kendrick, 1994) and has been hotly debated (Wolfensberger, 1980; 1989; Baldwin, 1985; 1989; O’Brien, 1987a, 1987b). The criticisms that SRV is more concerned with
roles than people (Szivos & Griffiths, 1990) and that it denies mental illness (Clifford, 1986) suggest caution when proceeding to develop such instruments for mentally ill people.

The first study in this dissertation reports recent work in a therefore understandably long process of developing and evaluating a paradigmatically challenging individual needs assessment instrument derived from SRV. This process was designed to produce a valid, reliable, SRV derived assessment instrument that also sensitively identified problems arising from mental illness. As the 5 Service Accomplishments (O’Brien, 1987a) are a ubiquitous sign of SRV in services, the instrument was based on them.

The Support Needs Questionnaire (SNQ) (Davis, 1999) assesses the support people with severe and enduring mental illness need for a culturally valued lifestyle. SRV theory and clinical experience of using the “Getting to Know You” approach (Brost & Johnson, 1982) and Life-style Planning (O’Brien, 1987a) were used to guide its construction. This use of O’Brien’s (1987a) and Brost & Johnson’s (1982) work can be seen as operationalising revalorisation for individuals.

The SNQ measures universal basic needs, the 5 Service Accomplishments and finance and identifies unique individual needs as problems arising from mental illness. The SNQ attempts to meet the criticisms above by redressing the balance between systems and individual interventions and balances social and health needs.
The SNQ is part of a Life-style Planning system developed by the author and colleagues (Davis & Lindley, 1991). This is desirable as established care planning does not address revalorisation needs (Phelan, Slade, Thornicroft, Dunn, Holloway, Wykes, Strathdee, Loftus, McCrone, & Hayward, 1995; SCMIR, 1998; Sayce, 1998).

The SNQ and the Life Planning system use SRV's purpose for human services as the context for delivering evidence based practice. Simultaneously they explicitly intend to imbue these methods with new meaning based on communicating to service users an understanding of their need for revalorisation in their own and others' eyes.

1.11.1 Research questions

Earlier work (Davis, 1999) established the reliability and validity of the SNQ with a representative sample of mentally ill people. The SNQ comprises eight scales; the first six derive from the 5 Service Accomplishments. The final two identify physical and mental health problems. The present study is designed to reveal whether the intentional separation of scales into universal basic needs and unique individual needs is reflected in the SNQ's underlying factor structure. A secondary question is therefore whether a single SNQ score is meaningful or whether there should be separate scores each indexing theoretically different needs.

1.12 Qualitative study

A further criticism of SRV is that although explicitly focussed on the rights and protection of devalued people it is seen by service user/survivor groups as just another
professionalised discourse (Lindley, 1998; Campbell, 1998; Sutton, 1998).

The SNQ, although designed with service user involvement, does not look deeply at "psychological" revalorisation from the user/survivor perspective. To address this a second study used the SRV concepts of "social devaluation" and "revalorisation" to explore the phenomenology of the "devaluation/revalorisation experience" from the service user perspective. The purpose was to see if new insights could be brought to bear on the psychological effects of social devaluation and what psychological revalorisation might mean to people with severe and enduring mental illness.

The study is qualitative and exploratory. It was conceptualised in an SRV framework. It develops the understanding of needs assessment previously operationalised in the SNQ by introducing the concept of support needs for "revalorisation" (Kristiansen, 1998) at the psychological as well as the "class" level. The potentially opposite devaluation and revalorisation processes were explored from the user perspective to see how this equated to or differed from an SRV perspective.

The aim was to develop a clinical framework within which to assess and find new ways of meeting the psychological revalorisation needs of individuals with significant "devaluation histories".

1.12.1 Research questions

This second study explores, with service users who have made explicit their revalued status and identification, which experiences, resources and supports made a difference
to their experience of devaluation, adjustment to disability (Moore, 1998), subsequent empowerment (Rappaport, 1987), recovery (Anthony, 1991) and ultimate "revalorisation".

### 1.13 Summary

This dissertation develops earlier work on SRV and mental health (Davis & Lindley, 1991; Davis, 1998; 1999). It reports two studies, one quantitative and one qualitative. A final section on clinical implications considers psychological revalorisation in the context of SRV as a service framework, the development of the SNQ to date and service users' conceptions of social devaluation and revalorisation. The purpose of the dissertation is to describe the themes and processes of psychological revalorisation that clinical psychologists might consider when people with severe and enduring mental illness come for a consultation.

### 1.14 Ethics

Ethical approval for the quantitative study was granted previously by the Local Research Ethics Committee's when approving the validity/reliability trial of the SNQ (appendix 3). An extension was granted by Chairman's action for the qualitative study (appendix 4). The BPS guidelines for use in clinical research were followed at all stages (BPS, 1993).

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1 N.B. This was for a research protocol amendment therefore the second approval bears the same research title as the first.
CHAPTER 2

Quantitative study

Introduction

An earlier study by the author (Davis, 1999) described the reliability, validity and utility of the SNQ. The SNQ measures the support severely mentally ill people need to lead a culturally valued and therefore socially inclusive lifestyle.

The measure was developed by the author, and colleagues from an established community mental health team (CMHT), using an iterative process of experience and reflection over a ten year period. Items were included to reflect universal basic needs and unique individual needs. Earlier versions of the questionnaire had made sense and seemed relevant to a wide range of mental health professionals (n=30) and service users (n=200). The SNQ was scrutinised by an independent user consultant and re-evaluated by the current staff of the CMHT for the earlier study.

The SNQ comprises six rationally derived rating scales based on domains designed to index O’Brien’s (1987a) 5 Service Accomplishments including a finance scale which extends the Competence and Skills concept.

There are also physical and mental health problem identification scales. The items for these were derived from clinical experience. This was achieved by gradually refining their importance in relation to good outcomes by using a process of shared
reflection on clinical experience over many years (e.g. Davis & Lindley, 1991) and from the appropriate literature.

Particular attention was paid to wording scale items to connote support as natural and valuable rather than disempowering and devaluing. The choice of support as the unit of measurement is particularly relevant. This is because of the emphasis SRV places on the paradigmatic shift services need to make from a dependency culture, which concentrates on the “eradication” of disability often at the expense of social value, to one that empowers people to develop and sustain valued social roles. Support therefore becomes a valued and necessary component of daily life, as it is for all people, rather than something only disabled people need or perversely, can be seen to do without in the name of “independence”.

Presently two forms exist, the SNQ-K (keyworker: Appendix 5) and the SNQ-U (user). Each has 160 items with approximately twenty items per scale.

The support needs of 82 CMHT community clients were rated and then rated again after two weeks by their keyworkers using the SNQ-K, the Global Assessment Scale (GAS) (Endicot, Spitzer, Fleiss & Cohen, 1976), and conceptually related problem severity ratings from the MARC-2 (Huxley, Reilly, Harrison, & Mohamad in press), to assess the reliability and validity of the instrument. The demographic characteristics of the population studied were similar to those found in other relevant studies (e.g. Phelan et al, 1995).
The aggregate support needs of the studied population, \textit{(sum of the population's scale totals for each scale)}, revealed a picture to CMET staff that had face validity. In line with previous studies of post hospital closure populations, support for physical integration was the least of peoples' needs and support for social integration was the greatest (Knapp et al, 1992).

The reliability of the SNQ-K was very good and its concurrent validity with the GAS acceptable (Table 1). The internal consistency and internal validity \textit{(scale total-scale criterion question score correlated with the scale criterion question score)} of the SRV derived scales were also good (Table 2). The internal and concurrent validities of the physical and mental health scales were less impressive. The results of the study are reported in full in Davis (1999).

\textbf{Table 1.} SNQ-K test-retest reliability and time\textsubscript{1} concurrent validity (Davis, 1999)

<table>
<thead>
<tr>
<th>Scale name</th>
<th>Test-retest Pearson's &quot;r&quot; (2-tailed)</th>
<th>$p$</th>
<th>$n$</th>
<th>$T_1$ vs GAS &quot;r&quot;</th>
<th>$p(T_1)$</th>
</tr>
</thead>
<tbody>
<tr>
<td>SNQ-K total</td>
<td>0.92</td>
<td>0.01</td>
<td>82</td>
<td>0.57</td>
<td>0.0001</td>
</tr>
<tr>
<td>SRV-derived scales (summed)</td>
<td>0.93</td>
<td>0.01</td>
<td>82</td>
<td>0.56</td>
<td>0.0001</td>
</tr>
<tr>
<td>Problem scales (summed)</td>
<td>0.89</td>
<td>0.01</td>
<td>82</td>
<td>0.34</td>
<td>0.0002</td>
</tr>
<tr>
<td>Community Presence</td>
<td>0.91</td>
<td>0.01</td>
<td>82</td>
<td>0.46</td>
<td>0.0001</td>
</tr>
<tr>
<td>Community Participation</td>
<td>0.87</td>
<td>0.01</td>
<td>82</td>
<td>0.54</td>
<td>0.0001</td>
</tr>
<tr>
<td>Choice</td>
<td>0.89</td>
<td>0.01</td>
<td>82</td>
<td>0.45</td>
<td>0.0001</td>
</tr>
<tr>
<td>Social Roles &amp; Respect</td>
<td>0.90</td>
<td>0.01</td>
<td>82</td>
<td>0.52</td>
<td>0.0001</td>
</tr>
<tr>
<td>Competence &amp; Skills</td>
<td>0.92</td>
<td>0.01</td>
<td>82</td>
<td>0.54</td>
<td>0.0001</td>
</tr>
<tr>
<td>Finance</td>
<td>0.93</td>
<td>0.01</td>
<td>82</td>
<td>0.37</td>
<td>0.001</td>
</tr>
<tr>
<td>Physical Health</td>
<td>0.88</td>
<td>0.01</td>
<td>82</td>
<td>0.38</td>
<td>0.0001</td>
</tr>
<tr>
<td>Mental Health</td>
<td>0.88</td>
<td>0.01</td>
<td>82</td>
<td>0.24</td>
<td>0.03</td>
</tr>
</tbody>
</table>

Informal keyworker feedback suggested they found the SNQ-K quick to rate.
In subsequent field trials however, the SNQ-U was found to be onerous for service users in any context other than to guide clinical interviewing for which it was considered excellent.

Table 2. SNQ-K time\textsubscript{1} inter-item consistency and criterion validity (Davis, 1999)

<table>
<thead>
<tr>
<th>Scale name</th>
<th>Cronbach’s “α” (“a” (inter-item consistency))</th>
<th>n</th>
<th>Pearson’s “r” (internal criterion validity)</th>
<th>n</th>
<th>p</th>
<th>Sub-scale items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Presence</td>
<td>0.97</td>
<td>73</td>
<td>0.83</td>
<td>82</td>
<td>0.001</td>
<td>20</td>
</tr>
<tr>
<td>Community Participation</td>
<td>0.97</td>
<td>72</td>
<td>0.84</td>
<td>82</td>
<td>0.001</td>
<td>20</td>
</tr>
<tr>
<td>Choice and Control</td>
<td>0.97</td>
<td>77</td>
<td>0.82</td>
<td>82</td>
<td>0.001</td>
<td>18</td>
</tr>
<tr>
<td>Social Roles and Respect</td>
<td>0.94</td>
<td>75</td>
<td>0.82</td>
<td>82</td>
<td>0.001</td>
<td>19</td>
</tr>
<tr>
<td>Competence and Skills</td>
<td>0.94</td>
<td>73</td>
<td>0.52</td>
<td>82</td>
<td>0.001</td>
<td>21</td>
</tr>
<tr>
<td>Finance</td>
<td>0.98</td>
<td>74</td>
<td>0.86</td>
<td>82</td>
<td>0.001</td>
<td>20</td>
</tr>
<tr>
<td>Physical Health</td>
<td>0.88</td>
<td>72</td>
<td>0.52</td>
<td>82</td>
<td>0.001</td>
<td>21</td>
</tr>
<tr>
<td>Mental Health</td>
<td>0.82</td>
<td>76</td>
<td>0.48</td>
<td>82</td>
<td>0.001</td>
<td>21</td>
</tr>
</tbody>
</table>

The present study used exploratory factor analysis to determine whether the rational process of deciding which scales to include in the questionnaire had succeeded in producing two sets of scales, one that indexed the concepts of the 5 Service Accomplishments and one that indexed physical and mental health problems. A secondary consideration was to determine the validity of a single total SNQ-K score (sum of the eight scale totals). These are important steps before empirical redesign can be considered to produce, for example, a shorter “user friendly” version.

The results are discussed in relation to SRV theory and its’ definition of needs (Kristiansen 1998). The implications of the results for future scale development will be addressed.
Method

2.1.1 Data

The data for the present study were obtained during an earlier study (Davis, 1999).

2.1.2 Participants

Davis (1999) reported 82 community clients rated by their keyworkers. The keyworkers were five women and two men in a S.E. London CMHT serving a middle class semi-suburban population with some inner city deprivation. The demography for the population is in Table 3. There were 53 (64%) men and 29 women (36%). 80% (n = 70) were white. 57 (70.72%) people had a diagnosis of schizophrenia and 8 (9.6%) of manic depression. The mean age was 47.8 years (SD = 13.65).

Raters were two G and one F-Grade Nurse, one Senior Occupational Therapist, one Care Manager, one Senior Care Manager and one Clinical Psychologist (not the author). All had post-qualification SRV training and experience (M = 4.3 yrs; range 1-8) including use of previous SNQ versions. Keyworkers' post qualification mental health experience was 66 years (M = 9.4; range = 3-21).

Raters received additional instructions to those on the questionnaire (Appendix 5), including an SRV based needs assessment manual for people with mental illness based on Davis & Lindley (1991) specifically updated for the present study. Raters also attended 1.5 hours group training in the specific use of the instrument.
Table 3. Demography for the SNQ-K study population (Davis, 1999)

<table>
<thead>
<tr>
<th>Factor</th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>47.82</td>
<td>13.65</td>
<td>24-76</td>
</tr>
<tr>
<td>Onset age</td>
<td>26.11</td>
<td>10.15</td>
<td>8-55</td>
</tr>
<tr>
<td>Years ill</td>
<td>21.86</td>
<td>13.78</td>
<td>1-51</td>
</tr>
<tr>
<td>Years service use</td>
<td>20.94</td>
<td>13.93</td>
<td>2-51</td>
</tr>
<tr>
<td>Last 2yrs admissions</td>
<td>1.35</td>
<td>2.12</td>
<td>0-12</td>
</tr>
<tr>
<td>GAS</td>
<td>38.91</td>
<td>13.56</td>
<td>11-81</td>
</tr>
<tr>
<td>Gender</td>
<td>53 M (64.6%); 29 W (35.4%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Past formal MHA status</td>
<td>52 Yes (63.4%); 30 No (36.6%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Category</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White British</td>
<td>70</td>
<td>85.36</td>
</tr>
<tr>
<td>Afro-Caribbean</td>
<td>2</td>
<td>2.44</td>
</tr>
<tr>
<td>British Asian</td>
<td>2</td>
<td>2.44</td>
</tr>
<tr>
<td>Other/Don’t Know</td>
<td>8</td>
<td>9.76</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>57</td>
<td>69.50</td>
</tr>
<tr>
<td>Paranoid Psychosis</td>
<td>2</td>
<td>2.44</td>
</tr>
<tr>
<td>Manic Depression</td>
<td>8</td>
<td>9.76</td>
</tr>
<tr>
<td>Psychotic Depression</td>
<td>3</td>
<td>3.66</td>
</tr>
<tr>
<td>Anxiety/Depression</td>
<td>4</td>
<td>4.88</td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
<td>9.76</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>53</td>
<td>65.1</td>
</tr>
<tr>
<td>Divorced</td>
<td>15</td>
<td>18.1</td>
</tr>
<tr>
<td>Separated</td>
<td>3</td>
<td>3.6</td>
</tr>
<tr>
<td>Married</td>
<td>6</td>
<td>7.2</td>
</tr>
<tr>
<td>Widowed</td>
<td>5</td>
<td>6.0</td>
</tr>
<tr>
<td>Living situation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alone</td>
<td>31</td>
<td>38.6</td>
</tr>
<tr>
<td>Parents</td>
<td>11</td>
<td>13.3</td>
</tr>
<tr>
<td>Spouse/partner</td>
<td>5</td>
<td>6.0</td>
</tr>
<tr>
<td>Spouse/children</td>
<td>3</td>
<td>3.6</td>
</tr>
<tr>
<td>Children - single parent</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td>Other family</td>
<td>6</td>
<td>7.2</td>
</tr>
<tr>
<td>Non-family</td>
<td>25</td>
<td>30.1</td>
</tr>
<tr>
<td>Accommodation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Homeless</td>
<td>2</td>
<td>2.4</td>
</tr>
<tr>
<td>Own home (without support)</td>
<td>25</td>
<td>32.1</td>
</tr>
<tr>
<td>Own home (with support)</td>
<td>30</td>
<td>35.7</td>
</tr>
<tr>
<td>Shared home</td>
<td>3</td>
<td>3.6</td>
</tr>
<tr>
<td>Residential home</td>
<td>16</td>
<td>19.0</td>
</tr>
<tr>
<td>Nursing home</td>
<td>6</td>
<td>7.1</td>
</tr>
</tbody>
</table>
Davis (1999) did not report statistics for inter-rater reliability. However raters, in addition to the general training about the instrument, also conducted “pilot” ratings for six longstanding, and therefore well known to all staff, CMHT users, not included in the eventual study, in order to assess whether they were rating to the same criteria and able to reach agreement. This process was supervised by the author who enabled raters to establish their differences and develop consensus.

One-way ANOVAs (two-tailed) found no systematic differences between raters on SNQ-K total scores \((F = 1.89, p = 0.09; df = 6; 75)\). Unsurprising significant correlations were found between age \((r = 0.28, p = 0.013)\), years ill \((r = 0.40, p < 0.001)\), years services use \((r = 0.42, p < 0.001)\) and increasing SNQ-K totals (Davis, 1999).

2.1.3 Scale development

Full details of the scale development is reported in Davis (1999)

2.1.4 Procedure

SNQ ratings were conducted on two occasions two weeks apart as part of a larger testing battery. SNQ ratings were completed first. The tests in the battery were rated in the same order on both occasions. Clients were rated in the same order on both occasions.
Results

To calculate scale totals, missing scale item scores \((\text{time}_1; n = 91); \text{time}_2; n = 84\) were replaced with the scale mean allowing four missing items per scale.

Davis (1999) used the Kolmogorov-Smirnov goodness of fit test to establish the distribution of scores on each scale as a check on the appropriateness of using parametric statistics. Inspection revealed normal distributions with good spread and no floor or ceiling effects on seven of the eight scales. A log transformation \(\log_{10}(1+\text{variable})\) was performed to correct slight positive skewing on Community Presence. Transformed data were used for the factor analysis. Means, standard deviations and ranges (Davis' (1999) for the SNQ-K total and its eight scales are shown in Table 4 using non-transformed data.

Table 4. Descriptive statistics for SNQ-K total and scale scores (Davis, 1999)

<table>
<thead>
<tr>
<th>Scale name</th>
<th>Full scale</th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
<th>Items</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>SNQ-K total</td>
<td>1050</td>
<td>573.00</td>
<td>159.92</td>
<td>244-964</td>
<td>150</td>
<td>82</td>
</tr>
<tr>
<td>Community Presence</td>
<td>140</td>
<td>59.14</td>
<td>29.98</td>
<td>23-137</td>
<td>20</td>
<td>82</td>
</tr>
<tr>
<td>Community Participation</td>
<td>140</td>
<td>90.44</td>
<td>30.83</td>
<td>30-140</td>
<td>20</td>
<td>82</td>
</tr>
<tr>
<td>Choice and Control</td>
<td>126</td>
<td>66.97</td>
<td>25.74</td>
<td>22-124</td>
<td>18</td>
<td>82</td>
</tr>
<tr>
<td>Social Roles and Respect</td>
<td>133</td>
<td>73.50</td>
<td>22.65</td>
<td>25-123</td>
<td>19</td>
<td>82</td>
</tr>
<tr>
<td>Competence and Skills</td>
<td>147</td>
<td>77.02</td>
<td>26.15</td>
<td>27-143</td>
<td>21</td>
<td>82</td>
</tr>
<tr>
<td>Finance</td>
<td>140</td>
<td>72.80</td>
<td>31.54</td>
<td>20-136</td>
<td>20</td>
<td>82</td>
</tr>
<tr>
<td>Physical Health</td>
<td>147</td>
<td>60.85</td>
<td>20.61</td>
<td>21-117</td>
<td>21</td>
<td>82</td>
</tr>
<tr>
<td>Mental Health</td>
<td>147</td>
<td>72.26</td>
<td>16.41</td>
<td>36-116</td>
<td>21</td>
<td>82</td>
</tr>
</tbody>
</table>
2.2.1 *Exploratory factor analysis*

**SNQ-K scale totals as variables**

A sample size of 82 did not permit a factor analysis of the full item set of the SNQ-K in a single analysis (Kass & Tinsley, 1979). It was not possible therefore to determine by this means whether a single “total” score for the SNQ-K has validity; to determine the instruments overall factor structure or attempt an “empirical” redesign of the scales. There are however valid alternatives.

To see if a total score is meaningful a factor analysis using the scale totals as variables was conducted. The number of participants to variables was 82:8, giving an acceptable ratio of 10:1 (Tinsley & Tinsley, 1987).

Exploratory factor analysis was conducted using the FACTOR routine of SPSS 8.0 for Windows with principal components factor extraction (Nunnally, 1978).

Two factors had eigenvalues above 1.0. A scree plot indicated that one factor should be retained. All unrotated factor loadings exceeded 0.5 on factor 1 except for the mental health scale which loaded above 0.5 on factor 2.

Although each scale was designed to be distinct, the first six were designed to measure *universal basic needs* and the final two to measure *unique individual needs* (problem identification) according to specifications derived from SRV. Theory suggests that each set of scales should be related but independent of the other.
The eigenvalues and theory suggested retaining two factors for rotation. To see if the factors were independent as predicted by theory an oblique rotation was first performed to establish whether the identified factors were correlated (Gorsuch, 1983). The resulting inter-factor correlation was 0.377. This low coefficient suggested an orthogonal structure was most appropriate for the analysis and so a varimax rotation was used (Kaiser, 1958). The resulting factor loadings are shown in Table 5.

Table 5. Rotated factor loadings for the SNQ-K scale totals

<table>
<thead>
<tr>
<th>Scale name</th>
<th>Factor 1</th>
<th>Factor 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Choice</td>
<td>0.90</td>
<td></td>
</tr>
<tr>
<td>Community Participation</td>
<td>0.86</td>
<td></td>
</tr>
<tr>
<td>Competence and Skills</td>
<td>0.84</td>
<td></td>
</tr>
<tr>
<td>Community Presence</td>
<td>0.84</td>
<td></td>
</tr>
<tr>
<td>Social Roles &amp; Respect</td>
<td>0.77</td>
<td></td>
</tr>
<tr>
<td>Finance</td>
<td>0.73</td>
<td></td>
</tr>
<tr>
<td>Physical Health</td>
<td></td>
<td>0.89</td>
</tr>
<tr>
<td>Mental Health</td>
<td></td>
<td>0.76</td>
</tr>
</tbody>
</table>

After rotation the items loading on factor 1 were the first six scales. In SRV terms these represent the “5 Service Accomplishments” or more generally “universal basic needs”. The two items loading on factor 2 were the “problem identification” scales. In SRV terms these equate to “unique individual needs”. There was no overlap on the factor loadings between the two sets of scales. Factor 1 had an eigenvalue of 4.88, accounting for 52.59% of the variance. Factor 2 had an eigenvalue of 1.10, accounting for 22.2% of the total variance.

An essentially identical result was found when the procedure was replicated using Davis’ (1999) Time2 data. Space does not permit reporting of the detail. The
two factor solution maps on to the theory and suggests the SNQ-K is a measure of support needs as defined by SRV.

SNQ-K scales

The approach taken above leaves many questions unanswered. Although beyond the scope of the present study’s research questions some further analysis was conducted. This is only summarised here as space does not permit a fuller report. Exploratory factor analysis was again conducted using the same methodology, including replication, for each of the individual scales.

A single factor solution emerged for each suggesting that most if not all the items within each scale belonged there (as indicated by their high factor loadings). This still leaves the question of whether some items might belong better on one of the other scales unanswered.

The original design process for each scale had demanded a number of themes be included in each to adequately sample the scale construct. It was therefore expected that each scale would have a factor structure of its own with subsequent factors correlating highly with the scale construct. For theoretical reasons and for use in the qualitative study further factor analysis was conducted for each scale, the results of which are in Table 6.
Table 6. SNQ-K scales factor structure

<table>
<thead>
<tr>
<th>Scale name</th>
<th>Factors</th>
<th>Eigenvalue</th>
<th>Rotated % of variance</th>
<th>Cumulative % variance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Presence</td>
<td>Access to places</td>
<td>13.54</td>
<td>31.48</td>
<td>79.09</td>
</tr>
<tr>
<td></td>
<td>Access to people</td>
<td>1.21</td>
<td>27.54</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Orientation/exploration</td>
<td>1.06</td>
<td>20.07</td>
<td></td>
</tr>
<tr>
<td>Community Participation</td>
<td>General socialising</td>
<td>13.48</td>
<td>49.47</td>
<td>75.37</td>
</tr>
<tr>
<td></td>
<td>Intimate relationships</td>
<td>1.60</td>
<td>25.90</td>
<td></td>
</tr>
<tr>
<td>Choice</td>
<td>Service related choices</td>
<td>11.93</td>
<td>36.42</td>
<td>72.68</td>
</tr>
<tr>
<td></td>
<td>Generic choices</td>
<td>1.15</td>
<td>36.26</td>
<td></td>
</tr>
<tr>
<td>Social Roles and Respect</td>
<td>Self-respect</td>
<td>9.50</td>
<td>25.93</td>
<td>71.18</td>
</tr>
<tr>
<td></td>
<td>Perceived valued image</td>
<td>1.56</td>
<td>19.92</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Respected by others</td>
<td>1.36</td>
<td>16.78</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Respect for gender</td>
<td>1.11</td>
<td>8.55</td>
<td></td>
</tr>
<tr>
<td>Competence and Skills</td>
<td>Looking after self</td>
<td>9.62</td>
<td>20.45</td>
<td>77.26</td>
</tr>
<tr>
<td></td>
<td>Educational development</td>
<td>2.54</td>
<td>16.02</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Literacy</td>
<td>1.86</td>
<td>15.64</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Domesticity</td>
<td>1.15</td>
<td>15.50</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Health</td>
<td>1.05</td>
<td>9.65</td>
<td></td>
</tr>
<tr>
<td>Finance</td>
<td>Day to day skills</td>
<td>13.72</td>
<td>43.47</td>
<td>74.92</td>
</tr>
<tr>
<td></td>
<td>Specialist skills</td>
<td>1.27</td>
<td>31.44</td>
<td></td>
</tr>
<tr>
<td>Physical Health</td>
<td>Somatic/side effects</td>
<td>6.53</td>
<td>15.32</td>
<td>64.36</td>
</tr>
<tr>
<td></td>
<td>Physical maintenance</td>
<td>2.32</td>
<td>13.14</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Fitness</td>
<td>1.79</td>
<td>13.02</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mobility</td>
<td>1.65</td>
<td>12.93</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Ageing</td>
<td>1.24</td>
<td>9.95</td>
<td></td>
</tr>
<tr>
<td>Mental Health</td>
<td>Psychosis</td>
<td>4.89</td>
<td>18.41</td>
<td>45.73</td>
</tr>
<tr>
<td></td>
<td>Neurosis</td>
<td>2.78</td>
<td>15.67</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mania</td>
<td>1.93</td>
<td>11.65</td>
<td></td>
</tr>
</tbody>
</table>

Discussion

The SRV derived scales and the finance scale were designed to measure the amount of support people require to meet their universal basic needs. The problem identification
scales were designed to measure the frequency of support required to meet unique individual needs. The two factor structure and the low correlation between the factors, suggesting they are orthogonal, support this distinction.

This structure is also consistent with the SNQ-K’s original design concept and mirrors the theory in distinguishing between the accomplishment derived scales and those designed to identify problems. A superficial view of the simple structure suggests strong support for the theoretical difference between universal basic needs and unique individual needs. However the methodological difference in the scales of measurement used for the two types of scale (amount and frequency) begs the question as to whether this is a genuine conceptual difference or an artefact of measurement. The resulting structure is however consistent with the design intentions for the SNQ-K.

The first factor indexes support for meeting universal basic needs. A score for this would be the summed totals of the first six scales. The second factor indexes support needed to meet unique individual needs arising from severe mental illness. A score for this would be the summed scores of the two problem identification scales. This result supports the separate analyses of these scales reported in Davis (1999) conducted at that time with only theoretical justification.

If however one were to rely on the scree plot alone in the determination of the number of factors for the SNQ-K then it would still be possible to argue for the validity of a single score. A single score might be characterised simply as "overall needs".
The initial single factor solution for each of the eight scales suggests the items they contain belong on those scales but did not inform us whether they would be better on another scale. The multi-factor solutions however revealed interpretable results which both matched the design intentions of the SNQ-K and theory.

Although steps were taken in the earlier study to bring raters to a consensus on their scoring of the SNQ-K inter-rater reliability data was not reported (Davis, 1999). This is a shortcoming of the earlier study with serious implications for the present study. There remains a chance that raters' observations cannot be treated as independent. If this were the case the validity of the statistical evidence produced in the current analysis would be undermined.

To deal with the above and to be sure of the correct factor solution for the SNQ-K a large scale replication is required using the full item set in a single analysis. 600 participants would be appropriate. In addition to this a confirmatory factor analysis (Byrne, 1994) should be performed to confirm the structure found in the exploratory factor analyses and to establish which factor structures predicated on theory produce the best fit with the data. This approach would also establish the generalisability of the results away from the site of the SNQ-K's development.

Although the approach taken was a theoretically valid substitute for using the full item set in a single factor analysis it cannot be relied upon with as much certainty as the latter method. It is however an indicative measure of the underlying structure of the SNQ-K that is supported by both the replication of the findings with the same population at a different time and by existing theory.
CHAPTER 3

Qualitative study

Introduction

Participants were interviewed about their devaluation and revalorisation experiences in order to build up an understanding of the two processes from the point of view of the "expert" service user/survivor.

Method

An idiographic case study was conducted involving four individual participants. The analysis involved looking in detail at one interview transcript before incorporating others. The idiographic approach to analysis was used by beginning with particular examples and slowly working up to more general categorisation or theory (Smith, 1995).

3.1.1 Sampling

A large group of "user/survivors" had identified themselves to the researcher as service "graduates" during an earlier project designed to establish a local values framework for mental health services (Turner-Crowson, 1997), the implicit purpose of which was to implement a local intervention to support service users' revalorisation needs at the
"class" level (Appendix 2). Four of these people were involved in the study. They met "loose" criteria for having "graduated" to valued status.

This approach represents theoretical sampling (Strauss & Corby, 1990). The people in the study were chosen to represent the psychological and psychosocial processes involved in the experience of devaluation and revalorisation not the population of people with severe and enduring mental illness.

3.1.2 Design

Semi-structured, audiotaped interviews were used to ask participants to answer questions about devaluation (interview one) and revalorisation (interview two) at the individual/intrapsychic; social/interpersonal and societal/political levels. The devaluation interviews were conducted with each participant in turn. Wordprocessed transcripts made from the audiotapes were sent to participants for error checking. The second interviews were conducted in the same person order. Transcripts were again sent for correction.

Interpretative Phenomenological Analysis (IPA) (Smith, Osborn & Jarman, 1999) was conducted on the corrected transcripts. A third interview was then conducted in the same person order, as a respondent validity check on the initial analysis. Following this, alterations were made to the interpretation of themes for each transcript. Individual transcript themes were then combined. A further respondent validity check was then conducted, with the participants as a group, to check the
results of combining their individual themes. Participants’ alterations and comments were included in the results.

3.1.3 Participants

Participants were recruited from the known group of user/survivor graduates by personal invitation from the author. The criteria for selection included balancing gender and “diagnostic” spread but most important was their obvious position within the user community as graduates of a mental health system they had used extensively, who were well informed, empowered, and articulate about their experiences of poor and helpful services in a balanced, thoughtful way. None had studied SRV but they had heard of normalisation. One participant had attended an introductory talk on SRV two years earlier. Their demographic characteristics are summarised in Table 7. All had used in-patient, out-patient, day and employment services and had experienced individual or group therapy. They lived in independent accommodation. They continued to take medication.

Table 7. Participants’ demographic characteristics

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age (yrs)</th>
<th>Status</th>
<th>Ethnicity</th>
<th>Service use (yrs)</th>
<th>Self Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>Man</td>
<td>55</td>
<td>Single</td>
<td>White</td>
<td>38</td>
<td>Personality Disorder</td>
</tr>
<tr>
<td>02</td>
<td>Woman</td>
<td>26</td>
<td>Single</td>
<td>White</td>
<td>10</td>
<td>PTSD with Severe Depression</td>
</tr>
<tr>
<td>03</td>
<td>Woman</td>
<td>33</td>
<td>Partner</td>
<td>White</td>
<td>11</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>04</td>
<td>Man</td>
<td>48</td>
<td>Divorced</td>
<td>White</td>
<td>10</td>
<td>Manic Depression</td>
</tr>
</tbody>
</table>
3.1.4 Informed consent

Consent was important methodologically. Potential participants were initially spoken to by telephone and invited to meet the author in person at a place of their choosing to discuss possible involvement. A half hour was given to explaining the context of the research and what had already been done with the SNQ-K. Questions were invited and answered without reservation.

Although known from the earlier “class” intervention participants were unknown to the author clinically nor were they likely to be. They used services in a different locality than that of the author.

Participants were informed ethical approval had been granted. They were told how to obtain independent advice or make a complaint about the research and that they could terminate their involvement anytime without prejudicing their care. They were offered the possibility of independent debriefing after interviews. Participants were asked not to speak to other participants before the interviews were completed. They were told there would be an opportunity to discuss the results and their experience of the research with the other participants at that point.

Confidentiality was assured by using only code numbers. Naming was avoided at interview. The transcriber was independent of participants’ services, at the author’s academic institution and subject to confidentiality. Participants were given an information letter (Appendix 6) transparently explaining the study’s purpose and
leaflets on advocacy and a local user group. They were asked to respond at their leisure after a week.

The first four people contacted agreed to participate and for their GP to be informed by letter (Appendix 7). Participants received copies. Consent forms were signed at interview one (Appendix 8).

3.1.5 Procedure

Data were collected individually during two, one hour interviews three weeks apart and at a half hour individual respondent validity interview two weeks later. A “group” respondent validity meeting took place over one and a half hours one month later. The interviews took place at the local mental health Trust headquarters and the local user group offices according to participants’ preferences.

The interviews explored participants’ personal, social, and service use histories, in parallel, to record the significant events they considered contributed to or protected them from devaluation and then helped or hindered their revalorisation. These processes were explored sequentially at individual, social and societal levels. The effects of the two processes on identity and status were emphasised. The researcher attempted to enable participants to develop personal theories of devaluation and revalorisation by feeding back emerging themes.

The interview schedule (Appendix 9) was piloted with an independent user consultant who was also involved in the earlier “class” intervention and who scrutinised the SNQ-
K. Pilot interviews were audiotaped, transcribed then read repeatedly to "sensitise" the author to the issues that might emerge and enable the author, as researcher not clinician, to be aware of the personal issues raised by such a conversation. A further purpose was to allow the author unpressured time to explore IPA.

3.1.6 Data analysis

IPA (Smith et al, 1999) was used because the study was explicitly theory driven. Many of the constructs investigated are clearly specified in the existing literature and have been described in the introduction. An alternative would have been to use a grounded theory approach (Glaser & Strauss, 1967) but this would have been more atheoretical than necessary.

All transcripts were read and reread. Individual transcripts were then categorised by events, experiences and insights. Categories were gradually built up to theme status. Examples relating to and exemplifying the themes were then re-identified in the text by closer and closer examination of the narratives. The connections between themes were explored in an attempt to develop an understanding of the participants' model of how themes were linked.

Whilst reading transcripts the researcher made notes in the left margin corresponding to summaries, associations or connections that came to mind. The right margin was then used to record ideas for emergent theme titles using key words to capture the essential quality of what was found in the text (e.g. Appendix 10). This information was assembled as a separate record for each process, at each level, for
each participant. The information was refined until a list of categories and themes was
developed from which a sub-set were identified that had super-ordinate qualities (e.g. Appendix 11). These were then clustered into theme tables or individual masterlists. These were again checked back with the text to assure the connection between theme and text was maintained as the most definitive data reduction (e.g. Appendix 12).

These appendices exemplify the analytic process and support the auditability of the methodology (Turpin, Barley, Beail, Scaife, Slade, Smith & Walsh, 1997). They should be read bearing in mind that the iterative nature of the analysis allows influences from other participants to affect the transition from one level to another for individual transcripts. In such instances this may appear to lessen the fit between different levels.

The masterlists for each participant were then re-analysed at a higher level, as “text” themselves, to find further super-ordinate themes that could be used to recode all the transcripts. Although complex, this method was suited to the small sample size as a general overview of the texts could be retained by the researcher.

The next stage was to aggregate the participants’ theme tables to produce a masterlist or full IPA matrix (Smith et al, 1999, p.226) for each process at each of the three levels of analysis. The resulting masterlists formed the content for the results of the study.

Before moving from one step in the analysis to another, multiple checking of the text against categories, categories against themes and furthermore text against themes was conducted to ensure continuity of meaning between text, categories and
themes. Only those themes with major relevance to the issues under investigation were retained and others found trivial or irrelevant were discarded. Care was exercised to maintain connections between text and themes and to inhibit the researcher's imagination. Themes were not excluded if they went in a different direction from the researchers pre-existing theoretical position.

Initially, alongside each theme, examples referenced to the text by page and line were also recorded. For the presentation of the results however the comments from the group respondent validity exercise are used as they were more illustrative and a potentially more valid alternative. It was helpful however in the analysis itself and for the discussion of the results to have marked these text examples in a way that identified the theme they were associated with.

The overall sequence for the analysis was to read and categorise each participants devaluation transcript beginning at the individual level and moving "up" to the interpersonal and societal levels in turn. Revalorisation transcripts were then categorised. Devaluation transcripts were then "themed", one participant after another. Revalorisation transcripts were then "themed". Devaluation themes were then aggregated for each level of analysis followed by aggregation of the revalorisation themes. An iterative approach similar to that used when moving between levels was used when aggregating across participants to ensure continuity and comprehensiveness.

Individual respondent validity interviews were conducted after analysing participants' transcripts. The themes from their devaluation and revalorisation transcripts were presented in order and discussed. Participants' comments, alterations
and emphasis changes were recorded on the researcher's result sheets, in red, to distinguish them.

Group respondent validity was established at a group meeting. The meeting was co-facilitated by the independent user consultant. The consultant was not aware of the emergent analysis. The consultant's role was to moderate the researcher's behaviour allowing concentration on recording rather than influencing the discussion.

At the group, aggregated theme analyses were presented as flow charts beginning with societal, interpersonal and individual levels of devaluation followed by revalorisation in the same order. Comments, alterations and changes of emphasis or meaning were added to the flow charts. These form the results of the study.

3.1.7 Methodological issues

Reliability and validity are as important in qualitative research as in quantitative work. To assess whether the coding system and the researcher's ratings were a good measuring instrument in this specific context a number of approaches were taken.

Inter-rater reliability was assessed by providing an alternative analyst (the researcher's supervisor) working independently with one randomly selected participant's transcripts. The transcripts, the initial coding and placement of text into categories, themes and super-ordinate themes were checked at the individual level of analysis. The categorisation and theme analysis were checked for both processes. The contribution of this participant's themes was then checked against the aggregated themes of all
participants. Checks were conducted to ascertain that important data had been retained and no inappropriate ones had been added; and that the connections between individual and aggregated themes remained meaningful.

This is a significant modification of a technique described by Silverman, (1993). The requirement for the modification was simple. Each participant’s transcript took the researcher approximately 2 days to analyse. To ask a colleague to give up such an amount of time to reliability checks was simply impossible.

Respondent validity was included iteratively at two levels to enable the participants then the reader to have an opportunity to verify judgements regarding the researcher’s interpretations of transcript materials (Silverman, 1993) and reveal any analysis bias.

Transparency to the reader’s evaluation was taken into account in the attempt to envision the analysis by the use of flow charts, with sufficient quotes and comments from the participants to bring their narratives alive.

Auditability was built into the study by giving examples of the analytic process in the appendices, and by making available the transcripts and researcher’s notes made during the analysis in a separate volume.

Generativity is considered to be an essential feature of any “good” theory and in this context Henwood and Pidgeon (1992) have argued that research quality should be judged in the same way. The generative power of the research and the implications for clinical practice arising from it are considered in the discussion.
Rhetorical power refers to the extent to which the reader is persuaded by the results and conclusions of qualitative research. This was assessed at several levels: the participants' understanding of the emerging analysis and comments on the process and results; the responses of SNQ-K raters; the responses of the user consultant and the responses of colleagues from the author's doctoral cohort. A written example is also presented. This is in the form of the thoughts of the secretary who typed the transcripts (Appendix 13). These were recorded without discussion with the researcher. They are offered unedited as an example of "lay" interpretation.

Coherence (Bannister, Burman, Parker, Tayley & Tindall, 1984) with other studies will also be assessed using triangulation (Redfern & Norman, 1994). The user, empowerment and recovery literatures will be referred to. The fit between these and the present results will be examined in the context of the fit between the present results and those predicted from SRV.

Results

3.2.1 Inter-rater reliability

The data used were the transcripts, completed analyses and respondent validity checks. The assessment was completed in one three hour period. No significant omissions or unexpected inclusions were found in the categories. The independent rater reported that "the themes were found to be consistent with the content of the topic and did not appear oddly put together". The flow charts were considered a good representation of the participant's "model". One theme, "poverty" was missing from the individual
devaluation chart. This was included in the reported version. Helpful comments were made regarding the layout of the aggregated chart for individual revalorisation. Alterations were made to increase the clarity of the reported version.

3.2.2 Individual respondent validity

To assess the level of shared agreement the emerging analysis was discussed with each participant after their interviews but before the group respondent validity exercise. Changes were unsurprising (e.g. Appendix 12). They included requests to reintroduce categories dropped in the refining process or to privilege one theme over others where causal relationships were at issue. Nothing was asked to be removed nor did anyone identify material they could not own. Participants’ comments added coherence to their accounts and were included in the later aggregation process. The flow charts taken to the group respondent validity exercise reflected these changes.

3.2.3 Group respondent validity

Comments included points of clarification, adding illustrative examples, concluding remarks or suggesting presentation ideas. All participants’ requested changes are reported in full in the flow charts used to portray the results.

3.2.4 Process observations

Being with the participants was powerful and moving. The depth of the experiences shared and the clarity of their expression was unusual outside therapy. The
participants trusted the researcher. There was clearly a correlation between the degree of self-disclosure and the participants' pre-existing relationship with the author.

There was anxiety in the devaluation discourse. This appeared to resolve sufficiently by the end of interview one to be "held" until the next. Participants mentioned this at the group. The participants' view of the researcher as a locally respected senior clinician appeared to have much to do with why this was possible.

During the devaluation interviews the researcher became aware of feeling responsible for participants' wellbeing. This alerted the researcher to the need to ensure an exploration of the degree to which the participants had integrated their experience and moved on. This took place during the revalorisation interview. Participants reported this contributing to deepening rapport and depth.

At the group meeting participants reported a sense of there being a "process" during the interviews. They experienced relief once the devaluation interviews were completed. This was replaced by renewed hope after the revalorisation interviews. By the time of this meeting there had been further processing of their experiences as they had communicated informally with each other. At the group meeting this was discussed again on a more intellectual level as various options for dissemination of the results were considered.

There was approval for the iterative approach to respondent validity. This was taken as a sign of valorisation in itself and of respect for the experience and opinions of the participants. Aspects of each participant's "narrative" were well rehearsed. This
reflected their experience as empowered user/survivors able to use opportunities to speak with interested professional audiences.

Participants were pleased with the "results of their efforts" and agreed to meet about disseminating the results. Their reflections on the research experience were positive. The interviews were painful and disturbing but reliving their experiences made participants realise 'how much things had moved on' for them and what a 'remarkable journey' they had taken. They appreciated the interview order and saw the parallel between the research process and their own journey. It became evident they had made good psychological use of their involvement.

3.2.5 Flow charts

Flow charts as used to portray the results of the present study are a methodological alternative to aggregate master lists. They are adaptations of a full IPA matrix (Smith et al, 1999, p.226). The themes and sub-themes found in the transcripts were placed into flow charts. These are then used to represent the aggregated "models" of devaluation and revalorisation captured by the procedure.

The first three charts (Figures 3-5) portray the themes and categories participants reported for devaluation at the three analytic levels. The second sequence (Figures 6-8) portrays "revalorisation" as it exists now or would if such experiences were more available.
The usual text conventions apply in “reading” the charts. The narrative begins centre top and flows downwards in a causal chain to the bottom of the page where the consequences of the depicted process are reported.

Each sequence is presented hierarchically, beginning with the societal level. This order was chosen because participants pointed out how each level contextualises the one below it. Understanding is therefore enriched reading from the societal level “downwards”.

Three further conventions apply. Themes within boxes represent the researcher’s analysis prior to the group respondent validity exercise. Items within circles or ellipses are comments, additions and emphasis changes made and agreed by the participants during the group respondent validity meeting. Arrows connote the stated direction of causality or order found in the transcripts. Supra-ordinate themes are capitalised.

Participants demonstrated a simple understanding of devaluation and comprehended the concept of revalorisation at the start of the interviews. The metaphor of a journey provided a useful frame for the interviews.

3.2.6 *Devaluation themes*
Figure 3. Societal level devaluation

FEAR AND BLAME

“You’ve failed”
“You are an embarrassment”

“Mentally ill people have given in and are weak”

NEGATIVE ATTITUDES TOWARDS MENTAL ILLNESS AS A DEVIATION FROM THE NORM

CATEGORISATION

“as mentally ill including diagnosis”

Segregation

Stereotyping

Congregation

Use of language

“Commodification”

NEGATIVE PORTRAYAL

Stereotyping

Social exclusion

Discrimination

Disbelief

Ghettoisation

AVOIDANCE

Lacking focus

Block treatment

Poor facilities

POOR SERVICES

“Ignore other co-existing problems”

Additional suffering

Inappropriate identification

Increased fear and anger in mentally ill people

Like the “THE WOUNDS”

“Getting stuck here is fulfilling society’s expectations”
Figure 4. Social level devaluation

SOCIETAL LEVEL

VIEWED AS ABNORMAL

The "Switch"

OTHER PEOPLES' CHANGED EXPECTATIONS

Failure to meet 'regular [ordinary]' expectations

"Self-labelling"

Negative discrimination

"Reduced expectations"

Exaggeration of existing social dynamics in the family

"No privacy - you become the object of almost everybody's advice"

World sees mentally ill peoples' 'behaviour' not feelings

'Negativity' - focus only on difficulty

Reliance on mental illness 'services' alone

"Negative identification - 'duped'; 'sucked in to it'; 'model patient'"

Overprotection & over-control

"It's DIY - you're waiting around left to your own devices"

Set apart from the 'normal' social world

CHANGED SENSE OF SELF
in relation to others: "a burden"; "a hassle"; "a failure"

+ Anger at the injustice

= CAN GET STUCK HERE AS A 'PASSIVE RECIPIENT'
Figure 5. Individual level devaluation

The "Switch"

PROCESS OF REDUCING STATUS

"Loss of control"

LOSS OF SELF-ESTEEM

"Spiralling interaction"

LOSS OF ESTEEM FROM OTHERS

REJECTION

Denial

"Avoid societal issues and own problems"

Categorisation

Social discontinuity

"No choice"

Realisation of 'failure'

"Buying into the 'system'"

Set apart in poor services/poor housing

"Poverty" "Passification"

Passivity

NEGATIVE INTERNALISATION OF DIFFERENCE

"Self-labelling & self-discrimination"

EMOTIONAL RESPONSE "Rock bottom"

GET STUCK HERE thinking "I’m no good"

or

"BOUNCE"

"Go to revalorisation!"

"Anger at others"

"Frustration"

"Avoid societal issues and own problems"

"Passivity"

"Social discontinuity"

"Reduced responsibility"

"No choice"

"Loss of control"

"Frustration"

"Avoid societal issues and own problems"

"Passivity"

"Social discontinuity"

"Reduced responsibility"

"No choice"
Participants' experience was uniformly grim. It reflected much that is known and well documented (e.g. Read & Baker, 1996; Sayce, 1998) (e.g. Figure 3). SRV has been criticised as a professionalised discourse. The opportunity to explore devaluation with user/survivors produced a richness missing from academic descriptions.

The three level analysis provides the reader with an opportunity to develop a multidimensional model of the devaluation process. Participants integrated their experiences at the three levels at different times and to different degrees but the kinds of experiences they reported were similar. Each began describing their early experiences of mental illness but reached a point where 'things changed'. One participant said it was like 'a switch was turned' (Figure 4). Participants agreed that once diagnosed, or on returning from their first hospitalisation, their social reality was permanently altered. In some instances this had an 'Alice in Wonderland' feel to it.

One participant returned from work one day to be admitted to hospital. He quickly became aware he had entered a world of people whose only interest was in him. This had the effect of feeding his manic grandiosity but also his denial:

_I was just whisked out of my life and put in this hospital. I refused to believe my psychiatrist that I was actually ill. He became totally disarming at one stage. This poor psychiatrist said to me 'I've been doing this for twenty years, this is a hospital, you've got a problem'. That's how desperate he became trying to convince me that I was actually ill_

(Participant 3: Revalorisation p.3)
Another participant referred to the reaction of family and friends when she did a 'positive story' for a local newspaper in which she disclosed her diagnosis. The reactions of others to the news was dramatic and negative:

They were my parent's friends who I'd grown up with and many of them were extremely shocked and didn't want to talk about it and what's gone wrong. I got the 'she was such a (good girl), brought up so well, why has this happened' sort of attitude and also after I'd come out of hospital and I was better, not well but better, and also I was, I'd had my paediatric training, I was actually refused work at the nursery at the church where I'd been brought up by friends of my parents and I found that very upsetting  

( Participant 2: Devaluation p.2)

The opposite could also happen. The same participant again:

It's my family, it's a bit like, 'Oh we've got the old Fred', cause I get called Fred at home, 'but we've got the old Fred' back sort of attitude, 'Oh you know, she went through a terrible time, but now she's back and she's one of us' (again) sort of thing, which is fine  

( Participant 2: Revalorisation p.5)

Themes reflected participants' and others' reactions to change and difference, as well normality and abnormality. Altered expectations (Figure 4) suggested to participants that revised judgements were being made about them individually and socially. Understanding of this led them to feel they were potential or real outcasts:
Well, one girl said that, 'I've never met anyone like you, you're totally out of order, you know your, I don’t want you coming round my house anymore and I don’t want you ringing me anymore' (Participant 4: Devaluation p.16)

Participants’ early experiences included a period of what professionals term “denial” but which they preferred to think of as disorientation, resulting from their own ignorance and fear combined with the ignorant and fearful responses of others. The potentially “collusive” nature of this was pointed out by the participants. They recognised repetition as part of devaluation especially when ambivalence was involved:

Yeah. So I go to (a drugs project), I'd explain why I thought I did it and they say 'yeah I think that is why, you know because of what's happened and you need to get a counsellor for that'. So then I’d go to someone who could give me counselling and they'd say ‘well you need to stop taking the drugs’ and that would frighten me because I thought well I can’t handle the flashbacks and the nightmares and everything so then I wouldn’t go. So then I'd go back to the (drugs project), and it went like on like that for quite a while

(Participant 4: Devaluation p.5)

It was possible to detect a devaluation “signature” that correlated with participants’ own descriptions of their mental health problems:

But like I say I’m sort of in a bit of a rut in terms of my own behaviour patterns and my own self image, it would be quite difficult to get out of that.
I'm still sort of in a situation where I'm not in and I'm not out

(Participant 1: Devaluation p.16)

Repeated engagement problems led to participants to see the results of individual ignorance and fear mirrored societally. Self-blame was both the cause and effect of misunderstanding:

Well, yeah, I suppose I have been angry about it but I mean I was more angry with myself about it cause I felt as though I'd let myself down that this illness was like you know something that I did to me

(Participant 3: Devaluation p.5)

Participants felt cut-off from previous and current realities. They had to survive alone in a world seemingly eager to make experience concrete as 'behaviour that needed to be treated with medication', rather than be understood. They also often became confused:

But as soon as we'd got (to the hospital) and we'd gone by ambulance, the stupid doctor saw us at Hilltop and I was in a terrible state thinking all kinds of (crazy) things and she sat there and said 'do you want to take her home on weekend leave', of course my parents were absolutely shocked and they said 'don't be so ridiculous we're not', and then they specialised me for the next couple of days, so I don't know”

(Participant 2: Devaluation p.5)
The most interesting themes from a psychological perspective reflected changes in participants’ sense of self. Reduced status operated at all levels but the intrapsychic effects seemed as potentially devastating as mental illness itself (Figure 5). Participants were clear that identification of themselves as causing their “ruin” came initially from them but their later experience, especially after diagnosis, only served to reinforce this. With their resources of self-esteem depleted they felt no match for changed social expectations and found it easy to lapse into devalued roles.

**People were scared of me, I mean student nurses were very scared and if they knew they were looking after me, they didn’t know what to do, they found it really upsetting and I remember them saying that to me. At that time I was never going to get better and I was going to die, this that and the other, so they found it very difficult** (Participant 2: Devaluation p.6)

In time disorientation became passivity. Passivity became intolerable which led to renewed efforts at gaining control. ‘Lucky chances’ played a part in changing cynicism into active involvement:

**So I then end up with a CPN and luckily very early on the CPN said to me how about trying Clubhouse, she didn’t know much about it herself, but she knew it wasn’t a day centre, so I then went along to Clubhouse….. and that’s really I would say the major turning point in my whole sense of wellbeing you know** (Participant 3: Revalorisation p.2)
I clicked with the (4th) counsellor and I warned her that when I got to a certain point I wouldn’t want to come anymore, so when we got to that point she said, ‘right we’ll have a holiday for two weeks and then you’re coming back’ (Participant 4: Devaluation p.6)

Well, I mean I was at the time I was living in the vicinities of Islington, was a group of us people on benefits and we would support each other …….. and feeling that I was really doing something, had purpose to go. I mean this wasn’t mental health it was unemployed, so single parents and long term sick, but was mainly people were on benefits that linked us together rather than any particular stigma of being either ill or unemployed or being a single parent (Participant 1: Devaluation p.8/10)

Well, (at 4/5th admission) just having someone to talk things through with……. being recognised…….that there were problems and being given that time you know by an OT is quite unusual (Participant 2: Revalorisation p.4)

Participants’ devalued status and identity presented them with two possibilities, ‘remain at the bottom of the human hierarchy’ or ‘bounce back’ (Figure 5). At that point participants recalled a pervasive, righteous anger, frustration and sense of injustice. During the present study these feelings were said to be reserved for when life conspired to echo troubled pasts. Recognising these feelings impacted positively on the capacity to ‘bounce’. This seemed to have as much to do with resilience as ‘lucky chances’:
It was like looking in an abyss, you know if I didn't quite pull myself together soon this is where I was going to be for the rest of my life and I was going to be stuck in it, but it was all down to me, just pull yourself together Bill, you know, sort yourself out and get on with your life because this is rock bottom, you can’t get any lower than this if you stay here

( Participant 3: Devaluation p.4)

SRV should take a more explicitly psychological position on the process of devaluation as it applies to mentally ill people. This might be in the form of a meta-theme characterised as “a societal reaction to the anxiety provoked by the uncontained fragmentation of the self that is associated with the seemingly inexplicable and negatively connoted emotional expression that is called mental illness”.

3.2.7 Revalorisation themes
Figure 6. Societal level revalorisation

"PURPOSIVE"

POSITIVE SOCIAL PHILOSOPHY

Collective responsibility

No Blame

All people are valued regardless of 'difference' and have +ve status

Mental illness is a social phenomenon not just internal

"i.e. Mental health is that of the whole community"

PSYCHOSOCIAL APPROACH TO MEETING NEEDS

Services adopt a 'Recovery' model

Emphasis on generic responses to meeting basic needs

Public education

Positive imagery/symbols, avoidance of -ve negative imagery/association

Expanding normative range of human experience

Use of the law to challenge mentalism

Use of the law to challenge mentalism

Collaborative therapeutic relationships

Support +ve role models who are 'out'

Positive media portrayal

"In the media because of problems of 'celebrity'"

"In the media because of problems of 'celebrity'"

"Adjustments to 'working arrangements' in the Disability Discrimination Act actively pursued"

Mentally ill peoples' contribution to society

"REDUCED IGNORANCE"
Figure 7. Social level revalorisation

SOCIETAL LEVEL

HOPE FOR RESTORING AND/OR SUSTAINING A VALUED LIFESTYLE

"From self"

PURPOSIVE SERVICE EFFORTS

Understanding

Valuing

Collaborative therapy

Exposure to positive role models

"Mutually supportive"

"Mutually supportive"

"Allowing/normalising distress"

COMMITMENT FROM SOCIAL NETWORK

Family/friends

Work colleagues/supervisor

POSITIVE SPIRAL OF BECOMING REVALUED

"Over time this may reduce"

"Coming out as someone who is recovering from or had a mental illness"

"I gained something as a person"
Figure 8. Individual level revalorisation.

**SOCIAL LEVEL**

"Supports this and makes the 'Bounce' possible"

"From self"  
BELIEF IN PEOPLES'  
CAPACITY TO RECOVER  
"From others"

**POSITIVE VALUING SERVICE PHILOSOPHY**

"Allowed to fail in safety"

**COHERENT APPROACH**

Engagement process/alliance  
Process of discovery  
Overcoming self-denial  
Faces reality

Focussed individualised development programme  
A planned process to deal with 'problems'

Belief in self  
Dealing with shame  
Valuing self by self  
Accepting challenge  
Adjusting to loss

Becoming empowered and becoming a positive role model

"Accepting oneself" + "Dealing with anger"

= "COMING OUT"

**SOCIAL INCLUSION IN VALUED ROLES**

Increased understanding & friendship

Valuing of self by others

"Having valued social roles helps get my sense of self to return"

Making up for lost time

**POSITIVE DEVELOPMENTAL SPIRAL**

Realistic psychological health/self actualisation

"[The chart] should be turned upside down to resemble an upwards spiral"
Revalorisation themes were not simple opposites of devaluation themes (Figure 6). Just stemming devaluation would be to perpetuate it. Difference and acquired difference had to be accepted. There could be no return to "before". Revalorisation experiences and wishes, had a revitalising or life giving feel that may be the effect of individualising what has previously only been described at the "class" level.

The emotional atmosphere of the revalorisation interviews had a tempered but hopeful air. Participants took pleasure in this. This was not however a denial of distress or reduced status.

The results suggest a view of revalorisation as a "purposive, hopeful and believing process" that takes seriously the recovery of personhood. These themes held the key to the striking differences between revalorisation and devaluation.

*I can actually do lots of very positive things, I can be very creative and use my imagination, my sense of humour, sure there's things that I can't do (anymore) and probably don't want to do is probably the truth, but there's some other good stuff that's still left over you know*

(Participant 3: Revalorisation p.5)

Devaluation was felt to be active but it was also considered "passive" because it supported the status quo. It required no effort or reflection to occur. Devaluation arose from ignorance, experienced as stubborn ignorance. Revalorisation was experienced as, and considered to require, a conscious, active process, considerable effort and shared reflection.
The active involvement of service users, families, mental health professionals, managers and politicians was important. Only when in harmony did participants feel there could be coherent support and direction to sustain their dealing with their difficulties. They were pointing to the same needs for consistency, boundaries and clarity of purpose so often called for by mental health professionals. They were also calling for simple humanity.

*If you're made to feel welcome and valued as a person, it doesn't matter what bloody label people give you, it really doesn't. And if you just walk in the door and someone says hello how are you, and you go 'Oh, how are you?' and you have a conversation then you're a human being. You know they say human beings talk to each other. It's not brain surgery is it?*

(Participant 3: Revalorisation p.12)

Although agreeing with this one participant felt no matter how much coming together there was he would never feel belonging. He later pointed out that he knew this was something particular to him and his self-concept.

*Well, it's a long time ago, but the fact that I can remember it shows that, well just feeling that I wanted to be one of them you know, I think that's merged over time that I've wanted that to feel that I belong and I still think I'm searching for that, this need to feel that I belong*

(Participant 1: Devaluation p.3)
There were direct references to the psychological components of revalorisation. A collaborative working partnership between psychological therapist or mental health professional and service user was important (Figure 7). This required trust, a non-judgemental stance and the normalising of distress. Therapist understanding of reality as the user saw it came before making suggestions for change. Challenge followed rebuilding self-confidence.

*I went to my counsellor and I said right, I want, I don't know how I'm going to do it, but I don't like the way I am now and I don't like the way I think about things and I'm fed up with being stuck in the past and I want to move on and she said 'well that's a tall order, you know we'll have to work it through' and, so, but I think, and she put a lot of, made me believe in myself and kept telling me all the good things I could do and all the positive things and I took it on board* (Participant 4: Revalorisation p.2)

The relationship between services and family was important. A mutually supportive understanding was critical to participants in coping with set-backs and consolidating success.

A planned approach to treatment and dealing with secondary problems was valued, each domain providing support for the other. Separation between the two was called for with periodic integration (Figure 8). Participants wanted their adult role boundaries maintained and bemoaned their infantilisation. They described the difficulty people had adapting to change. Friends who could not had to be given up.
As the revalorisation discourse proceeded, the linear journey metaphor, useful for framing participants' narratives, broke down. As participants reflected on changing from being a devalued person to their present position, devaluation remained just around the corner no matter how "revalorised" they felt. Revalorisation and devaluation were seen to co-exist in dynamic tension. At any time one or other might be strongest. Participants could separate genuinely personal setbacks from the social pitfalls of devaluation better when revalorisation was in the ascendant.

One participant described a potential pitfall. She was a development officer and regularly participated in management discussions. She was easily accustomed to a high level of debate. She discussed policy with senior personnel at conferences and such like. However:

_The barriers that people put in your way. For example, when I first started in my job I was having lots of trouble with the communications manager so I took it upon myself to arrange a meeting and my line manager came for support and I confronted her about how she wasn’t giving me enough leeway, like enough ownership of my projects because everything I did she’d change and she came back with ‘I've worked in mental health for nearly ten years’ and I said, ‘well I've been a mental health service user for ten years, so who’s more qualified’_ (Participant 4: Devaluation p.18)

The discussion was about a leaflet on dealing with mental health crises! She felt "invisible" but dealt effectively with the situation because she was empowered knowing her manager would support her.
One issue emerged in a strikingly different way from how SRV theorists usually portray it. The participants talked of “coming out” as someone who was gay might. This was important because they had emerged from their experiences of mental illness enriched in ways that meant more than simply having been restored or refurbished. They felt this even though the degree of their recovery varied considerably.

The SRV injunction to protect vulnerable people from devaluation by living within culturally valued limits is considered by some to mean “acting straight” or “passing” (Breakwell, 1986). Participants had an interesting interpretation of this. They agreed with the SRV position but felt no need to deny their difference. On the contrary, they felt they had to expand the normative range of human behaviour through education and positive role modelling, if not for themselves then for others. One participant who “came out” said:

Yes, it did, yeah and they (local user group) felt proud that I’d done it and they supported me and even gave me a card and said congratulations and everything, but because I had so much negative stuff around it became quite difficult (for me) for a few weeks  

(Participant 2: Devaluation p.2)

There was no incompatibility between these two positions. In fact a close reading of Wolfensberger (1972) reveals an understanding of how what is valued is time and fashion dependent; ‘We should work for greater acceptance of difference’, and ‘life-style modelling may be necessary to convince the public that deviancy is of our own making, and is often harmless’ (p.41).
Participants felt equipped to deal with personal distress only if they also had a "valued" purpose, a shared task and real challenge. Revalorisation had to be worked at. It also had to be part of the conflictual world not just services. At their worst services simply mirrored the denial, unresolved conflicts and pain of mental illness. In a revalorising world service users' identity and status would only be modulated by the strength of their self-esteem and boundaries.

A meta-theme for revalorisation would account for the integrating power of collaboration, continuity and consistency in relationships, valuing of difference and the creative potential of trust and mutual understanding. It was equally important to acknowledge devaluation experiences as part of revalorisation. The anger devaluation engenders should not be underestimated nor should its creative use.

Discussion

The discussion will first place the results in the context of SRV. Then they will be compared and contrasted with findings from similar studies of users views of their needs and the empowerment and recovery literatures.

3.3.1 SRV

The general principles of SRV resonated with the different forms the results took. Revalorisation was not simply the avoidance of devaluation but proactive, requiring effort and planning. This is consistent with SRV where watchfulness, mindfulness and personal commitment are emphasised (Wolfensberger, 1996).
Societal level devaluation (Figure 3) was fragmentary and fragmenting. Revalorisation was integrating (Figure 6) requiring a coherent response. Model coherence (Wolfensberger & Glenn, 1975) in SRV is used to design services so only what they explicitly set out to do occurs thus avoiding devaluing “side effects”.

The wounds were clearly evident (Figure 3). The extent that mentally ill people experience a “double jeopardy” was disturbing. It is generally accepted that becoming mentally ill threatens the sense of self. The present study suggested that the identity and status of mentally ill people is also threatened politically, socially and by services.

Real client needs were addressed very late. Years passed before effective psychological help was found. One participant felt so estranged he could no longer conceive accepting it. Basic needs were neglected in favour of time spent on ineffective treatments (Figure 4). Once these were balanced a naturally integrating and mutually supportive context emerged.

Anger at injustice, and self for accepting a negative, and false identification with blaming attitudes coming from the social and service worlds (Figure 4) was said to be hard to bear but, at the point of ‘rock bottom’ (Figure 5), became an energising force for change. Participants pointed out that “getting stuck” in a self-blaming cynical position was pervasive amongst users of traditional services such as day centres.

Supportive relationships between services and participants’ significant others were emphasised (Figure 7). This is only referred to as “Physical Settings: Accessibility to Clients, Families and Public” in the hierarchical model. Wolfensberger

The recurrent themes were all evident: living in the familiar community, having good access to facilities, sustaining and developing supportive relationships, individualisation, positive imagery and competency enhancement, access to effective interventions including psychological therapies, roles, role expectations and modelling and positive compensation. Space does not permit an exhaustive description of how each theme is reflected in the present study. Examples pertinent to developing psychological therapy are described below.

Stereotyping and changed expectations were evident in how participants saw themselves perceived and how their achievements were judged. These factors modulated the degree of devaluation or revalorisation experienced.

The importance of roles could not be overestimated. Loss of previously valued roles reduced responsibility and self-determination after becoming mentally ill and had negative consequences for participants’ sense of social reality, self-esteem and esteem in others’ eyes.

Some devalued roles not mentioned by but consistent with SRV emerged including becoming “the object of almost everybody’s advice” and a “commodity” after categorisation by diagnosis. Reduced expectations and overprotection were also reported.
Redeveloping valued roles was a fillip to self-esteem even when participants felt unwell. Challenge and access to positive role models were consistent with SRV. The results of 'coming out', however, were seen differently from traditional SRV interpretations. Sufficient culturally valued precedents were seen to exist in the disability world to suggest SRV theorists should re-evaluate this issue because of the opportunities 'coming out' provides to increase the range of valued roles. Participants reported a personal cost but thought it was worth it because of its value to others. The cost matched the traditional SRV position.

The importance of the developmental model was evident (Figure 8) and was described as needing a coherent approach. A focussed individual programme was required which built upon existing or past strengths but also offering challenge in activities chosen by service users.

Age and culture appropriateness were not mentioned directly but infantalisation was. Being a woman and a service user was not mentioned specifically although the women participants reported the effectiveness of a womens' group based on empowerment. Perhaps it was because of their obvious empowerment that gender was not as pressing as other themes. The gender of the researcher may have inhibited the discussion. The lack of cultural themes may reflect participants' "dominant" racial and religious status as white Christians.

The three kinds of need (Kristiansen, 1998) were referred to repeatedly.
Universal basic needs were seen to be ‘ignore(d by services and relegated to) other co-existing problems’ (Figure 3). Housing, social, vocational, educational and emotional needs were cited. These were mentioned as “problems” in the context of service neglect but as “needs” in relation to participants’ lives. In the revalorisation charts these were included in a “focussed individual development programme” (Figure 8).

Unique individual needs were mentioned. They required ‘a planned process’. Figure 8 details a psychological journey from ‘self-denial’ through ‘engagement and alliance’ to ‘discovery’ where people ‘face reality’ then develop a ‘belief in self’, ‘deal with shame’, come to ‘value self by self’, ‘accept challenge’ and ‘adjust to loss’. This journey led to empowerment and positive role modelling for people that completed it. The results were ‘accepting oneself’, ‘dealing with anger’ and ‘coming out’.

Revalorisation needs were implied. There was also explicit mention of positive compensation in employment. Using the Disability Discrimination Act (1995) was mentioned (Figure 6). Participants suggested it incorporate workplace guidance specific to integrating mentally ill people. One participant described the value she placed on her line manager’s enlightened approach. When she couldn’t work this was taken as part of her general health needs with no recrimination. This was very good general management and a prime example of the conservatism corollary.

The same chart lists other revalorising practices. These ‘reduce(d) ignorance’ and expanded societal horizons and dealt with abuse. Reducing ignorance was the antidote to the “blame and fear” of devaluation (Figure 6).
Wolfensberger (1996) portrays devaluation as a constant. He now encourages preventing devaluation at the individual level. He suggests most revalorisation should occur through personal commitment as this reduces systemic resistance to revalorisation and models social change most effectively.

The importance of hope was considerable. Not mentioned in SRV, hope may however be equated with personal commitment. The ingredients are portrayed in Figure 7. This chart depicts the connection between hope and what ought to be valid aspects of mental health care.

Conscious understanding of the relationship between anger, cynicism and the process of devaluation was considered an important step towards recovery and revalorisation. This was rarely seen to be achieved. Examples included a women's group and a Clubhouse based on empowerment.

Education about mental illness was a pervasive theme. The distinction between ignorance and denial was made. Having had to develop their understanding of 'all this' on their own was resented. Finding intellectual allies in the user movement was formative.

Collaborative relationships provided opportunities to understand one's position as a mentally ill person. This could take place in psychological therapy or with keyworkers. Collaboration had profound effects on the capacity to "bounce".
Working alongside people is consistent with SRV as 'intense and focussed effort to deal with real handicaps' (Figure 2) is required for effective change. SRV promotes understanding of the risks devalued groups are subject to as essential to developing staff awareness (Wolfensberger, 1983). The effectiveness of acquiring this kind of knowledge has yet to be evaluated in mental health services. The themes that emerged might aid such a task.

The 5 Service Accomplishments and the factors underlying the SNQ-K (Table 6) were obviously relevant. They required more attention paid to them or where they were attended to they needed careful planning and co-ordination (Figure 8). The participants' view, checked carefully by group respondent validity, was that problems and universal needs require different approaches and different boundaries. Both required the involvement of the person concerned and, whilst respecting adult role boundaries, family members. Tighter boundaries were preferred for personal problems. Dealing with problems required confidentiality and individuality which were more important than anything else.

The SNQ-K's two discreet domains (Table 5) allow for the separation described above. The congruence of the participants' view and the SNQ-K's two factor structure (universal and unique needs/problem identification) adds validity to the confidence CMHT staff had about using in that way. The relevance of the concepts indexed by the deeper factor structure of the SNQ-K scales was confirmed. However, the present SNQ does not yet reflect those themes, as they emerged here, that represent psychological revalorisation.
Triangulation

Method and theory triangulation (Redfern & Norman, 1994) are now used to test the convergent validity of the present findings with those of studies using different methodologies and theoretical perspectives.

3.4.1 Users' views

A broad consensus exists about users' views of their needs. A comprehensive review of quantitative studies conducted to determine how service users construe their needs by Strathdee, Thompson & Carr (1997) found consistent themes as follows (SRV defined needs in italics):

- A home (*physical integration*)
- Enough money to live on (*sustenance*)
- A meaningful day (*valued roles and activities*)
- Support and friends (*social integration and respect*)
- Relief from suffering (*unique individual needs*)
- "Expert" professionals (*treating real impairments*)

They cite evidence supporting the effectiveness of meeting each need (Craig, 1994; Rose, 1996) and evidence revealing that traditional mental health services fail to meet these needs (Smith, 1985; Conning & Rowland, 1991; Slade & Powell, 1994).
Faulkner & Layzell (2000) report a user led, qualitative study looking specifically at strategies for living with mental illness. Their study develops previous work (Faulkner, 1997) where 400 service users completed postal questionnaires about using mental health services, treatments and self-help. “Strategies for living” reports results from 71 in-depth interviews conducted with a structured sample of participants from the previous study.

The results were reported (The Psychologist: March, 2000) as services ‘need to switch their focus to individuals rather than diagnoses’ (p. 173). The results revealed common strategies and supports (Table 8).

Table 8. Users’ strategies for living (adapted from Faulkner & Layzell, 2000)

<table>
<thead>
<tr>
<th>'Most helpful’ strategies and supports</th>
<th>Medication</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Relationships with others</strong></td>
<td>Physical exercise</td>
</tr>
<tr>
<td>• Friends</td>
<td>Religious/spiritual beliefs</td>
</tr>
<tr>
<td>• Other service users/people with similar problems</td>
<td>Money</td>
</tr>
<tr>
<td>• Mental health professionals</td>
<td><strong>Other activities</strong></td>
</tr>
<tr>
<td>• I feel accepted</td>
<td>• Hobbies and interests</td>
</tr>
<tr>
<td>• Counsellors/therapists</td>
<td>• Information</td>
</tr>
<tr>
<td>• People encountered in day centres, drop-ins, voluntary sector projects</td>
<td>• Home</td>
</tr>
<tr>
<td><strong>Personal strategies</strong></td>
<td>• Creative expression</td>
</tr>
<tr>
<td>• Peace of mind</td>
<td></td>
</tr>
<tr>
<td>Thinking positively, taking control</td>
<td></td>
</tr>
</tbody>
</table>

Themes common to Faulkner & Layzell, (2000) and the present study included acceptance; shared experience and identity; emotional support; hope; purpose; peace of mind; choice and control. In addition to these shared themes, meaning, security, safety and pleasure also emerged.
Faulner & Layzell's (2000) recommendations reflect many concerns in the present study. They also called for formal recognition of service users' expertise (implicit in the present study), encouragement and support for self-help as complimentary services and more funds for black and minority ethnic projects.

Although stigma and fear were mentioned this was only as two minor sub-themes describing the effects of being diagnosed. The only effect of devaluation mentioned by Faulkner & Layzell (2000) was poverty. There was no mention of redressing the effects of deprivation prior to illness or ill-treatment consequent on it nor what effect both might have on users' identity. The themes related to the conservatism corollary and revalorisation were specific only to the present study.

Faulkner & Layzell (2000) asked “What helped you most?”. The present study appears to have uncovered valuable other material about the lives of severely mentally ill people by also asking about devaluation.

3.4.2 Empowerment

Rogers, Chamberlain, Ellison & Crean (1997) have developed and field tested a questionnaire designed to index the domains of empowerment as envisaged by an advisory board of leaders (Whyte, 1991) from the self-help movement. The scale has good psychometric properties. Many of the items it contains are similar to those of the SNQ-K. A factor analysis revealed five factors: self-esteem-self-efficacy; power-powerlessness; activism and autonomy; optimism; control over the future and righteous anger. Factors and themes from both the present studies are present.
3.4.3 Recovery

"Recovery" is a professional discourse not specific to mental illness, but widely publicised in US mental health journals. The theory takes seriously the plight of minority groups in society. At the present time it is gaining a following in the UK rather like SRV did in learning disability services in the 1980's. It was mentioned directly by participants in the present study.

Like SRV, the recovery model (Anthony, 1991) challenges traditional notions of a return to a unitary pre-morbid state (Vassallo, 1998). Anthony (1991) describes his vision of recovery as expanding traditional concepts of service outcome to include the dimensions of self-esteem, adjustment to disability, empowerment and self-determination. Anthony is neutral about the causes of mental illness. Self help, belief in recovery, stepwise change and the expert user contribution are mentioned. Similar to revalorisation, recovery can occur though symptoms recur. Interestingly from an SRV perspective, recovery from the consequences of illness (unemployment, poor housing, loss of rights and equal opportunities) is seen as sometimes more difficult than recovery from illness itself.

The "recovery" model is broadly compatible with findings from the present studies, the results of Faulkner & Layzell (2000) and of Chamberlain et al (1997). Recovery specifically mentions the problems people have in dealing with the secondary handicaps they experience as a result of the social consequences of mental illness.
The common themes of recovery are consistent with those of the present studies and include: belief in recovery; peer validation, being with trusted people; having a voice; taking care of oneself and taking responsibility for one’s own life. ‘Transferring anguish into suffering that can have meaning’ and ‘having hope and wondering what can be achieved and getting in touch with one’s emotional and spiritual side’ (Fisher, 2000) are similar to the ‘bounce’ participants mentioned here.

Service users’ views about recovery, are also familiar. The voting of a group exercise conducted at the National Summit of Consumers and Survivors in the US is reproduced (IAPSRS, 2000) in Table 9.

**Table 9. Users’ ratings of the important principles in recovery (IAPSRS, 2000)**

<table>
<thead>
<tr>
<th>Important principle in recovery</th>
<th>Number of votes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basic needs met</td>
<td>14</td>
</tr>
<tr>
<td>Recovery is possible for everyone</td>
<td>13</td>
</tr>
<tr>
<td>Belief in recovery</td>
<td>12</td>
</tr>
<tr>
<td>Humanist philosophy</td>
<td>11</td>
</tr>
<tr>
<td>Employment</td>
<td>11</td>
</tr>
<tr>
<td>Education</td>
<td>9</td>
</tr>
<tr>
<td>Informed choices</td>
<td>8</td>
</tr>
<tr>
<td>Peer support</td>
<td>7</td>
</tr>
<tr>
<td>Consumer-run drop-in centre</td>
<td>6</td>
</tr>
</tbody>
</table>

**3.4.4 Summary**

The findings above are broadly compatible with the factors and themes that emerged in the present studies. The consequences of devaluation are mentioned directly and are taken seriously. What is missing is a clear exposition of the psychological effects devaluation has on peoples’ identity and what might be done about them.
What distinguishes the results of the present study from others is the clarity with which the analysis captured the participants' struggle with a false identification of themselves as the cause of their downfall (devaluation). Participants in the qualitative study also articulated what was most helpful in enabling them to "bounce" back (revalorisation). These findings provide valuable data for understanding and answering the main research question of the present study: "does revalorisation mean anything psychologically?".

Critical review

IPA has strengths and limitations. It is potentially transparent and auditable. If well recorded it should enable a process replication if not a similar interpretation.

Transparency and auditability are desirable, not so much in the search for a definitive interpretation, but more to allow the reader to follow the logic and reasoning used by the researcher during the analysis. In turn this should allow the reader to decide if the interpretation makes sense in its own terms, even if alternatives could be developed using different processes or theory (Smith et al, 1999).

In writing this report methodological and theoretical transparency were also given priority. The auditability of the study was addressed by providing examples of the researcher's records in the appendices and the full transcripts in a separate volume.

It was obvious during the analysis that the themes were over-determined. The subsequent use of flow charts to portray the results was a significant development of
existing methodology but their use required connections and disconnections to be made between themes. Usually the transcripts guided this process. Where this was impossible some other rational process had to be employed. Much of what emerged during the present study was well known in the literature; so to “make the analysis work” this knowledge was used to enable linking and separation between themes. IPA became the servant of the study not the master.

This is not the same however as saying the author reported what he wanted to find. It is important to stress the careful, exhaustive approach adopted at every stage to check that the reduction from a large volume of data was the best solution to reflect participants’ experience. The most difficult aspect of the analysis was determining the hierarchical order of the themes. Accuracy was limited by the time available.

IPA requires self-discipline to assure that confirmatory and disconfirming or novel data are retained at every step. The incorporation of traditional individual respondent validity, and because of the aggregation of the themes across participants, the group respondent validity exercise, imposed further constraints on the researcher. The inclusion of the independent user consultant at the latter stage may have assisted in this or introduced new bias. This may be judged directly. The changes made at the group respondent validity exercise were fully reported in the results.

Further inter-rater reliability data would strengthen confidence in the interpretation of the results. The main methodological problem however was the limited range of theoretical sampling possible. It was beyond the scope of the present study to include for example, participants with a wide range of minority ethnic
experiences or at different stages of recovery. Further research should also include people who acknowledge the experience of being “stuck” or relatively unempowered, ignorant of mental health services, new to service use and past or present residents of institutions or community homes.

Participants in the present study all had some work but it was in mental health services rather than the “ordinary workplace”. It would be informative to interview complete system leavers. As one participant put it:

*I'd read a lot of stuff about people joining Clubhouse and I said to Jenny have you any material on people trying to get out of Clubhouse......but she'd never seen anything about exiting Clubhouse. Maybe I was the first to write a paper on getting out of Clubhouse*  (Participant 3: Revalorisation p.6)

The limits this places on generalising from the qualitative study may however, where conceptually relevant, be offset against the results from the quantitative study which relied on data from a representative sample of mentally ill people. It can also be argued that the contexts in which devaluation and revalorisation occur are stable but differences in content for service users with different “handicaps” would be expected. The results of triangulation with similar studies supported this contention. The picture of the context in which mentally ill people live was strikingly similar across studies.

Despite the differences between the quantitative and qualitative methods used in this dissertation the researcher found factor analysis and IPA to share considerable conceptual similarity.
CHAPTER 4

Clinical implications and conclusions

An ecological approach to psychological therapy for people who have been socially devalued and whose experience, status and identity require revalorisation is explored.

The results suggest themes that should be considered in making adaptations to existing psychological therapies and keyworking practices, especially when assessing and treating service users with significant "revalorisation" needs. These consist of ways to recontextualise the therapeutic relationship, possible new content areas, and process modifications to standard therapeutic techniques. Therapist acuity to potential devaluation and revalorisation experiences in the therapeutic relationship is discussed and consideration is given to which social and societal interventions might support this.

Warner (1994) has given a thorough analysis of the social, economic and political influences on outcome for schizophrenia. The research is persuasive. It is gradually becoming part of staff awareness in CMHTs. The results of the present study however suggests this needs to be balanced by also paying attention to the psychological tasks of revalorisation.

Clinical experience tells us that for most long term users of mental health services "valorisation" is actually a process of revaluing. Many problems that arise in engaging disaffected services users may stem from the lack of understanding services have in this area.
The present study tends to confirm this. Revalorisation requires a journey from membership of and identification with a devalued “class” to renewed membership of and identification with a valued “class”. The present research suggests the new valued class is not simply the one identified with prior to illness but a class of people with experience of mental illness who consider their experience valuable to society and who are prepared to say so.

The many examples of people who have made the journey back from devaluation include “user/survivors”, “self advocates”, and “graduates”. They are distinguished by their relative empowerment (Rogers et al, 1997), and having left the identity of “patient” behind. In Anthony’s (1991) terms they have “recovered”.

The experiences of people subject to devaluation may be referred to as their “devaluation histories”. Clinical experience suggests these are repetitive in form and are identifiable by a “devaluation signature”. Repetition was a theme in the present study. It has also been referred to recently in the depression literature. Parker, Gladstone & Roussos (1998) suggest early adverse experiences establish “locks” that can be activated by “keys” mirroring the earlier adverse experiences. Having a “lock” that can be “opened” by an environmental “key” is seen as one basis for vulnerability. The findings of the present study suggest attention could usefully be paid to establishing more formally whether devaluation experiences, in addition to being possible “keys”, can also create “locks” of their own.

The above echoes concerns in the psychosis literature about the ubiquitousness of loss, humiliation and entrapment. Birchwood, Mason, MacMillan & Healey (1993)
suggest loss, humiliation and entrapment stem directly from the experience of becoming psychotic and only partially recovering. The kinds of devaluing experiences recounted in the present study suggest there is also a readily available complementary source of experiences that are likely to contribute to or amplify these feelings.

Research on service users' ethnosemantic beliefs about psychotic illness focuses on reactions to being diagnosed. This work finds that people develop different coping styles using "denial" (Shepherd, 1984); "sealing over" or playing down the impact of illness thus rejecting help and labels (McGlashan, Levy & Carpenter, 1975). Acceptance on the other hand is viewed differently from different perspectives. The labelling model sees acceptance as a passive conforming to stereotyping. Shepherd (1984) sees people exaggerating their problems by adopting the sick role as a means to preserve dignity. McGlashan et al (1975) see this as simply one outcome of an integrating process in which the patient accepts responsibility for their illness, searches for meaning and attempts to integrate this with previous experience. Others see control through acceptance as a form of empowerment (Birchwood, 1991).

Ethnosemantics has recently been considered in the understanding of secondary depression in psychosis (Birchwood & Iqbal, 1998). In a study where depression co-existent with psychosis was examined two factors were causal: level of control over illness and internalisation of 'pernicious cultural stereotypes' (Birchwood et al, 1993). These results are seen to support Warner, Taylor, Powers & Hyman's (1989) approach which suggests psychotherapy should promote a blame-free acceptance of illness which should be combined with learning to control illness through, for example, anticipating
and controlling relapse (Birchwood, 1995) and voices (Chadwick & Birchwood, 1994).

Research also suggests that treating primary psychopathology without addressing the secondary or acquired psychopathology of a devaluation history has significant moral implications. For example, it is not acceptable to treat someone's paranoia alone when people around them are "actually" engaged in devaluing them (Haywood & Bright, 1997).

The present research was partly about determining whether the practice of revalorisation at a "class" level was sufficient to address mentally ill peoples' needs. The question was then asked whether revalorisation should encompass dealing with the psychological needs that arise not just from adjusting to mental illness but also from the effects of additional devaluing experiences. The results appear to confirm this.

The present study also explored the reframing of mental illness that SRV implies. Revalorisation seems compatible for example, with the guiding philosophy of narrative therapy, where, "challenging normalising judgements - the evaluation and classification of persons and relationships according to dominant 'truths'" (Epston & White, 1989) is considered paramount in the promotion of personal change (Vassallo, 1998). This seems particularly relevant to whether people get stuck with a devalued identification or whether they "bounce".

The results of the present research support the idea that internalising contemporary negative societal attitudes about mental illness is harmful. The author
takes a slightly different position to those mentioned above regarding the implications of this for clinical work and for the social meaning of psychological therapies for people with severe and enduring mental illness.

Therapists may need to work hard to really hear the truth of their patient’s devaluation narrative and convey that they accept much of it as true. This may allow the patient to realise for the first time that some of what they previously considered internal might actually be external. An important step in therapy might then be to enable the patient to reprocess their devaluation experience before moving on to more traditional therapeutic work about inappropriate internalisations made during pre-adult development.

This reprocessing may require converting the anger and cynicism of the “stuck” position into positive motivation for change. This might promote “the bounce”. The likelihood of this might be increased where therapist and patient shared an understanding of the devaluation that mentally ill people face. In the author’s experience this may need to be made explicit to the patient or may be facilitated by their membership of mixed groups of “graduates” and less empowered users. Narrative approaches in such groups have been reported (Vassallo, 1998).

Clinical experience suggests significant, life changing progress can be made in psychological therapy for people with long devaluation histories, even those with marked devaluation signatures, if the patient is enabled to give up false identifications they may have made whilst being made into a “mentally ill person” (Scott, 1981).
Clinical psychologists (and others) should consider how much they attribute devaluation to social or to intrapsychic origins. This is likely to differ for each patient. Such judgements can, as has been recorded in the present study, be either devastating or empowering.

Some may construe this process simply as a collusion between therapist and patient to split-off bad parts of the self and to project them into "devaluing others". Of course this is sometimes what mentally ill people do. Therefore the approach suggested here requires a careful exploration be made of the social and interpersonal processes that "make available the hook on which to hang the projection". The process of therapy can also be used to develop clarity about what is projection and what is equally collusive but socially denied devaluation. Once such clarity is achieved the process of revalorisation may proceed relatively straightforwardly.

Therapists will require skill, clarity of purpose and close professional support to sustain the validity of this stance, challenging as it does some valued traditional practices such as detachment and the disinclination to be "political" and not least because therapists are inherently part of a potentially devaluing context.

If the conservatism corollary were adopted then the current practice of working with people with a psychosis might be perceived as less "specialised" and more like general adult mental health work. In time the content of such work may begin to shift from dealing mostly with devaluation histories and current devaluation issues to the more familiar and culturally valued focus on peoples' concerns about their current lives and its echoes in their pre-morbid pasts.
Psychologists should therefore encourage early access to their services especially for people with a psychosis. People with a severe mental illness should not have to wait for experiences designed to enable them to adapt positively to mental illness. The cost of waiting on their own in a devaluing environment is too high.

4.1 *Specific individual interventions*

An SRV analysis based on the results of the present research has suggested some adaptations to current assessment and treatment practices to take account of peoples’ devaluation histories. There are also examples in the existing literature that suggest a similar understanding of the special psychological needs of the enduring mentally ill is emerging.

For example, CBT for psychosis involves collaboratively making sense of delusions in the context of a person’s life history and individual vulnerabilities. This takes on a wider significance when peoples’ responses to devaluing experiences are heard and something is also done about them (Fowler et al, 1998).

Similarly it is unreasonable to challenge self-denigrating beliefs without enabling people to challenge discrimination and improve their access to social and economic life (Haywood & Bright, 1997). CBT courses designed to inoculate against discrimination have been advertised recently purporting to:

*Assist clients to manage potentially debilitating experiences of ‘isms’, combating the internalization of negative psychological effects on self-*
esteem; thus promoting the capability to learn, cope and achieve

(Pernell-Arnold, 2000)


4.2 Social interventions

SRV advocates shifting from a dependency based service culture to one based on partnership and community. This can be supported systemically and socially by psychologists taking on the keyworker role. This would allow keyworking to be modelled in culturally valued terms as "mentor" not surrogate parent. Keyworkers may wish to follow the present study’s participants’ recommendation to plan meeting universal and unique needs separately. Keyworking also provides a valid route to address devaluation in family, social and staff systems. Holistic family interventions for schizophrenia (Smith & Birchwood, 1990; Fadden, 1998) are also important here.

Psychologists may offer support to colleagues to develop their capacity to distinguish primary handicaps from the PTSD that may follow breakdown (McGorry et al, 1991), secondary handicaps, and peoples' adaptive withdrawal from devaluing environments. This will require staff and family education and some myth breaking amongst long standing service users and practitioners (Fowler et al, 1998).
Supporting the development of hearing voices groups (Romme & Esher, 1993) which normalise the experience of mental illness is also consistent with the implications of the present research. Support could be offered to developing individual circles of support (O’Brien & O’Brien, 1991) for grossly excluded individuals as a way of recreating and sustaining valued roles for them in natural and freely given relationships.

4.3 Systems and societal interventions

SRV informed consultants can work at the systems level. Understanding valorisation and devaluation processes at the interface between service user and services can reduce institutionalisation in community homes and the anxieties that prevent culturally valued means being implemented more widely can be addressed in conjunction with psychoanalytic consultation (Obholtzer, 1994).

The values base of SRV may be shared amongst staff, users, carers and purchasers whilst developing locally agreed values frameworks (Turner-Crowson, 1997) to support later change in attitudes and practices. User involvement and in particular public involvement are also resources that are only recently being tapped in any constructive way (Strathdee, et al, 1997) and require active support.
Conclusions

*Mentally ill people may only shed their shame if society can treat them with greater value*  
(Sayce, 1998)

The degree of generalisation of the results of the present study was addressed through multiple triangulation. The comparison of the results of the present study with those of other discourses and methodologies confirmed the effects of social devaluation. Neither its causes nor those aspects of revalorisation that promote personal development were mentioned.

It would seem therefore that an SRV generated analysis of the experiences of people with severe and enduring mental illness has enabled the serious negative psychological consequences of devaluation that are rarely mentioned in mental health services but which are otherwise well known in studies looking at the experiences of other devalued populations (Breakwell, 1986; Scott, 1981) to be highlighted.

Whereas the SNQ-K was designed to quantify the support any person needs to meet their *basic universal needs* (Part 1) and *unique individual needs* (Part 2), the qualitative and quantitative studies reported in this dissertation attempted to validate the constructs required to understand *revalorisation needs* at the psychological level. The results will be useful when developing a future Part 3 of the SNQ-K designed to enable better clinical assessment of severely mentally ill peoples' all too often neglected but significant psychological "revalorisation" needs.
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Toronto: National Institute of Mental Retardation.


### APPENDICES

**Appendix 1.** PASS & PASSING factors and items *(adapted from Flynn et al, 1999)*

<table>
<thead>
<tr>
<th>PASS factors &amp; items</th>
<th>PASSING factors &amp; items</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Factor 1: Program (Pgm) - 14 items</strong></td>
<td><strong>Factor 1: Program - 15 items</strong></td>
</tr>
<tr>
<td>16. AA personal appearance</td>
<td>16. Image-related other integrative client contacts &amp; personal relationships</td>
</tr>
<tr>
<td>17. AA activities, routines &amp; rhythms</td>
<td>18. Service worker - client image match</td>
</tr>
<tr>
<td>19. AA autonomy &amp; rights</td>
<td>20. Image projection of program activities &amp; activity timing</td>
</tr>
<tr>
<td>20. AA possessions</td>
<td>21. Promotion of client autonomy &amp; rights</td>
</tr>
<tr>
<td>21. AA sexual behavior</td>
<td>23. Image-related personal possessions</td>
</tr>
<tr>
<td>23. CA personal appearance</td>
<td>35. Competency-related intraservice client grouping-composition</td>
</tr>
<tr>
<td>24. CA activities, routines &amp; rhythms</td>
<td>36. Competency-related other integrative client contacts &amp; personal relationships</td>
</tr>
<tr>
<td>27. Model coherency</td>
<td>37. Life enriching interactions among clients, service personnel, &amp; others</td>
</tr>
<tr>
<td>29. Social overprotection</td>
<td>38. Promotion of client sociosexual identity</td>
</tr>
<tr>
<td>30. Intensity of relevant programming</td>
<td>40. Program address of clients’ service needs</td>
</tr>
<tr>
<td>33. Individualization</td>
<td>41. Intensity of activities &amp; efficiency of time use</td>
</tr>
<tr>
<td>34. Interactions</td>
<td>42. Competency-related personal possessions</td>
</tr>
<tr>
<td><strong>FACTOR 2: Setting (Set) - 3 items</strong></td>
<td><strong>Factor 2: Setting (Set) - 8 items</strong></td>
</tr>
<tr>
<td>8. Function congruity image</td>
<td>1. Setting-neighborhood harmony</td>
</tr>
<tr>
<td>28. Physical overprotection</td>
<td>5. External setting appearance congruity with culturally valued analogue</td>
</tr>
<tr>
<td><strong>Factor 3: Administration (Adm) - 5 items</strong></td>
<td>7. External setting age image</td>
</tr>
<tr>
<td>38. Education of the public</td>
<td>10. Image projection of setting-history</td>
</tr>
<tr>
<td>40. Ties to academia</td>
<td>12. Image projection of program-to-program juxtaposition</td>
</tr>
<tr>
<td>47. Planning process</td>
<td>13. Service-neighborhood assimilation potential</td>
</tr>
<tr>
<td>48. Program evaluation &amp; renewal mechanisms</td>
<td><strong>Factor 3: Accessibility (Acc) - 3 items</strong></td>
</tr>
<tr>
<td><strong>FACTOR 4: Accessibility (Acc) – 3 items</strong></td>
<td>28. Setting accessibility-clients &amp; families</td>
</tr>
<tr>
<td>1. Local proximity</td>
<td>29. Setting accessibility-public</td>
</tr>
<tr>
<td>3. Access</td>
<td>30. Availability of relevant community resources</td>
</tr>
<tr>
<td>4. Physical appearance</td>
<td><strong>AA=Age appropriate</strong></td>
</tr>
<tr>
<td><strong>CA=Culture appropriate</strong></td>
<td><strong>AA=Age appropriate</strong></td>
</tr>
<tr>
<td><strong>CA=Culture appropriate</strong></td>
<td><strong>CA=Culture appropriate</strong></td>
</tr>
</tbody>
</table>
Appendix 2. Example of SRV principles at the service system level

VALUES IN ACTION (VIA) FRAMEWORK
Agreed 1 July 1997

The statement below was developed as a basis for implementing and evaluating the effectiveness of the Joint Mental Health Strategy. The framework draws on a review of sound policy and good practice, and seeks to reflect purchasers, providers and service workers will be expected to review their work against, and to progress continually toward puffing the values into practice.

Purchasing Values

The values listed below will be used by policy makers to plan, fund, monitor and evaluate contracts with service providers.

Policies and service provision should

- Be comprehensive to meet the needs of the whole population
- Be based around the needs of service users
- Give priority to people with severe difficulties
- Be located in the communities in which people live and work
- Be accessible, approachable and accountable
- Use practices that are based around evidence of effectiveness
- Be multidisciplinary and integrated with primary care
- Be provided for the length of time necessary
- Promote a culture in which expressing dissatisfaction can be accepted as an opportunity for improvement

2 Adapted from Turner-Crowson (1997)
VALUES IN ACTION FRAMEWORK

Practice Values

Purchasers will support providers that show development of services according to the values below. Services and practitioners should consistently operate to the following values:

- Communicate respect by taking users and carers seriously, as credible equals
- Fully involve service users and carers at all levels of provision
- Work together across disciplines and agency boundaries using an holistic approach
- Provide individually tailored services by trained and informed personnel
- Ensure informed choice
- Enable service users and carers to lead valued lives in the community
- Use language, actions and imagery to promote positive perceptions.

Adapted from Turner-Crowson (1997)
Appendix 3. Ethical approval for the quantitative study

Department of Public Health

Our Ref: LREC/328

24 December 1998

Dear Mr.

Re: Measuring Need According to the 5 Service Accomplishments: The Properties and Utility of the Support Needs Questionnaire

Thank you for your research proposal which was reviewed by the full Local Research Ethics Committee meeting held on the 16 December 1998. I am writing to confirm that the Committee were able to provide ethical approval for this protocol. The Committee wanted to commend you on your effort to involve service users in this work.

I would, however, remind investigators that our approval is conditional. Approval may be withdrawn if the Committee review the study and are concerned about the conduct or consequences of the work. The Committee require that the investigator inform them of any changes to the protocol, or any adverse events during the work, and expect to be given a copy of the final research report.

I wish you well in your research endeavours.

Yours sincerely

[Signature]

Dr. [Name]

Acting Chairman of Local Research and Ethics Committee

---

4 This is a scan of the original document with all identifiers including logos removed
Appendix 4. Ethical approval for the qualitative study

Our Ref: LREC/328

25 June 1999

Dear Mr,

Re: Measuring Need According to the 5 Service Accomplishments: The Properties and Utility of the Support 3 Questionnaire

Thank you for your letter of the 14th May 1999. I am able to provide ethical approval for this protocol amendment on Chairman’s Action. This decision was ratified by the full LREC when it met on the 18th June 1999.

I would, however, remind investigators that our approval is conditional. Approval may be withdrawn if the Committee review the study and are concerned about the conduct or consequences of the work. The Committee require that the investigator inform them of any changes to the protocol, or any serious adverse events during the work, and expect to be given a copy of the final research report.

I wish you well in your research endeavours.

Yours sincerely,

Mr.
Chairman of Local Research and Ethics Committee

---

5 This is a scan of the original document with all identifiers removed including logos
6 This permission was given as a protocol amendment to the quantitative study and therefore bears the same research title
Appendix 5. The keyworker version of the Support Needs Questionnaire (SNQ-K)

Developing Valued Lifestyles
Support Needs Pack
(SNQ-K)

On the following pages are lists of the sorts of things we all might want to do in our lives. This questionnaire is to help you judge how much support your client would need to achieve these things. We all need support more or less from someone.

Suppose your client wanted to do the things mentioned in this questionnaire and estimate how much support you feel they would need to do the things on the lists now. Put a circle around the amount of support you feel they need.

There is also space for you to write down the three most important things you think your client needs support with so they can meet their personal goals and objectives in the next six months.

Name: ..........................................................................................................................
R.T. No: ....................................................................................................................... 
Keyworker: ..................................................................................................................
Admin: ................... 1 ...................... 2 (Please circle)
Date: ...........................................................................................................................  

(snq-k1)
### Living in their neighbourhood

<table>
<thead>
<tr>
<th>My client would need</th>
<th>No help</th>
<th>Hardly any help</th>
<th>A bit of help</th>
<th>A fair amount of help</th>
<th>A good deal of help</th>
<th>A lot of help</th>
<th>A great deal of help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spend time exploring locally</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Find interesting places in the day</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Find the library</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Get a better place to live</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Travel on public transport</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Find a good corner shop</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Find the nearest supermarket</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Get to their bank/building society</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Get to the Post Office</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Find places with local social life</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Find the mental health centre</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Get to the dentist</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<td>7</td>
</tr>
<tr>
<td>Find a chiropodist</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Get to their place of worship/study</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Visit their friends/family</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Get to the GP surgery</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Find the Police Station</td>
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<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<td>7</td>
</tr>
<tr>
<td>Go out alone</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Go anywhere without hindrance</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Get to know their neighbourhood</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

---

**My client needs support to help them get to know their neighbourhood:**

1

2

3
## Getting involved in their community

<table>
<thead>
<tr>
<th>My client would need</th>
<th>No help</th>
<th>Hardly any help</th>
<th>A bit of help</th>
<th>A fair amount of help</th>
<th>A good deal of help</th>
<th>A lot of help</th>
<th>A great deal of help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Make more women friends</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Get on with their partner/best friend</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Stay in touch with their family</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Stay in touch with their friends</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Talk to their neighbours</td>
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<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Have friends to stay</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
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<td>7</td>
</tr>
<tr>
<td>Join a local association</td>
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<td>2</td>
<td>3</td>
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<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Visit their friends at home</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Eat out with other people</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Join a religious service</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Go to the pub/cafe with people</td>
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<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Join a sports or social club</td>
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<td>2</td>
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<tr>
<td>Go out in the evenings socially</td>
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</tr>
<tr>
<td>Enjoy company at the weekend</td>
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<td>2</td>
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<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Join a hobby/interest club</td>
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<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Look after their friends/family</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Make more men friends</td>
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<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Join a college course</td>
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<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Have people round to visit</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Get involved socially</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

### My client needs support to help them get more involved socially:

1
2
3
## Making their own decisions

<table>
<thead>
<tr>
<th>My client would need</th>
<th>No help</th>
<th>Hardly any help</th>
<th>A bit of help</th>
<th>A fair amount of help</th>
<th>A good deal of help</th>
<th>A lot of help</th>
<th>A great deal of help</th>
</tr>
</thead>
<tbody>
<tr>
<td>So they could</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Choose their own clothes</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Choose who they live with</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Have a say in who their support staff are</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Decide how to spend their money</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Have more say in what happens at home</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Choose their professionals</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Know and exercise their rights</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Decide who they spend time with</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Decide about their future life</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Decide who comes to their CPA review</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>See the records that staff keep about them</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Choose to join a service user group</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Find out their Mental Health Act rights</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Have more say in their day service/job situation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Decide how to use their time</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Get independent advice &amp; information</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Choose their CPA goals</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<td>7</td>
</tr>
<tr>
<td>Make decisions for them-self</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

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My client needs support to make more choices about:

1
2
3
## Being Respected

<table>
<thead>
<tr>
<th>My client would need</th>
<th>No help</th>
<th>Hardly any help</th>
<th>A bit of help</th>
<th>A fair amount of help</th>
<th>A good deal of help</th>
<th>A lot of help</th>
<th>A great deal of help</th>
</tr>
</thead>
<tbody>
<tr>
<td>A good neighbour</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Someone who looks good</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Respected by staff</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Someone with a job</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>A volunteer</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Someone who votes in elections</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Respected as an adult</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Valued for their achievements</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Someone who is not teased or laughed at by people</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Helpful to other people</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>A valued family member</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Safe from abuse/prejudice</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Listened to properly</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<td>7</td>
</tr>
<tr>
<td>Treated in a non-sexist manner</td>
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<td>2</td>
<td>3</td>
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</tr>
<tr>
<td>Respected for their religious beliefs</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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</tr>
<tr>
<td>Someone who dresses well</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<td>7</td>
</tr>
<tr>
<td>Valued for their cultural background</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Valued for their experience</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Respected for themselves</td>
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</table>

### My client needs support so they could be someone who:

1
2
3
### Building on my client’s strengths

<table>
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<th>My client would need</th>
<th>No help</th>
<th>Hardly any help</th>
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<th>A fair amount of help</th>
<th>A good deal of help</th>
<th>A lot of help</th>
<th>A great deal of help</th>
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<td>Go to adult education classes</td>
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<tr>
<td>Read a map/bus timetable</td>
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<td>Improve their reading</td>
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<td>Improve their cooking</td>
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<td>Do their housework</td>
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<td>Maintain their home</td>
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<td>Look after/mend their clothes</td>
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<td>Do their laundry</td>
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<td>Plan for their future</td>
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<td>Develop to their fullest ability</td>
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</tbody>
</table>

---

**My client needs practical help to develop their abilities to:**

1.

2.

3.
### Money matters

**My client would need**

<table>
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<tr>
<th>So they could</th>
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<th>Hardly any help</th>
<th>A bit of help</th>
<th>A fair amount of help</th>
<th>A good deal of help</th>
<th>A lot of help</th>
<th>A great deal of help</th>
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<tbody>
<tr>
<td>Get their benefits sorted out</td>
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<tr>
<td>Borrow money</td>
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<td>Deal with being in debt</td>
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<td>Save for a rainy day</td>
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<tr>
<td>Give money to charity</td>
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<td>Pay their rent/mortgage</td>
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<td>Find ways of getting more money</td>
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<td>Pay bills on time</td>
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<td>Recover a debt</td>
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<tr>
<td>Use cash/cheque/bank cards</td>
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<td>6</td>
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<tr>
<td>Understand bills</td>
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<td>7</td>
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<tr>
<td>Get the best value for their money</td>
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<td>Deal with home insurance</td>
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<td>Manage their money overall</td>
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</table>

**My client needs the following assistance with their finances:**

1.

2.

3.
### Being fit and healthy

<table>
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<tr>
<th>Needs help with</th>
<th>Never</th>
<th>Scarcely</th>
<th>Rarely</th>
<th>Now and then</th>
<th>Often</th>
<th>Usually</th>
<th>Always</th>
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</thead>
<tbody>
<tr>
<td>Seeing properly</td>
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<td>2</td>
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<td>Losing some weight</td>
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<tr>
<td>Stopping feeling stiff</td>
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<tr>
<td>Improving their hearing</td>
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<td>Stopping having a dry mouth</td>
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<tr>
<td>Looking after their teeth/dentures</td>
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<td>Breathing more easily</td>
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<td>Getting about indoors</td>
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<td>Being regular</td>
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<td>Going up/down stairs</td>
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<td>Getting enough exercise</td>
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My client needs help in order to be fit and healthy with:

- 1
- 2
- 3
## My client’s peace of mind

### Needs help with

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<th>My client</th>
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<th>Rarely</th>
<th>Now and then</th>
<th>Often</th>
<th>Usually</th>
<th>Always</th>
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<td>Worries about their health</td>
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<tr>
<td>Feeling too aggressive</td>
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<td>Feeling life is worth living</td>
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</tbody>
</table>

### My client needs the following help with their mental health:

1.

2.

3.
Appendix 6. Information leaflet supplied to participants in the qualitative study

CMHT headed notepaper

//

Dear [Participant],

Let me introduce myself. My name is [Consultant Clinical Psychologist's Name]. I am the Consultant Clinical Psychologist in Rehabilitation for Mental Health Services.

As a long term user of mental health services I would like to invite you to participate in a research project I am conducting.

As you may know we routinely ask people to fill in a questionnaire about their needs or go through it with their keyworker about once a year at the time of their Care Programme Approach review. This questionnaire is called the Support Needs Questionnaire.

Our project so far has been to find out if this questionnaire is a reliable measure of peoples' needs and to see how well it compares with other measures. If it is good then we could begin to use it to check on our work to see how we are helping people. In other words if the questionnaire is a good one then we could use it to see what kind of progress people make as a result of getting our service. This will help us to know what our strengths and weaknesses are as a service so we can make improvements to your care. We should also be able to make the questionnaire shorter and therefore easier to fill in in the future.

The project required that instead of the usual once, service users completed the questionnaire twice, about two to three weeks apart. Keyworkers were available to assist people as required on each occasion.

So far this project has allowed us to see how well the questionnaire works and also to make a more accurate assessment of peoples' needs now and in the future. What I wish to do next is to make some further checks on the ideas used to generate the questionnaire items. This will entail interviewing some people who have used services for some time but who have identified themselves to me as "survivors"; "graduates"; "self-advocates" or whatever - people who feel they have been there, done it and returned from their experience as valued citizens once again as a result of their experiences. I am interested in charting both negative and positive experiences of becoming a person with a mental illness and in making some sense of them with respect to the questionnaire and its validity, from the service users point of view.

For your further information you can speak with me about the project by contacting me by telephone, by writing to me or meeting me in person at a place of your choice. If
You would like an independent view of the project we have made arrangements for you to speak with of Advocacy Project and of User Group if you wish. I enclose their brochures. Do remember to ask specifically for or by name as the other staff may not be aware of the project. In the event of you wanting to discuss a problem such as making a confidential complaint you may also contact or .

If you decide to join in the research but change your mind after we have begun this will be respected, just let me know that you want to stop and that will be just fine. Please feel free to assert your wishes.

If you do wish to join in the project I ask only one other thing: that I have your permission to let your GP know. If your prefer not to give this permission I will understand and not pursue the matter any further.

Please take your time to consider if you would like to participate or not in this research project.

If you decide "yes" please complete the consent form attached to this letter when we meet and give it back to me. Once I know you are willing to participate I will then arrange the time and place of your choosing for you to be interviewed on two occasions each lasting approximately 1 hour and to attend a “focus” group with other participants on one occasion for an hour and a half.

After each interview, which will be tape recorded I will supply you with a transcript to check for accuracy and after both interviews and before the focus group I will share my interpretation of the themes that emerge so that we can develop an account you feel happy with, that you feel is authentic and meaningful to you. You will also receive a summary of the report of the results of the research within a few months of taking part.

If you decide "no" please let me know and things will just continue as normal with no further reference to the research or any effect on your care whatsoever.

If you do decide to join the project and you find you have a query that I could help with please do not hesitate to contact me at any time. All your enquiries will be dealt with in the strictest of confidence.

With many thanks for taking the time to consider this request,

Yours sincerely,

Consultant Clinical Psychologist in Rehabilitation

encl: Leaflets from User Group and Advocacy Project
Appendix 7. GP letter informing of participants’ involvement in the qualitative study

CMHT headed notepaper

December 1st 1999

Dear Dr.

re: Participant’s full name, address and postcode

I am writing to inform you that the above named client of the CMHT has agreed to participate in a research study I am conducting in the next couple of months and has consented to my letting you know. The study is known as: Measuring Need According to the Five Service Accomplishments.

The study is designed to assess the validity of our current Support Needs Questionnaire. This questionnaire is designed to make a detailed assessment of needs for people with social disabilities consequent on severe and enduring mental illness. The study will allow us to see if we can use the instrument in the future as an audit tool giving us the ability to determine overall levels of need on our caseload and to use it to assess our performance in providing adequate support in various life domains for people who use our service.

The research requires that participants are interviewed on two occasions and attend a focus group. The content of the interviews will focus on experiences that they have had that have helped or hindered in their recovery from severe mental illness. It will be my responsibility to deal with any consequences of your patient’s participation in this research. Past experience tells us this is very unlikely. In a previous audit our clients told us they felt valued by our approach to involving them in research and that it enhanced their relationship with their keyworker. Please note this was when we operated as the District Rehabilitation Service.

This research programme went to the Local Ethical Committee for approval in December 1998 and was approved. An extension was granted for the present interviews in June 1999. If you have any concern about your patient taking part in this research now or during the period of the research from mid December 1999 to February 2000 please feel free to contact me directly.

With many thanks,

Yours sincerely,

BSc DipClinPsych AFBPsS CPsychol
Consultant Clinical Psychologist
Team Leader

c.c. Participant
Appendix 8. Consent form used in the qualitative study

CONSENT FORM

Phase III: The User Perspective on Social Devaluation and Revalorisation

I, the undersigned, have read and understood the information sheet about the above research.

It has also been explained to me in writing and by the researcher that I may withdraw my permission at any time during the research without any consequences whatsoever to my care.

I agree to the audio-tape recording of the interviews I have with the researcher.

I understand I will have complete confidentiality and no identification of my interview information will be made in any subsequent publication of the research.

I agree to participate in the research study about Social Role ValOrisation and the twin processes of devaluation and revalorisation.

I give my permission for my GP to be written to informing them that I am participating in this research.

I have received information about UG and AP and understand that I may contact them in confidence should any problem arise out of the research during its course.

....................................................  ....................................................
Signed (Participant)  Witnessed (Researcher)

Date: .............................
Appendix 9. Semi-structured interview schedule for the devaluation interviews

The researcher described devaluation and revalorisation to the participant by quoting Jenkins (1999) and Kristiansen (1998). The participant is encouraged to ask questions for clarification. The researcher then asked the following questions in sequence.

Starter questions: What do devaluation and revalorisation mean to you generally?

Do you consider that at any time you became a devalued person as a result of becoming mentally ill?

Do you consider that you have become “revalorised”?

The “Journey”: If we consider that the process of devaluation is like a journey with many experiences and landmarks on the way to our destination can I ask you some questions about your experiences, feelings and thoughts about your own personal journey and how it turned out?

Individual level: Could you describe some of the experiences that you have had and the feelings that they evoked that you think led to your sense of identity, your internal sense of yourself becoming devalued?

Social level: Could you describe some of the experiences you have had socially in your roles as family member/friend/employee or with local services as a user that have made you feel devalued?

Societal level: Could you describe some of the things that contributed to you becoming a devalued citizen when you became a member of the “class” of mentally ill people. Things that happened in the wider world that you felt contributed to your sense that as a mentally ill person you were being devalued. Could you describe things that happened at a local or national level/perhaps at the political level within society that affected you?

Exploration: Participants were asked if there were common themes in their experience, and if there were patterns especially repetitions of experiences that crossed the personal-service user role divide.

Further questions were used to deepen the conversation by reflecting back emergent issues to obtain a more detailed or reflective account of participants’ experience.

Participants were finally asked if there was anything else they would like to say that they felt was relevant to pursuing the research topic in general.

7 The second interview replicated the first but concentrated on the participants’ revalorisation experiences instead. The “journey” was thus travelled full circle.
Appendix 10. Researcher’s notes of the initial coding into categories and emergent themes for participant 3’s devaluation interview transcript

A piece of shit basically. So, you know, I couldn’t work, couldn’t find a job and to pass the time I went to this place with these rather sad people.

And what did you think of a place where this is what you got for being mentally ill, what was your reaction to feeling you were in this position?

It was like looking in an abyss, you know if I didn’t quite pull myself together soon this is where I was going to be for the rest of my life and I was going to be stuck in it, but it was all down to me, just pull yourself together, Phil you know, sort yourself out and get on with your life because this is rock bottom, you can’t get any lower than this if you stay here. I did some interesting jobs during this time actually, because I got myself some temporary some casual work. I worked with people with learning disabilities and I had a great time doing that I really enjoyed it and it was really fun.

And were you assisted in doing that by the service or anybody you had contact with?

Not really, I was technically unemployed so what I had to do was declare to the unemployment office that I was doing this casual work so they would reduce my benefits by the amount of money I was receiving as a casual, but screw that, I thought to myself what am I doing, I actually enjoyed doing this cause I was working with people with all sorts of physical and mental health problems and I had a great time, the were tremendous people I mean probably the bravest man I ever met was down in Maidstone, a guy with cerebral palsy, he couldn’t move his arms, he was deaf, he knew how to sign, but he couldn’t sign cause his hands, he couldn’t move his hands and he’d spent twenty years in a bed in Oakwood Hospital and they’d got him into a wheelchair, so for Mike, this particular guy, he was triumphant because he was in a wheelchair, he’d cracked it, you know he could see what was going on yeah. And to be around that guy was such a pleasure, but the money didn’t mean anything to me I was actually with Mike you know and that’s I began to be really altruistic at that time, OK, I didn’t have enough, to buy myself another packet of cigarettes or go down the pub and have a beer, but an afternoon with Mike, that was worth much more than anything else you know.

Obviously your relationships with other people have a big impact on you and your life. You moving on to the positive one’s which we’ll be able to spend more time next time, but I wonder if you could talk a bit about the sort of reactions that other people in your life had to you when you became ill.

My ex-wife, who became my ex-wife during the process of my being ill told me that she didn’t think I was ill at all, that I was just doing it to hide from my responsibilities and, but that was fairly par for the course, and that’s probably why I divorced her, but that’s how she felt about me you know. She told me she didn’t trust me with the children and she wouldn’t let me see the children so I didn’t see my children, I haven’t seen my children in ten years, they’re no longer little kids. My youngest daughter at that stage was eleven and I haven’t seen her and she’s now twenty-one, so that was how my ex-wife viewed me, but she was so bitter and angry about the divorce that you know, with hindsight now, it doesn’t surprise me that she was bitter and angry, but that’s how, that
Appendix 10. Researcher’s notes of the initial coding into categories and emergent themes for participant 3’s devaluation interview transcript

was the sort of feedback I was getting from people around me. My oldest friend, I worked with him originally in 1968. I see about once a month for a drink and have continued to see him for once a month, and I like my standard of living has gone like this as his continues to up here somewhere. I’ve tried to explain to him about being mentally ill, but how can you explain to someone whose never been mentally ill about mentally ill, its impossible. All I can tell you is that continues to be my friend, we’re good makes, yeah. So, you know in terms of friends, that really hasn’t changed it. You see the bulk of my friends when I got ill were people I worked with, they were either, cause I was teaching for city bank when I got ill and every year I would get a new crop of graduates that I trained and they would then go into the bank and work and of course they were like generations of my ex-students stacked up in city bank. I couldn’t go into a bar in Covent Garden in those days without getting involved in someone else’s party. Of course all those disappeared cause I never went back to Covent Garden once I got ill and never haven’t been there since.

I Was that a conscious choice?

P Um.

I On the basis of what?

P Well how could I go into a pub

I Its alright, it’s a naive question.

P I couldn’t go into a pub and enjoy myself with my friends if I didn’t have enough money to buy drinks or if I had to borrow the money to come up there in the first place, so I deliberately didn’t have any contact with them.

I There’s a great loss of pride and status.

P Yeah, and history. I mean some of the best times of my life were with the students I was teaching at just a brilliant time and it was before that I was a trader financial markets trader, and shared a whole lot history with those times and I just couldn’t go.

I Somehow, the history and the changes that had happened to you could be brought together. It must make you feel terrible.

P Yeah, it was, I feel very isolated, very cut off from people that I really shared a lot with you know, but that’s life isn’t it.

I Your not angry about that cause its too long ago now.

P Well, yeah, I suppose I have been angry about it but I mean I was more angry with myself about it cause I felt as though I’d let myself down that this illness was like you know something that I did to me.

I Is it like that, should it be like that?
## Appendix 11. Initial categories/themes for participant 3 at the individual devaluation level

<table>
<thead>
<tr>
<th>Emergent theme</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Loss of control</strong></td>
<td>Exploited/deleted (p.6)</td>
</tr>
<tr>
<td>and status</td>
<td>Follow the system (p.3)</td>
</tr>
<tr>
<td></td>
<td>Self-denial (p.3)</td>
</tr>
<tr>
<td></td>
<td>Categorised by services/aggregated and segregated/what if you don’t fit category well? (p.3)</td>
</tr>
<tr>
<td></td>
<td>Paradox; get well, get shunned (p.3)</td>
</tr>
<tr>
<td></td>
<td>Passivity encouraged (p.8)</td>
</tr>
<tr>
<td><strong>Demeaning</strong></td>
<td>Rotten services (p.7,12) and facilities (p.3)</td>
</tr>
<tr>
<td><strong>Loss of hope</strong></td>
<td>Trust (p.4,5,9)</td>
</tr>
<tr>
<td></td>
<td>Responsibility removed (p.4,5,7,9)</td>
</tr>
<tr>
<td><strong>Discontinuity</strong></td>
<td>Divorce (p.4)</td>
</tr>
<tr>
<td></td>
<td>Children kept away (p.4,9)</td>
</tr>
<tr>
<td></td>
<td><em>Getting “lost”</em> (p.4,5,8)</td>
</tr>
<tr>
<td></td>
<td>Loss of job/work world (p.6,7,9)</td>
</tr>
<tr>
<td><strong>DIY [do it yourself]</strong></td>
<td>Pull self together (p.4)</td>
</tr>
<tr>
<td></td>
<td>Get casual work (p.9)</td>
</tr>
<tr>
<td></td>
<td>Get switched on to the system! (p.8)</td>
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<tr>
<td></td>
<td>Have to take responsibility for self (p.6,8)</td>
</tr>
<tr>
<td><strong>Negative reactions</strong></td>
<td>Denial (p.3,4)</td>
</tr>
<tr>
<td>of others</td>
<td>Blame (p.3,4,5)</td>
</tr>
<tr>
<td></td>
<td>Reduced responsibility (p.4,7,9)</td>
</tr>
<tr>
<td></td>
<td>No consistent response (p.7,8)</td>
</tr>
<tr>
<td></td>
<td>No compass (p.8,9)</td>
</tr>
<tr>
<td><strong>Poverty</strong></td>
<td>Knowledge of illness (p.4,5,8)</td>
</tr>
<tr>
<td><em>(Just need to note in the write up that this is poverty in the widest sense not just financial)</em></td>
<td>Experience of redundancy (p.5,6)</td>
</tr>
<tr>
<td></td>
<td>No money (p.5,7)</td>
</tr>
<tr>
<td></td>
<td>No more power (p.5)</td>
</tr>
<tr>
<td></td>
<td>Relationships/loss of peer group (p.5,9)</td>
</tr>
<tr>
<td></td>
<td>Exclusion self induced by shame (p.3,5) and poverty (p.3,5,7)</td>
</tr>
<tr>
<td></td>
<td>Reactions of others, and loss (p.5)</td>
</tr>
<tr>
<td><strong>Feelings about self</strong></td>
<td>Anger (p.5)</td>
</tr>
<tr>
<td></td>
<td>Disappointment (p.5)</td>
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<tr>
<td></td>
<td>Embarrassment (p.5)</td>
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<tr>
<td></td>
<td>Self-blame (p.5)</td>
</tr>
<tr>
<td></td>
<td>Isolation (experience you can’t share) (p.5)</td>
</tr>
</tbody>
</table>

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* Comments added by independent analyst during inter-rater reliability exercise
Appendix 12. Respondent validity for participant 3 at the individual devaluation level

- **LOSS OF SELF CONTROL**
  - "illness"

- **LOSS OF STATUS**
  - **LOSS OF CONTROL**
    - money/social etc
  - **POVERTY**
    - Insecurity/Stress/Worry
  - **NEGATIVE REACTIONS OF OTHERS**
    - Become passive recipient
    - Self-denial
    - "Poor" services
  - **DISCONTINUITY**
    - (e.g. divorce, loss of children)
  - Aggregate/Congregate
  - Perverse incentives
  - Probs with minority in a minority (MD)
  - **FEELINGS ABOUT SELF**
    - Loss of hope
    - Demeaning/shame/guilt
    - Loss of responsibility
    - Anger/disappointment etc
    - The "BOUNCE"
    - DIY (get myself together)
    - ?Good or bad outcome
  - Get information
  - I've got loads of skills so let's use them
    - Responsibility
    - Found new ones

Key: □ Researcher's analysis (Bold=initial themes)  ○ Participant stressed  ● Participant added
I think that most of the participants could have done with therapy at an earlier stage of their illnesses. There was certainly an issue with both the lady participants of possible side effects from traumatic events not being picked up until quite late on, which of course then led on to mental illness. I'm not sure where the blame should lie for this because several people could have picked it up, i.e. family, friends, work colleagues/boss, GP, etc.

All the participants had strived to “get on with their lives” without an awful lot of support from services at the early stage. This is in a round about way a positive result but, if they did not have a strong inclination to get better, they would still have been in the same mental state today.

It seemed that what would have been really important whilst they were all very ill was to still treat them as human beings and somehow keep them interactive with the outside world. (I'm not sure if I've quite put this right!).

There seemed to be a common theme around the issue of being labelled mentally ill. Most seemed reluctant to disclose to the outside world that they were mentally ill for fear of being treated differently. It is making sure that although they do have problems, pretty much like everybody else, they need to be treated like equals/normal human beings.

For most, working in the “normal world” as they progressively got better didn’t seem to work out, so most seemed to end up working in a mental health service environment. It seems that this is very rewarding for them because they are helping others in similar situations and they can relate to how they are feeling.

All seemed to really benefit from joining the Club House. It was a place that they could go and be themselves without having to worry about what other people thought of them. It also seemed to really encourage them to participate in rewarding activities like the newsletter, etc.

Overall, I feel that, as I think one of the participants said, “normal” people need to be educated more about mental illness and how easily it could happen to them. I certainly think this can be achieved through the media, i.e. television advertisements, etc. as has been happening with the give up smoking campaign. I think the main message would be: “be considerate, but not patronising”!

(Phillipa’s Thoughts)