Could Occupational Therapy Activities Chosen for Psychiatric Rehabilitation Produce a Community Experience in which Service Users attain Citizenship, Autonomy and the Capacity for Self -Representation?

Introduction

Occupational therapy is concerned with facilitating health service clients to return to "*productive occupation*" (Hagedorn 2000:27) following trauma or illness. However, rehabilitation outcomes often overlook the client's capacity to be a producer of value, and the citizenship issues which may arise with the status of producer (Pilgrim and Rogers 1993, Beresford, Gifford and Harrison 1996, Thomas 1997). This study considers the activity of community publishing as "*useful unemployment*", i.e. a voluntary role which produces value for *others* (Illich 1978:29), as an example of the many voluntary activities which might be available to rehabilitated clients.

Some 23 million people are engaged in voluntary activity in the UK, often contributing the greater part of the work of running some organisations and maintaining the services they provide. Voluntary work is a significant element in the economy (Davis Smith 1997, VAN nd circa 1998), within which a sizeable proportion of activity is based in the arts.

One of the most popular arts activities, and one in which there is substantial growth, is writing, which eclipses many performing and visual arts in popularity (VAN nd circa

1997). Writing requires little equipment, unlike photography, and can be practised discreetly, in a wide range of environments, unlike many musical instruments. Writing can be a matter of private exploration of feelings and ideas, for example, in the keeping of a journal. However, many people like to share and disseminate their writing with others, and through performance and publication have made the liberating discovery of their expressive 'voice' (Morley and Worpole 1982, Shohet 2000). Amongst these are a number of disability and mental health survivors' groups.

As an occupational therapist working with the severely mentally ill in the community, and with a long history of involvement in community publishing groups, these issues have a strong resonance for the author. Prior to the study the author had often discussed with colleagues the feasibility of community publishing as a development from occasional creative writing and newsletter activities with mental health clients. However, there appeared to be little evidence to support this idea. The activity of writing did not appear to extend from self-exploration to the challenges of self- representation in publication.

Literature review

Introduction

This study originated from a combination of interests in occupational therapy's concept of *"purposeful…"* (Moyers 1999:253) or *"productive occupations"* (Hagedorn 2000:27), and the activity of community publishing as "*useful unemployment*", i.e. a voluntary role which produces value for *others* (Illich 1978). Voluntary activity is widespread in the UK, involving 23 million people a year, often performing key roles in organisations and bringing their creativity, skills, talents as well as extending the range and enhancing the public image of the activities to which they contribute (Davis Smith 1997). Health outcomes in rehabilitation appear to overlook as objectives issues concerned with the rights of the individual beyond being a recipient of services to emerge as a *citizen,* e.g. being a producer of value, having an equal right with health staff to hold opinions (Pilgrim and Rogers 1993, Beresford, Gifford and Harrison 1996, Thomas 1997).

Writing follows 'embroidery/sewing/knitting', photography, and 'film/video' as the fourth most popular arts and craft activity in Britain, undertaken by 11% of adults (11% men, 10% women), over performing music, dance, drawing, painting, woodwork, and many others (VAN nd circa 1997). In the British Isles language and literacy has often been used in a discriminatory and disabling way against those who do not speak official English, Irish or Welsh (Bardon 1992; Bolger 1986; Williams 1985). Writing is least popular in Wales, 4% participating as opposed to 16 % in Yorkshire (VAN nd circa 1997).

Shohet (2000) argues that community publication has always been an issue of social inclusion, and this idea of a popular citizens' challenge to an official or establishment literacy is neither new or limited to these islands. For example, in the early 19th century, the Choctaw nation sent a number of boys to gain English literacy and become brokers to ensure its cultural survival in a White state. These scholars soon demonstrated their citizenship by using their new tools to publish critiques of their learning establishment (Pitcock 2000). Part of the impetus to establish a network of community publishers stemmed from teachers' critical evaluation that school reading material often did not reflect the lives of pupils and therefore was unable to engage them. Schoolchildren were encouraged to produce their own books to fill the gap (Worpole 1977), a process which Searle (1997) has continued, and describes as "*client centred*" (p68) since the educational practice of literacy is directly relevant to their participants' situation irrespective of cultural origin.

In a recent explanation of the Model of Human Occupation Keilhofner and Forsyth wrote that occupational therapy

> *"should always proceed with an appreciation of the life an individual has lived and might live in the future"* (1997:110).

This statement has a number of apparently client-centred implications: one concerns the unfolding narrative nature of clients' lives, another concerns the variety and potential of life during and following rehabilitation.

Increasingly, occupational therapists working with mental health clients are being directed toward work rehabilitation (McDonald 1997, Munday 1997). While work is considered to be a goal in the attainment of citizenship (Hagedorn 1995), it has frequently been the only, or a principal measure (Jackson 1993, Prior 1993). Hagedorn's discussion of social roles suggests a range of ways and functional levels through which individuals engage in the world around them, acknowledging that

"societal limitation and disability affect performance" (2000:37).

This does not appear to address the political social model of disability concerns which demand citizenship and equal rights in the face of these 'environmental' limitations (Drake 1996, Sumsion 1999a).

Strategies

Government documents outline a detrimental interaction between unemployment, poor education, deprivation and poor health (Barnsley, Doncaster and Rotherham Health and Local Authorities 1996, NHS Executive, 1998, Department of Health 1998a, Department

of Health 1999). Strategies at local and national level, including those concerned with an assertive outreach approach to severe mental illness, demand networking between statutory and voluntary services to remedy this through social firms, (venturing into areas such as print and reprographics) and providing alternatives to day activities (The Northern Ireland Urban Initiative 1996, Black 1996/7, Rooney and Davison 1997, Doncaster Healthcare NHS Trust 1998a, NHS Executive HSC 1998/045, Tasker 1998, Wood and Carr 1998, Doncaster Healthcare NHS Trust 1999 (following Shepherd 1997)).

Users' needs for non mental health service related networks, multiple approaches to work and occupational activities as alternatives to the patient role have been sparsely researched (Duggan 1997, Durham 1997, Department of Health 1998a, Seymour 1998). Research into these areas has been difficult to fund due to:

- an environment geared to a medical evidence base
- concerns for mental health clients about over-stimulation, or limited opportunities in time of high unemployment (Durham 1997).

Yet in the field of severe and enduring mental illness, the importance of early work on social skills deficits, maintaining non-family contacts and working to reduce the effects of social isolation on work performance is well documented. Clients require flexible and needs oriented approaches to re-develop or maintain themselves in the community. These may be outside normal pathways to employment, and vocational issues may be secondary

to other needs (Jackson and Birchwood 1996; Falloon et al 1998). The implementation of effective treatment requires:

- networks to be established with parallel employers and community organisations (Shepherd 1997, Burnett 1998);

- education and development work towards a non discriminatory community;

- this in turn requires that people with mental health problems are more easily able to openly discuss their experiences (Falloon et al 1998, Lincoln, Harrigan and McGorry 1998).

There appears to be little reported on the impact of supported employment measures, including unpaid work, for this group. Vocational schemes which include voluntary work and supported employment may be effective stepping stones to competitive employment, particularly when attached to multidisciplinary services and integrated treatment approaches (Bond, Drake, Mueser, Becker 1997; Harkapaa 1998).

Therapeutic Work

The social importance and definition of work and leisure activities may vary, even overlap (Hagedorn 1995, Thurgood 1997, Di Bona 2000). Participants may see therapeutic work by itself as simply "*drudgery*" Gilbert (1990:15) and themselves as disenfranchised through care packages which reinforce segregation, exclusion and dependency (Hachey and Mercier 1993, Robinson 1997). In both psychiatry and mental

handicap it has long been recognised that work has to be accompanied with social and educational measures including carer support:

- It is important to operate in natural environments rather than institutional settings (Bond, Drake, Mueser, Becker 1997, Brown and Bowen 1998)

- Programmes should meet individual needs if a client is to achieve the steps towards regaining an 'ordinary life' (Gilbert 1990, Hachey and Mercier 1993, Pilgrim and Rogers 1993, Durham 1997, Thurgood 1997, Brown and Bowen 1998).

- Job skills developed in one situation do not always transfer to others (Warner 1994).

Poverty is a major barrier to gaining health and overcoming the "*civil death*" (Goffman 1961:25) associated with mental illness (Hachey and Mercier 1993, Pilgrim and Rogers 1993, Langridge 1997). Stokes (1997) argues that although some clients perceive it as a second choice to paid employment, voluntary work is often offered to them, because most clients cannot earn more than they receive in benefits unless they can obtain full time work. Potential loss of benefits makes employment an unrealistic goal for many service users.

Users themselves may place more value and gain benefits from *social* aspects of voluntary work programmes, or indeed, any therapeutic or leisure activities (Hachey and Mercier 1993, Durham 1997, Di Bona 2000). Some professional health literature examines how work rehabilitation, using the arts, and therapeutic activities may translate into natural activities which rehabilitated mental health clients pursue outside the hospital

(e.g. Bertram and Linnett 1995, Oxley 1995, Martin 1996, Walsh and Connelly 1996, Durham 1997). Many opportunities have been created under the voluntary sector option of the new deal for arts organisations to provide placements for those on benefits (VAN 1999).

Some 11% of voluntary work in community arts concerns writing, particularly amongst young adults (VAN nd circa 1997, Matarasso 1998). While nursing authors have explored community resources for developing health education programmes (Cunnanne, Wyman, Rotermund, Murray 1995, Butterfoss, Goodman, Wandersman 1996, Paine-Andrews et al 1997) and touched on the issue of adult literacy and basic education, little is concerned with *voluntary participation* in arts activities such as community publication. This apparent oversight is significant given the growth in cultural industries across Europe, and that aspects of mental health policy mirror

concerns in educational strategies of the arts:

- motivating lifelong learning,

- combating social exclusion,

- facilitating social inclusion,

- and creating equal opportunities

VAN nd circa 1998, DFEE 1999, Department of Health September 1999b, Parkes 1999).

Community Publishing and Mental Health

Until recently, neither the mentally ill, nor other people with disabilities featured much in the 'communities of community publishing' (Bornat 1992; Walmsley 1995). There have been exceptions (e.g. Wiltshire 1985, Millbanks 1986, 'Fay' 1989, Labelled Disabled Collective 1991, Osmond 1993a, Osmond 1993b, Chatshow Writers 1996), some of which (e.g. Turner 1985, Cullen 1991, Cullen 1992) originated in hospital environments.

Survivors' poetry has seen a rapid growth through the last decade with several significant poetry anthologies, including one with Anvil published on a national scale (e.g. Bangay, Bidder and Porter, 1992, Ford, Hambrook and Porter 1995, Allan, Butler, Crawford, Graham, MacBain, Watters, 1996, Gerhard and Patel, 1996, Leeds Survivor Poets 1996, Thornton 1996, Smith and Sweeney 1997, O Keeffe and Boardman 1999). A writers' 'cookbook', Nibbles (Butler, Hay, and Paisley 1999) and a quarterly magazine, *Nomad*, is published by Survivors Poetry Scotland. Many survivors groups have produced their own publications and organised support performances, attracting funding through arts grants and health education monies.

Community publishing has rarely interested occupational therapists or other authors exploring the uses of creative writing as therapy, such as the members of LAPIDUS[1] (e.g. Bokrikar and Bumstead 1988, Foster 1988, Dynes 1988, Dynes 1989, Gersie 1991, Inglis 1993, Dwivedi 1997, Jensen and Blair 1997, Ruddock and Worrall 1997, Hunt and Sampson 1998, McDowell 1998, Schneider and Killick 1998, Bolton 1999). That work

which has made the link between health services and the community has mostly arisen through voluntary worker contacts (e.g. Chatshow Writers 1996).

It seems remarkable that this field of literature should be invisible to these authors, many of whom have worked in adult literacy, the Workers Education Association, or as librarians, and may well have used literacy materials or reminiscence aids produced by community publishers such as Gatehouse or Age Exchange.

Many community publications have a close relation to oral language. This relationship is reflected through production methods which sometimes include transcription of text from the spoken, rather than the written, word; the Federation of Worker Writers and Community Publishers favours a wide interpretation of "publishing", which includes public performance. Within the indigenous living cultures of Britain, this may hark back to Irish bardic, folk song, and Welsh folk poetry traditions as antecedents for a community literature, and oral transmission of craft knowledge (Evans 1960, Kinsella and O Tuama 1981, Morley and Worpole 1982, Palmer 1988, Jones 1997), but has close parallels with the methods occupational therapists use to disseminate knowledge, i.e. primarily, spoken narrative (Schwammle 1996, Detweiler and Peyton 1999).

Further these activities share, with contemporary health professional practices, a concern with reflection on participants' own experience with a common origin in the work of Paulo Friere (1972) (Morley and Worpole 1982, Fitzgerald 1994).

Reasons for this invisibility may be as follows:

- O' Rourke (1995) suggests that many literacy tutors simply ignore these materials, and so cannot effectively introduce them to others. Consequently much community publishing goes unread and unexplored. Szczelkun suggests that much of this material is "*filtered out*" (1997:5) by the middle class values of publishers and editors, and we might contend by extension, other authors, facilitators and therapists.

- Community publishers lack the distribution mechanisms available to large publishers. Instead publications are marketed through alternatives to bookshops like events at working men's clubs, or a rack at the newsagents (Morley and Worpole 1982, Schule and Woolley 1996). While intense sales can be generated in specific localities, community publishing is accessible mainly to those who go looking for it.

- Barris, Cordero and Christiaansen (1986) argue that occupational therapists' choice of treatment media is influenced most by their previous interests or exposure to activities during training. As few occupational therapists have arts backgrounds, arts interests are rarely carried through into treatment. Thus the limited awareness of community publishing identified above results in its absence from occupational therapy programmes, with clients being denied the opportunities and potential benefits which may result.

Community publishing generally describes the means by which groups of people produce publications about and for the communities they live in. As community art forms, these produce value and at the same time enable those involved to participate socially according to the commitment they can make, the work is done co-operatively, with little remuneration for those involved, and on a non-profit basis to minimise retail costs (Mace 1995, VAN nd circa 1998, Philips, Linington and Penman 1999). Though linked to literacy campaigns community publishers also put together educational resources such as community history and cultural products (poetry, cookbooks, theatre and other performance) (Mace 1995, VAN nd circa 1998). Survivors' Poetry and its individual member groups are mental health user led community publishers (Smith and Burgieres 1996).

While therapeutic writing remains part of contemporary occupational therapy practice (Philips, Linington and Penman 1999), some of the component skills of community publishing are perhaps less available now than at the start of the decade. The Adana 85 printing machine (featured in Hume 1990) is now rarely seen in a psychiatric occupational therapy department, nor do many have computers for client access (as featured in Reid 1990).

Running print equipment is prohibitively expensive, so most community publishers take their finished copy to a printer (Schule and Woolley 1996). At the Creafi workshop in

Lille, lead type is still used in literacy work. Participants include people with mental health problems, learning difficulties, as well as immigrants from former French colonies. The repeated demand of recognising typeface in reversed letters, composing text from the printers' case, helps teach romanised letter shapes (Lecointe nd circa 1998). Lecointe (p61) describes his approach, which uses print as a '*pedagogical tool*', as also that of a professional printer. Participants' acquisition of the knowledge of letters and their use to print text is treated as an '*apprenticeship*'[2].

One shift in thinking about literacy has been to move away from the idea of *illiteracy* to focus on a needs-led approach, based in everyday life. This emphasises what people *can* do rather than on what they can't, ultimately to express themselves through publication (A.B., Griffiths, Jones, Mackrell, Malone, Ragusa, Scott 1995, Barton and Hamilton 1996; O Mahony and Moss 1996).

Given this direction the practices of community publishing appear to blur across those of literacy and any other kind of publishing – e.g. ordinary writing groups may be concerned with their use of language, literacy students may produce historical or fictional as well as autobiographical writing (Mills 1985). While Mace (1996) is talking about publication by literacy students, many of her claims have potential application in mental health. She advocates (p69-70) the practice of student publication against the ideas that:

- literacy is about "*other peoples' power*" (p69)
- authors of texts in any public arena are 'other people'

- literacy students would only be concerned with the writing of reaction to others' demands (the proper way to write letters, fill in questions on printed forms, etc)

- that literacy students have a deficit in their own intellectual and expressive abilities, and that this is their fault

- "*literacy was only a small part of themselves… literacy means schooling… being literate is only about being schooled*" (p70)

Affirmation and Participation

Friere's concern in developing literacy was not merely teaching the mechanistic ability to read and write, but to employ these skills in expressing democratic participation, in utopian liberation (Friere 1985). The acquisition and extension of these skills is clearly part of the publication process for community publishers, for example through publication launches:

> "*This kind of display of the self-confidence generated by the new social relationships of writing and reading, are, for the majority of those attending, very important moments in the dis-establishment of literature and the mystique of publishing. For every reading is always permeated by the assumption that the listeners are now potential writers themselves.*"
> (Morley and Worpole 1982:41).

In some forms community publication represents, like its possible antecedents, a form of counter culture, a voice of opposition (Kinsella and O Tuama 1981, Morley and Worpole 1982, Palmer 1997, Szczelkun 1997). This can, however, be one which is socially beneficial, owing more to folk humour than to ideology, the

"pure unmixed expression… [of] a chorus of laughing people"
(Bakhtin 1984: 474).

It can also be simply concerned with human values (Shohet 2000), as amongst such autobiographical fore-runners of contemporary community publication as Kitchen ([1940]1982), Reynolds ([1908] 1982), Thompson ([1945] 1973), and Williams ([1915] 1984 and 1981). An oppositional voice may be claimed for all artistic endeavour, in the sense that art becomes an expression of being-in-the-world (Camus 1971, Kristeva 1984). In Sumsion's (1999b) discussion of client-centred practice, these ideas would appear to be coherent with the occupational and performance components of the model of human occupation, both feeling productive and expressing one's beliefs about the meaning of life.

The obverse of this is that personal experiences are also being socially valued and affirmed (Morley and Worpole 1982, Smith and Burguieres 1996, Bower 1997, Stuart 1998, VAN nd circa 1998, Philips, Linington and Penman 1999, Shohet 2000). An example is Life Story Work, where the production of video, tape and booklets with

clients is used to ease the transition of learning disabled people into the community from hospital by enabling them to communicate a presentation to new staff about themselves as individuals (Hewitt, Branton, Dunn, Willcocks 1997).

The sense that one's experiences are socially valued can also develop through the exchange of writer and listener roles in the publishing group (Shohet 2000). Silcock's (1998b:4) "*enabling practice*" aims to mirror the forms of organisation and decision making which occurs in writing workshops in health service settings, without the introduction of 'therapy' . This is an individual needs led approach to all aspects of "*writing for health*" (1998b:5), including the possibility of publication. Silcock suggests that enabling practice may be promoted in health premises, but take place in independent community venues.

Silcock's concern is to free individual expression from the constraints of therapy while encouraging the health benefits and pleasures which may result from it. She appears to agree with the ethical concerns of Walmsley (1995), Booth (1996), Nettle (1996), and McClimens (1997) in research. McClimens' discussion of 'emancipatory research' (with learning disabled participants) argues that the process of enabling clients to tell their own narratives often does not acknowledge inequalities in the process of dissemination. Clients may be asked questions they might not have been able to devise themselves, introducing inequalities into the production of material. Academic journals in which research appears are often inaccessible, and information is therefore unavailable to the

client, but this may also be the case if the client is simply unable to read back oral transcriptions.

Such challenges to client-centredness have also been identified by therapists using Canadian Occupational Performance Measures (Pollock, McColl, Carswell 1999), where deficits in the client's cognitive ability to express the self in language leave the therapist to interpret meanings on the client's behalf. Booth (1996) describes how the production of " *'readable'* " (p242) client narratives loses the sense of individual vulnerability and of short-term day to day planning associated with dependency on others. Rather than expressing their own feelings, responses may reflect clients or users' perceptions of the health professionals' expectations of them (Booth 1996, Nettle 1996).

This parallels a complex debate about writing and publishing within the FWWCP (Morley and Worpole 1982), which sets its members at odds with literature. A literary or a research establishment requires more consumers than authors, a balance of power which favours the writer or researcher over the reader or researched. The FWWCP, Silcock and McClimens would assert that people are the *authors of their own lives*.

Some creative writing practitioners in health suggest that defining therapeutic objectives may be unhelpful and detract from the participants' goals and benefits, or as part of a mechanism to contain mental illness, threatens the expressive value of writing (Chetcuti,

Monteiro and Jenner 1993, A.B., Griffiths et al 1995, Clayburn 1998; Natzler 1998, Silcock 1998a; Silcock 1998b, Philips, Linington and Penman 1999).

However occupational therapy recognises that

> "*all people create themselves and shape the world they live in by what they do on a daily basis*" (Wilcock 1999:78).

In enabling individuals to explore potential for making social contributions occupational therapy has the potential to enable a holistic account of citizenship, individuality, need and ability, by confronting the social and cultural production of disabilities (Sumsion 1999).

Occupational therapists are concerned to form better understandings of how work and leisure roles enable their clients' integration into the society beyond the hospital gates (Dyck 1989, Suto 1998). Where the needs of the mentally ill have long been marginalised from public consciousness (Murphy 1991, Tomlinson 1991) therapists can draw reflective lessons about their practice, as a narrative art, toward the facilitation of

> "*choices about occupational and human potential within a community of others*" (Peloquin 1989:225).

Peloquin, like Wilcock (1998), draws the relationship between art and occupational therapy as being essential to the holism of a profession which empathises with patients' "*feelings, ideas, and values*" and the meaning the patient places on "*life, relationships and the environment*" (Peloquin 1989:220).

Client centred occupational therapy, (i.e. in which the client is empowered to negotiate goals with the therapist) has to operate in a culturally diverse society, in terms of ethnicity, class and education. It also has to reflect the increasingly complex interrelations between individuals and their environments within and between these elements (Dyck 1989, Sumsion 1999a). Marginalised peoples' activities in determining their own needs and solutions may question some of the values and obligations, such as 'citizenship', which are group or social demands (Philips, Linington and Penman 1999, Pitcock 2000). These tensions can obscure central purposes, pulling apart rather than together, a problem for both community publishers (Campbell 1999) and therapists; Wilcock (1999) argues for occupational therapy to revisit its social activist roots. The therapy value in some rehabilitative activities may be in breaching, rather than confirming, conventional mores and values (Peloquin 1989).

Advocates for disability and mental health user rights describe disability as a cultural response to impaired functioning in individuals (Beresford, Gifford and Harrison 1996, Marks 1999). Because of disability, underprivileged minorities are rarely empowered to define the terms of citizenship, since the terms are set by a professional authority (Roche

1992, Kymlicka 1995, Marks 1999). If a therapy programme includes occupational opportunities such as voluntarism, clients can "*hang with the normals*" (Rebeiro and Allen 1998:283), thereby achieving social *acceptance*, but the social onus is that of a minority having to conform with a social majority through a normalization which integrates without according equal rights (Redworth and Redworth 1997, Myers, Ager, Kerr and Myles 1998).

This returns us to the ideas with which we began this section. Writing and publication are areas long associated with maintaining identity and purpose against social and political marginalisation (Davies 1990). Rebeiro and Allen (1998) argue that the benefits of activities geared to preserve social identity may depend on not "coming out" (p283) with one's mental illness, but preserving "*identity control*" (p285). Kristeva (1984) suggests that categorisation into either *madness* or *art* is a negation of the value of expression, since neither has to be taken seriously. Survivor poets aim to assert their reason through "*celebration, pride and unity*" (Smith and Burguieres 1996:4), i.e. as themselves.

Wilcock (1999) suggests that occupational therapists become politically active and develop secondary careers, e.g. as novelists, to similar ends. Community publishing offers a vehicle for people to be "*doers and writers*", not "*sitters and watchers*" (Froom 1985:73), thereby entering the "*politico-legal community*" (Roche 1992:3) through dialogic expression (Bakhtin 1981, Morley and Worpole 1982, Bakhtin 1984, Friere 1972). Thus community publishing and occupational therapy may share a view of a social

participation which enables people to emerge through the written word and through

publication stand witness for themselves (Bahktin 1981[3], Ragon 1986, Smith and

Burguieres 1996).

'Consumerist' approaches to client choice have produced an increase in user

representation in service developments, but clients' opinions do not outweigh

professionals in applied policy[4] (Davis 1991, Mangen 1991, Hoyes and Means 1993,

Rogers, Pilgrim and Lacey 1993,Walker 1993, Robinson 1997, Gummer 1998).

Redworth and Redworth (1997) argue that a more pluralistic society opportunity does not

have to compromise identity. Survivor poets agree:

> "*the reduced situation of the survivor DOES NOT prevent us from being*
>
> *creative*" (Smith and Burgieres 1996:17).

Many of these points are echoed in the Voluntary Arts Network briefing on persuading

policy makers and funders to support voluntary arts participation. Particular emphasis is

given to issues of enabling cultural diversity and facilitating access (VAN nd circa 1998).

Local initiatives like community publication may involve clients throughout, in collecting

the content material and the publication process. Clients themselves can directly work

against an assumption that those marginalised through their mental health should also be

excluded from history or community representation (Bower 1997, Fullagar and Owler

1998, Rolph 1998). Thus an arts based, self expressive route to active citizenship in

mental health entails giving clients the opportunity to question issues of consent and of everyday health practice (Bolton 1999).

Some professionals will still not read the results (Hart 1996). The role of the therapist as facilitator may have to be reformulated into that of 'kindred spirit' as trainer, consultant and advisor, a transformation consistent with the partnership objectives of client centred practice shared by Occupational Therapists (Banks, Crossman, Poel, Stewart 1997).

Transformation may also be demanded of the client. Some clients who seek publication entry to the public domain may encounter a family wish for privacy. Ethical committees have sometimes sided with the family against the publication of life story based research (Rolph 1998). In the small geographical spread of community publishing audiences family members have sometimes voiced suspicions about writing and strong objections to publications which may portray them to others (Morley and Worpole 1982). Many authors prefer pseudonyms, anonymity (Morley and Worpole 1982), or, as is evident from many survivor's anthologies, use the opportunity to construct new poetic identities[5].

Practicalities

Currently 40 FWWCP community publishers in Britain employ 140 people in full or part time paid work. There are numerous volunteers (Diggles 2000). Most community

publishers operate as co-operatives (Morley and Worpole 1982, Hunt 2000), some have evolved to charitable status (VAN nd circa 1996).

Most co-operative businesses involving mental health clients have had to be subsidised although this does not imply that they are not cost effective, since they may indirectly reduce other benefit costs by providing employment, services, skills training and promoting health and better life quality (Warner 1994, VAN nd circa 1998).

While co-operative enterprises may suggest a perception that new citizens have purchasing power through their benefits and the services they command, the low status and poor quality of some subsidised co-operative employment schemes can be very different to the experience of real (i.e. non subsidised) work (Roche 1992, Warner 1994). Community publishing co-operatives have experienced conflicts over production between paid workers and volunteers' varying abilities to give realistic commitment (Minority Press Group 1980). Similarly, difficulties with selling and design complications have arisen from the need for learning on the job (Hunt 2000, Szczelkun 1997). Stein and Santos (1997) describe working towards establishing the acceptance of mentally ill people in the workplace alongside vocational rehabilitation programmes, but this is given a different emphasis to the Trieste experience – work, rather than citizenship - appears more important.

With these enterprises the local community is confronted with a public experience of mental illness, an admission of what was formerly excluded to the asylum. In Trieste the community had to take responsibility for dealing with the issues this raised, no longer having a mechanism or facility for marginalising the individuals who were affected by them. While individual service users thus gained civil rights as "*'citizens with mental illness'*" (Del Guidice, Pasquale, Reale 1991:203), in any cultural activity this also negatively confirms that they, as participants, are different (Fullagar and Owler 1998).

While Survivors' Poetry may demonstrate a niche market for community publishing produced by user co-operatives and charities it may be too early to determine whether this is more than a trend (Worpole 1984, Worpole 1985, Smith and Buguieres 1996). It is important to consider potential audience and how it may be reached with a publication before producing it (Morley and Worpole 1982, Schule and Woolley 1996, Hunt 2000). These authors advise the market for community publications operates within the limits of:

- how many bookshops will actually take the books,

- how many books a local publisher can sell,

- how many such community enterprises can be supported in a particular area.

- the number of books a group can produce running on volunteer labour. Realistic print runs vary between 300 copies to 3000 depending on print method and market. It can be feasible to produce publications on a photocopier (Morley and Worpole 1982, Worpole 1984, Worpole 1985, Schule and Wolley 1996).

While these issues may be constructed negatively, they represent the kinds of creative

challenges and responsible risk taking opportunities that voluntary arts projects offer

(VAN nd circa 1998).

Community publishing may offer a means of linking social, civil and political dimensions

of citizenship (Roche 1992; Szczelkun 1997). While reciprocal relationships appear to

feature prominently in its operation, the focus is on cultural expression, the production

and promotion of an emancipatory literacy and history (e.g. A.B., Griffiths et al 1995,

Szczelkun 1997). While there is a sense of mutually achieving social obligations to

create, work or produce, in a diverse and accessible social and political community arena

(Roche 1992, Kymlicka 1995, Myers et al 1998, VAN nd circa 1998) there is a keen

emphasis on answering the needs of the individual as a creator of verbal expression in a

society of voices (Bakhtin 1981, Morley and Worpole 1982, A.B., Griffiths et al 1995,

Smith and Burgieres 1996). In these respects, and as we have disussed earlier in the

chapter, community publishing practice apparently shares similar terms and has strong

parallels with occupational therapy in 'client-centredness'.

Methodology

A literature review, using Medline, Assia, Cinahl, and hand searches (due to the

extensive 'grey literature' in this field) explored the possibility of connections between

the goals of occupational therapy and community arts activities, specifically community

publishing. Forming the basis of the dissertation proposal, it aimed to draw appropriate parallels with other arts forms and work in other disciplines. Few articles from health disciplines deal with these forms as actually practised in community settings.

Accessing the experiences and needs of those involved in community publishing was crucially important to the study. Much of the data on community publishing (as a vehicle for both community arts and voluntary work) included published narratives in small locally produced editions, pamphlets and leaflets, occurring in widely dispersed but dense localities. This publishing on an ad-hoc basis consists largely of what Strauss and Corbin term "*nontechnical literature*" (1998a:49). Often it has not been collected by libraries but can be found in storerooms of community facilities or private book collections.

This archive material, and previously published autobiographical material allowed individual experiences to be considered alongside focus group data to give both the immediacy of direct experience in community publishing and an historical perspective and determine common points and divergences and strengthen validation (Baszanger and Dodier 1997).

To subject this and any new data to a systematic analysis and produce a study open ended enough to allow further research a grounded theory methodology was initially decided upon (Glaser and Strauss 1967, Strauss and Corbin 1998b). The potential for applications of community publishing in a health sphere is apparently unexplored, and so

the study would have the task of building theory and would be qualitative and 'conceptually dense'.

Grounded theory has a popular usage in practitioner fields (Strauss and Corbin 1998b). Hagedorn suggests this as one research methodology because occupational therapy

> *"has more of the features of a social science than a pure science… where experimental or quasi-experimental techniques are inappropriate"* (1995:194).

It has been

> *"a significant influence on nursing research"… "of most use when little research in the subject area has been completed"* (Smith 1997:18)

and in others, e.g. a personal "*valuing process*" in oral histories (Keddy, Cable, Quinn, Melanson 1993) linked to community publishing processes. This individual perspective in developing research fits well with Hagedorn's discussion of the occupational therapist as "*artist-scientist-inventor*" (1995:111-2) and Sumsion's (1999c) discussion of therapists finding their knowledge base challenged through client centred practice. One role for the practitioner is generating theory from the evidence of practice.

Qualitative Studies and Approval

Due to the use of qualitative methods to explore hypothetical social phenomena gatekeepers to research approval require detailed explanations before accepting them as valid (Smith 1997, Marshall and Rossman 1999). In the case of grounded theory, both the originators and other researchers' methodological divergences may have discredited the approach (Burgess 1984, Smith 1997[1]).

Questions of methodological validity present an ethical problem, since participants cannot give informed consent if the approach used in the study lacks coherence (Doncaster LREC 1997). However, the Department of Health defines coherence narrowly, emphasising a "*scientific*" basis for policy (Department of Health 1995). The NHS Executive's discussion of clinical effectiveness concentrates on randomised control trials (RCTs) but also accepts "*other robust experimental or observational studies*" (NHS Executive 1996:10).

The positivist assumptions of these policy demands do not allow for qualitative studies, which are not wholly generalisable, to identify aspects which are replicable. It can be difficult for quantitative studies to accommodate or represent the description of feelings and attitudes in user centred ways. Often users respond to clinicians with answers they think researchers may like to hear rather than a genuine reply, as a product of conditioning to interactions with authority figures (Nettle 1996). Responsible informant

centred information sharing is a concern of grounded theorists (Strauss and Corbin 1998b). These studies need to be thoroughly descriptive in order to generate sufficiently useful data to identify which findings could be transferable to other contexts (Schofield 1993).

These issues, some of which are recognised in *Keys to Engagement* (Seymour 1998), an influential document on severe mental illness policy, challenge those professional groups whose practice may lead them to pose different viewpoints. Randomised control trial practices do not take into account contextual features, such as patients' and clinicians beliefs and attitudes. These may prove important to successful treatment (Black, 1996, cited in Kendall, 1997) and are seen as vital in enabling services to meet user needs (Duggan 1997, Seymour 1998).

Random Controls and the Arts Based Therapies

Concerns with attitudes and beliefs are particularly relevant to professions such as nursing (Kendall 1997) and occupational therapy which deal with individual needs. Often treatment outcomes cannot be replicated in client-centred approaches (Sumsion 2000). It is hard to see how evidence solely gained from RCTs can fit with the professional philosophy and practice of clinical professions, which are, none the less, expected to produce an evidence base for their human interests and address pathways back to social inclusion (Durham 1997).

The origins of research, including RCTs, are in person beliefs. This throws up potential problems such as researcher bias which the theoretical sensitivity required by grounded theory can explore and explain (Strauss and Corbin 1998b). Research in arts related therapies has to accommodate diversities and exceptions (Grainger 1999). In contrast with a government demand that evidence based practice is routinely applied in everyday practice and that its impact is monitored (Department of Health 1998b) grounded theory recognises that researched solutions for specific groups have a trajectory rather than a necessarily immediate generalisability (Strauss and Corbin 1998b).

For Grainger the application of arts therapies in achieving individually meaningful outcomes for clients is problematic for scientific reasoning, and understanding low cost of drug free but individual and "*pragmatic*" therapeutic work may be outside its scope (Grainger 1999:14). Strauss and Corbin argue, conversely, that lay and practical understanding must be incorporated amongst the multiple perspectives which inform grounded theory. By incorporating this data "*in conversation*" (1998b:172) with received theory a testing takes place which may accommodate evidence-based practice.

It is not research that replicates findings of "*what is already known*" which is required (Blaxter 1995:14), but which finds innovative and "*alternative*" strategies to ameliorate these issues, processes immersed in the social world. Thus because NHS research policies may reflect the concerns of the provider rather than those of the consumer, they may not

be the best equipped to investigate and understand problems its own agencies have identified (Blaxter 1995).

Community publishing often has the same object as social science – of its writing "*making sense*" of reality (Morley and Worpole 1982:92). Though grounded theory is supposed to generate theory from the data of social research (Glaser and Strauss 1967, Strauss and Corbin 1998b) Glaser and Strauss acknowledge that no research is without antecedent (1967). This study did not start from a *tabula rasa*. One reason for the author's interest in the field is an experience of writing workshops and community publishing over two decades, including using these activities as therapeutic media in mental health. With a study based in lived experiences it would be foolish, and impossible, to deliberately ignore prior knowledge of the field in the data set.

Reflexivity

This issue increases the difficulty of ordering data systematically to provide a credible analysis which can generate theory (Glaser and Strauss 1967. A diary was maintained through the entire study to relate the study's development to the author's past and present experience. This also introduced a quality enhancing 'reflexivity' to combine with data from the literature search and the focus groups (Henwood and Pidgeon 1993). The use of a reflective diary parallels the production of autobiographical material (which mostly constitutes the content of community publishing) and the generation of data and discovery of substantive theory.

Since the distinction between data and theory is not always clear, the researcher should be prepared to accommodate new developments in "*a rich, deep and well integrated conceptual system*" that *"works"* (Henwood and Pidgeon 1993:22). A diary allows the researcher to be "*questioning, questioned, and provisional*" at each progressive stage of the study (Strauss and Corbin 1998b:173) accommodating prior knowledge with further data, testing and analysis until there is sufficient information to write a reliable proposition (Glaser and Strauss 1967).

It is also compatible with the way in which occupational therapists and other health workers discuss their professions (Fish 1998, Detweiler and Peyton 1999). Reflective practice enables the identification of critical incidents and offers this data to critical analysis alongside new material. By making the ordinary extraordinary, critical analysis problematises what is assumed knowledge (Fitzgerald 1994). As with grounded theory, it would be presumptuous to theorise before subjecting "*prior knowledge*" to the same rigour as new data (Glaser and Strauss 1967:34).

Much of the study data is composed of narratives, each of which is a reconstruction, and the social reality presented in it is only partly consensual – each narrative admits the possibility of other narratives interpreting differently the same events (Clandinin and Connelly 1998, Manning and Cullum-Swan 1998[2]). A study drawing on subjects' personal experiences and perceptions and a variety of theories requires open-endedness

(Glaser and Strauss 1967, Strauss and Corbin 1998b)[3] and the flexibility of allowing

multiple methods for triangulation and strengthening validity (French 1993).

Grounded substantive theory enables the identification of controllable variables in

interactions, thus firming up the internal consistency of the study (Glaser and Strauss

1967, Strauss and Corbin 1998b). This is important to the exploration of data derived

from non-clinical sources and other disciplines such as community publishing, but

particularly so with occupational therapy, where beneficial outcomes are attributed to the

quality of interactions between participants as well as the pursuit of a specific activity.

Preliminary reading suggested complex issues of empowerment, artistic ownership, and

tensions about citizenship, a dynamic and progressive relationship between people and

potential for societal change through voluntary arts participation. Furthermore, because

the occupational therapy profession shares its knowledge base dynamically with other

frames of reference, there is a risk that elements claimed by the discipline are not

synchronous with core principles (Hagedorn 1995). This suggests a problem of coherency

and need for the examination of process, which is also identified as a concern of

grounded theory (Strauss and Corbin 1998b).

Given these issues, the data may not easily combine to produce useful statistics or a

credible history. Like Glaser and Strauss (1967) Baszanger and Dodier (1997) describe a

tension between data gathering and mechanisms for ordering, in which the outcome may

be too diffuse or distorted by the methodology. They suggest, however, that an approach which allows exploration of plural narratives will generate factors for statistical comparison and a sense of historicity.

Here a multi-site study would generate a considerable amount of data and make striving for coherency difficult. This problem of coherency is well documented in occupational therapy literature (e.g. Hagedorn 1995, 2000). Occupational therapists work in many different specialisms, reading any professional journal reveals a diversity of practice. Similarly amongst community publishers there are many different approaches to publishing. The FWWCP membership reflects considerably diversity of interest: adult literacy, oral history, local history, writing issues connected with mental health, ethnicity, disability, gender, and poverty, language rights, performance, alternative arts and combinations of these interests.

A master's dissertation cannot resolve these issues, which might be termed "*non-emergent categories*" Glaser and Strauss (1967:193). While later developments might investigate subsets in the data, the author's initial object was to find a loose coherency that 'works' from what is already disparate. Given these issues, it was thought that the author's prior involvement in community publishing would assist entry to the field and generate good data (Marshall and Rossman 1999). While it also carried a risk of introducing categories which were "*forcibly indexed*", the product of charismatic individual views within community publishing but without theoretical relevance (Glaser

and Strauss 1967:193), the main advantage, of producing a pilot study identifying issues for further research was felt to outweigh this concern.

<u>Focus Groups</u>

Focus groups were proposed to gather the data. Focus groups marry with grounded theory in having the advantage of only requiring small numbers to produce theoretical saturation (Krueger 1994), a combination which has previously been employed in health research to gauge experiences, attitudes and needs (Kitzinger 1996, e.g. Mayer et al 1998, Lloyd, King and Maas 1999).

The small numbers required for the sample allowed participant diversity to be manageable within the limitations of a Master's size study (Krueger 1994). The interviews were arranged with a sample of convenience drawn from contacts in community publishing groups. With sparse professional literature on community publishing it was initially decided to interview organised groups in the community.

This facilitated access since participants would not be patients, and contact could be mediated without negotiations through an ethics committee. Furthermore, subjects who had already identified themselves as community publishers would have relevant practical experience to inform data.

During the planning of the study opportunities arose to interview meetings composed of participants from different groups from around the country. These were included as a means of increasing the diversity of the sample and enriching data. The meetings, to be held at FWWCP events would enable wider representation of different types of community publisher. It was also anticipated that focus group discussions which reflected multiple group experiences may produce different data to single groups.

Groups were contacted by phone or in person to a group organiser prior to the interviews. The organisers liased with their group members to see if they would agree to meeting the author. Issues such as confidentiality were outlined with the organisers at this stage so that members could make a decision whether they wanted to proceed with the focus group, and where they agreed, arrangements were made for the author to visit. For the focus groups held at FWWCP events a brief describing the purpose of the session was written into the programme, as an option for participants.

4-6 focus groups were planned with 8-10 participants, allowing a total sample of 30-60 participants. A total of four focus group interviews were conducted between March and July 2000. Given that locations and times were arranged at groups' convenience it was not practical to involve a co-facilitator. The sessions varied in length between three quarters of an hour (constrained within a conference programme which was running late) and one and a half hours. Although a schedule was used to maintain a similar structure

between groups to facilitate analysis (see appendix), the earlier and longer sessions were extended by participants arriving late.

Each interview was recorded on cassette tape and subsequently transcribed. The resulting transcripts were then reviewed and coded to identify key issues for the study. As the data was complex data coding was done by hand rather than through a computer programme (Strauss and Corbin 1998a, Silverman 2000).

Ethical concerns

A wide range of community publishing experiences was sought through contacts with arts and publishing organisations. While it was intended that the sample would include Survivor Poets and members of disability arts organisations, no group actively engaged in therapy was involved, for the following reasons:

1. Survivor group concerns about an appropriate paradigm for their inclusion as research subjects. Although there are defining ambiguities about an inclusive "*social model of madness*" (Beresford and Wallcraft 1997:84; Fulcher 1996), a focus on individual differences may restrict any revelation of social responses from the data. Community publishing appears to be an inclusive practice, a source of narratives which may give access as Booth suggests, to

"the subjective worlds of people… who are not easily reached using textbook methods and formulaic thinking" (1996:246).

Therefore defining participants in terms of an unequal relationship between organisations for survivors and survivors' organisations characterised 'ideology of mental illness' or of 'consumerism' might lead to inadequate or skewed interpretations of data (Beresford and Wallcraft 1997; Priestley 1997). Even Strauss and Corbin do not, apparently, question definitions such as "*nurse*" or "*patient*" (1998a: 208ff).

2. Although there have been precedents for community publishing work with psychiatric clients, it involves a protracted process of seeking approval, funding and suitable venue, as well as negotiating the publishing process itself. It was therefore impractical to set up a test group for this study. As none of the participants was sought as an active client of a therapeutic service Local Research Ethical Committee approval was not necessary.

Participants' confidentiality and safety was a primary concern (Krueger 1994; Survivors' Poetry 1996). Sometimes community publishing practices, which involve working on narratives in groups, make this difficult. Therefore focus group references to specific texts have been deleted. While the exclusion or fictionalisation of material may compromise *"transparency"* and *"reproducibility"*, the interests of the study cannot be

allowed to detriment the participants (Huberman and Miles 1998:203). The purpose of the sessions was made explicit and permission sought before recording to use the material in research.

All participants were informed that they would:

- Retain confidentiality – and will not be named in the study. Tapes and transcripts will be retained for verification purposes and will be securely stored.
- Be able to leave the group at any time, if they wished. They could also withdraw their data if they desired, the opportunity for this to be given at the closure of the focus group. In this case the entire interview would be void.
- Have time available after the focus group for individuals to discuss and defuse issues which may have arisen with the researcher.

These issues were also confirmed in advance in initial contacts with group organisers.

Subjects are owed information about the results to which they contributed. Research is pointless without dissemination; as discussed earlier, NHS policy, as well as Grounded Theory (Strauss and Corbin 1998b) requires that plans for appropriate dissemination be built into any project, in line with demands for studies to be generalisable or transferable. Participants were informed that the study would contribute to an MSc dissertation and that papers from it would be submitted to professional journals. Participants were

promised access to a report of the findings, which would be made available to the FWWCP through its magazine, a paper presentation at the 2001 Festival of Writing, and, if wished, to individual participants. One participating group and two individual participants asked for these.

In this way the study will be offered to the direct scrutiny of the participants, and there will be opportunities for at least some of them to discuss any issues arising from it. Throughout this study the author has attempted to keep a focus which will enable further work which will have practical outcomes for clients, and for those already involved in community publishing.

Analysis

The analysis section groups the data supplied by the four focus groups into loose themes. These have been grouped under headings to identify and summarise core findings with representative quotations from participants. The original interview schedule is given in the appendix.

What makes community publishing

What makes 'publishing'?

1. Publication includes performance and any other way of getting work across to an audience.

2. Publication is about exchanging creative ideas in some way

3. Publication through a community press, or self publication, rather than a commercial press can seem more important, more rewarding and a more realistic objective to the writers and producers

> *"We see community publishing as…publishing the stuff that we feel is worth to be published, in our local community, and we can either publish it ourselves through desk top publishing and we also …perform at local venues, and local rest homes, and places like that and we see that as a form of publishing, performing."*
>
> (Focus group B)

What makes it <u>community</u> publishing ?

Participants' comments (from focus groups B and D) seem to indicate a wide range of perceptions about the role of publishing in the community, expressed in comments like those below:

1. Giving the community, often a geographical locality and the cultures which feature in it, a voice, empowering it to represent itself, to enable others in the community to recognise and find out about a shared culture (or perhaps to share this culture with others in the same geographical base).

2. Sharing experiences and communicating them. Asian-ness, the experience of mental illness or of living in Grimsby may be reflected in some aspect of the writing, but writers in these groups typically write about the same kind of things as everyone else.

3. Talking directly to a local audience is the source of much of the rewards (Focus groups A, B, C and D). This is not parochialism, but a way of making local culture work through the community doing it for itself, finding its' own funds, venues, audience and setting its' own agenda. Authors and publishers in community publishing see themselves and their work as part of the community, with the aim of illuminating or reflecting on aspects of community life, a role available to anyone in the community.

> *"...we're not writing for a specific community, but on the other hand people, probably by and large go for that sense of community... who've experienced the effects of being mentally ill and so on, who read about it from that point of view, rather than somebody who'll want to discover some brilliant new poetry."* (Focus group B)

" … you can tell a story in a Grimsby publication, and you can use that language, it's got all that implication about knowledge of Grimsby, knowledge of the ways, knowledge of the people, knowledge of the geography… those people who live within that geography can understand it and actually get a lot out of that book, more so that they would of someone writing on a similar issue but somewhere else…" (Focus group D)

The examples from focus groups A and C, below, raise further issues:

4. Participants operate as a community in themselves, one based around validating and appraising each others' work in a way which seeks to find some degree of critical objectification. It is not clear how these objective criteria are arrived at, but there is an expectation of 'honest opinion', not mere polite praise.

5. There are expectations within this community that people will help and facilitate each other. Groups welcome and encourage newcomers.

    "Being very new… I've thoroughly enjoyed the time I spend here." (Focus group C)

6. There are different concerns about audience. The comments from Focus Group A, an adult education group, indicate writing primarily intended for written publication for

other adult learners or people who might be encouraged to become so. Focus group C, a writers' workshop taking all forms of dissemination as publication, is as much concerned with how a paying audience appreciates and understands work which was not originally intended for a performance context.

7. An important factor, across the sample range, from adult learner with learning difficulties through to postgraduate professional writer, is that writing ability is not necessarily held to be as important as enjoying meeting a variety of people.

> *"...helping one another ... with what difficulties they might have, like with spelling, enabling them to check out these things, you know. I don't believe that we're just doing it for us-selves, we're doing it for the college ... Like we can invite people and show them what we've been shown by other people. To seek out their interests, cos it comes off of one another's experience."*(Focus group A)

> *"We've got a responsibility to get sommat down on paper*
> *N: You've got a responsibility to write, to publish?*
> *A: Yeah. If you don't put it down then we're not doing us jobs."*
> (Focus group A)

X: Generally the feedback with this group is extremely positive. Even if people are saying negative things, what they're saying is generally beneficial… it's not much help to you if somebody say pats you on the back and says …very nice … it doesn't really tell you what you need to be doing to improve the quality of your work...

Z: …Some of the things which have remained with me the longest … weren't the obvious performance pieces, but they had a kind of power … A friend [who] came to the annual reading… was really struck by … the huge variety of age and background of people reading, and she felt that was a real strength."
(Focus group C)

('N' denotes the researcher)

How do community publishers work?

1. *Fame is not everyone's aim: different levels of participation.*

Participants suggested many different levels of involvement and ways to be involved. Some came to the focus groups out of curiosity, having come to a publishing event for the first time. Others had been workshop members for many years.

Some participants describe their writing groups as "*a social group*" (Focus groups C and D). One publisher talks about encouraging people who at first only want a book for an intimate audience, or family members, to consider a wider readership (Focus group B).

Some participants had very active roles in organising publications and events, others much less. Publication and performance, even participation in demonstrations were described as outcomes from joining writers' groups. People enjoyed relating to an audience and the self confidence they found in performing their own material, and having performances were sought after for local events.

> "*Being very new… I've thoroughly enjoyed the time I spend here. …I wanted something like this on a one to one where somebody could say 'sorry, that's rubbish but try again'… I feel as though I've got that here. So thanks everybody.*" (Focus group C)

> "*The things that we do quite clearly spell our attitude out. We've already done the three festivals. We've produced a CD, we've produced an anthology and three magazines and four broadsheets… We're not funded – we've managed to do that, and we haven't until this year taken a penny off us members in subscriptions…*" (Focus Group D)

Not all are interested in publication, commitment to publishing varied between the individuals and their groups. Individual fame is not perceived as a legitimate community publishing aim over working with and for other people:

> *"if you're the sort of person that could be high profile ... and you want to be selfish and just promote yourself well it's probably not for you community publishing."* (Focus group B)

Some community presses work a kind of skills' exchange, which contributes to the richness of participation. Members can exchange their ability to type, use a computer, or edit in return for help in other parts of the process (Focus groups B and D). People also help each other with more basic issues like spelling and finding better expression (Focus groups A, B, C and D).

> *"I went into publishing people's books with them being the distributor themselves ... I would type them up, typeset and print em, make em into books. They would distribute them.*
>
> *...we encourage them and maybe go with them to the likes of Waterstones or [alternative book][1] shops, and ...the local library.... To somebody who only wanted maybe half a dozen books, that's a big step forward. And maybe the next time they want to get something published they might look further afield to a*

bigger publisher, you know, even if it's a bigger community publisher." (Focus

group B)

2. Marketing is more than publication

Few participants were aware of the experience of fellow publishers in other communities,

other than those professionally involved. Community publishing workers stressed the

importance of marketing. Publication is part of a greater whole, giving a focus for

publicity, opportunities for wider contact or audience, something that performances can

be built around. It can be part of a larger project, such as promoting the attainments of

Asian children. Developing a publication (whether to raise concerns or promote itself)

may also be a key stage in the development strategy of a voluntary organisation.

> *"You can influence people outside the group, you can influence the group*
>
> *cohesion, from their working together there's solidarity there where maybe there*
>
> *wasn't before, but if it's a good idea and it's well presented the influence can*
>
> *spread further and can change people even though they're fraction changes…*
>
> *anything is possible in effect, so there is something there besides the actual*
>
> *publishing process, there is a value."* (Focus group B)

3. Community publishers' responsibilities

Participants are concerned about the way they are represented in publications. The discussions outlined a number of community publishers' responsibilities:

1. ***"To put sommat down on paper".*** Several participants in the adult learning group felt a responsibility to record their lives and by doing so encourage others to do the same. The group supported an outreach programme by facilitating new members in their group, one member was actively involved as a volunteer outreach worker for the group. Many of these participants had been involved locally in publicising the work of the college to which they belong as writers (Focus group A).

2. ***Considering the effect of publications upon community relationships,*** for example local controversies about the miners' strike which continue fifteen years later. Some suggested that work could be compromised by official attitudes of those who might be giving access to venues. Another gave examples of how one could evade these strictures creatively – officialdom is not seen as part of the community, though it may be the source of funds and as such may be a motivator of some activities (Focus group D). Most participants saw their main responsibilities as being to each other or to the client group the community publishers were trying to facilitate.

3. ***Dealing appropriately with situations where individuals do not accept the general principles of the grou****p***. Participants generally felt that the needs of the group take precedence, but that attempts should be made to reason with the person, and offensive

material (e.g. racism) should not be published or condoned. Sometimes an individual will attempt to change the nature of the group to meet individual demands. Here group cohesion is needed to keep the objectives of the publishing group on the rails:

"We did have a crisis at one point we had to say it's either him or the group, and it was him, because we'd lost three or four people from that and we're still not fully recovered. We just had to say, sorry mate, we're sorry if you're sorry, but you can't go on doing this." (Focus group D)

4. ***Not publishing libellous material***. This was not discussed in depth.

What do you learn from community publishing

" … you feed each other up with ideas and to some extent it shapes your writing, it gives your writing more power." (Focus group A)

The process of participants learning from and "facilitating each other" depends on the character of their groups. One participant discussed how proposed adult literacy publications were formally submitted through a committee process. Another described how she developed individual projects with writers and, through the publication process, expanded the ambition they had for their writing (Focus group B).

Several participants, mostly with disabilities and/or were survivors especially but not exclusively those in the adult education group, had changed from being recipients of the groups' services to facilitating others in their groups or even running their own writing groups or connected activities, such as getting involved in editing or computer skills. One ran a writing workshop at work (Focus groups A, B and D).

Skills and attributes which participants[2] felt they had acquired through community publishing:

1. Increases in self confidence (Focus group A and C).

2. Confirmation and direction of individuals' interests and skills in writing (Focus group C).

3. The ability to perform material or at least feel comfortable reading to an audience (Focus groups A, B, C, and D).

4. The ability to take constructive criticism, not only about the content of writing, sometimes on personal issues, but also in terms of basics like spelling and grammar, problems which literacy students may have previously tried to conceal (Focus groups A, B and C).

5. Being enabled to talk about interests in writing with others (Focus groups A, B, C and D).

6. Self development through meeting a wide variety of people (Focus groups A, B, C, and D).

7. *Careers.*

   One participant became a full time writer and another developed a career in open adult learning.

8. *Transferable skills:*

   One adult learner used his experience in negotiating issues with his writing and publishing group to develop structures for the new sports group of which he was an active member (Focus group A).

Mental Illness and Writing

 "… we wanted to say something, we had something to say and we wrote poetry and at a later stage decided that there might be a possibility of getting this out to the wider community than we had done before at poetry readings and so on. So we didn't have to account to our particular audience or particular institution because we'd already written our poems." (Focus Group B)

This participant raises several crucial issues about being mentally ill and involved with writing.

1. Community publishing is liberating because the process is easier than dealing with a mainstream publishing house. An accessible process is more motivating; one can

achieve an involvement in the whole and see the project develop. Though community projects often founder the participant did not feel her involvement in them was time wasted, but experience gained.

2. Community publishing is limiting because associating a publication with mental illness may undermine perceptions of artistic merit to a niche market with limited audience reach. Mention was made of a poetry competition which discriminated against writers with mental health problems. To apply a mental illness label through design, blurb and even the person selected to comment on the book may not have the same meaning for people who are not disabled, have no connection with mental illness.

   "...people, probably by and large go for that sense of community... who've experienced the effects of being mentally ill and so on, who read about it from that point of view, rather than somebody who'll want to discover some brilliant new poetry." (Focus group B)

3. Some participants became involved in wider activities through publishing, such as campaigning at the town library for colleagues who are unable to speak, or raising money for Nicuaragua (Focus groups A and B) .

Whether limits placed by others' attitudes on support and acceptance for mental illness and disability was not much explored in the focus groups, but raised in the researcher's reflective diary.

4. One result of the variety of Federation members is the experience of differences and of developing an understanding of the boundaries and possibilities they produce.

> *"you think… maybe they haven't got the inhibitions I've got, they've had already established for them that they are different. So now [they] can do or be anything that nobody expects."* (Reflective diary)

Disabled writers have criticised presentations of disability which are intended to evoke pity, or to attempt to see the person behind the disability. This makes a problem of disability, rather than the problematisation *of* disability (Hevey 1992). Even where disability and mental illness writing is framed by service uses, it carries a risk of being a passing interest:

> *"When voluntary arts methods are applied to the field of disability the product becomes even more of a good cause and even less about art. It's only good as long as the audience's voyeurism is satisfied…*

... using voluntary arts as a vehicle for citizenship may be limited; how do

survivor poets aim to break out ... of positive marketing on the basis of disability;

how would Occupational Therapy tackle this question in terms of

'normalisation', and how could this translate into terms of societal entry?"

(Reflective diary)

5. Another was the problem of men with mental health difficulties stalking and
harassing women after workshops. All denied the problems created by their
behaviour, and this was exacerbated by group members' initial reluctance to confront
the problem:

> *"...potentially destructive influences in the group are the inevitable consequences*
>
> *of running facilities in the community which have open policies of access and*
>
> *membership. It is possible to survive with clear democratic principles as long as*
>
> *people believe in the values of the community enterprise they have founded.*
>
> *Perhaps these occasions provide moments of group definition."* (Reflective
>
> diary)

The writers' groups eventually asked them to change or leave. None returned to the
group.

6. Community groups have to be "open" in order to provide an enjoyable learning experience of writing, yet I found limits and many potential dangers for mental health clients and staff seeking to join them:

> *"I would not be keen for my clients to join my local writing group (too close to the private me for a start)"* (Reflective diary)

My clients might not be keen to find me joining their group for the same reason. This potentially mutual discomfiture about disclosure in community groups implies a boundary to inclusive practice. These issues are bound to be called into question because

> *"...people with mental illness [are]...more likely to act inappropriately or suffer misinterpretations. Other group members may not ... react constructively, or... have had the opportunity to find out how to deal appropriately with these difficulties ... instances are quite infrequent and strategies are based around individual circumstances [but] ...it is unlikely that many women would want to risk waiting to find whether these strategies were effective."* (Reflective diary)

7. Finally there are issues of vulnerability arising from lack of insight

" ... writing ... can involve the emotions as much as music can and the consequences can be [personal] entanglements. How does someone with limited social skills, who may be prone to stress as a result of emotional pressure, react to this and can they be protected? ... There are probably many avenues for exploitation (several mentally ill and handicapped people have had their stuff published at vast expense through a vanity press, without realising...that the publisher is not a bona fide publisher)... The distinction between this an community press is not always evident and many ...vanity press companies target writers groups with mailings. " (Reflective diary)

From this data it is apparent that community publication is about people working together in a practice of creative dissemination intended to serve local needs. Because this practice is open participants sometimes find situations where the behaviour of other individuals produces difficulty, but generally the data suggests that most community publishing is done in a co-operative, inclusive and user-participative way.

Discussion

Community publishing is a diverse field. The literature search and the range of groups represented in the focus groups revealed many different ways of publishing and disseminating many kinds of writing. Community publishers have developed around local objectives and needs, including specific identity issues such as ethnicity or mental

health. This range of community experience offers plenty of opportunities for occupational therapists and their clients to develop rehabilitative links.

The study has produced a wealth of data and suggested numerous issues for further investigation. Therefore this section will deal with some key findings and identify some of the areas for future research.

The search revealed little previous investigation of community publication in an occupational therapy context, and a sparse literature documenting the practice of community publication groups. Although 11% of the adult population participate in writing based arts activities, (VAN nd circa 1997), few of them might be involved in community publishing. The literature also suggested that much community publishing was not valued, or ignored by potential readers. This may explain why occupational therapists have not realised the possibilities of this medium.

It was important, therefore, to interview people involved in community publishing and explore their views. My prior involvement in community publishing enabled me to arrange interviews with FWWCP groups and 'piggyback' focus groups to other events without difficulty (Krueger 1994). It appeared to be important that these took place in venues which participants saw as supportive environments (Marshall and Rossman 1999), and this is borne out by the relaxed and free flowing nature of the discussions. In grounded theory terms these factors appear to have enhanced data management and

analysis, particularly understanding the context of participants' nuances (Huberman and Miles 1998, Strauss and Corbin 1998b, Marshall and Rossman 1999).

Established communication networks and understandings between individuals may introduce elements of bias, and even divert the aims of the study:

- The researcher has been the FWWCP's magazine editor for ten years, and obtained the FWWCP's co-operation, who therefore might be seen as a "*sponsor*" of the study (Krueger 1994:95). Participants may have felt that they were talking to one of the organisation's representatives, discouraging them from voicing negative experiences.

- The researcher's position might have admitted ideas which were "*forcibly indexed*" (Glaser and Strauss 1967:193), or "*inextricably linked with the politics*" (Papadakis 1993:84ff) i.e. based in individuals' strong views but without theoretical relevance, which could compromise the study as an objective evidence base for practice. For example some FWWCP members' view community publishing as a form of experiential political education (Focus Groups A, C, D). This was a concern also addressed in the researcher's reflective diary, however, the variety of issues raised from the data suggests that forcible indexing has not been significant.

- To some extent the issue of obtaining non-FWWCP views is answered by the inclusion in each focus group of participants who were new to community publishing. This also brought problems of potential influence. While the researcher must not intervene during the session (Krueger 1994), participants often asked for information. While these questions were fielded within the group, often specific questions were

directed to the researcher as magazine editor and an authority on the FWWCP, especially in focus groups A and B. In focus groups C and D, however, there are far fewer interventions. From the range of the discussion, however, it appears that focus group data has been objective, and that this has been represented in the analysis.

Attempts were made to contact groups outside the FWWCP. These were unsuccessful:

- The convenor of a newly set up group of black writers on mental health issues felt that his members were not ready to discuss these issues at an early stage of the groups' development.

- Another group had formed to produce one publication. Having completed this the convenor did not know whether the group would continue.

- Other convenors felt their members would not want to use time set aside for their own publications to contribute to this study.

These issues served to underline the need for local acquaintance with the field. It could be argued that the researcher's position facilitated and enabled the study, providing a means of access to the data.

The sample

The focus groups were conducted in Yorkshire and Leicester. They comprised the following:

- an adult learner publishing group (Focus Group A);

- a writers workshop (which has published a number of magazines, broadsheets and tapes) (Focus Group C),

- two focus groups conducted at FWWCP events involving people from several groups (Focus Group B and D).

In this way a total of 16 FWWCP groups were represented, spread over most of England. Although all these groups were members of the same umbrella organisation, they represent a considerable diversity of practice and composition.

The focus groups involved 37 people, nineteen women and eighteen men. Of these, three (two women, one man) made no comment during the sessions. Because the event-based interviews were open workshops two male participants attended two of the focus group interviews. The researcher allowed this rather than disturb a natural occurrence and create unnecessary divisions when the possibility of their contributing additional data did not conflict with the grounded theory methodology.

Participants were not questioned about their ethnic origin, disabilities or gender, though many references to these issues occur in the discussions. The specific reason for not operating categories is due to the practice of community publishing at least as operated by FWWCP groups, which aims to be inclusive. Focus group discussions freely explored ethnic, gender, disability and literacy issues, and questions about the use of power within their own organisations. The researcher felt that asking for evidence of categories, such

as educational status (for example, many members of focus group C appeared to have experience of higher education), might be intrusive, distracting, and prevent spontaneous discussion. From the recordings, however, it is possible to identify some participant characteristics:

Ethnicity: The majority of participants appeared to be White European with English as a first language, but three persons identified themselves as originating from the Indian subcontinent. From their recorded speech it would appear that two of these participants had English as a second language. One other participant came from the Caribbean.

Mental Illness and Disability: Six people identified themselves as either belonging to a survivors' group or else recovering from or working through mental health problems. Two of these reported having had a chronic illness. While one of the interviews was conducted with an adult learner group set up to provide access to learning those who missed earlier opportunities for education through learning difficulties, physical difficulties, mental health problems and poor literacy, people with disabilities and experience of mental health problems were part of every focus group.

These categories are significant in that FWWCP groups describe themselves as "*accessible to all*"[1]. Discussions were frank, but did not use disablist categories such as 'pity' or 'tragic but brave' to describe disability or mental illness (Hevey 1992, Marks 1999, [see p49] [*]). Many participants were clearly familiar with each other and had shared

common interests in community publishing for some years, providing strong evidence for this socially inclusive practice and its' positive benefits for users [see p38, 39, 40, although some caveats to this are discussed later, see p61].

Thus while participation in community publishing can be an individual outcome of previous therapeutic contacts, it is also a natural or 'normal' activity. For occupational therapy a 'productive activity' has to be 'real' beyond the therapeutic context, with a meaning mirrored in the social world, potentially available to a service user based in the community or on discharge, and able to answer a range of 'purpose' needs for users (Hagedorn 1995, 2000).

The data suggests considerable diversity in participants' experiences of community publishing and in involvement, intention, form and content in current practice. Much of this was acquired idiosyncratically with local influences; participants in most cases reflected their own, or local experience, few were able to talk about publications by other groups [see p43]. This relates to the issue of community publishing not having impacted on the work of occupational therapists or those working in literacy [see p9, 10], and suggests that networking and study of community publishing from different localities will enable building on the experiences on others and avoid the reinventing of processes.

What might our clients gain from being involved in community publishing?

Personal growth through expression

At the core of all the data gathered for this study, whether from literature, focus groups, or the reflective diary, are narratives of individual growth which have been clarified through their organisation into a community publication. Much community published material is autobiographical, or based in personal experience [see p14]. In developing these stories through interaction with others the individual makes sense of and uses personal experience as a resource, evaluating the effect of each version of the data presented to others [see p40, 43]. Community publishing is about individuals reaching out to others using their own personal material [see p13, 47].

A consequence of this experience is that many participants were able to identify specific personal gains, [see p41]:

- increased self confidence,

- performance skills,

- ability to accept criticism [see p39],

- developing and being able to express interest in writing [see p39],

- increased social skills, extended ability to work with others [see p44]. In FWWCP groups people apparently work in a multicultural community, or gain some direct awareness of the experiences of different minorities and different age groups

- vocational development,

- transferable negotiation skills

- skill sharing, suggesting that skills are offered voluntarily to the other members of their groups to facilitate publication, but also that these skills are shared and learned by others [see p37, 40]. Although the processes of publication (in the widest sense) were not broken down in the discussions, the range of methods included performance, print and recorded media, as well as the internet (focus group A, B, C, D). Each of these requires specific skills, some of which are listed below, and are covered in the literature (Schule and Wolley 1996, Baxter 1997, Davis Smith 1997, VAN nd circa 1998, Hunt 2000):

- negotiating funding, costing and prices

- design (covers, posters, artwork)

- organisation, meeting deadlines, and distribution

- computer skills (word processing, desk top publishing, internet use)

- numeracy skills (costs, dimensions, word counts) simple book keeping, and more complex accountancy for fundraising applications.

- promotion and marketing

- business communication, secretarial skills and administration

- people skills – motivating and encouraging volunteers; talking to funders and arts officers

- proof reading and editing

Often people have had to work things out as they go along, which while leading to mistakes, has demonstrated considerable creativity and initiative.

Social participation and inclusion

Frequently focus group participants were people whose experiences of education, health and artistic expression are marginalised by other social forces [see p40, 48]. The study did not attempt to distinguish between people who might be service users (though some participants identified themselves as such) and those who might not; the author himself has been a service user. Some are still acquiring literacy skills, are psychiatric survivors, or have learning and physical disabilities, but who feel strongly, like their Choctaw antecedents, that they have "*a responsibility to get sommat down on paper*" (focus group A), and, in effect, write a community publication which serves as a manifesto for citizenship (Mace 1985, [see p13, 40, 44, 45]).

Social inclusion is assumed by the participants as a right, though not a fact. Publication, or enabling people to tell their stories, occurs through helping each other, "*cos it comes off of one another's experience*" (focus group A). Community publishing, broadly then, is a co-operative enterprise which often depends on volunteers working with minimal resources in their leisure time. It therefore necessarily relies on the sharing of skills and strengths so that all may be facilitated.

Education and self actualisation

Frequently publications have educational objectives such as literacy, or awareness of community history, but these are carried into process as well as content (Mace 1995, VAN nd circa 1998, [see p11]). Objectives can be both direct and indirect. Through making publications people learn about book production and marketing, and personal development [see p43]. The publishing of Caribbean cookbooks, Asian poetry and experiences of mental health also provides a means of building local awareness of cultural and social issues [see p39]. This social education purpose has more directly political antecedents in Frierean literacy campaigns and British socialist realism (Worpole 1977, Morley and Worpole 1982 [see p14]), but community publishing strongly emphasises the *social* aspect of belonging (Morley and Worpole 1982, Froom 1985, Smith and Burgieres 1996, Szczelkun 1997, Stanley 1997, [see p39, 40, 41]). The education which participants receive is attained more through free association and mutual exploration than didacticism, therefore having the potential to be more needs focused.

Group structures

Writing and publishing group structures and how these work require further study. Most of those to which focus group participants belonged appear to have developed to answer local needs (Morley and Worpole 1982, [see p38, 39]). Writing based groups seem to

have less formal structure [see p41] than community publishing based groups [see p45]. The latter are often co-operatives or charitable trusts receiving grant funding, and therefore required to have formal proceedings, directors and annual meetings, maintain proper accounts and conduct themselves as businesses (Prescott 1997, Finlayson 1997, Hunt 2000).

Giving and receiving constructive criticism entails that writers often have to alter their work for a group publication. Community publication often requires those who would be published to contribute to the effort of production [see p58]. It includes values of listening to and reading others' work, and being committed to a shared enablement process which allows this to happen, which celebrates everybody's contribution (Morley and Worpole 1982, Mace 1995 [see p13, 42, 49]). The poetry survivors' movement also uses formal procedures to enable participants to work safely through any issues which occur through the sharing of writing, for which reason two facilitators are recommended (Smith and Burgueires 1996). This practice would seem to be endorsed by the accounts of participants [see p45] and in the reflective dairy [see p49] of difficulty dealing with individuals who threatened other group members or did not want to share group ideals.

As discussed above, community publishing groups aim to be accessible, but this openness has caveats. In their personal behaviour participants need to be able to take account of the needs of others. Harassment or abuse is not tolerated and might result in exclusion from the group. When individual group members behaviour presents difficulties focus group

participants talked about using democratic procedures and reasoning to deal with them, but concluded that the survival of the group and the group's interests mattered more than trying to accommodate someone whose work was intentionally offensive [see p45]. My experience, explored in the reflective diary, was that groups do not always have the experience to approach these issues sensitively when presented by people with mental health problems [see p49].

Opportunities and links

While for participants' safety Smith and Burgueires (1996) recommend that workshops be specifically tailored for survivors issues there are some caveats to a tailored approach from focus group participants, e.g. that publishing under a 'survivor' label restricted potential readership to other survivors or people with an interest in mental health rather than a broader public [see p48]. Networking and co-operating with other community publishers enables the wider marketing of publications or events and gives members access to training, funding, and links with other groups toward further development (Mace 1995, Shepherd 1997, Smith and Burgieres 1996, Burnett 1998, Philips, Linington and Penman 1999, [see p5, 41]). Adult learner participants gave examples of bringing their issues into public events [see p48]. As people with a range of disabilities whose organising principle was about having a second chance to learn, all remarked on their co-operation with each other in this endeavour.

Therapeutic applications of community publishing where a department has only the resources to develop a short-life focussed group experience should consider those individuals who want to take their writing further. Making links to community facilities with support as necessary should be envisaged as a potential outcome of writing groups (Philips, Linington and Penman 1999). Given the range of activities which have resulted in community publications, therapists might consider community publications as a productive outcome from many activities, domestic cookery, reminiscence, art, music as well as those where users are asked to reflect on their experiences. (Mace 1995, VAN nd circa 1998, [see p11]). This can include experiences of specific illness or disability, and carers' issues (Labelled Disabled 1991, Osmond 1993a, 1993b, Thornton 1996)

Some therapists and their co-workers may be able to develop publishing groups which mirror community publishing group structures. Community publishing organisations welcome and even facilitate approaches from such groups to develop and obtain funding for writing projects with health clients (past examples, albeit those which have arisen through voluntary worker initiatives, have been Gatehouse (Gatehouse 1987) QueenSpark (Osmond 1993a, 1993b) and Eastside (Chatshow Writers 1996)).

Tasks

Community publication depends on groups agreeing about what and how they want to publish, whether using print, performance or other media (A.B., Griffiths et al 1995, [see

p42, 47]). Group members negotiate with each other according to their different capacities for commitment to a project. The less confident are nurtured to take a bigger role, to go from wanting "*half a dozen books*" to selling them through Waterstones' bookshops (focus groups A, B, and C, [see p43]).

Whether working individually as a group member to taking responsibilities on behalf of the group, these activities involve a range of social skills. Internal formal processes such as publication committees, or external activities such as arranging performances and marketing involve skills which may also be useful vocationally. Community publishing offers a limited number of employment vacancies but provides accessible opportunities to practice and evidence skills such as word processing, desk top publishing, book design and selling, problem solving and the art of persuasion (Diggles 2000, [see p41, 43]).

Community publications offer many possibilities: community histories, novels, plays, songbooks, cartoons, comics, recordings of people telling their own stories, or music mixed with poetry or fiction. Wide definitions for 'publication' were given in all focus groups [e.g. see p42]. Aside from publication in book form, cassette tape, CD and the internet[2] were all possible avenues for distribution. Performances were regarded as an important form of 'publication', but most of the discussion was about print, implying that this was the goal for most people [see p43].

Projects have a slow rate of development, allowing people time to develop their expertise at their own pace, though experimentation with the product frequently inhibits sales (Szczelkun 1997). Though mistakes were not much discussed, one focus group participant found them a positive learning experience [see p47]. Other community publishers, such as Szczelkun (1997), may be sanguinely optimistic about them, but as he earlier remarks (p5) there is an expectation of "*low standards*". In the focus groups community publishing workers tended to put more emphasis on marketing and successful product formula (e.g. in the production of adult literacy readers (focus group B)). There was little evidence for less formally organised community publishers learning from material produced by their peers.

Potential community publishers need to consider how they will achieve a balance between free experiment and having something which will sell. They need to learn from the successes and mistakes of other community publishers, and acquire familiarity with the range of publication and media for 'publishing'. Gatehouse (1987: loose pages) suggest that publishing projects may be obstructed because "*other staff can't see the point*" and "*my boss thinks it's a waste of time*". Therefore, as community publishers stress in both the focus groups and the literature, it is important to market well.

One focus group considered how the expectations of writers were built up from a small number of copies to a full print run (focus group B). Some return to the literature is necessary: community publishing print runs may be under 500 to 2,000 copies (Hunt

2000; Morley and Worpole 1982, Schuhle and Woolley 1996, Szczelkun 1997). These may seem small but some community publishing antecedents, Lawrence and Wisharts' 1950s working class novels, sold between 1,000 to over 3,000 copies on a national scale (Von Rosenberg 1982). Locally these would represent big sales and could generate good local publicity. Some participants referred to print publishing as a vehicle for a larger exercise [see p42, 48]. Therapeutic and voluntary arts writers (Bond, Drake, et al 1997, Harkapaa 1998, Hunt and Sampson 1998, VAN nd circa 1998, Bolton 1999) stress many benefits from voluntary arts participation, including health and consequent reductions in public spending, which therapists developing projects can harness to obtain support.

Publishing, employment and volunteering

Texts which explain how to publish (e.g. Schuhle and Wolley 1996, Hunt 2000) are themselves often published by small or community presses and difficult to access. How community publications are put together varies between groups and projects. Which ever parts of the process are done by the group or contracted out depends on the volunteer skills and resources available to them (Morley and Worpole 1982, Schuhle and Woolley 1996, Hunt 2000). This is especially the case given the diversity of 'publication' technologies described by focus group participants.

None of the participants and little of the literature referred to basing therapeutic community publishing activities around print technologies. Most of the participants

published infrequently, making it more cost effective to deal with professional printers. Creafi ([see p12], Lecointe, nd circa 1998) is, however, an interesting and lively example of users' creative use of print used to produce small publications given value by the sharing of the print process, which is worth further investigation.

Smith and Burguieres (1996) point to writing (and by implication publishing) offering personal development, including 'coming out' as a survivor and training and employment opportunities in the arts including performers, writers and workshop facilitators. Most participants mentioned performance as part of their repertoire and many performed for free, often to promote books (focus group B, C, D), suggesting that audiences responded favourably to their material [see p38].

The adult learner group produced a number of cheaply produced publications, as part of their ongoing programme, for free distribution (focus group A). Other focus group participants advocated broadsheets as cheap but cost effective publications. One maintained that everything his group had published over an eighteen month period, including a CD, had paid back production costs (focus group D, [see p42]). Therefore, although literature suggested that community publishing was difficult to distribute and is ignored [see p10] participants had avenues and markets for disseminating their work.

Vocational and voluntary roles

Most of the participants came from small self funded community publishers, most of which depend on volunteers. Hunt (2000) details various roles needed in a co-operative press. The majority, such as treasurer, secretary and chairperson, administer the group through and between specific projects. Some focus group participants suggested that their groups do not have, or do not define these formal roles [see p41]. They could not, therefore, apply for long term funding to cover administration and day to day running costs (Baxter 1997). Many larger community arts organisations depend on, and can only obtain, funding for specific projects, which limits survivors' work by non-survivor community publishers to one-off publications (Schuhle and Woolley 1996). Most voluntary opportunities arise from facilitating roles rather than producing print media (Hunt 2000).

Therapists seeking to develop these opportunities for their clients need to reflect cautiously on the implications of operating from one project to the next without revenue funding, or without formal roles. For some individuals these situations may offer scope for creativity, they may be able to successfully plug the gaps in group organisation and provide continuity (Davis Smith 1997). Other clients may find it difficult or even stressful to work in an organisation without clear structures, or where gaps in funding produce crises in planning and resolve. These issues may confirm the concerns of some health professionals regarding voluntary work producing stress or environments where it is difficult to discuss concerns (Durham 1997, Falloon et al 1998).

Conclusions and recommendations

If our profession is concerned with enabling our users to make

> "*choices about occupational and human potential within a community of others*"
>
> (Peloquin 1989:225)

it may seem occupational therapists' have a natural responsibility to develop activities alongside community publishing and similar groups, which can cross over into self organisation. As a field of study community publishing is very diverse, presenting many potential opportunities for occupational therapists to develop alongside community arts organisations. These connections have not been reviewed previously in occupational therapy literature, while representations of mental illness and disability in community publishing also appear to be little explored.

For the purpose of building theory the combination of grounded theory and focus groups used by the researcher generated more data than could be accommodated within the limits of this study. Although the focus groups were drawn from groups established for purposes other than therapy, in terms of the research question forming links with them would produce for service users "*a community experience in which* [they] *attain citizenship, autonomy and the capacity for self representation*".

As with any other public activity, people entering community publishing groups have to observe behavioural norms, such as respecting the rights of others. Failing to do this may result in exclusions or censure. It is evident from the discussions that those participating in community publishing share an understanding of having 'a right to write', and a principle of toleration. Through activities around a broad understanding of publication and writing people have formed a community of interest. Participants in this study interacted and co-operated with each other in producing a community literature, irrespective of abilities, disabilities, gender, ethnicity, or standards of literacy:

> *"the huge variety of age and background of people reading… was a real strength."* (Focus group C)

The study found parallels between facilitating this heteroglossia (Bakhtin 1981) and the individual needs focus of client centred practice, towards feeling productive and expressing one's beliefs about the meaning of life (Sumsion 1999b). However tensions and contradictions may arise through working with these groups, as follows:

- There is a possibility that the hitherto invisibility of community publishing may be due to its having being overlooked as worthless, if not by occupational therapists then at least by some of the literacy tutors and writing therapists they may work with. To temper this criticism, however, we have also considered how alternative distribution methods result in patchy availability and access.

- The survivors' poetry movement, as its name implies, is inherently critical of mental health practice. While the current spirit of the NHS is toward open debate, client and carer representation, the corporate requirements of trusts require the control of external communications. This may be a legitimate interest on the grounds of confidentiality, responsibility for communications about health issues, and avoiding prosecution for libel.

- Community publishing activities are often ill defined, difficult to replicate, and unsuited to quantitative evidence based practice since (as many of the focus groups suggest) each project will be oriented to the needs of a particular community and the individuals within it at that time. They suit an approach based in arts and crafts, in practical work, and in enabling individuals to achieve their own solutions. This improvisational creativity is fundamental to the way much community publishing has necessarily developed, but suggests problems of continuity and structure both for publishers (Szczelkun 1997) and funders (Baxter 1997).

This combination of arguments can place health bodies in an unacceptably authoritative and powerful position with regard to the presentation of disabilities (Shakespeare 1996). Many biographical or narrative studies of clients produced by clinicians have been selective, concentrating on disability rather than ability, presenting the authors as problems for others to live with or care for (Booth 1996). This prevents the 'coming out' which survivor poets want to address (Smith and Burgeires 1996), and the reaching across positively which other clients, who may not want to define their mental distress in

political terms, may still wish to achieve. Survivor poetry groups and health authorities can resolve these issues very positively in joint projects grant assisted from health (Allan, Butler, Crawford, Graham, MacBain, Watters, 1996).

We have identified that community publishing (like community theatre groups, or community music workshops) offers opportunities for self development and gaining many employable characteristics [see p41]. However, this depends on a belief that

> *"We've got a responsibility to get sommat down on paper… If you don't put it down then we're not doing us jobs."* (Focus group A)

and on the particularity of adherents who 'come out', who are not ready conformers. Focus group A's workshop discussions developed into mounting a protest at a local library for better facilitation of members with communication difficulties. Community publishing has included vociferous protest against the literary and educational establishments (Morley and Worpole 1982, Stanley 1997). It might be described as a living literature in dialogue with the community, so that

> *"those people who live within that geography can understand it and actually get a lot out of that book"* (focus group D)

Community publishing offers very different experiences to the vocational activities which have been traditionally offered through industrial therapy or sheltered employment schemes in service or light industries. Like them community publishing looks beyond the hospital entrance to a 'real' setting, but its' principal focus is the natural environment itself rather than the institution (Bond, Drake et al 1997, Brown and Bowen 1998). Community publishing encourages individuals to interact with each other through a variety of expressive media. It enables them to address the community, to be part of local history, to participate in the combination of narratives which inform our society, and contribute to local economies (VAN nd circa 1998). This is "*productive activity*" (Hagedorn 2000). Therapists should enable their clients to explore how these contributions offer substance to citizenship, demonstrating Peloquin's (1989:225) *"occupational and human potential in a community of others"*.