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"A Golden Age of Independence?
Service User Partnership in a Housing Organisation"

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Jacqueline King-Owen
May 2013

CONTENTS

Abstract

Abstract

This report describes the story of a voluntary organisation involved in the delivery of housing with care to, for and most importantly, with adults with learning difficulties.

As a single case study based in a shire county, a ten year period is explored via documentary analysis and group interviews. The interviews were conducted with board members, including service users as members of the board and other key staff in order to illuminate epiphanies that have defined Involve Housing Association and to report the lessons learned from their collective journey over the given period.

The report considers the development of community care for adults with learning difficulties post 1971 and the move away from institutionalisation. Themes are identified that both particularise the elements of Involve and also offer ideas for service user involvement in the future.

In telling the story, it would appear that the period 1997 to 2007 represented a golden era in terms of both investment and service user engagement within health, social care and housing in England. Although the age of austerity has replaced the vision and direction offered by the recent Valuing People agenda the report offers a glimpse of a possible future which Mulally (1993) extols for a prototype organisation such as Involve. Based on a sound value base and social work approach which is in turn grounded in the social model of disability and mutual respect between the participants, it is hoped that history can indeed repeat itself and that the contribution and real difference that service users can bring to the debate will be recognised and celebrated.

Chapter 1

Background to the Research: Setting the scene

This thesis reflects my interest and working life from 1970 to the present day in the development of community care in relation to adults with learning difficulties. In particular, I want to describe and explore the impact of a small voluntary organisation, to be referred to as Involve Housing Association, which is based in a shire county in England. As a key player in the establishment and running of Involve, I wanted to explore the organisation from an insider-researcher perspective and as a qualified social worker within the social model of disability. Established in 1990, the organisational structure and subsequent delivery represents an alternative approach to community care in relation to adults with learning difficulties. I regard this as an example of what Mulally (1993) describes as a 'prototype organisation' or glimpse of the (then) future in terms of service delivery within structural social work. This will be in undertaken through a case study method using both a documentary analysis of Board minutes over a 10-year period and interviews with key staff and board members including tenants who are adults with learning difficulties. The findings will then be discussed thematically in order to consider the development of services for adults with learning difficulties and any implications for the future. This is qualitative in approach working within a participatory or emancipatory paradigm.

In this chapter, I will define certain terms before considering the overall context of the case study from an historical perspective using Layder's research map (1993). I will explore the socio-political, ideological and legislative context within

a social (as opposed to medical) model of disability and an emancipatory paradigm. I will then consider the setting of the case study, its local background and development focusing on its governance at Board level before introducing the significant others (including myself as an insider-researcher) and the Board members who were interviewed as part of my research. All names have been changed using a pseudonym in order to provide anonymity and protect confidentiality.

Definition of terms used

a)   The People First (or self-advocacy) movement in the United Kingdom adopted the term 'learning difficulty' in 1985 based on a rejection of the predominantly medical model of disability. The self-advocacy movement prefers the term 'learning difficulty' as opposed to learning disability or disabled person. Whilst acknowledging that there is a wider debate about the nature of terminology I intend to use the term learning difficulty throughout this piece of work unless I use direct quotations from other authors who in turn may have adopted another label for their own reasons based on a particular historical context or world view.

b)   Service user – someone who receives services provided by the organisation, usually as a tenant of supported housing, resident of a registered care home or participant in day activities.

c)   Carer – usually a parent of a service user although the term is increasingly used to describe people who are paid to be support workers or are employed in a professional capacity.

d) Board – the governing body of the organisation which is ultimately accountable to external authorities for service delivery, eg commissioners in health and social care, the Charity Commission, the Care Quality Commission and others (eg for financial accountability, Companies House, Audit Commission).

e) Management Committee (alternative name for Board) relates to d) above.

f) Trustee – the Charity Commission requires a higher threshold of accountability. The Care Charity is part of the overall group structure of the case study. There are 8 Trustees who are appointed at the Annual General Meeting. None of the Trustees can be direct recipients of services, for example, or be service users as this is contrary to the wider social and charitable aims of the charity. Beneficiaries are not deemed to be independent or accountable to the Charity Commission.

g) Staff member – a paid employee of the charity.

h) Executive members – senior staff team made up of paid employees (including myself) and responsible for the day to day running of the business and attendees rather than voting members of the board.

i) Social enterprise where, for example, money is reinvested into companies with a desirable social aim. Social businesses see the confluence of business and philanthropy used to achieve social progress.

Before 1990, most people with learning difficulties (if they indeed survived into adulthood) could be found living in long-stay institutional care, often in former Victorian workhouses operated as total institutions or asylums (Goffman, 1961)

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or "intentional communities' (Collins, 2000). Service users, referred to as patients, lived in large, mixed-sex wards (30 plus beds) with few personal possessions or space. Their lives were characterised by hospital regimes involving lack of choice, privacy or recognition of their individual needs. Atkinson, Jackson and Walmsley (1997) have explored the history of adults with learning difficulties giving consideration to 'their forgotten lives' in institutional care. There was scant evidence of care-planning and any intervention was based on a medical model of assessment. Food, social activities and even clothing were chosen by staff employed to exercise control, keep order, attend to basic needs, such as, feeding or bathing and administer any prescribed medication. The patients' voice was largely unheard and there was a sense in which people were 'done to' in what Duffy (2006) described as a charitable or gift model. Choice and Voice, or the concept that service users were actively consulted about their lives, was the exception rather than the rule.

Forty years later this type of environment is predominantly absent in the United Kingdom. Between the late 1970s and early 1980s many people moved out of the institutions under a planned discharge scheme promoted by the Department of Health. However the alternative accommodation up until 1993 (and the full implementation of the National Health Service and Community Care Act 1990) was still largely institutional in nature albeit in smaller residential care homes situated in the wider community. This was due to many factors, for example, lack of knowledge regarding housing options or the sheer impact of the large numbers of patients involved (30,000 plus) but Race (1995) asserts that insufficient funds, that is, money were made available to develop alternative

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provision in the community. My study will illustrate alternative solutions to an

institutional model of community care. Further as an alternative to an hospital

based service, I will explore the often creative alternatives through an analysis

of Board meetings over a ten year period and interviews with board members

which includes tenant service users. In addition there was an ideological shift

over the period in question moving from institutional thinking through a process

of normalisation to the participation-emancipatory paradigm which is more

prevalent today. Table 1.1 illustrates this paradigm shift over time.

Table 1.1 Paradigm shift

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                                    ┌─────────────────────────────┐
                                    │ Emancipatory approach began  │
                                    │ in 1990s (Beresford and Croft,│
                                    │ 1992) (Nicholl, 2011)         │
                                    └─────────────────────────────┘
                                              ▲
                        ┌─────────────────────────────┐
                        │ Participation began in the 1980s │
                        │ (Joseph Rowntree Foundation,      │
                        │ People First Movement)            │
                        └─────────────────────────────┘
                                    ▲
                ┌─────────────────────────────┐
                │ Normalisation 1970s onwards  │
                │ (Wolfensburger (1972) O'Brien │
                │ (1989)                        │
                └─────────────────────────────┘
                          ▲
        ┌─────────────────────────────┐
        │ Institutional Model late 1960s │
        │ (Goffman)                      │
        └─────────────────────────────┘
```
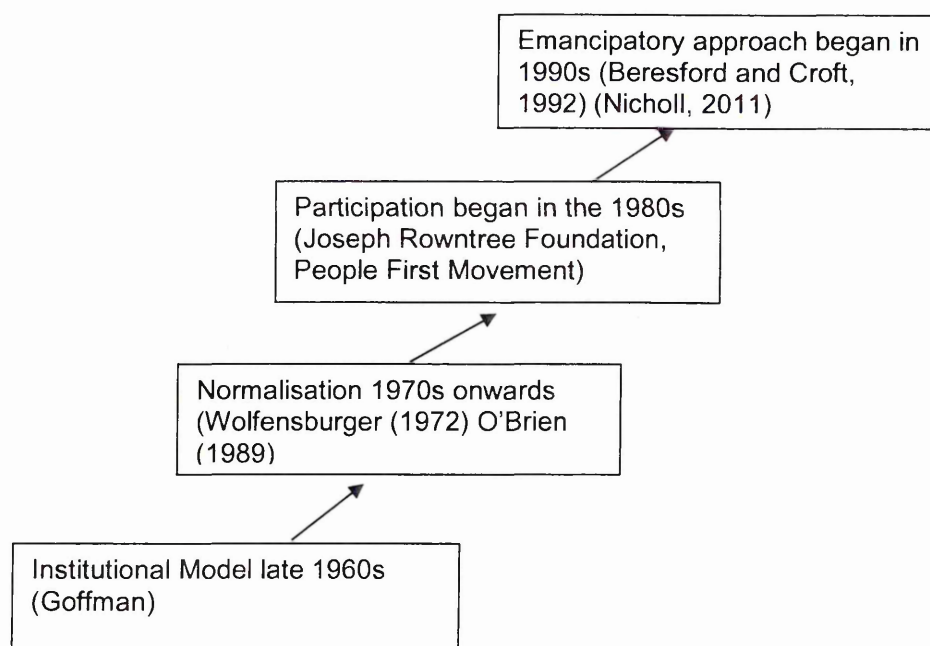
Although some larger care homes dating from the initial discharge programme

in the late 1970s still exist, these are now in the minority. People with learning

difficulties have become more visible, living in smaller, more domestic settings,

in local communities. They are often supported to live independently due to their particular care needs. However, staff are now expected to exercise a different, more supportive role, with an emphasis on helping people with learning difficulties to exercise personal choice and day-to-day control over their lives. This is recognition of their rights under equality legislation and is enshrined in the Valuing People White Paper (2001) and Valuing People Now (2006). Duffy (2006) refers to this model as one of citizenship. Entitlement via citizenship replaced the idea of the gift model offered by charity and self determination arising from the recognition of citizenship.

Citizenship has been described by Duffy (2006) as "*The word we use to describe what it is to be recognised by other people as an individual who is a full member of the community.*" (2006:2)

For Drake (1991) the opposite of citizenship is social exclusion. Barbalet (1988) argues that citizenship is a concept that essentially defines "*those who are and who are not members of a common society*" (1988:1) Barton argues that a fundamental ground for the exclusion of disabled people has been "*the definition of their difference from others in mainly negative and offensive terms*" (1993:18) Nicholl (2011) urges people to remember the importance of recent history which at its most extreme culminated in the Eugenics movement and the extensive use of euthanasia in concentration camps.

Citizenship is important as it celebrates equality whilst recognising individuality

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or difference. The role of social worker or professional is still needed under this model. Duffy sees them as *"valuable members of society with skills, passion and a positive professional value base."* (2011:167) According to Barnes (2006), professionals can form equal and mutually beneficial partnerships with disabled people as citizens. Morris (1998) acknowledges the importance of allies and supporters in achieving civil rights. Gross (2011) urges co-production at all levels or *"Nothing about us without us."* (2011:103)

For Duffy (2006:7) self-determination requires three essential ingredients:

Legal status (*rights to be a citizen*)

A system of communication (*which is appropriate and accessible*)

A decision-making process (*for example, at Board level*)

Mulally describes empowerment as:

"a process through which people reduce their powerlessness and alienation and gain control over all aspects of their lives and their social environment" (1993:161)

Mulally (1993) refers to dialogical practice which is built around certain features described by Moreau and Leonard (1989) which include for example, the basis of the dialectical relationship starts at the micro (or individual) level and is demonstrated by the Board members. Transparency and openness are key elements in the dialogue. Moreau and Leonard (1989) discuss features of dialogical practice which include:

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"   -   *Sharing with the service user the content of case recordings.*

        -   *Directly involving service users in decisions that affect them.*

        -   *Directly involving the service user in providing feedback on the kinds
            and quality of services provided.*

        -   *Reducing the social distance between worker and service user by use
            of self-disclosure, casual dress, giving the rationale for techniques and
            questions. Personal empathy, home visits, first names, direct clear
            speech and use of body language.*

        -   *Sharing with the service user one's personal biases and limits as part of
            the "helping" contract.*

        -   *Providing information on the role of the agency and the rights of the
            service users, and letting him/her know the worker is there to service
            the service user.*" (1993:175)

Mulally further discusses the need for people to work together within social work
with a view to achieving positive change. This can take the form of political
education based on active communication and the articulation of the day to day
life experience of service users.

I am interested in exploring the impact of the organisation in question on the
lives of individuals, particularly adults with learning difficulties. This involves
both describing the emerging model of service delivery over a given period of
time and reflecting on the role of service user Board members at the
governance level in order to achieve this. In particular I wish to explore the
involvement of service users at Board level. This is part of the overall

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empowerment agenda described above. It is an educational process set within an emancipatory paradigm. It is not purely descriptive but rather can point to prescriptive strategies for future service delivery within the overall framework of structural social work promoted by Mulally and others. The general involvement of Board members as volunteers has been explored recently by the National Council for Voluntary Organisations.

Reasons to engage – why do people volunteer?

- "I wanted to improve things/help people" – 62%
- "The cause was really important to me" – 40%
- "I had spare time to do it" – 33%

- *'Making a difference'*
- *'Wanting to give something back'*
- *'Being committed to the cause'*

Source: Citizenship Survey 2008-2009. Volunteering and Charitable Giving Topic

The reasons for board member involvement will be explored later. However, I was particularly keen to explore the impact of service user involvement. Tyson (2011) urges the recognition of innovation from passionate and committed organisations who have striven to put people they support in control of their lives.

Brown and Smith (1992) state that user participation was a neglected area but since that time user involvement has been encouraged. (Barnes and Wistow, 1994) This has been particularly noticeable with the growth of Direct Payments following changes in legislation in 1996.

Barnes and Mercer (2006) describe the focus of service user involvement during the 1990s as a 'consumerist' approach (2006:72). For example, service users as potential consumers being involved in planning and advisory meetings or as 'lay' inspectors of care homes, or indeed as direct payment recipients.

Barnes and Mercer highlight the barriers to disabled people's involvement in 'social care' services. An underlying criticism from them is that...

> *"the policy process is often so complex and bureaucratic that non-participation is too easily rationalised."* (2006:74)

Thomas (1999) discusses "psycho-emotional" barriers to participation including lowered self-esteem and self-confidence. There may indeed be physical or historical barriers based on someone's past experiences in institutional care. The combined impact on service users may prevent individuals becoming involved. Other barriers include the use of inaccessible information, difficulties with physical access, lack of reimbursement for travel expenses and the timing of meetings. The advocacy movement stresses the importance of group membership or peer support in developing the confidence of service users. The discussion of the case study will demonstrate how the barriers have been overcome and I will use Braye's (2000) checklist as a means to assess service user involvement.

Disabled people have had to come to terms with the consequences of living in a society which devalues, segregates or oppresses people viewed as 'disabled'. The epistemological impact of this is the essence of an emancipatory research

approach developed by Beresford and Croft (1993) and epitomised in the Shaping our Lives agenda (2001 onwards) which is a national user controlled organisation and network. Further, the emancipatory approach was endorsed as early as 1991 by the Joseph Rowntree Foundation which characterised social research as an essentially political process. It stressed seven core principles, including control, accountability, empowerment, the need for rigour, the choice of methods and the role of experience as well as the social model of disability.

In order to contextualise this study of Involve Housing Association it is necessary to set the scene over a defined period of time. This is the essence of the case study approach. In order to do this I find Layder's concept of a research map (1993) useful. This allows me to better describe the organisation as it highlights the macro and micro levels in relation to its existence. He identifies four elements: context, setting, situated activity and self (all located within a timeframe or historical perspective).

Table 1.2

Layder's Research Map (1993)		
H I S T O R Y O R D E V E L O P M E N T O V E R T I M E	1. CONTEXT	Macro-social organisation (Health and social care in the United Kingdom post 1971)
	2. SETTING	Intermediate social organisation, (For example, Involve Housing Association)
	3. SITUATED ACTIVITY	Group of actors, for example, Board Members or Executive Management Team
	4. SELF	Individual social experience

1.   CONTEXT

I intend to discuss health and social care for adults with learning difficulties in England and Wales since 1971. The particular emphasis on England and Wales

is in order to avoid complication in relation to other United Kingdom law in relation to health and social care for example, in Scotland. It is vital that boundaries are set from the outset in order to make the case study both more manageable in terms of time, content and relevance as well as useful in terms of rigour, generalisability and transferability. The implications of this are discussed later, in Chapter 2.

The overall context is divided into three separate but interrelated sections Socio-Political, Ideological and Legislative.

a. Socio-Political context

The White Paper *'Better Services for the Mentally Handicapped'* (DHSS, 1971) was a watershed: a "signpost pointing away from the institution" (King and Harker, 2002). The creation of the National Health Service in 1946 had shifted responsibility from local authorities to the health services. Adults with 'mental handicap' were seen as ill, uneducable and in need of long-term institutional care. The asylums (often based in former workhouses) and colonies, often intentional communities created by well meaning charitable bodies but strongly criticised by Collins (2000) as being institutional and paternalistic were taken over by the National Health Service in 1948. By 1959 and following the Mental Health Act, local authorities were once again engaged in providing long-term residential accommodation.

During the 1960s there was much debate about the impact of asylums

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(Goffman, 1961) and the Ely hospital scandal in Cardiff (DHSS, 1969) reinforced awareness of the oppressive regime within total institutions and triggered the 1970 Royal Commission into Better Services.

Following the 1971 Act, which considered exclusively the situation of adults with learning difficulties, and the subsequent local government reorganisation in 1974, there was an emphasis on reducing the numbers of people with learning difficulties living within hospital environments. £40 million of capital expenditure was allocated by central government between1971-1975. (Raynes *et al,* 1987) The anticipated timescale to increase the number of residential places in the community from 4,000 to 30,000 bed spaces (King and Harker, 2002) was envisaged to be achieved over a 15-20 year period. However, the emphasis during that time was still on residential options based on a care home model rather than supported living. In addition Race (1995) has noted that insufficient funds were made available to develop alternative provision. There was little partnership working between Health and local authorities: even less so in shire authorities (epitomised by the case study). Social services departments had scant knowledge of housing possibilities which was a district council function in shire areas. Following the introduction of the Local Government Act (1992) social services and housing were located within the same unitary authority. This did not apply to shire authorities. After the Housing (Homeless Persons) Act (1977) there was an emphasis on the statutory duty to re-house homeless or vulnerable people but the hospital environments housing adults with learning difficulties remained hidden or were of a low priority.

At that time most of the voluntary sector initiatives were based on the residential home model run by national charitable organisations like Mencap (which was established in the 1950s by carers (and originally known as the National Association of Parents with Backward Children) as well as private providers. During the 1980s, there were a number of more radical initiatives, for example, dowry payments for discharged patients, enabling them to move out of the hospital. The Ordinary Life Project (supported by the King's Fund) reinforced both an ideology of people living outside institutional care and the genesis of the National Development Team. The idea of "people living in the mainstream of life, living in ordinary streets" (1980) gained momentum. The Green Paper on Community Care (DHSS, 1981) was followed by the Griffiths Report (1988) and this culminated in the ground breaking National Health Service and Community Care Act (HMSO, 1990). This Act was a watershed as it highlighted the inter-relationship between health and social care. It involved the introduction of a new managerial strategy which was supplemented by the development of a mixed economy of public, private and voluntary sector non-profit or charitable organisations. In the future, the statutory services were to be purchasers (or commissioners) rather than providers. The government at that time promoted various charters to inform the wider public about their rights and choices. Oliver (1996) refers to this as "an empowerment strategy" and Beresford and Croft (1993) noted that there was a move towards citizenship based on equality legislation.

During the 1980s and in another government department, the Department of the Environment, there was a growing emphasis on supported housing for a range

of client groups. Following the inner city riots in 1981 and the subsequent

Scarman Report (HMSO, 1981) certain cities saw a significant investment in

community based hostels by the minister John Stanley (known collectively as

the Hostels Initiative). This was reinforced by the Housing Corporation as the

quasi-autonomous non-governmental organisation (or quango) responsible for

both capital and revenue funding to the increasing number of registered housing

associations. In Leicester, for example, the East Midlands Regional Housing

Corporation Office funded a range of special needs accommodation during the

1980s and early 1990s which focused directly on supported housing needs and

included initiatives for adults with learning difficulties.

The National Health Service and Community Care Act 1990 was driven by a

Conservative government committed to developing a mixed economy of health

and social care provision including the development of Community Health

Trusts within the National Health Service. This new Act had a wider context and

affected other client groups and not just adults with learning difficulties. It also

signalled a move away from focusing on buildings or resources to assessing

individual need. It was encouraged in part by critical, largely international,

thinkers, for example, Wolfensburger (1972) O'Brien (1981) and Brandon

(1989) as well as the rise in the disability movement in the United Kingdom.

This movement represented an ongoing ideological shift in relation to adults

with learning difficulties from 1970 onwards. There has been a significant

movement from institutional thinking through the normalisation process, which

started in North America, to a participatory, and more recently, an emancipatory

paradigm. This has paralleled the development of the social model of disability over a similar time scale.

In relation to service delivery, there is a position held within the disability movement epitomised by Gibbs (2004) which is of relevance. Gibbs worked in the same shire county as a member of the Centre for Integrated (now Inclusive) Living. He interacted with champions of the independent living movement, particularly the late Ken Davis. In 1990, Davis had developed the initial concept of seven needs which highlighted the fundamental areas of care and support in order to promote independent living by providing personal assistants. This concept had been adopted by the local social services department as care assessment criterion. As such it was radical, focusing on holistic or person-centred planning in the 1980s ahead of the NHS and Community Care Act 1990; although it has since been further developed by others for example, the Senses Framework promoted by Nolan, Davies and Grant (2001). The concept of the seven needs was highly innovative in its time and was further developed by the Southampton Centre for Integrated Living (SCIL) which subsequently highlighted 12 basic needs based on an holistic model of community living as outlined below.

Table 1.3 - 12 basic needs of community living based on an holistic or person-centred approach

1. Full access to our environment

2. A fully accessible transport system

3. Technical aids – equipment

4. Accessible or adapted housing

5. Personal assistance

6. Inclusive education and training

7. An adequate income

8. Equal opportunities for employment

9. Appropriate and accessible information

10. Advocacy (towards self-advocacy)

11. Counselling services

12. Appropriate and accessible health care

Source: Southampton Centre for Independent Living.

For Gibbs, the advent of one of the first centres for Inclusive Living in the late 1980s symbolised a radical approach to service delivery based on a politicised model of social disability and described below as part of the philosophy of the independent living movement. This was further highlighted by the Direct Action Network (DAN). Barbara Lisicki, a prominent member of DAN stated:

"The disability movement is obviously a set of ideas that presents a challenge to dominant ideology that says disabled people are burdens on

society and that they should be taken care of but the disability movement is also about people who believe that they have a right to life." (Quoted in Oliver, 1996:5)

In summary the philosophy of the Independent Living Movement states that:

(a) all human life is of value.

(b) anyone, whatever their impairment, is capable of exerting choices.

(c) people who are disabled by society's reaction to physical, intellectual and sensory impairment and to emotional distress have the right to assert control over their lives.

(d) disabled people have the right to participate fully in society.

Elder-Woodward (2002:3)

This overtly political dimension underpins the activism of the disabled people's movement: the direct action or call-to-arms in relation to social change and real improvement for disabled people. Barnes (1991) highlighted the power and authority exercised by the so-called "caring professions" as well as the perception of disabled people as having "special needs". However, within the disabled people's movement there is some disagreement about this radical (or materialist) stance. Corker (1999) feels that this emphasis on materialism ignores the value of personal experiences. Barnes (1998) refers to this as "sentimental autobiography".

The Disability Movement started with a core value base approach to service delivery involving a management structure and service user self-management and involvement: it was radical.

In brief, Gibbs defines the essential features of a Centre for Integrated Living (CIL) as:

"1. *an underlying principle of peer support, in which disabled people come together and support each other;*

2. *disabled people's control on the governing body;*

3. *an applied social understanding of disability; and*

4. *an integrated approach to support needs, recognising that a social model cannot be applied by services that meet needs in isolation."*

(2004:146)

The creation of Involve Housing Association in 1991 largely adopted this model in its philosophy and value base although there are issues regarding point 2 above which will be explored later in my discussion.

Until the rise of People First in the 1980s, the Disabled People's Movement, including the local centres for Integrated (now Inclusive) Living, focused on people with physical or sensory impairments and largely excluded adults with learning difficulties. Within that context, service users with learning difficulties played a minor part, being back stage rather than centre, for example, the forgotten population in long-stay hospitals were still waiting for their lives to improve. Thomas acknowledges this in a debate with Corker (2002):

"It is certainly the case that specific forms of disabilism [Note: her social definition is of discrimination, exclusion, prejudice] *encountered by people with ...learning difficulty have been relatively ignored by social modelists within disability studies until very recently"* (2002:25).

O'Brien's work in Georgia, USA during the 1980s was particularly significant as he concentrated on the needs of adults with learning difficulties. His stated five accomplishments – choice, community presence, relationships, respect and competence had a direct impact on developing alternative strategies to institutional care within the UK. In particular, his ground breaking approach led to the expansion of the United Kingdom's National Development Team in the late 1980s.

Felce (1996) details the growth in the independent sector which included both private (that is, profit making) and voluntary or charitable organisations (generally referred to as the not-for-profit or third sector). Involve Housing Association is an example of the latter.

Voluntary organisations are usually run by a Board or management committee which needs to demonstrate good leadership by adopting six key principles identified by National Council for Voluntary Organisations (NCVO) namely:

- Understanding their role or purpose.
- Ensuring delivery of the organisation's purpose.
- Working together effectively as both individuals and as a team.

- Exercising suitable control over legal, financial, managerial and regulatory matters.
- Behaving with integrity.
- Being open and transparent in order to ensure accountability to service users.

Thirty years after Better Services (1971), a second White Paper appeared which concentrated exclusively on the needs of adults with learning difficulties. This National Service Framework was known as Valuing People (Department of Health, 2001). This report focused on four principles: Rights, Independence, Choice and Inclusion. It intended to redress the lack of focus on learning difficulties (often referred to then as a 'Cinderella service' due to the lack of funding and strategic direction) over time. There has been progress in relation to developing person-centred approaches (Sanderson, 2006) based on "active support" (Felce et al, 2000) and service user involvement. However, there is still an overall emphasis on risk assessment and this tends to be dominated by the paternalists (Deeley, 2002) or from the carers' perspective (Booth et al, 1990) who tend to emphasise security and supervision which is largely risk adverse rather than focusing on independence and positive risk taking.

Following the scandals highlighted in, for example, the inquiries into Cornwall Health Trust (2006), it became necessary to commission a further report known as Valuing People Now (Department of Health, 2006). This was welcomed as there was deemed to be a distinct lack of progress in certain areas, particularly in respect of staff attitude and lack of compassion. Partnership Boards set up by

local authorities had a varied record in terms of delivering services to and for adults with learning difficulties. In particular there was a lack of co-ordination in relation to two areas that is, housing options for people with learning difficulties and the negative experience of bullying in local communities (sometimes referred to as hate crime) and highlighted poignantly in the Pilkington Report (2011).

b. The ideological context based on the social model of disability

The individual or medical model of disability focuses on bodily 'abnormality' and the way that this causes some degree of functional limitation or incapacity. This in turn is used *"as the basis for a wider classification of the individual as [an] invalid... this forms the basis for the 'personal tragedy' approach where the individual is regarded as a victim, as someone who is in need of 'care and attention' "* (Barnes *et al*, 2008:21*)*. Oliver (1996) asserts that **"***the assumption is, in health terms, that disability is a pathology and in welfare terms, that disability is a social problem"* (1996:30).

In the United Kingdom, a group of disabled people known collectively as the Union of Physically Impaired Against Segregation (UPIAS) produced a document called *The Fundamental Principles of Disability* in 1976. One of the leading protagonists was Mike Oliver, himself a disabled person, who became a university lecturer and established the Disability Studies Unit at Leeds University, sometimes referred to as the Leeds School. UPIAS criticised the control of experts or so called professionals who defined disabled people or

their disability as 'the problem':

> *"We as a Union are not interested in descriptions of how awful it is to be disabled. What we are interested in is the ways of changing our conditions of life, and thus overcoming the disabilities which are imposed on top of our physical impairments by the way this society is organised to exclude us."* (UPIAS, 1976:4-5).

Hasler, Director of GLAD, the Greater London Association of Disabled People states that:

> *"during the 1980s the disabled people's movement has changed the discourse on disability in Britain. It has done this both by enabling disabled people to be active in public life, and by redefining the meaning of disability."* (Hasler, 1993:284)

The medical model makes an underlying assumption that the impairment (whether physical or intellectual) is the reason why disabled people are disadvantaged. The social model of disability stresses economic, environmental and cultural barriers, that is, the external forces of oppression not the impairment affecting the individual. However, the social model of disability can ignore questions and concerns relating to impairment and/or the importance of medical and therapeutic treatments. Thomas (2002) states that these must be debated within the overall paradigm of the social model of disability:

"The potential for impairment to limit activities is not denied, but such restrictions do not constitute disability." (2002:43)

Thomas (2002) describes the redefinition of the 1970's biologically determined (medical model) into a social relational phenomenon (the social model) as part of an ideological shift and awareness of disability. She further locates the foundation of disabilism *"in the historical emergence and development stages of capitalist relations of production."* (2002:19). This Marxist theoretical stance fits well into a structural social work analysis of the United Kingdom in the 21st century. As a disabled woman herself, Thomas further develops a feminist perspective highlighting *"socially constructed gender difference"* (2002:19).

Lee (2002) also recognises that adults with learning difficulties are often subjected to increased social isolation and marginalisation and they may be absent from the vanguard of the disability movement. Chappell (2011) considers why adults with learning difficulties are largely absent from the literature on disability. She notes the emphasis on bodily or sensory impairments as well as the fact that written narratives of their views and experiences have not always been conveyed without the involvement of non-disabled allies or supporters.

Part of this was due to the fact that the medical model against which the social model retaliated in the 1970s focused on impairments using a definition based on physical characteristics. Oliver's definition of disability in 1996 as a *"form of disadvantage which is imposed on top of one's impairment"* widens the

possibility of this being applied to adults with learning difficulties who, as stated earlier, were largely hidden in institutional environments until the hospital closure programme impacted on their lives in the late 1980s. His literature review in the same year mentions no writers or debates specific to learning difficulty (Chappell, 2011).

Goodley and Rapley (2002) work towards a social theory of impairment using a *"post-structuralist stance"*. They seek to deconstruct the either/or, medical/social, disability/impairment debate. Instead they wish to bring together impairment and disability *"as co-existing social and political facets of disenchantment"* (2002:138). Their earlier work (2000) highlights the possibility of using the lived and actual experiences of adults with learning difficulties within a materialist (or structural) paradigm of a disabling society.

Referring to adults with learning difficulties' particular stance and behaviours as "incidents of resistance", Goodley and Rapley (2002) see the possibility of change through a political struggle against disablement and consequently its impact on an individual's life. In short, the medical versus social model of disability is not a linear either/or debate but a three-dimensional interactive discourse.

In 2001, the World Health Organisation determined that disability was a socially created problem. The new International Classification of Functioning, Disability and Health (known as the ICF) was created based on an integration of the medical and social approach or the so called "biopsychosocial" approach which

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aimed to achieve a coherent view of different perspectives of health from a biological, individual and social perspective (World Health Organisation, 2001). Three dimensions were defined – the domains of body functions and structures, activities and participation and environmental factors.

> *"The issue is…an attitudinal or ideological one requiring social change, which at the political level becomes a question of human rights…disability is a political issue"* (World Health Organisation, 2001).

Barnes and Mercer (2006) noted an absence of the involvement of adults with learning difficulties in the mid-1990s. Within the disabled people's movement as a whole there was sometimes a reluctance to involve service users with learning difficulties due to, possibly, ignorance or a fear of being further stigmatised. Oliver suggests that all the "big" ideas about disability have emerged from the disability movement itself and not from the more traditional or mainstream voluntary sector. This position appears extreme but does allow some analysis of where particular voluntary organisations may lie on his traditional to radical spectrum. Oliver ignores the contribution of allies and supporters who may also be non-disabled people but Jenny Morris speaking at a conference in Australia in 1998 recognises the need for partnership with non-disabled people in order to achieve disabled people's civil and human rights.

> *"All civil rights movements need allies and the most effective ones are those who relate their own experience of being disempowered to our experiences…..we don't need people to do things **for** us but **with** us."*

Earlier, Morris (1993) recognised the ideological impact of the independent living movement on the new model of community care after 1990. The opportunity to take control and work within the new legislation was seized. It is difficult to remember how radical the strategy was at the time. Twenty years on there has been much debate about empowerment, choice and self-determination, for example, the In Control Project promoted by Glasgow Inclusion and Duffy in particular (2006). However, the establishment of the subject of this case study pre-dates not only the wider empowerment agenda but, in terms of practical service delivery, it used new forms of funding ahead of other agencies and involved tenant service user representatives on its board ahead of other organisations (which in the main were post-2003). I wish to explore the themes relating to this within my case study.

Overall the environmental conditions generated by the increasing influence of the social model of disability had an impact on the development of service users' empowerment. The growth of tenant participation, the self-advocacy movement and emphasis on consumer choice all served to reinforce service user involvement. This fitted into the wider emancipatory social work paradigm celebrated by Mulally (1993) and Beresford (2003) amongst others, and is a major influence in the current debates around personalisation of transformational service delivery which focus on an individual's self-assessed need.

The Emancipatory School of Disability Studies started in the United Kingdom by Morris (1980s), Barnes, Oliver and Mercer (1990s) and later Beresford (2003

and ongoing) highlights issues of inclusion, citizenship and ultimately human rights. Arnstein (1969) described a ladder of citizen participation with consultation as a tokenistic approach and therefore the bottom rung. The new politics of post-modern United Kingdom strengthens involvement at all levels. The Valuing People White Paper (2001) had a stated objective:

> *"To enable people with learning disabilities and their families to have greater choice and control over where and how they live"* (2001:707)

and stressed the need for increased use of Direct Payments, advocacy, involvement in decision making and the provision of more accessible information.

Walmsley (2010) explores prospects and problems in respect of research within the emancipatory paradigm. She highlights the uneasy relationship between the disabled people's movement and learning disability: the former *"more often than not ignoring its existence"* (2010:489).

> *"The word 'mental' in mental handicap linked more directly to the area of mental illness and indeed the legislative framework of the 1959 Mental Health Act applied both to mental illness and to 'subnormality' as learning disability was then called."* (2010:489)

This was certainly the case under the medical paradigm. For example, consultants linked to a local long-stay hospital were employed as psychiatrists

within mental health rather than other areas of the National Health Service. The prevailing ideology with its emphasis on normalisation in the 1980s and the impact of the Valuing People agenda post 2001 has led to a realignment away from mental health (medical model) towards the wider disability movement and a focus on rights and choices (or empowerment as it is collectively described) and located within the wider social model of disability.

Ideologically, the impact of the disability movement in the broadest sense cannot be denied. Oliver (1990) states that it is important to everyone as:

"the disability movement is moving inexorably to the centre of the stage, and its significance lies not in the legacy it will leave behind, but in the new forms of social relations it will be instrumental in creating." (Oliver, 1990:93)

Oliver (1996) in his report to the commission on the future of the voluntary sector, stresses the need for overall user control as a challenge to the traditional disability (and typically) voluntary sector organisations. As a disabled person himself, he writes an "insider account" of the rise of the disability movement. His classification into five various kinds of voluntary organisations is useful but his critical distinction is whether they are controlled and run by disabled people themselves. His position is uncompromising as it was written in the mid-1990s: it may have been viewed as unrealistic or utopian. It was certainly inappropriate in relation to adults with learning difficulties given the time-lag in terms of the developing emancipatory paradigm in respect of their

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needs.

The dichotomy between emancipatory or participatory models in relation to service users with learning difficulties will be developed later. Issues of mental capacity and understanding as well as the reality of accessibility are critical areas of analysis. The debate regarding "user-led" as opposed to "user-influenced" organisations also needs to be explored within this context and the overall responsibilities of Directors under legislation relating to companies. This in turn raises the fundamental debate at the heart of the running of voluntary organisations that is, governance.

Given the limitations of full and active participation in academic research, Walmsley describes the role of people with learning difficulties in research as a junior partner to non-disabled researchers with the latter *"more akin to an expert advisor to people with learning disabilities"*. This differs from the wider disability research field.

> *"Physically impaired academics do not need plain text versions, Makaton or illustrated reports to be able to understand research, whereas most people with learning disabilities do."* (2010:495-6).

Given the barriers, both social and medical, Walmsley concludes that 'user participation' or partnership is more suitable for learning difficulty research than 'emancipatory' approaches promoted by the Leeds school. It calls for a special approach: different but equal treatment.

c. Legislative Context

Table 1.4 below highlights the key legislation which has an impact in relation to this area of research.

Table 1.4 Key Legislation since 1971

HEALTH	SOCIAL CARE
1. Better Services for Mental Health 1971	Registered Care Homes Act 1984
2. National Health Service Act 1977	National Health Service and Community Care Act 1990
3. Health and Social Services and Social Security Adjudications Act 1983	Small Homes (Amendment) Act 1991
4. Health Act 1999	Carers (Recognition and Services) Act 1995
5. Valuing People 2001	Direct Payments (Community Care) Act 1996
6. Mental Capacity Act 2005	Carers and Disabled Children Act 2000
7. Valuing People Now 2006	Care Standards Act 2000
8. Health Act 2006	Carers (equal opportunities) Act 2004
9. Mental Health Act 2007	Health and Social Care act 2008
10. Health and Social Care Act 2001	
HOUSING	**DISABILITY MOVEMENT**
1. Housing (Homeless Persons) Act 1977	Mental Health Act 1959
2. Housing Act 1996	Disabled Persons (Services Consolidation and Representation) Act 1986
3. Housing Grants, Construction and Regeneration Act 1996	Disability Discrimination Act 1995 Disability Discrimination Act 2005
4. Homelessness Act 2002	
GENERAL	
1. Charities Act 2006	Data Protection Act 1998
2. Companies Act 1985	Human Rights Act 1998
3. Companies Act 2006	Freedom of Information Act 2000

Further legislative change in health and social care was rapid post-1997 and the change of government to New Labour. It is fair to say that change within the

Health Service was more rapid than within Social Care. Although the two areas are related, the main responsibility for adults with learning difficulties has remained with the Department of Health under the Health and Social Care Act 2008 (although there were earlier influences in the transfer of responsibility and some funding under the Health Act 1999). In practice, changes in the NHS were implemented more speedily by formal means (for example, changing structures from Health Authorities to Community Trusts to Primary Care Trusts). The 1990 Act had only eight clauses relating to social care with its emphasis on care assessment. Changes in formal health structures post-1990 were progressed whereas changes in social care were delayed for two years until 1993. Until then the Department of Social Security continued to fund residential care homes. Care management took some time to develop. The growth in the 'mixed' economy after 1993 was indeed varied in terms of the range of options and services provided by different local authorities across the country, often described as the 'postcard lottery' of provision.

This was partly to do with the emerging care management function as well as the practical availability of alternative service delivery at the time. Shepherd (1995) describes the development of the care manager role as the gatekeeper of scarce resources or 'pump-priming' funds. There was also an economic dimension given the severity of public expenditure reductions, particularly in the early 1990s following the 1992 recession. The government funded some transitional arrangements via Special Transitional Grants (STGs) but this was a time limited initiative.

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The changes in the socio-political, ideological and legal context led to an increasing awareness of the need to update the 1971 White Paper (Better Services). In 2001, the Valuing People White Paper was introduced.

The Valuing People White Paper (2001) had its emphasis on the social model of disability and the four key areas of Rights, Independence, Choices and Inclusion. The White Paper was different in terms of its aims, style and delivery. From the outset it focused on redressing inequality for adults with learning difficulties by for example, tackling notions of accessibility. It simplified the language, launched an interactive website, used concepts of "jargon busting" and aimed to fully involve service users and their families. Its weakness was the fact that its implementation was to be co-ordinated by local authorities, which faced other challenges and did not always adopt an holistic approach to social delivery. For example, many partnership boards, which were enthusiastically set up in 2002, have since lost their direction and focus.

Barber (2011) noted the lack of emphasis on housing options following the Valuing People agenda. Lack of knowledge of suitable options together with low expectations of support and fear of potential risks influence service users' (including carers') experience. The involvement of carers is often lacking due to time constraints, the inevitable burden of caring responsibilities, low expectations and, as Bovey and McGaughlin (2005) state, the issue of "letting go." Possible solutions might involve the great emotional wrench of allowing a son or daughter to leave home, an obviously huge decision for caring parents. Over protection or reluctance to let go is largely risk averse rather than focusing

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on independence and positive risk taking. Care is necessary to ensure that people do not become more vulnerable or at risk: there is a delicate balance between safeguarding and independence. Manthorpe et al (1997) argue the need for "well managed risk" to ensure that the necessary supports are there. Carers need support and success stories to believe in positive outcomes and reduce anxiety.

The importance of housing options is vital for the delivery of non-institutional community care. Bovey and McGlaughlin (2005) assessed the barriers to achieving genuine housing choice for adults with learning difficulty by explaining the views of families and professional groups using focus groups. Their research highlighted barriers to independence, including the lack of information on which to make an informal choice as well as a fear about their son or daughter's ability to live independently. McGlaughlin and Gorfin together with Saul (2004) found that service users were in fact realistic about their need for support. They also found that the experience of residential or nursing care left service users feeling powerless and unhappy so that the emotional risk of leaving them in that environment was deemed greater than the risks inherent in independent living.

Stevens (2004) regarded the Valuing People White Paper (2001) as a watershed: an opportunity to see *the development of greater choice in housing for people with learning disabilities."* He agrees with the government's view that professionals limit housing placement decisions and that local authorities are conservative in developing a range of options. Stevens concludes that user

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involvement, either as carers or service users themselves, is still largely missing from the current (government) policy *"other than in examples of good practice"* (Stevens, 2004). These issues were supposed to be addressed following the introduction of a new funding and monitoring regime known as Supporting People (2003).

2.   SETTING - Introducing Involve Housing Association (the case study)

In 1990 and against the national background described above, the local shire authority together with the area Health Authority agreed to an alternative not-for-profit strategy to close down the local long-stay hospital for adults with learning difficulties. At that time over 300 patients were still living in the hospital.

Most of the housing accommodation was developed by Involve Housing Association, the sister organisation to the care charity. Collectively the two organisations are referred to as the Involve Group. The Group's primary purpose was to transfer as many patients as possible from the hospital using the Residential Homes Allowance system administered by the Department of Social Security. Under section 23$_{2(b)}$ of the National Health Service Act 1977 the charity was eligible, as a voluntary organisation, to receive staff, buildings or equipment in order to achieve its purpose. This was a radical strategy and until the termination of the residential homes allowance system in April 1993, it enabled 141 former patients to move into small registered homes together with over 300 National Health Service staff seconded to the charity in order to

provide necessary care and support, including nursing care. The average size of accommodation was five bed spaces. Even the nursing homes were small by national standards, the largest being 24 beds and the smallest 15 bed spaces configured as three, five-bed bungalows.

The range of accommodation was a vast improvement on the physical conditions and 30-bedded wards encountered in the hospital. Once the window of opportunity to use Residential Homes Allowance closed in 1993, Involve Housing Association began to develop supported tenancies, relying financially on housing benefit and individual or 'spot' contracts generated by the local authority in relation to the new community care assessments carried out by newly created care managers. Individuals were assessed by their care managers, and 'spot' contracts were developed for each person in place of the previous system of block contracts, which had been based on the purchase of all five beds, say, within a care home. The development of supported housing was rapid: housing opportunities within Involve Housing Association for the period 1993-2003 expanded from five to 150 tenancies.

Although housing is often referred to as the foundation of community care (various Joseph Rowntree reports), Raynes *et al* (1987) acknowledge that:

> *"Ordinary houses by themselves cannot generate integrated or individualised care, or practices which recognise adulthood"* (1987:43).

Their emphasis is not just on 'bricks and mortar' but based on *"an articulated*

set of principles from which quite specific standards can be derived". (1987:143)

As part of the 1990 Act, local social services departments were given a Special Transitional Capital Grant (STG) in order to pilot new initiatives based on needs assessment and ensure the generation of the mixed economy. Involve Housing Association was a local, Shire based agency clearly located in the voluntary or third sector and therefore ideologically suited to the then governing party at the County Council. Essentially it was in the right place at the right time. Some of the provision was innovative and for a shire authority, ground breaking. For example, in 1995/96 Involve Housing Association was given £1 million of STG in order to purchase three houses (and re-house 10 people from a local authority hostel) and provide the first out-sourced day service for 40 people. This expansion predated the Valuing People White Paper (2001) and is illustrative of the opportunistic or serendipitous development of Involve Housing Association.

Table 1.5 Structure of Involve Housing Association as at 2007

Board
Consists of members including 3 Service User Representatives reporting to and from the Service User Forum Meets bi-monthly Appoints 8 trustees to the charity at the AGM (September each year)

Executive Officer

Heads of Service

1	2	3	4	5	6	7
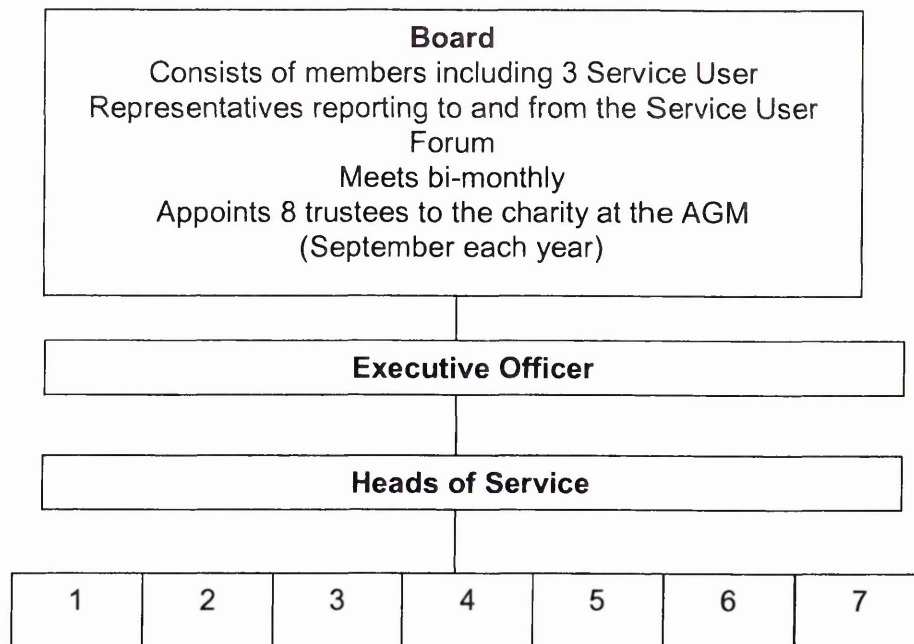
Key

1. Head of Finance
2. Head of Human Resources
3. Head of Training, Research and Information
4. Head of Property Services
5. Head of Registered Care
6. Head of Supported Living
7. Head of Day Services

The Involve Group consists of Involve Housing Association and its wholly owned subsidiary Involve Care and Home Support

3.   **SITUATED ACTIVITY (How the case study operates at Board Level)**

The care charity was established in 1990 as a limited company and consisted of

representatives of health, social services, voluntary organisations (including

other housing associations), carer and advocacy groups and local charities. It was built around what was then referred to as a consortium model, that is, representatives were appointed from different organisations. The two initial subscribers to the company were the Chair and Vice Chair of the local Social Service Committee at that time. There were limitations in terms of the charity rules. People with learning difficulties benefitting directly from the charity were barred from being trustees in order to avoid conflicts of interest or potential abuses of power in respect of the decisions taken regarding service delivery or financial investment. In the early days of the charity this was not a particular problem as all the beneficiaries were hospital in-patients, most of whom had been living in the institution for many years. They had little or no contact with family members and most of this forgotten population had moved to the hospital from a wider geographical area than the focus of trustee recruitment which concentrated on local involvement and representation. There was also more limited mental capacity of hospital patients to engage as voluntary board members. Their physical needs, together with their limited communication or the impact of many years living in the hospital, severely restricted their prospects of participation at the Board level.

Involve Housing Association was established in 1991 and was based on individual membership which facilitated, in time, the inclusion of tenant or service user representatives as Board members. As an exempt charity it did not have to comply with the stricter rules of the Charity Commission (nor submit annual returns). The Association was constituted as an Industrial and Provident Society under model rules which had, for example, governed the creation of

housing co-operatives in the late 1960s. It offered a more open, democratic structure. It allowed for a wider and larger membership, issuing shares of £1 to each member approved by the existing members of the management committee. Such fluidity was a major factor in the organisation being able to involve tenant Board members at a later date and could, in theory, still allow Involve Housing Association to become a user-led organisation in the future without any necessary structural changes to the constitution.

The structure had to be adapted once the new health and social care legislation introduced in the 1990s became effective. There was a subsequent split between the commissioning role and that of provider. Following the closure of the long-stay hospital in 1996 and the subsequent introduction of Primary Care Trusts, the inclusion of representatives from the health community was not deemed appropriate. This created the opportunity for new members to join and the first tenant service user was appointed to the management committee in 1998. In addition, and with the increasing emphasis on supported housing as an alternative model to residential care, it was increasingly important to involve service user representatives particularly in relation to best practice and the tenant participation agenda of housing associations. The increase in the number of service users (from one to three) on the Board in 2003 was partly a consequence of this changing priority. They represent 25% of the Board of Involve Housing Association.

There are currently 12 Directors on the Board or management committee of Involve Housing Association which meets bi-monthly. Since 2003, three of the

12 directors are elected tenant Board members nominated from the service user representatives on the Service User Forum.

In 2006, Involve Housing Association became the 'parent' of the care charity and the sole appointee of its eight Trustees. This is a wholly owned subsidiary. Both the association and the charity represent different sides of the same coin in terms of the local and integrated delivery of housing with care and support. This is a more holistic approach to service user delivery and will be discussed later as part of its prevailing ideology. Separate accounts are prepared for each legal entity. These are consolidated into group accounts, the entire set being subject annually to external accounting, monitoring and audit. There is an overarching joint business plan which has further developed the group year on year. All the generated surplus is used for the benefit of the client group.

Meetings of the two inter-related organisations which constitute the Involve Group take place on the same day and in the same meeting room. One meeting is held directly after the other with separate minutes to ensure compliance with internal governance, best practice and charity law. In particular, the eight trustees of the Charity cannot be direct beneficiaries of the service delivered by the organisation.

The trustees of the wholly owned subsidiary (the charity) are appointed by Involve Housing Association annually. As both meetings take place on the same day and in the same room, service user Board members of Involve Housing Association are present at the Trust Board meetings. In the rare event

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of a vote being taken by the trustees, service users do not have a vote. However, they are present at the discussion, can influence the debate and as discussed later, have an impact on the overall governance of the organisation.

4.   SELF – Players and Actors

Layder's (1993) Research Map refers to the impact of individuals or selves. This is a development of Goffman's (1959) work in relation to significant others. At this stage I need to acknowledge my own self as key player in the history and development of the organisation.

Having qualified as a social worker in 1978, I had chosen to work in housing, particularly with homeless people. I lived at that time in a large city which had experienced both social unrest and a subsequent significant injection of capital funds to address inequality, for example, homelessness. I was able to combine my social work training with housing expertise in order to deliver practical solutions and address housing need. During the 1980s I was responsible for developing major capital housing projects and co-ordinating partnership arrangements with over 35 voluntary organisations including housing associations. I was also an elected member of the National Housing Federation's Care and Support Committee which met in London and I chaired the regional supported housing committee.

Significant voices were around in the advocacy movement in the 1980s. I recall meeting the late David Brandon (a mental health service user who later became

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Professor in Social Policy at Anglia University). His approach to service users was based on his own experience in hospital, gentle teaching as a Zen Buddhist and mutual respect for human kind. I remember his talk having a profound effect on me. Shortly after, I moved to the shire authority as its Principal Development Officer for Mental Handicap (sic) and within 6 months was seconded to set up an alternative strategy for the patients living in the local long-stay hospital. I was able to put part of this ideological approach into practice in terms of shaping service delivery by using my housing knowledge to co-ordinate an alternative housing with care strategy for adults with learning difficulties. This role was not in isolation from the wider structural and national context mentioned earlier. However, the local context and its influence on the new organisational structure cannot be under estimated. Gibbs (and other disabled people) were also a critical influence on my thinking. Through regular meetings I was able to engage in key debates particularly concerning the involvement of adults with learning difficulties which I will return to later.

At the time, the shire authority was perceived as a progressive local authority comparable to other Labour-run authorities, for example, Sheffield City Council and the Greater London Council in London. The shire authority had resisted the excesses of Thatcherism in relation to public expenditure continuing (even until 2011) to provide non means-tested home helps to people in their own homes. The Council had also sponsored the development in the 1980s of one of the first national Centres for Integrated Living. This group of self-advocates campaigned for personal support to and for disabled people and the recognition of the social, rather than the medical model, of disability described earlier and

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championed by Davis *et al.*

As Principal Development Officer, I reported to the then Assistant Director of Development in the Social Services Department. In 1989 I was seconded by him to explore the alternatives to the long-stay hospital and implement change which would result in its eventual closure. The Assistant Director was one of the founders of the organisational structure and later became (and still remains) its overall Chairman.

The secondment lasted 12 months and at the end of this period I was encouraged to transfer to full-time employment of the new charity and in 1991 I became its Housing and Development Manager. In January 1991, I set up Involve Housing Association as a separate legal entity in order to explore and possibly receive capital funding for housing. During the period 1990-93 (when residential homes allowance ceased and the National Health Service and Community Care Act became fully operational) I was personally responsible for the discharge and re-housing of 141 patients from the local hospital. The residential homes model was adopted but by creating smaller, more homely environments including three nursing homes, the largest of which accommodated a total of 24 people but in a domestic environment based on four, six bedroom bungalows.

Most of the patients who were re-housed were unable to communicate using words. They were classed as residents rather than tenants: their tenancy status was one of a bare licence offering minimum security of tenure, although the

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accommodation was regarded as a home for life. Residents living in registered care shared communal areas and received only a personal allowance each week which, although an improvement on their previous in-patient status was still below the income level of tenants living in supported housing. However, this was a relatively limited option at the time.

The process of re-housing all the hospital patients took place over six years and the institution was finally closed in 1996. As director of the housing association, I had continued to develop the housing side of the business until my colleague and general manager of our care and support staff retired in 2002. To deal with this, the two Boards decided to create a joint post of Executive Officer covering the separated yet related activities of housing and care. I was promoted to this overarching single role. Further measures strengthened the service delivery, internal management structure and external accountability, and were indeed necessary to cope with the rapid expansion to meet need. The service now supports 350 adults with learning difficulties and employs over 650 staff. As the executive director I am directly employed by and accountable to the Board of the parent body which includes the service user board members. I am not a voting Board member or director. On the Board's behalf, I am its responsible officer for the running of the charity.

Significant Others

This includes a consideration of the governing body, or Board of Directors. The critical area of governance refers to the players (or other selves) that is, Board

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members who have been interviewed as part of my research. There is a natural dialectic in relation to the strategic and executive functions: an inter-connectedness which is the essence of the case study and will be addressed later.

The documentary analysis served to describe the development and growth of the Association over the given period and recorded the 'thick description' anticipated in Denzin's (1989) interpretive approach in relation to case studies. Understanding the content and implications of the minutes necessarily involves an understanding of individual social experience of the actors involved. This was further explored in the group interviews. The definition of 'actor' (Goffman, 1961) is not to be taken in isolation from the overall context described by Layder's mapping process. Individual roles are contextualised and often interrelated – as volunteer (that is, unpaid) Board members, as adults with learning difficulties or carers, as retired professionals, as staff members and, in my own case, as insider-researcher and also the key person ultimately responsible for implementation of decisions taken at Board level. The ethical and methodological issues involved in this will be further explored in Chapter 2. However, the importance of studying Involve Housing Association through the eyes of the actors involved in an individual capacity but within a wider historical and socio-political context is the essence of my case study and part of the sociological imagination celebrated by Mills (1959).

Similarly, the legacy of the past *"helps us to comprehend the mosaic pattern"* (of provision) (Raynes *et al* 1987:8). In writing the story of Involve Housing

Association using the methods described below I intend to work within the qualitative research approach of Denzin who noted we need to connect biographers of lived experiences within a sociological context.

In conclusion, the opportunity provided in 1990 by the move from institutionalisation to community care, which led to the setting up of first the charity and subsequently Involve Housing Association, was timely. Not only did the new legislation pave the way for more person-centred approaches but the focus on independent living was put "centre stage" in terms of the disabled people's movement. The promotion of lifetime homes and individual care packages often involving self-selection of staff and the use of direct payments (certainly post 1996) all flowed from the national socio-political and ideological influences sponsored and developed by the disability movement and described above as part of the overall context of the case study.

By describing the development of the association over a ten year period and by the use of both documentary evidence and the interviews with the key actors involved, I hope to both emphasise the critical growth and evolution of new approaches to services for adults with learning difficulties demonstrated through this case study and further develop analytical themes for discussion which may have resonance for similar organisations, and provide pointers for future direction.

Communication Matters

Before moving onto the next chapter, I want to highlight issues regarding communication with adults with learning difficulties. Overall the act of communicating or transmission involves the exchange of thoughts or information, by speech, signals, writing or behaviour. It involves "interpersonal rapport" which essentially links the art of communication to an act or human activity. It can be defined as active listening and making oneself understood or simply being heard. In respect of adults with learning difficulties it is often assumed by the general public that communication is difficult. Arguably it is different but not necessarily difficult.

First, it is necessary to understand communication matters in relation to adults with learning difficulties. By making everything more accessible to adults with learning difficulties this makes it easily accessible for everyone. There is a similar debate about physical access in the design of what are described as lifetime homes. Making a house accessible for a wheelchair user and installing a ground floor toilet for example, makes the house accessible for pushchairs and people with young families as well as useful for the occasional visitor who may have restricted mobility. Inclusion involves thinking through the implications for everyone. This approach reduces marginalisation or a focus on disability. Conversely, it focuses on the ability of everyone to participate: it is empowering. Second, in order to be equal members of the Board it is necessary for all participants to understand what is happening. Indeed it is an expectation in relation to directors' liability. Many of the discussions are verbal

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and/or visual, that is, they do not involve verbose reports which are difficult to read and understand but concentrate on key themes and these are expanded by presentation and verbal discussion. Sometimes items are projected onto a screen using PowerPoint and flip chart. This is particularly useful when looking at financial matters, for example, budget setting.

The educational literature in respect of communication with adults with learning difficulty tends to focus on younger people in schools. This is not surprising given the historical emphasis on service users' ineducability (as enshrined in the terms used in for example, the Education Act 1921). This approach was clearly located in the medical model of disability – stressing in a negative manner what could not be done and focusing on the individual's "impairment". The changes in legislation and post-war education, together with the adoption of the social model of disability has led to a significant improvement in communication. This links to the advent of the Disability Discrimination Act (1995) and Human Rights Act (1998) and the general climate of disability awareness which has moved the emphasis from the medical profession through to a carer focus and on, in more recent years, to the service user themselves.

The Valuing People White Paper (2001) encouraged better communication not only with carers but service users themselves. Terminology, or jargon, has been simplified. Reports are now routinely produced in accessible format in plain English often with pictures as well as simplified text. Better understanding or expectations of participation based on informed choice have been encouraged. Integration into mainstream schools or colleges has for some

service users become a reality. Speech and language therapy has become an expected strand of the care assessment process introduced since the NHS and Community Care Act 1990. As Styring (2003) states:

"This is extremely important to enable individuals with communication problems to make informed choices and be actively involved in decisions about their care." (2003:119)

Styring further discusses the role of independent advocacy which is fairly recent in the UK. The advent of People First in the 1980s developed a role for self (or peer) advocates. (Brechin and Swain 1988). The People First movement began in North America with the first international conference held in 1984 and the second held in 1986 in Twickenham. (Goodley, 2000). Usually the service users who were better able to speak out that is, used words to communicate, were encouraged to promote their views or those of their peer group. McGinnis (2003) highlights one issue of self-advocacy as a matter of creating space and opportunity to support people to formulate their own opinions. In his extensive work around personal communication he develops the concepts of translators – both credible and expert.

"This is…..because different people tend to hear different things and because the communication of the person at the centre may actually vary between different audiences and different settings" (2003:156)

Professional advocacy has developed more recently, aimed specifically at the

interface between services and service users. Services are usually located in the voluntary sector (but funded by the statutory services thereby bringing ethical dilemmas to the fore as well as an ongoing negotiation regarding future funding). Nevertheless professional or citizen advocates are often better able to highlight the concerns which arise in terms of communication or service delivery. Based on values which promote independence and an empowering approach to service user involvement, as well as being firmly embedded in the social model of disability, advocates can act as a broker between service users and professionals or indeed service users and their own families or carers. Styring (2003) stresses the need to avoid "tokenism". She also emphasises the difference between consultation with carers rather than directly with service users themselves.

> *"Both groups have very distinct needs and desires, and it is important for*
> *practitioners to recognise that these views, though both valid, can be*
> *very different from the wants and desires of the immediate carers, this*
> *can pose difficulties and tensions for practitioners."* (2003:126)

In addition, language is a powerful tool in itself. As Allen states *"language plays a pivotal role in enabling us to feel in control of our lives and the world around us."* (2002:74) Although focusing on work with adults with dementia, Allen's research is applicable to the experience of adults with learning difficulties. She acknowledges that language which is "muddled or unconventional" may be dismissed as meaningless. This can be devastating and lead to further marginalisation, as often happens, for example, in relation to people with

dementia. For Allen, spoken language is only one form of communication.

> *"Most of our communication is a mixture of the verbal and non*
> *verbal.....the meanings of the words we utter are clarified and shaded by*
> *the subtlety of non verbal signals, including rhythms and timing, tone of*
> *voice and facial expression."* (2002:74)

Words can have different meanings to different people. Adults with learning difficulties may have a limited vocabulary or experience more dramatic impact in respect of regional dialect, second language or terminology. They may not pick up the nuances of body language, subtle innuendo or sophisticated dialogue.

Allen (2002) discusses the impact of encouraging people to talk about the meaning of words. This can be "enlightening" as words *"reflect our values, priorities and vulnerabilities."* (2002:150)

Jargon is a specialist form of language often developed or used by professionals. The use of jargon can act as a way of exclusion or segregation. It underlines the power dynamics between the people involved. However, it can also be supportive, for example, in respect of Makaton, which was developed as an enabling language for adults with learning difficulties. Its frequent use and specific training for staff is essential if it is not to be a restricted form or code. Allen suggests coming up with an alternative word for each jargon term. This could be achieved by group discussion or role play. Jargon-busting is a powerful tool in improving dialogue and achieving equality of understanding.

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Essentially communication involves active listening, looking for the verbal and non-verbal meaning and allowing time for someone to express themselves in their own particular way.

The debate around communication was potentially made more complicated by the introduction of the Mental Capacity Act 2005. Certainly the requirement for increased advocacy may be essential to ensure that the views of people with learning difficulties are heard and understood and that people's best interests are followed.

Other aspects of communication discussed in the literature refer to the overall understanding of time (Flynn 1986). Events, sequence and timescales may have a different chronology for adults with learning difficulties. For example, McGlaughlin, Gorfin and Saul (2004) carried out a housing needs questionnaire amongst service users in order to assess current and future housing needs. The wording was checked with significant others and resulted in the removal of timescales confirming that timescales can be a difficult concept for adults with learning difficulties to grasp. It is worthwhile noting that this is sometimes a problem for people who do not have learning difficulties.

Plummer (1995) discusses the power process which shapes people's lives and if there is a lack of power – as with marginalised groups – this is regarded as a negative force. Plummer advocates the "power of participation" (1995:148) stressing the importance of active participation. Communication is the end: advocacy is the means. Goodley et al (2002) stress the importance of the

development of self-advocacy for challenging the possible oppression of adults with learning difficulties.

> *"However the experience of self-advocacy is still limited to a relatively small number of this group."* (Ward and Flynn, 1994)

For Plummer,

> *"It is therefore necessary to provide opportunities to listen to the silenced voices of the broader community of adults with a learning disability."*
> (2004:711)

Sometimes adults with learning difficulties can express themselves and are well aware of the support they may require. However, due to their powerlessness and the fact that decisions about their lives are often taken by others, for example, professionals and/or carers, they may say little. In summary, the ability to communicate may well be possible but their vocabulary and opportunity to speak out may be limited.

Sometimes there is a tendency for adults with learning difficulties to "say the right thing" or agree with the person who is talking to them at that particular time. There is a wealth of material relating to this acquiescence (something known as yea-saying) in interviews with adults with learning difficulties. Finlay and Lyons (2002) carried out an extensive literature review from 1950s onwards. Acquiescence is defined as the tendency to say "yes" to statements or questions regardless of the content or factual accuracy of the items,

particularly if the questions are difficult or ambiguous.

The language used and the way the question is asked, together with an understanding of the relationship between the interviewers, the interviewee, the power dynamics and the interviewees' understanding of the purpose and intention of the interviews may also be contributory factors to a "yes" response. Sigelman *et al* (1981) found acquiescence to be inversely related to IQ and later (1982) they graded responsiveness in terms of either/or, yes/no questions with open ended questions producing the least level of response. Later researchers disagreed with Sigelman for example, Booth and Booth (1994), Rapley and Antaki (1996) and stated that yea-saying in interviews was not as common as Sigelman had indicated. In particular, Sigelman's research was conducted in state institutions and with children.

Simons *et al* (1989) believed that acquiescence may be due to a lack of control in service users' lives or their powerlessness rather than due to a disability. It may indeed be more about social relationships and naïve politeness rather than lack of understanding. Clarification can be improved by attention to detail, breaking down the question into an either/or format and using pictures or symbols to avoid confusion.

The research into acquiescence is interesting to a degree: it explores the means, the process of interaction between adults with learning difficulties and the interviewer. It may help to frame the research question, to increase understanding about the potential obstacles and widen an awareness of the

impact on adults with learning difficulties. However, Goodley and Rapley (2002) state that there are political consequences in dwelling on acquiescence. It may lead to the effective silencing of adults with learning difficulties. It disempowers them: it labels people (with learning difficulties) as incompetent: it denies their contributions and confirms their "intellectual disabled" identity.

It is important not only to understand the socio-economic position of disabled people but also their individual experience as disabled people. The focus on individuality and intensive interaction was the essence of the work at Harperbury Hospital School in the 1980s. Wibberley, Hewett and Irvine (et al) developed an alternative approach to communication (see for example Nind and Hewitt, 1994). It can be viewed as either a way of teaching or simply a way of "being" with people. It is based on human interaction and an attitude which values and respects that individuality. Therefore it has different philosophical roots: it is organic. It changes in relation to each person. As such it may seem to go against the principles of normalisation or of appropriateness. For example, by the use of "motherese" adopted by care givers to support linguistic development. (Ephraim, 1986) However:

"Learning to "listen" so sensitively gives [people with learning difficulties] the chance to have a say that they are unlikely to have otherwise. Being playful does not have to mean losing dignity" (BILD Factsheet 2005:3))

Cameron and Bell (2001) stress the need to adapt communication skills or styles to those of people with learning difficulties. The use of intensive

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interaction and its underlying yet simple approach to human interaction is helpful. Technical aids for example, communication boards, or other types of assistive technology may well help individuals to better communicate with the "able" world but the approaches offered by intensive interaction and the parallel philosophy of gentle teaching will offer a more direct and interpersonal connection (Brandon, 1989).

My research is primarily aimed at people who use words to speak and are deemed to be more able to express themselves by being more verbal. This is evident in their status and role as board members. However, my overall approach is based on a more holistic understanding of people's position within a socio-political arena as consumers or recipients of social housing and care. My work is located within the emancipatory paradigm or more empowering research approach offered by my earlier definition of the social model disability and the implications of this will be discussed later in Chapter 5.

Chapter 2

Methodology and Methods Used

The aim of this research was to uncover the ways in which this organisation has developed over the period in question, as well as highlighting the impact of involving adults with learning difficulties at board level. The study was conducted from an epistemological basis of social constructionism and an interpretivist theoretical perspective adopting a case study methodology that employed the analysis of documents and interviews with key participants.

In the previous chapter I looked at the overall context of adults with learning difficulties post-1970 in order to describe the setting of my study. This chapter will present the methodology and design in more detail and the following issues will be addressed:

- The context and aims of the study.

- The values and purpose of this research.

- The theoretical approach taken.

- Case study methodology.

- The research methods: Documentary Analysis and Qualitative Interviews.

- Data collection and analysis.

- The challenge and benefits of being an insider researcher.

- The ethical considerations within this research.

The context and aims of the study

Since 1970 the visibility of adults with learning difficulties living in the wider community has increased. Several writers have discussed the move from institutions for example, Pring (2011) and there is some limited oral history telling the individual stories of former patients living in long stay institutions. (Atkinson *et al* 1997)

This case study of a housing association serving the interests of people with learning difficulties covers a period of rapid change in this service area which was described earlier. The aim of this research was to uncover the ways in which this organisation has developed over the period in question, as well as highlighting the impact of involving adults with learning difficulties at board level. Given the limited involvement of adults with learning difficulties in the running of voluntary organisations, this presented a unique opportunity to explore their engagement. In general, there is a paucity of research in this area. Most references to service user involvement promote the idea rather than reflect on actual involvement.

For example, there is a growing body of research involving service users in shaping their own lives, speaking out and sometimes involving advocates to be co-researchers (Beresford & Evans 1999) and (Reason, 1994). However, there is little research relating to the practice of involving service users at an organisational, managerial or board level. As part of my study I wanted to analyse the impact (or otherwise) of service users at Board level. The key

questions to address were as follows:

- How did the organisation develop over the period in question?

- How were service users engaged?

- Did service users make a difference and if so, in what ways?

- What was their added value?

- How did other board members view their involvement?

- What were the collective concerns about the future?

Locating the research within its wider macro framework is important in order to increase the understanding of the experience of participants (at the micro level) over a given period of time. In Chapter 1, I described the impact of the national situation in relation to adults with learning difficulties (the macro level) on the experience of individuals (the micro level). Located within this framework is the organisation which is the subject of the case study. This in turn has its own organic entity as shown in the interactional model below which also acknowledges the role of the insider researcher.

2.1   Interactional Model used in the research

<u>MACRO</u>

(socio – political)   Community Care or Health
and Social Care in the United Kingdom

(ideological)   Social Model of Disability –
adults with learning
difficulties in particular

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The growth and development of Involve
Housing Association as an organic entity over a
period of time 1997 to 2007

<u>MICRO</u>

Individual Board Members (who may
or may not have learning difficulties)

Role and impact of significant
others/selves (including that of the
Insider Researcher)

(after Layder 1993)

The values and purpose of this research

As a social work practitioner, albeit a manager at a senior executive level, I

wished the research to be located on the spectrum of Emancipatory Disability

Research (EDR) described and celebrated by Barnes and others at the School

of Disability Studies in Leeds.   It is by definition, participatory leading to the

possibility of advocating for positive change. Barnes *et al* (2002) describes
EDR which in essence has an emphasis on:

1. Accountability to and with disabled people.
2. Commitment to empowerment and change.
3. An acceptance of the social model of disability

Research within the emancipatory framework is an active process: it is organic,
iterative, building on itself and leading to action.   Cresswell (2003) describes
the advocacy or participatory framework as an agenda for action which can
involve changes (for the better) in the lives of participants. This approach
acknowledges macro factors including oppression, domination, suppression,
alienation and hegemony: together these factors form the theoretical lens.
Stansfield (2011)   recognises the role of allies and supporters as partners in
policymaking and in relation to the pursuit of change. Whilst ideally
emancipatory research should be controlled by disabled people themselves,
this is not always practical or indeed possible. In order to achieve social change
it may be the case that disabled people form alliances with significant others
(including providers, academics and even local authorities).   This is sometimes
referred to as co-production. Whereas Silverman (1998) is concerned that any
political ideology can deny the significance of other perspectives, actions or
beliefs, Barnes states that this is true of all research. Users of an emancipatory
approach must be explicit regarding bias from the outset.

As a key player within Involve Housing Association, I wanted to conduct the

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research *"among rather than on them"* (Wolcott, 1990:19) By grounding the study within its overall historical, socio-political context, I tried to study not just the actions of individuals but the dialectic between the micro-macro interaction. I believe that the evidence collected offers an opportunity to understand the importance of interaction at Board level, to educate others in relation to social work practice and to influence policy in relation to service user involvement at a governance level. This is the essence of co-production which Stansfield (2011) describes as:

> *"The idea is that we work in partnership with people who are experts by experience, both for their intrinsic value and the power of their contribution, but also because these experts are more committed to seeing things through in the long term."* (2011:247)

Debate continues around whether this form of study is academic research or simply activity involving service users. Hammersley (2000) denies the term *"research"* to apply to user involved activity as for him, research must involve the production of knowledge with some reasonable possibility of generalisability. However, Gomm (2004) asserts that no one has the monopoly on the use of the term research. For him, research leading to further action may be educational in its broadest sense and it may also be prestigious: a way of elevating practice beyond activity to something more meaningful and explanatory. From a social worker perspective, I believe that practitioner research is valuable: it is action-based leading to professional development or improvement within the organisation where the research was conducted.

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Further, participatory research is deemed to produce other effects for example, enhanced self-image, better political understanding, or a more empathetic relationship between practitioners and service users. (Reason, 1994)

Friere (1972) developed the concept of *"conscientization"* as a means of engaging the oppressed (or marginal groups) in critical thinking about themselves and their relationship to wider society. Conscientization results in action which generates reflection. This process (or praxis) further affirms the concept of conscientization. Friere's dialogue between an educator and the oppressed is built around authentic, creative and empathetic relationships which Mulally (1993) describes as *"dialogical"*. There is critical debate about Friere's work (for example, Blackburn 2000: Barrosso 2002) crucially stating that to place the educator in a position of power is described as *"a very subtle Trojan Horse, one which appears to be a gift to the poor, but can all too easily contain a hidden agenda."* (Blackburn 2002:13). The implications of this perspective will be discussed later in Chapter 4 in relation to the concept of tokenism as a possible indication of an implicit power imbalance.

Rossman and Rallis (2003) specifically question what *apriori* assumptions actors bring to the study, in particular the values and benefits apparent in their actions and interactions. Layder (1998) reiterates the view that actions are not value-free:

> *"one is ...importing underlying assumptions, values –*
> *prejudices...towards the social world...without even realising it"*
> *(1998:113).*

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Theoretical Approach Taken

Guba describes a paradigm or world view as *"a basic set of beliefs that guide action"* (Guba, 1990:171). My research is situated within an interpretive paradigm. In descriptive terms my research is based on an epistemological stance of social constructionism which is often a feature of interpretive research (Denzin, 1989). Meaning or truth is not discovered but is socially constructed: there are multiple truths or realities within the qualitative perspective. *"Thick description leads to thick interpretation whereby description provides the framework for interpretation"* (1989:32) *and "Interpretation creates the conditions for understanding"* (1989:33). Data collection is less structured, more flexible and inductive. Qualitative research adopts this form of interactive sociology.

Further, my research is located within an emancipatory approach, based on the social model of disability. This approach was recognised by the Joseph Rowntree Research Foundation in 1992 and forms a further paradigmatic boundary in relation to my own research.

The process of interpretation is shaped by history and power as well as emotionality and beliefs concerning knowledge (often referred to as ontological assumptions) and discussed by Denzin (1989). Essentially the research is holistic, exploring the phenomenon, Involve Housing Association, in its context, describing how things are inter-related. Lincoln and Guba describe a *"naturalistic"* approach which asserts that:

"Realities are wholes that cannot be understood in isolation from their

contexts, nor can they be fragmented for separate study of their parts"

(Lincoln and Guba, 1985:39)

The epistemological roots of my research are based on a belief that meaning is

not *"discovered"* but is socially constructed. Within that world Giddens states:

"social life......is produced by its component actors..." (1976:79)   Crotty adds:

"They are one human world. We are born, each of us, into an already

interpreted world and it is at once natural and social". (1998:57)   Using

Denzin's interpretive approach I wanted to better understand the key elements

over the ten year period in question which have helped to create the organic

entity known as Involve Housing Association. This would further be understood

from the perspective of the Board members or key players as well as an

analysis of the minutes of Board meetings over the period.

The connection between the micro and macro level is evident in an organic

organisation such as Involve Housing Association. Thus the socio-political

context of the organisation is significant as well as the impact of the individual

actors. Layder (1993) describes the research map (Table 1.2) which is useful in

locating the research. Overall interpretivism connects the individual with

society, the micro with the macro view within an historical timeframe.

Cresswell (2003) describes interpretive research as making sense of meanings

others have about the world. Reality is socially constructed: meanings are

negotiated socially and historically. Denzin calls for *"sophisticated rigour"*

(1978:167). This can avoid the inherent difficulties involved in interpretivism which can never be value free. Denzin acknowledges the partiality of his approach but insists *that "in the world of human experience there is only interpretation"* (1989:8). Biography and history join together in his interpretive process building on the sociological imagination of C. Wright-Mills (1959) and within the larger, historical context of Layder's research model (1993). Denzin (1989:7) through *"interpretive interactionism"* makes an attempt to join biography with history by:

> *"using an interactionist approach and methods including "open-ended, creative interviewing, documentary analysis, semiotics, life-story construction, participant observation and thick description"*

Interpretivist approaches focus on the transparency of the research processes in order to provide a trustworthy analysis of the data collected. McDermott (2002) suggests that social workers are particularly adept at using this approach with their emphasis on interviewing, observing, attention to process and interpretation of meaning.

Case Study Methodology

I have used a case study methodological approach as my overall strategy (Stake, 2000) which Yin (1994) describes as:

> *"an empirical inquiry that investigates a contemporary phenomenon*

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within its real-life context, especially when the boundaries between

phenomenon and context are not clearly evident." (1994:13)

Stake (2000) refers to the use of case studies as an overall strategy rather than a distinct genre of research. Manageability of the data is important in order to avoid what Lofland (1971:109) describes as the potential *"chaos"* or *"anarchy"* in qualitative field research reports.

Table 2.2

Case study research characteristically emphasises:		
Depth of study	rather than	breadth of study
The particular	rather than	the general
Relationships/process	rather than	outcomes and products
Holistic view	rather than	isolated factors
Natural settings	rather than	artificial situations
Multiple sources	rather than	one research method
		(Denscombe, 2007)

Stake (1995) refers to a *"functioning specific"* or *"bounded system"* as an individual unit or single case study which he earlier describes as *"intrinsically interesting"*.

The findings may reach a wider audience although there can be a degree of scepticism about uniqueness of the case restricting the ability to generalise. Denscombe (2007) suggests that this should be challenged directly. Importantly there is a need to create a clear boundary of the case in question Yin (1994) identifies the potential misuse of the case study method and warns that there is a danger of losing focus. Denscombe (2007) identifies a checklist for the case study approach which I have used in my own research. Although not statistically significant, case study research offers the possibility of deeper analysis and a wider implication or a form of generalisability.

I have focused on a single case, Involve Housing Association and use Yin's 'descriptive' approach which covers the scope and depth of the object (case) being described in its real life context.

Denscombe (2007) suggests that when undertaking research which involves the case study approach you should feel confident about answering 'yes' to the following questions. I have stated Denscombe's nine criteria and acknowledged evidence relating to each one arising from my own research.

1.   "Is the research based on a "naturally occurring" situation?"

Yin (1994) stresses that the case is a *"naturally occurring phenomenon"*. It exists in the real world both prior to and beyond the research project itself. It is not artificially generated for research purposes. I believe that as an organic entity Involve Housing Association fits the criteria.

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"In the practical world of research, with its limits to time and resources, the selection of cases is quite likely to include a consideration of convenience" (2007:41). The single case study of my own organisation fitted the criteria and the requirements of the masters degree.

Further Denscombe acknowledges:

"The case study approach can fit in well with the needs of small-scale research through concentrating effort on one research site." (2007:45)

2. **"Have the criteria for selection of the case (or cases) been described and justified?"**

The selection of the case is also driven, in part, by the requirements of the academic study and the need to relate the research to an area of professional engagement. Originality is a key feature together with accessibility to the area of research. Given the caveats in relation to insider-researcher which are explored later, nevertheless there was an opportunity to capture the elements of the case study and consider the possibility of generalisability albeit from a single case. The issue of generalisation in single case study research is contentious. There is a view that generalisation on the basis of an individual case cannot be achieved and hence cannot contribute to knowledge. This particular single case study is intrinsic (Stake 1995) focusing on the uniqueness of

the case but Mason (1996) argues that generalisability is possible using a single case study. Alasautari (1995) argues that generalisation should apply only to surveys but that extrapolation (from data analysis) is more typical in qualitative research. This offers the basis for a non-statistical form of generalisability akin to qualitative research.

> *"the logic behind concentrating efforts on one case rather than many is that there may be insights to be gained from looking at the individual case that can have wider implications."* (2007:36)

3.   **"Has careful consideration been given to the issue of generalisations stemming from the research?"**

Denscombe acknowledges that a researcher using the case study method, in particular the use of a single case study may have to deal with scepticism. This may be in relation to the issue of generalisability. Denscombe advocates confronting this issue directly. For him, the case may be a single example of a broader class of things, that is, one of a type. The reader of the research may need to make some assessment of how far the findings have implications across the board for all others of the type or how far they are restricted to just the case study example.

The term generalisability does not necessarily apply to qualitative research (Glesne and Peshkin, 1992). What is more relevant is the uniqueness of the case study and the lessons learned for its future in

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terms of, for example, the emancipatory framework. Such a qualitative study may illuminate an under-researched area, or add to evidence based literature regarding a certain topic. The detailed, multi-faceted approach which comes from utilising different sources of data enables an holistic approach. This can lead to both innovation and broader application. This approach is entirely within the paradigmatic framework of structural social work celebrated by Mulally (1993). The broad theoretical influences on the study as a whole (for example, Layder, Mulally & Friere) and on the methodology in particular (for example Denzin, Stake) have enhanced this process. In terms of generalisability, the significance of this particular case study is in its usefulness and application of any lessons learned. This may be referred to as 'reasoning by analogy' whereby similar lessons learned in one case can be assumed to apply elsewhere. Schon (1983) refers to this as intuition of the reflective practitioner. Bateson (1979) notes the importance of seeing *"the difference that makes a difference"*.

4. **"Has the case (or cases) been identified as a particular instance of a type of social phenomenon? (for example, kind of event, type of organisation)"**

Involve Housing Association is a distinct, possibly unique example of a not-for-profit organisation by involving tenants with a learning difficulty an equal status at Board level. The case study approach allows the

researcher to study things in depth thereby offering a greater opportunity to delve into the case in more detail.

5. **"Have the significant features of the case been described and have they been compared with those to be found elsewhere among the type of thing being studied?"**

By focussing on one organisation, Involve Housing Association, I hope to have been able to, as Denscombe describes, *"deal with the subtleties and intricacies of complex social situations"* (2007:45). This may offer generalisable themes which will be discussed later. The overall socio-economic context of the organisation was described in Chapter 1 locating the study within a macro frame of reference in relation to health and social care for adults with learning difficulties.

6. **"Is the case a fairly self-contained entity?"**

The case in point is a self-contained entity with a clear legal structure located in a health and social care environment in 21st century United Kingdom.

As there is little research relating to user involvement at organisational level *"What a case study can do that a survey normally cannot do is study things in detail."* (2007:36).

7.   "Have the boundaries to the case been described and their
      implications been considered?"

      The boundaries of the case study are clearly identified as a single

      organisation involving the study of documents over a ten year period

      (1997-2007), the involvement of active Board members and key staff

      engaged in the delivery of services to, for and with adults with learning

      difficulties. This period of ten years was selected because it is a

      substantial period of time bridging a period of rapid structural change in

      Health and Social Care. The election of a New Labour government in

      May 1997 heralded some of that change together with substantial public

      investment, particularly in the National Health Service. There was a

      substantial amount of data contained within the documents which

      provided rich information pertaining to the specified period. Patton (1990)

      asserts that information-rich cases can provide a great deal about issues

      of central importance to the purpose of the research. The period also

      covers the involvement of service users on the organisation's Board of

      Directors. The first service user to be elected was in 1998 and several

      more service users joined him in 2003 following a decision to include

      more representatives.

8.   "Does the research make suitable use of multiple methods and
      multiple sources of data?"

      Different sources of data can be collected in order to better describe the

complexity of a single case and provide validation through the use of mixed methods. Webb *et al* argue that data collection methods 'used alone' (1966:1) are inferior to the use of multiple methods.

The study used different methods, particularly in relation to data collection. Analysis of documents (board minutes over a ten year period) and interviews with groups of individuals working at board level were conducted in order to provide "thick" description and hopefully better validation. Denscombe states that a key point in a case study strategy is *"that it allows for the use of a variety of methods depending on the circumstances and the specific needs of the situation."* (2007:45)......*It more or less encourages the use of multiple methods in order to capture the complex reality under scrutiny."* (2007:45).

9.   **"Does the research give due attention to relationships and processes, and provide an "holistic" perspective?"**

The case study method is interconnected and holistic focusing on relationships and social processes in what Yin describes as *"a naturally occurring phenomenon"*. Rossman and Rallis (2003) ask: *"What is going on in this case? What are the actors doing? What are the outcomes?"* (2003:94). Rossman and Rallis (2003) also note that description can highlight the complexity of events over time and offer vivid material or perspective from the different people involved. They are interested in

inquiry not just for its own purpose but in terms of the creation of new knowledge which leads to action. The case study approach looks at the how and why things happen *"giving a detailed description of what the facts are with respect to............ the outcome."* (2007:27).

In summary, Denscombe's questions are evidenced in the chart below:

Table 2.3 Descriptors against Denscombe's checklist

Questions	Descriptors of evidence
1. Is the research based on a 'naturally occurring situation? How?	• Organic • Real world research (Robson, 2002) • Humanistic
2. Have the criteria for selection of the case (or cases) been described and justified? How?	• Fits criteria for academic study
3. Has careful consideration been given to the issue of generalisations stemming from the research? How?	• Lessons described and learned within wider context of health and social care in late 20^{th} century
4. Has the case (or cases) been identified as a particular instance of a type of social phenomenon? (e.g. kind of event, type of organisation) How?	• Unique case? • Access possible • Not for profit organisation • Insider knowledge
5. Have the significant features of the case been described and have they been compared with those to be found elsewhere among the type of thing being studied? How?	• Descriptive case study data from analysis of documents and interviews but single case study not a comparative study
6. Is the case a fairly self-contained entity? How?	• Yes, separate legal entity – documents are governing instruments and actors are board members
7. Have the boundaries to the case been described and their implications considered? How?	• Ten year period of unique case study has been analysed
8. Does the research make suitable use of multiple methods and multiple sources of data? How?	• Multiple methods and sources of data used
9. How does the research give due attention to relationships and processes, and provide a holistic perspective?	• Descriptive but unobtrusive data set within ten year period verified by documentary analysis and interviews narrating the journey.

Denscombe (2007:47)

Rigour is essential both in data collection and its subsequent analysis which should focus on a few key issues (or analysis of themes) in order to demonstrate the depth and complexity of the research. Merriman (1988) stresses the importance of the context of the case. I believe that it is important to locate the case study in its wider environment as described earlier in relation to Layder's research map. Lincoln and Guba (1985) state that within the case study approach the problem, context issues and "lessons learned" are all necessary in order to convey thick description and analysis. My single case study offers the possibility of more depth than for example, multiple case studies which by definition are only able to compare themes across different cases.

Methods used in the study

a.   Review of documents

Minutes of meetings and other organisational documents are described by Marshall and Rossman (1999) as useful in developing understandings of the setting to be studied. Lee (2000) considers the use of such historical documents as an unobtrusive method. The gathering and analysing of documents can usefully supplement interviewing and other qualitative methods in studies (Marshall and Rossman, 1999). This case study employed both document review and interviewing. The use of written records was a strategy to better understand the history, context or functioning of the case in question. Minutes of the Board meetings and written strategy, operational and policy reports to the

board provide the key governing documents of Involve Housing Association over the ten year period (1997 – 2007). Given that Involve Housing Association was established in January 1991 there is obviously information that traces the growth of the organisation prior to 1997 (and indeed since 2007). However, it was deemed important to limit the period in question in order to define a clear boundary and allow for an in-depth analysis.

Objectively these Board documents represent verifiable records. The use of documents is an unobtrusive measure which cannot be altered; that is, it is non-reactive and cannot be altered by the fact that it is being used (Lee 2000). However, Robson (2002) suggests that the analysis of such records is akin to *"structured observation"* (2002:350) which implies a degree of subjectivity using interpretation. There can be important concerns about the accuracy of minutes of meetings which are in themselves a summary of the discussion and decisions taken. Grix (2001) acknowledges the need to be aware of the original audience of the documents. A document, unlike a speech, can have an independent existence beyond the writer and beyond the context of its production (Jary & Jary 1991). Denscombe acknowledges that minutes and similar records tend to be partial, recording possibly decisions but not the whole story or rationale: *"The researcher......needs to be cautious about accepting such records at face value"* (2007:236). This would be characterised by Denzin (1989) as 'thin' description as opposed to 'thick' description which is the cornerstone of interpretative studies. Robson (2002) stresses the use-value of documentary analysis as an additional method in a multi-method study. I was therefore aware that although valuable in their own terms, the minutes could not

be relied upon as the only source of data in my study. Mogalakwe (2006) states *"Payne & Payne (2004) describe the documentary method as the techniques used to categorise, investigate, interpret and identify the limitations of physical sources most commonly written in the private or public domain."* Minutes from a non-governmental organisation such as the case study would be regarded as private (Mogalakwe 2006). Scott (1990) has formulated quality control criteria for handling documents. These are authenticity, credibility, representativeness and meaning. Mogalakwe (2006) states *"It is the theory that re-orders the data, and inferences come as a matter of interpretation of the raw material informed by theory."* (2006:228). Mogalakwe concludes that the use of the documentary research method is a valid choice if appropriate.

b.   Interviews

Mogalakwe (2006) acknowledges that documentary analysis is often supplementary to in-depth interviews, and seldom the main or principal research method adopted. *"Occasionally social scientists combine research methods in order to enhance the reliability and the validity of their analyses. This is referred to as method triangulation"* (2006:228) or the use of two or more research methods to investigate the same phenomenon (Grix 2001). Mouton (1996) suggests that the researcher can rise above personal biases and a reliance on a single method by using multiple methods. *"The researcher may augment documentary data by in-depth interviews with a few key informants..... Key informants are people who are familiar with and or knowledgeable about the social phenomenon under investigation."* (Mouton quoted in Mogalakwe

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2006:229) Interviews were used to add value and interpretation to the documentary analysis.

I had a clear purpose in using interviews with Board members and key staff to access the story of Involve Housing Association from multiple voices. In many ways the use of documents supported the interviews rather than the reverse. The creation of a crib-sheet or summary of milestones generated from the documentary analysis aided the interview process. Service users in particular would have found reading and understanding ten years worth of minutes difficult given their level of literacy and understanding. It would also have been time-consuming. There would have been concerns about timescales and order of events which applied to everyone who was interviewed. The creation of the crib-sheet proved useful in all the interviews. The tenant board members also had the support of the tenant participation officer who is used to advising and supporting them at the service user forum. This provided an extra layer of support in an advocacy capacity.

Purposeful Sampling

Selecting an adequate sample is essential to the rigour of all research. In qualitative studies adequacy refers to how representative the sample is of the total population being studied in order to enable generalisation. (Bryman, 2008) In qualitative research, adequacy refers to the extent that participants have experienced and can discuss the phenomenon of interest. Sampling procedures are therefore purposeful in that the researcher selects participants

who can best help the researcher understand the research problem or question. (Cresswell, 2003) This can result in relatively small samples in numerical terms.

Purposive sampling is used to study a diverse or limited number of observations. This tool is useful for in-depth case studies.

In order to select my sample I used the list of shareholders (see table 2.3) as they were able to provide in-depth, first-hand knowledge about the phenomenon in question. The sample constitutes the legal membership of the organisation. Only shareholders can be elected (or appointed) to serve on the Board, usually at the Annual General Meeting in September. The records have been anonymised to protect confidentiality.

Table 2.4

Involve Housing Association
Membership History from Record Book

Membership number	Male (M) Female (F) Tenant Board Member (TBM)	Date became member	Current status * interviewed
1	(M)	28/3/1991	Deceased
2	(M)	28/3/1991	Retired
3	(M)	28/3/1991	Deceased
4	(M)	28/3/1991	Active *
5	(M)	28/3/1991	Resigned
6	(M)	28/3/1991	Active *
7	(F)	28/3/1991	Member of staff
8	(F)	27/1/1992	Active
9	(M)	25/2/1993	Active *
10	(M)	25/2/1993	Deceased
11	(F)	25/2/1993	Resigned
12	(M)	8/2/1995	Active *
13	(M)	8/9/1995	Resigned
14	(F)	13/9/1996	Resigned
15	(M)	13/9/1996	Retired
16	(F)	21/2/1997	Retired
17	(M)	9/4/1998	Non-active
18	(M) (TBM)	24/9/1998	Active *
19	(F) (TBM)	24/9/1998	Non-active
20	(F)	1/3/1999	Non-active
21	(M)	28/5/1999	Deceased
22	(M)	28/5/1999	Retired
23	(F)	27/9/2001	Resigned
24	(M)	1/8/2003	Retired
25	(M)	1/8/2003	Active *
26	(F) (TBM)	25/9/2003	Active *
27	(M) (TBM)	25/9/2003	Non-Active
28	(F)	1/8/2003	Retired
29	(M)	26/1/2004	Non-Active
30	(F)	21/9/2008	Retired
31	(M)	21/9/2006	Retired
32	(M) (TBM)	21/9/2006	Active *
33	(F)	21/9/2006	Member of staff
34	(F)	21/9/2006	Active
35	(F)	27/10/2008	Active
36	(F)	27/10/2008	Active
37	(M)	27/10/2008	Active
38	(M)	18/2/2009	Non-Active

From the list (which is by definition limited and finite) I contacted all active members up to 2006 with a view to them being interviewed as part of the research project. It may have been interesting to interview newer members as a separate group. This was not carried out as most of the new members of Involve Housing Association have only joined post 2007 when, following the sudden death of the Chair of the Association, there was an active recruitment campaign to plan for the future succession of Board members. As researcher, I felt that interviewing newer members would not add particular weight to my focus on the ten year period although the newer members may have had a particular view on service user involvement or the way forward for the organisation. Arguably, it could be stated that newer members had been recruited with fuller knowledge and awareness of service user involvement partly due to the explicit and stated value base of the organisation. In the interests of clarity and rigour, I decided to concentrate on the principal actors who had participated over the ten year time period 1997 – 2007. One founder member, Number 8, agreed to be interviewed but was seriously ill at the time of the interview and therefore did not take part. Hence only two founder members were interviewed. Another, Number 34, only joined the organisation at the Annual General Meeting in September 2006. She had no prior knowledge of the organisation and did not feel that she could contribute regarding the history over the time period covered 1997-2007. Number 32 did agree to be interviewed even though he only joined at the same annual meeting in 2006. However, he did have prior knowledge of the organisation having been a tenant since 1993.

Once sampled, I approached the interviewees. I did this both face to face and in writing (Appendix 1). First to explain the rationale for asking for their participation in the interviews and second as it was particularly important to use verbal communication when approaching adults with learning difficulties as they are not always able to read or comprehend written protocols. I produced a simplified consent form using plain English and symbols (Appendix 2) as well as a set of ground rules (Appendix 3) which created the ethical boundary discussed below.

It was important to ensure that the interviewees all agreed to subscribe to an ethical perspective in relation to the research (as discussed later in the chapter). I sent everyone a letter to their home address detailing the date, time and nature of the planned interview. In addition, I telephoned each person to confirm arrangements and offer help with transport to attend the interview. This was particularly important for the service user board members. After the interview I wrote to each participant asking for their thoughts on the experience of taking part. Only one written response was received and this was from a member of the senior team who is more accustomed to reflecting on her involvement in research projects.

It was essential that the arrangements were not deemed to be threatening or intrusive. Further, the verbal nature of the research supported the Board members who have difficulties in literacy or comprehension, that is, in particular the tenant board members. Generally, there is an issue of consent in relation to adults with learning difficulties. Indeed under the Mental Capacity Act (2005)

this capacity is assumed to be the case unless determined otherwise by a formal process (Appendix 4). This was not a problem in relation to my research. The tenants who serve as Board members are amongst the most able and articulate within the tenant community. They all have the ability to give their own consent and participated freely and willingly in the interviews.

Data Collection

a.   Documents used in the study

The governing documents of the Involve organisation during the ten year period of January 1997 to July 2007 provided the key documentary data. Over that period there were 47 board meetings. The documents I surveyed included minutes of all meetings as well as supporting reports on particular agenda items.

b.   The Interview Data

The data was collected via four sets of group interviews (involving 3:3:3 and 2 participants) conducted in March and April 2010. In all, four sets of interviews took place – one with service users who serve as Board members, the second (split in two sessions due to time constraints) with two Assistant Directors and the Head of Training, Information and Research, the third with three long-serving Board members purposively sampled from the wider membership of Involve Housing Association covering the period in question and the last

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interview with two founder members of Involve Housing Association who started the organisation and are still both actively involved after 20 years. I decided to interview the service users first as I was particularly keen to get their views as voluntary Board members prior to interviewing others. I was interested in assessing Involve Housing Association as a user-influenced (as opposed to user-led) organisation. User-influence relates to a significant input from service users but this is not from a majority point position whereas user-led would imply complete self-directed management (and ownership) by service users. Therefore the service user voice was deemed more significant or of primary purpose to confirming my standpoint. Rather than viewing this as a partial, discriminatory assessment, I regarded this as an act of positive action: a way of redressing an imbalance experienced by marginal groups. It was also a "test" of the raison d'être of the organisation: an opportunity to explore whether service user involvement was authentic or tokenistic. This provided a unique opportunity to "test" my idea that Involve Housing Association is a user-influenced organisation, committed to change and improvement in the lives of service users. The reality of day to day operational management would involve senior executive officers in the implementation of service user involvement.

One of the groups of three consisted of senior management staff. I felt that it was important to explore their views as an executive (that is, part of the day to day operational management) team. Although the questions asked of the Board members were tailored to their role as decision makers, I used the same questions as a base line for my group interview with the executive team. This was partly to triangulate the data collected but also to offer a critical friend

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approach in relation to, for example, the involvement of service users on the Board.

Interviews took place in my office which was familiar to both Board members and staff, smaller and less corporate and had better acoustics for taping the interviews. There was not an issue in relation to power dynamics as Board members (and staff) were all used to "popping in for a chat" on a regular basis.

Interviews were taped (with full consent) and put onto disc. In addition someone (a member of staff who had signed a confidentiality agreement) took verbatim shorthand notes (known as my "belt and braces" strategy in case the tape recorder did not work!). Robson (2002) believes it is good practice to do both as equipment can fail. The impact of using this approach will be discussed in the findings chapter. However, one of the methodological criticisms of the case study method is that it can be too descriptive and the researcher may not know when to finish either data collection or analysis. I used the interviews with Board members to derive their meaning of actions or decisions taken. The focus on active Board members aided interpretation. By sampling based on the period over which the Board members had been involved in the organisation and the number of meetings attended over the ten years, I was able to achieve a natural finishing point for the data collection and harness the commitment of their time served and voluntary contribution.

This was important as *"Emotionally and shared experience provide the conditions for deep, automatic understanding"* (Denzin, 1993:33).

Long (1992) refers to the data problem in researching groups as the interaction itself affects the meaning or understanding. In order to counteract this McDermott (2002) asserts that we need to understand the overall context (both internal and external to the group). Internally, for example, there is some kind of group dynamic or relationship which also has an impact.

Thus the internal dynamics (or dialectic) could be likened to a mini-action cycle more akin to participatory action research – action, reflection on action, further action.

Questions asked

Cresswell (2007:107) suggests that research questions in qualitative studies are "open-ended", evolving and non-directional.   Marshall and Rossman (2006) divide research questions into four types: exploratory, explanatory, descriptive and emancipatory. My questions were exploratory in relation to the individual's experience and views (Appendix 5). I adopted a conversational style of interview by focusing on group rather than individual interviews. This presented a number of challenges. As the researcher's involvement and influence could lead to distortion, I was conscious throughout the interviews of my need to be somewhat detached and not engage in the conversational interview. The accuracy of what is reported (or its truth value) is important and I believe that my methodological approach in terms of data collection supports this and generates rigour in terms of the findings.

Advantages and Disadvantages of Group Interviews

Robinson (1999) describes the advantages of group interviews. These can be summarised as follows:

1. A highly efficient technique for qualitative data collection by collecting from several people at the same time.

2. Group dynamics help in focusing on the most important topics... easy to assess the extent to which there is a consistent shared view.

3. Participants tend to enjoy the experience.

4. Natural quality controls on data collection operate...checks and balances on each other and extreme views tend to be weeded out.

5. Participants are empowered and able to make comment in their own words, while being stimulated by thoughts and comments of others in the group.

6. Contributions can be encouraged from people who are reluctant to be interviewed on their own feel they have nothing to say or may not usually participate in surveys.

7. People who cannot read or write or who have other specific difficulties are not discriminated against.

The group interviews conducted over several weeks did prove to be an efficient way of collecting data. The division into groups of similar experience (whether service users, founder, long-servicing members or executive team) helped shape the collective memory and led to an enjoyable experience. Interviewees

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did tend to "spark" off each other, recalling events or elaborating on their own experience in an easy, conversational manner. There was no reluctance to speak out. This was partly aided by the fact that people know each other well and feel comfortable together. All interviewees reported that they enjoyed the experience. Denscombe stresses the nature of group interviews they can be seen as an opportunity to interview more people or, as I discovered, by stressing the group characteristics it improved the representativeness of the particular group category, for example, role of service users, founder members, long-standing members and executive team. The conversational style of interview allowed participants to relax with each other and offered more opportunity for group identity, reflection and illumination. Denscombe suggests that this *"trades on group dynamics"* (2007:178). I consider that it allowed the naturally occurring synergy of each group to develop its identity. In particular the long standing knowledge of each other aided dialogue and in many ways replicated the behaviour at Board level over the years.

Robson (2002) suggests that group interviews may allow for better group interaction. Brown states that a homogenous group of interviewees (similar to my purposive sample) have a common background position or experience which:

"

- *Facilitates communication*

- *Promotes an exchange of ideas and experience*

- *Gives a sense of safety in expressing conflicts of concerns*

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- *May result in "groupthink" (unquestioning similarity of position or views)"*

Derived from Brown (1999:15) and cited in Robson (2002:286).

Robinson (1999) also identifies disadvantages in adopting the group interview technique, namely:

1. The number of questions covered is limited.
2. The interview process needs to be well managed or the less articulate may not share their views.
3. Confidentiality can be a problem between participants when interacting in a group situation.

In relation to any disadvantage the number of questions was limited due to the nature of the research topic rather than the length of interview. Everyone contributed to the discussions, probably due to the small number in each grouping (3, 3, 2, 3). However, particularly in relation to tenant Board members it was necessary to stress that people should not talk over each other. This was covered by the ground rules. The topics covered did not cover difficult to discuss areas which may have led to distress, over disclosure or breach of confidentiality. However, again the agreed ground rules clearly stated the confidential nature of any part of the discussion: this was acknowledged at the time consent was obtained. Finally, during the process of analysing the data, names and references have been changed in order to ensure confidentiality and anonymity.

Thematic Analysis of the Data

A process of thematic analysis was employed for both sets of data. Thematic analysis is an approach which identifies, analyses and reports patterns (or themes) within data.

Thematic analysis is a widely used analytical strategy (Braun and Clarke, 2006) which they regard as a method in its own right. Richards (2005) proposes that a theme refers to an integrational idea drawn from the data, but Bazeley (2009) consider that researchers generally consider thematic analysis to be the identification of elements from the text. This is the approach taken in this study. Braun and Clarke (2006) describe a theme as capturing something important in the data in relation to the research question.

The researcher plays an active role in their identification.

> *"Any theoretical framework carries with it a number of assumptions about the nature of the data, what they represent in terms of 'the world', 'reality' ...... A good thematic analysis will make this transparent."* (Braun & Clarke, 2006:81)

The aim of this study was to describe the development of an organisation over a ten year period. Documentary analysis took place first and 'important' events were coded and grouped into themes, a process described by Miles and Huberman (1994) as abstraction. The aim was to find some level of patterned

meaning (Braun and Clarke, 2006) within the data. Themes identified in the documentary data were then used to generate discussion in the interviews.

For the documentary analysis, I categorised the minutes in order to provide an historical overview of the ten year period in question. This remained factual in an attempt to be objective and was used in the subsequent group interviews to recall 'significant' dates, events and decisions. I made an analytic choice on how I filtered the substantial amount of data generated from the minutes. As I was trying to describe Involve Housing Association's journey through a particular time frame it was necessary to categorise my findings at an early stage and prior to the interviews with Board members. This was in order to describe the long journey and simplify the data which was in written format for use later in the interviews with board members.

The minutes describe the story of Involve Housing Association and its growth over the period in question. Making sense of the data gathered from the minutes over a ten year period was critical to the subsequent generation of categories using a thematic analysis (Aronson, 1994). Having collected the data, I divided it into five sections:

1. The item discussed (as a broad heading, for example, purchase of a property, development of day services, recruitment of a particular member of staff).

2. The year and month this took place. This was to put the item in a particular context and time frame.

3.   A brief summary of the item discussed in order to clarify the particular issue at that specific meeting.

4.   The implication of the item discussed for Involve Housing Association and

5.   The implication, if any, for service users. This was a particularly important area to me as I wanted to 'test' the relevance to service users and the impact of their involvement at Board level post 1998. In the course of my group interviews I wanted to further explore the implications for the development of Involve Housing Association by the practical and regular involvement of elected service users at Board level. This was not just an ideological discussion about whether it was 'the right thing to do': it was trying to test whether it had a direct impact on the collective decisions taken at Board level and the direction of Involve Housing Association both in the past and the future.

Next, I colour-coded the data into similar groupings or 'patterns of experience' (Aronson, 1994) which led to the definition of several categories in order to better describe the case study. There are inevitable dilemmas regarding this as Berelson (1952) points out: *"since the categories contain the substance of the investigation, a content analysis can be no better than its system of categories".* (cited in Robson, 2002:355). The process of coding is part of analysis as the researcher is organising the data into meaningful groups. Braun and Clarke (2006) acknowledge the active role of the researcher in acknowledging themes and patterns. *"What is important is that the .... methods match what the researcher wants to know, and that they acknowledge these decisions, and*

recognise them as decisions." (2006:80). Bazeley (2009) further develops this *"description alone is not sufficient. The data must be challenged, extended, supported and link in order to reveal their full value."*

Themes need to be integrated into a cohesive and purposeful analysis. Richards (2005) suggest **five** signs of sufficiency for an analysis:

- Simplicity – a *"small polished gem of theory"* rather than *"a mere pebble of truism"*.
- Elegance and balance – it is coherent.
- Completeness – it explains all.
- Robustness – it does not fall over with new data and
- Relevance - it makes sense to relevant audiences.

I coded the data collected from the minutes and then generated themes described later, asking the question – what is this decision an example of? Aronson (1994) describes this as relating the themes to the already classified patterns. Codes and labels may be changed and a piece of data may have several labels. I used this technique at a descriptive level: the intention was to keep the basic data collection accessible, informative and as a possible prompt to Board members during the interview process.

Coding itself presented particular challenges. For example, there were three different minute takers during the ten year period: there was a recognisable difference in the writing style and record taking. Inevitably a "snapshot view" is

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partial and limited: some of the items being discussed in 1997 and beyond had already been the subject of earlier debate. Other items may be seen as potential errors of categorisation, for example, the attendance of a service user at the People First Conference in Alaska in 1998 had been preceded by a similar involvement at the People First Conference in Toronto in 1993. Coding must establish whether this is an example of innovation, or a further example of increasing partnership with service users, or business as usual. Sometimes there were several sub-themes. However, 'themes that emerge........ are pieced together to form a comprehensive picture" (Aronson, 1994) and a pattern emerged.

Robson (2002) notes that researchers start to draw conclusions about meaning at the start of data collection *"noting patterns and regularities"* (Robson, 2002:476). Robson also acknowledges that qualitative real world research is about making sense of *"the complex and messy world around them"* (2002:480). Social work in the UK relies on clinical judgements which harness elements of technical rationality but utilise intuition and interpretation (Hollows, 2003). Schon (1987) describes the *"swamp of important problems and non-rigorous inquiry"* (1987:3) Analysing data is contextual, based on the particular setting and negotiated meaning which may involve multiple truths evident in the qualitative paradigm.

Analysis of Interviews

I have already described my way of categorising the documents and with

respect to the interviews I adopted a similar thematic approach to the analysis.

"A theme captures something important about the data in relation to the research...... and represents some level of patterned response or meaning within the data set." (Braun & Clarke 2006:82)

Themes do not have to be statistically significant as in qualitative research the question of prevalence does not necessarily mean that the theme is more critical. *"Researcher judgement is necessary to determine what a theme is."* (2006:82) Holistic analysis may involve a description of the entire data set in order to provide *"a rich overall description"* (2006:82) This then progresses from description to interpretation (Patton, 1990) in particular exploring the significance, exploring the significance of patterns and broader meanings or implication. Thematic analysis identifies and describes ideas within the data, that is, themes.

Applied thematic analysis is a pragmatic approach to analyse data in a transparent, efficient and ethical manner. Braun & Clarke (2006) describe thematic analysis as:

- A relatively easy and quick method to learn and do.
- Accessible to researchers with little or no experience of a qualitative research.
- Useful to summarize key features and offer "thick description" of the data set.

- Useful in informing policy development.

As described earlier, the interviews were guided by the earlier analysis of the documents. Each interview recording was listened to several times and transcripts were read several times to generate general themes as well as highlight explicit differences from the documentary data, the significance of which will be discussed later.

Challenge of Being an Insider Researcher

As a social work practitioner operating at a managerial level, I needed to be explicit about my own role and bias. I do not claim to hold a value-neutral perspective. Gomm (2004) supports the possibility of a researcher being value-led rather than value neutral. He notes the difficulties in maintaining value neutrality but highlights the importance of *"particular expertise in making moral judgements about social arrangements and attempting to change them."* (2004: 285) This position falls within a Marxian perspective which is in turn reflected in critical or emancipatory research (Lather 1986). It is essentially partisan and based on a world view that society is unequal and discriminates against marginal groups, for example adults with learning difficulties. The thrust of emancipatory research is to *"give voice"* (Elbow, 1981) to people who would otherwise not be heard, often involving a collaborative and participatory approach and leading to political action.

"Being there' also known as 'prolonged engagement' (Rossman and Rallis,

2003) further ensures credibility and rigour. My case study is not just a snapshot view although there are all the well documented challenges of being an insider-researcher, that is, subjectivity, over-involvement, the possibility of misinterpretation. However Stake (1995) acknowledges that good qualitative research be supported by the history, culture and personal experiences of the researcher who both places themselves within the study and acts as the instrument of data collection. Thomas (2011) describes a local knowledge case as being one where the researcher is familiar with the topic or case study. This approach is particularly relevant for a social work practitioner like myself. The key components include being aware of the ethical dilemmas, acknowledging bias, involving rigorous data collection procedures and accepting that there is not one right story but multiple realities.

Data generated is always subject to interpretation and is therefore not immune from the influence of the researcher's self. *"Practitioners must act and action requires making choices among different interpretations of a particular situation"* (Keeley, 1984 cited in Reason et al 2006:132) Denscombe (2007) suggests that researchers should acknowledge the influence of their own history and personal experience on the research topic.

He stresses the importance of the researcher's self in terms of both impact and resource contribution. The influence of an insider researcher in shaping a research project, cannot and should not be denied. However reflection on action as a key player/researcher/influence is warranted as well as an open minded approach in respect of both data collection and its subsequent analysis. I had

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to constantly remind myself of the need for detachment as a researcher (albeit on the inside). Feagan *et al* (1991) call for critical reflection on the researcher's role. They recognise the impact of the researcher's background, value base and position of authority within the organisation.

Further I adopted a case study strategy which Feagin *et al* concur *offers "a voice for vulnerable or disadvantaged people"* (1991:69). I proceeded as an insider-researcher: Harris (1992) refers to this as being a *"knowledgeable-insider"*. Certainly access to Board members as my employer/colleague/friend was easy and everyone who participated was excited about the research.

I am accountable and employed by the Board and I therefore anticipated that any hierarchical power dynamic would be reversed. Not only am I employed by the Board but I was also a student undertaking research. I was aware of my dependent and somewhat subordinate status. Conversely in terms of interviewing the three staff members (two Assistant Directors and one Head of Service) I regarded this as colleague engagement: a form of peer review, reflecting on organisational delivery and governance in a co-operative and explanatory manner. However, I acknowledge that this perspective is contentious. For example, despite wishing to work in an inclusive way with the executive team, there is a power dynamic as accountability to the Board is through myself. Equally, the longstanding relationships between the Board members and myself can lead to a blurring of boundaries. This may be a particular issue for service user board members and will be discussed more fully in Chapter 5. Denscombe (2007) accepts that researcher involvement in

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the construction of data is a critical feature of qualitative research. The researcher is the crucial "measurement device" and

> *"the researcher's self (their social background, values, identity and beliefs) will have a significant bearing on the nature of the data collection and the interpretations of that data" (2007:250).*

Turner (1988) reflects that there is an impact of the researcher's mental well-being on the shaping and production of the research, leading sometimes to 'chaos' and 'ambiguity' (1988:118) especially when dealing with masses of data. Conversely, simplification into a few categories may lead to *"low level of analysis"* (1988:119). In order to mitigate this possibility he suggests a multi-faceted approach to qualitative research, linking theory to practice and a conceptual map which illuminates the topic. Manipulation of data is a consequence of priority setting and part of telling the story but interconnections must be done carefully and with a degree of detachment or rigour which enhances the potential use (or truth) value. The professional background of the insider-researcher has an influence. McDermott (2002) identifies that as social workers the interpretation meaning is a particular strength which should be utilised. She usefully categorises researchers as 'researcher only' or 'outsider' and 'practitioner-researcher' or 'insider'. The latter is the approach I adopted.

The interpretivist position relies on trustworthiness and authenticity. McDermott (2002) describes the *"goodness"* criteria in interpretivist research that is,

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multiple methods, rigour, attention to detail, transparency which must remain central. In particular the insider-researcher must acknowledge their own impact, ensuring a degree of detachment and reflection in action. Turner (1988) acknowledges the relevance of bringing a distinctive "perspective" to an enquiry which whilst achieving some objectivity equally allows for the *"significance of the values, the passions and the subjectivity of the observer"* (1988:115). As an insider-researcher I brought a degree of connoisseurship or what Polanyi (1958) calls variously personal, tacit or craft knowledge. Connoisseurship implies an ability to write in an authentic way: tacit knowledge also implies knowing the perceived audience and the appropriate mode of communication. Similarly Schon (1983) refers to the knowing in action of the intuitive practitioner. Empathetic understanding of the organisation in question and as an insider-researcher certainly enabled me to write with *"real voice"* (Elbow, 1981). Having established the organisation over 20 years ago, I have a particular passion and commitment to its *raison d'être*. This can be regarded as highly subjective but enables me to speak with knowledge and authority and, given my own investment in terms of time and energy, authenticity.

As Executive Officer, I was present at every Board meeting over the ten year period as a key player. This was particularly important as many of the matters brought to the Board as ideas for either development, or relating to staff recruitment were generated by myself as a key actor. My role in instigating and developing new business has been and is still critical. At the time, I was more involved in the operational detail (or implementation) as I did not have an assistant at senior level until 2007. Trawling through the minutes was akin to

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"déjà vu" and I relived some of the debates and given the passing of time, I often knew how things had progressed in terms of the decision being taken at the time. The official record of each set of minutes is essentially the reported decision or activity finally taken not the wider discussion preceding the decision.

In conclusion, whilst acknowledging certain limitations I believe that an insider role can have a positive influence but researchers involved in this approach must be aware of their own impact and be comfortable with ambiguity as well as be ethically and politically sensitive.

Ethical Considerations

Berg and Smith (1988) discuss the ethical challenge of good qualitative research which Rowan (2001) describes as humanistic as *"it has the qualities of non-defensiveness, of openness, of authenticity.....of the real self"* (2006:114). Such characteristics require a serious consideration of research ethics as the personal and social impact is greater. There are interpersonal ethics to consider in terms of mutual respect between for example, board members as well as the wider social ethics and the prevention of harm or distress. Rowan stresses the need to make a difference and the maintenance of an authentic approach which is identified by understanding *"the humanistic value system"* (2006:115) which underpins my type of research.

Gomm (2004) states that value-led researchers tend not to separate discussions about ethics from discussions of research in general. Gomm

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(2004) notes that there is a potential conflict involving service users. For Gomm, the idea of participatory research is in conflict with the notion of a professional code of ethics as participation, by definition, involves a 'de-professionalised practice'. Value-led research must still be driven by the need to be rigorous and truthful. The usual caveats regarding freedom to participate (or not), informed consent and doing no harm (physically or emotionally) were observed (see Lewis, 2004, Harding and Higginson, 2003). In addition, in qualitative research there is an acceptance that there are multiple truths but accountability to those researched is paramount.

Gomm (2004) notes the close relationship between "accountability" and "ethicality": value-led research often demands that *"for research to be ethical it must do some tangible good to the people researched"*. (2004: 322). For Gomm there is an overriding (ethical) dilemma: elevating subjects to researchers may dilute overall ethical responsibility and limits the value of the research. By blurring the boundaries it may result in a professional researcher being unable to prevent harm or promote good. Gomm argues that to regard the professional researcher as the one ethically responsible for the research may be patronising and demeaning of their non-professional co-researcher subjects. Equally he asserts that other people might say: *"You're the professional researcher; the buck stops with you."* (2004:316). However, I question this assertion. Co-production of research must be based on an equality and mutual respect (Brandon 1989). For Stake (1995), being ethical is simply being aware of the dilemmas inherent in the research topic. Whilst acknowledging that my research does not adopt the model of co-operative

inquiry within action research promoted by Heron and Reason (1997), nevertheless, the case study is built on similar values, in particular being transparent and open. *"This skill is about empathy, resonance and attunement, participating in the way of being of other people"* (2006:149). Based on practical knowing the case study is both descriptive and transformative: the ethical viewpoint underpins this approach.

At all times it was essential to be aware of the power dynamics especially given the fact that tenant board members were in receipt of housing and care services from the organisation and I was the Chief Executive Officer. *"Positionality is indicative of the particular social, structural and organisational positions that individuals occupy that define the identity, power structures and social fields of the individual which mediate their interactions."* (Das, 2010)

However, the fact that tenants had equal status as voluntary board members (and that I reported to them on a regular basis) allowed for more transparency and horizontal exchange built on trust. Ethical issues regarding confidentiality, using anonymity and 'informed consent' all needed to be observed.

Das (2010) acknowledges the need to understand and give consent to the research process. *"The agency of the researched has to be considered alongside the agency of the researcher, or else there is a risk of silencing the authority of...... participants and forcing a vulnerable position on them."* (2010)

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Given the long-established relationships at Board level, the reverse power relationships between the researched and researcher and the use of a symbolised consent form, this was not a particular issue in my research.

Approval to conduct the study was obtained from the University Ethics Committee (Appendix 6) and as the tenant board members were in receipt of community care funding, individual social workers were informed about the nature and purpose of the project.

Conclusion

This chapter has set out my overall approach to the data collection and analysis within the case study methodology. I have acknowledged the challenges of being an insider researcher as well as the ethical dimension within my approach. I contend that my research acknowledges both the individual and societal context of adults with learning difficulties as described in Chapter 1 and is therefore an appropriate approach in relation to the exploration of partnership within the Involve Housing Association over the given period.

Chapter 3

The Findings

This chapter describes the growth and development of Involve Housing Association through an analysis of documents (Board Minutes) over a 10-year period (1997-2007) and through several group interviews with Board members and key staff. The data collection is in two parts.

However, it is necessary, before proceeding to the main substance of the findings, to say something about the local historical context from 1990 onwards. Although outside the period of the data collection an understanding of the historical context is essential to sound interpretation of the material.

Local Context: The Charity in 1990

The discharge of 141 patients from the long-stay hospital to the care of Involve Housing Association occurred over a relatively short period of time (1990 to 1993). There were several objectives at the time:

a. The need to find a solution in order to close the hospital.

b. The need to discharge patients to better accommodation.

c. The need to redeploy hospital based staff; and

d. The need to act quickly as there was changing ideology within health and social care which was particularly evident following the Griffiths Report (1988) and the introduction of the 1990 Act.

In order to close the long-stay hospital, an organisation was created as the vehicle to achieve this goal. Given the ambitious time scale for closure it was based on a consortium model, that is, several organisations coming together as stakeholders and co-ordinated by a colleague from the Health Authority and myself from Social Services. The initial charity was composed of:

Two representatives from the Health Authority

Two Voluntary Sector representatives (Mencap and the local Spastics Society which later became known as SCOPE)

Two Housing associations involved in special needs housing

Two Carer representatives which represented the service user voice but as citizen rather than self-advocates

Two local advocacy organisations

In addition, the initial subscribers to the not for profit (charitable) company were the Chair and Vice Chair of the Social Services Committee. This gave the organisation gravitas, status and quicker access to decision making: an overtly political manoeuvre. The composition of the charity was a reflection of several strands of radical thought at that time.

First, it brought together Health and Social Services Departments in a model of service delivery that did not simply focus on joint planning but joint-action. This predated the concept of joint-commissioning more pertinent to Primary Care Trusts which emerged post-1999 following a further reorganisation of health care. It was a radical break with tradition at the time.

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Second, it focused on a common goal, that is, the closure of the local long-stay hospital which would benefit:

a)   The patients concerned.

b)   The Health Authority, by enabling the closure of the hospital and thereby releasing land for capital receipts.

c)   The Social Services Department, by providing an alternative model of community care which would be accessible for future referrals (given that access to the hospital would not be possible once it was closed).

Third, the philosophy concentrated on individuals in terms of planning their discharge from hospital by focusing on named groups of patients who had lived together for many years and were known to be compatible in terms of their needs. This attempt at a person-centred approach pre-dates the People First policy of the 2008 Act.

Fourth, the structure of the newly created organisation reinforced partnership working. Clearly located in the voluntary sector, it offered representation at Board level to local groups (for example, Mencap and SCOPE) and recognised the lay expertise of carers and advocacy groups. This was ground breaking at the time although it would be a minimal expectation of the required skill mix of Board members in today's climate given its emphasis on consumer involvement.

However, there were no service user representatives per se (although there is now greater emphasis on direct consumer involvement rather than indirect representation by others). At the time of setting up the organisation direct service user representation was not possible. This would have to wait until service users were living in the community as part of the organisation. In addition, patients who were part of the first phase of discharge would not have been able to participate as part of the charitable company given their level of disability, limited mental capacity and communication. The role and significance of Board members will be discussed later. However at this stage it is important to acknowledge the inclusive paradigmatic approach based on the participatory model which was adopted in the membership structure of the organisation from the outset.

Fifth, the importance of the shift in the balance of power between health and social services cannot be underestimated. The Health Authority could have developed its own alternatives to the hospital: there are examples of group home developments in the 1980s which were still based on a dispersed hospital model. Patients were simply moved into alternative accommodation but without an official discharge; consultants merely carried out ward rounds in the community and therefore retained power and control. The alternative model was developed using the consortium approach and this resulted in a more integrated approach both in the wider local community as well as between health and social services.

The model which was developed involved a huge commitment from the local

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Health Authority to invest in alternatives in the community. It is vital to acknowledge the 'leap of faith' which occurred at the time as well as the injection of resources amounting to £2 million between 1990-1993. This was funded by the Health Authority rather than Social Services. There was a clear statement that the hospital population was the responsibility of the NHS even if re-housed into the local community. The explicit transfer of power and control of the new charity to the Chair and Vice Chair of Social Services was not necessary but occurred as a gesture of goodwill and in anticipation of the future direction of service delivery.

The organisation was able to develop over a three year period 1990-93 without any retraction of funds for the seconded (formerly hospital based health authority) staff. In short, revenue funding was converted into a development fund for capital investment. This resulted in the creation of three nursing homes and twelve residential homes accommodating 141 people: all of whom were discharged from the hospital between 1990 and 1993. It also sponsored the establishment of Involve Housing Association in 1991 as an alternative housing provider. The significance of this was to allow the development of community-based housing options some of which are described as part of the documentary analysis.

Documentary Analysis of the Board Minutes 1997 – 2007

In order to describe the growth and development of the organisation that is the subject of this case study, I collected the minutes of Board meetings over the

specific ten year period. For the first part of my data collection, I analysed the minutes of meetings (1997-2007) into a colour coded matrix bringing together items relating similar events or decisions taken by the Board. I then put these into a framework for the case study, Involve Housing Association, thereby generating key categories or areas of interest. I initially produced eight categories but these were refined on more detailed analysis into five (with two of the categories, Development and Working in Partnership, being further divided into sub-categories).

The five identified categories were:

1. *Developments which were:*

a.   Person specific

b.   Strategic

c.   Opportunistic

2. *Working in Partnership*

a.   Working with an **internal** partner primarily the charity

b.   Working with a partner **external** to the Involve Group

3. *Strengthening the Organisation*

     Developing the internal governance structure of the organisation

4. *Innovation*

     For example, a new direction into uncharted territory or award for a particular practice

5. *Withdrawal (or exiting) from a particular service*

     This may have been a specific project or area of work

This categorical framework (set of categories) was most useful in analysis of the rapid growth and development of Involve over the ten-year period between 1997 and 2007. Particular episodes were applicable to more than one category. An episode might involve both working in partnership and be an example of innovation, so one category mapped, so to speak, on to another. The categories could not be regarded as mutually exclusive. I developed a colour coding method for use on the documentary material which took this overlap into account.

1. **Developments (The documentary analysis of the minutes shows three types of development – specific, strategic and opportunistic)**

a. **Person Specific**

Specific developments involved, for instance, the purchase of an individual property across the street from a local authority hostel to meet the needs of a named person. Investment decisions were made at Board level with a particular service user in mind and a guaranteed income stream.

A had lived for 10 years in the hostel. She has learning difficulties and poor mental health. She wanted to move into her own place but was concerned about losing contact with the staff at the hostel. In 1998 Involve Housing Association was asked by the local County Council to purchase a house nearby so she could maintain the links and have support in an emergency. Twelve years later A is still living in her own home as an Involve Housing association tenant across the road from the hostel.

Another example of a specific development involved B.

B had lived in the local hospital for years. Prior to its closure in 1996 B was moved to the former gatehouse at the entrance of the hospital. The Health Authority wished to sell and Involve Housing Association was asked to re-house B. His needs were assessed – he required a house with a garden and near to the local day service he attended daily. Involve Housing Association bought him a house in 1999 and more recently, as his needs have changed, a bungalow in 2007.

During the period in question, the main area of operation for Involve Housing Association was the former Health Authority area (roughly half of the shire authority). A specific decision was taken in 2002 in respect of property in the south of the county.

C had lived in his mother's house all his life. After she died he shared with a friend D from the local day centre. They had outreach support of 12 hours a week from the Social Services Department. An approach was made to Involve Housing Association as C's brother who lived in Australia wanted the house to be sold so he could inherit his share. In 1997 the property was to be auctioned in London with C and D as sitting tenants. This can be problematic depending on the new owner(s). Involve Housing Association agreed to buy out the share of C's brother so that C and D could continue to live there with their existing support arrangements and a sympathetic landlord – Involve Housing Association. They are still living there.

Throughout the 10 year period there are a number of further examples of specific solutions to meet identified need. Reinvesting the surplus generated by Involve Housing Association year on year has increased the property portfolio as well as satisfying identified need.

In 2003 E and F were due to leave residential college and wished to live together. Both are wheelchair users. I met with them and their families to identify a suitable solution. Initially we were pursuing a new-build option but this would involve a significant time-delay. I then looked for an existing bungalow in the geographical area they had chosen. Involve Housing Association purchased a suitable property which had the added advantage of an adjacent building plot for 2 additional properties (yet to be built). This was an example of a specific solution with an opportunistic dimension. A 3rd young man G has since moved in with E and F.

Specific examples continue to be a key feature of Involve Housing Association's work. However, service delivery or specific developments are not always housing related, for example, they included day services.

One of the former Trustees of the Involve Charity has a son with learning difficulties. She had resigned due to ill health but was aware of creative opportunities provided by the charity. When her son left school in 1999 she was adamant that G would not go to a traditional day centre some 20 miles away. She asked the Charity to provide a more local service for G. Using staff resources funded as part of the day services contract, Involve Housing Association rented 2 rooms in the local community centre and provided a 1:1 service for G. This specific example became an opportunity for others and now 30 people attend the Centre instead of accessing the more traditional alternative. The funding is via 'spot' contracts or using Direct Payments following the Direct Payments Act, 1996.

This example of a person specific service has led to wider opportunities being developed for other adults with learning difficulties.

b.   Strategic decisions

Involve Housing Association had opened the first not-for-profit day services in

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1995 using Special Transitional Grant provided from central government via the County Council. This followed the implementation of the National Health Service and Community Care Act 1990. Forty people still attend this day service and the finance for the service is provided by a block grant (this includes the cost of staffing). In response to identified need and gaps in provision, day services have further developed in two other towns using the core funding from the initial service and spot contracts for the individuals accessing the service. The move into one of the towns involved a significant change of direction regarding the use of the head office. This was a strategic move by the Board based on the need to develop links with the neighbouring authority and also provide alternative day care for residents of one of the nursing homes run by the Charity. It is also an example of property purchased for one identified need being used to meet another need.

Prior to 2001, 10 service users with profound learning difficulties living in one of the homes run by Involve attended a day service in the local town provided by another voluntary organisation. This was funded under contract with the local Primary Care Trust. There were problems with the way the service was provided as well as transport difficulties. The final reason to change was the insistence by the Commission for Social Care Inspection (CSCi) that service users living in the 24/7 nursing home should have access to qualified nursing care at all times. This was not provided at the day care centre. Involve Housing Association decided to use the funding and the existing nursing staff to provide a person-specific service based in its former office premises. This has now expanded to cater for other service users with similar needs. In 2007 the Involve Resource Centre was part of the TUILIP Project and was celebrated as a beacon site for innovation and good practice.

The Board minutes display examples of more strategic development decisions being taken, in particular working in partnership with seven other housing associations, or Registered Social Landlords, as they became known after the

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Housing Act 1996. The relationship has been particularly strong with Middle England Housing Association. (Appendix 7 shows the range of work over the years with that particular housing association). Sometimes the strategic direction was in relation to expanding into other geographical areas, for example, the neighbouring shire county (2000) and a city 20 miles away. (2006).This was in response to tendering opportunities but nevertheless needed a strategic vision in relation to the overall Business Plan and appropriate decisions taken at Board level.

Another example of strategic developments is the emphasis on social work training as a key part of the organisation. Involve Housing Association is a City and Guilds accredited training centre and provides most of its training courses 'in-house' thereby not relying on external agencies and venues for training. The decision to become accredited was strategic and provides valued recognition from an independent body. The added value of providing social work placements is not only financially attractive. It offers students the opportunity to work with adults with learning difficulties within a specialist service. Conversely, adults with learning difficulties can reflect on the student experience. There are formal arrangements with several universities in the region and over 30 students have successfully completed their placements with Involve Housing Association.

c.   **Opportunistic decisions**

That is, decisions taken within a given year that were not in the organisation's

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business plan but represented an opportunity to meet a particular need.

Examples include:

- A decision to rent property from the local County Council in a rural town where there is a serious shortage of social housing at affordable rents.

- The purchase of a 3 bed property in 2000 opposite the flats above the local Resource Centre. This was to meet, at the time of the decision, unidentified need but given the limited social housing in the area there was an opportunity for staff outreach support from the Resource Centre.

- The purchase of a 4 bed house in 2002 as potential move-on accommodation from the nearby local authority hostel.

- The purchase of an existing bed and breakfast establishment in Chesterfield in 1998 using mortgage finance from a charitable bank and based on a house keeper model funded out of housing benefit. (This has proved highly successful in meeting the needs of four older men with learning difficulties who formerly lived alone or with elderly parents and wanted shared facilities of a good standard based on a tenancy rather than registered care model).

2.   Working in partnership

Often positive outcomes require working in partnership and the documents reveal numerous examples of both internal and external partnership working with Involve Housing Association.

a.   **Internal partnerships**

As described in Chapter 1, internal partners include staff, service users and the charity, within the Group. My appointment as Joint Executive Officer in 2002 formalised the implicit arrangements and I created a group structure between Involve Housing Association and the charity in 2003. This made the governance arrangements more explicit and strengthened the decision-making and representation of service users on the Board. Three Service User representatives were appointed at the Annual General Meeting in 2003.

Prior to my appointment as Joint Executive Officer, the Board of Involve Housing Association had always been the stronger of the two committees. The meetings were quorate. Attendance at the charity was less regular however meetings often had to be reconvened to secure a quorum. This challenged the governance structure and compromised the efficiency of the charity.

The membership of Involve Housing Association included tenant or service user representatives whereas the Trustees of the care charity did not include primary service user involvement due to issues regarding beneficiary status and charitable law. Carers, that is, "secondary service users", were involved in the charity but could only be a Trustee if their son or daughter was not in receipt of specific Independent Living Funding (ILF). This excluded several previously active committee members. The restructuring of the Involve Group that took place in several stages between 2003-2006 strengthened the governance structure. This involved the addition of two more service user representatives on

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the Board and the creation of a new executive structure involving the senior

management team.

Internal Partners - and their impact on the development of Involve

Housing Association

Table 3.1   Examples of Internal Partnerships

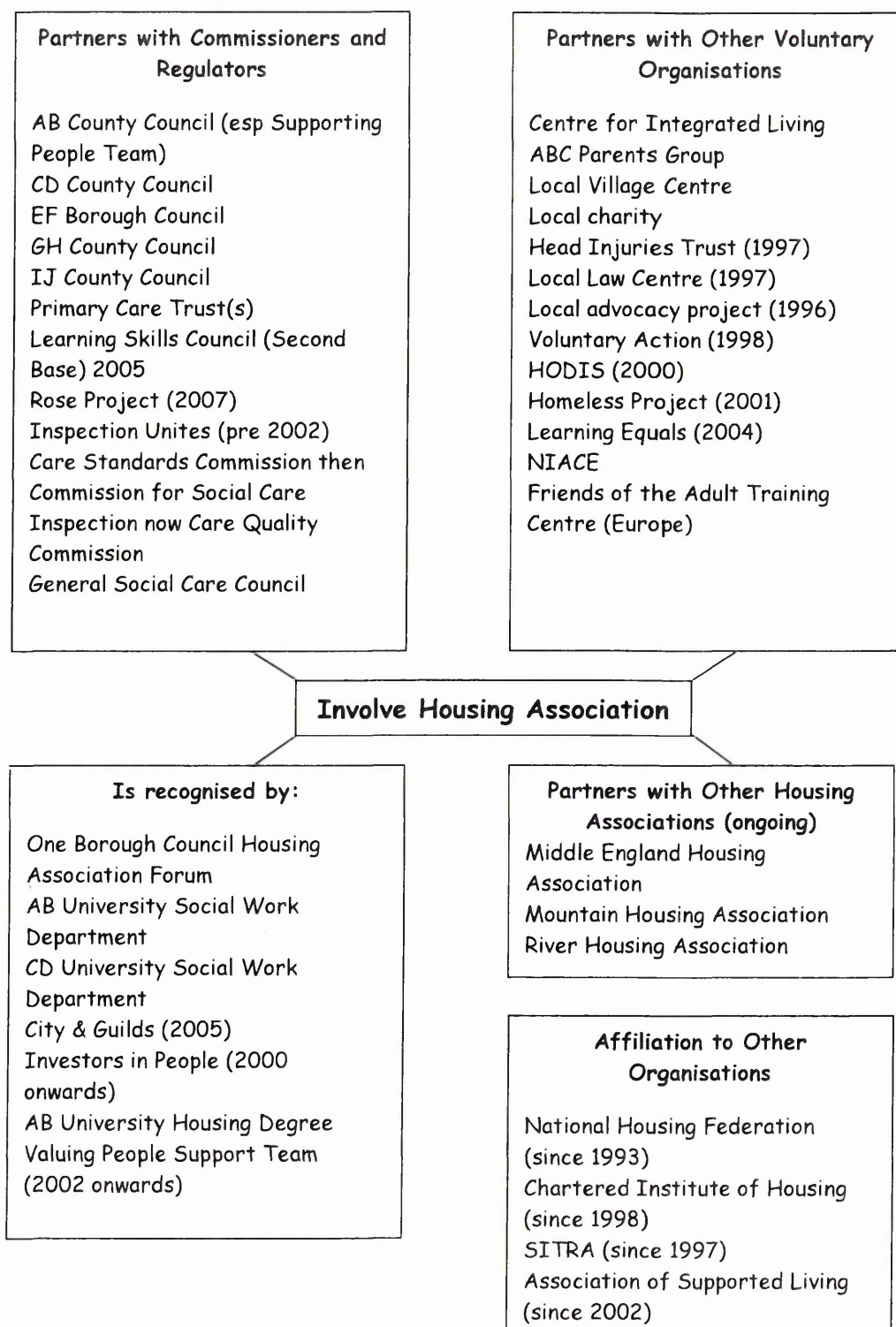| 1994	• Care charity (established 1990) sponsor setting up of Involve Housing Association (1991)
1998	• Tenant goes to Alaska to promote Involve Housing Association
1999	• Member of staff seconded from the Charity to Involve Housing Association to explore alternative day services.
2000	• First joint action of 2 organisations in order to provide "a more holistic approach to service delivery". Launch of corporate pack promoting holistic service.
2001	• Secondment of AB to promote supported housing and strengthen relationship with the charity. • Joint referral system established housing and care two sides of the same coin. • Transfer of properties from the charity to Involve Housing Association to strengthen Involve Housing Association's asset base in anticipation of Registered Social Landlord status.
2002	• Formal group structure established Involve Housing Association sole appointing body of Involve Care and Home Support and National Housing Federation (1998) rules adopted.
2004	• First group accounts
2005	• AB appointed Responsible Person for Domiciliary Care, Inspection results in 3 star rating.

b.   External Partnerships

Many of the developments in terms of service delivery were in co-operation with

external partners, that is, other agencies or organisations separate and

independent of Involve Housing Association.

Table 3.2   Examples of External Partnerships

1997	• Partnership with a local builder to provide 3 self-contained flats for adults with learning difficulties. • First DYSO (Do It Yourself Shared Ownership) scheme with Middle England Housing Association.
1998	• Creation of a Village Centre in a deprived area of a town using Lottery funding. • Purchase of 2 adjacent building plots on a private housing estate so the builder could provide a wheelchair accessible bungalow designed by Involve Housing Association.
1999	• Conversion of vacant space above a shop using a council grant in order to provide accommodation for 2 men with learning difficulties who could not reasonably live in a residential setting due to their particular behaviour and needs.
2000	• Partnership with local churches group to provide emergency accommodation for homeless young people.
2001	• Established Housing Forum across North Derbyshire. Involve Housing Association acted as secretariat and co-ordinated meetings.
2002	• Established as a twinning arrangement with a Mediterranean island. • Handed over the Village Centre to local community after four years of Lottery/Involve Housing Association funding. • Members of staff (13) seconded from the Charity to Involve Housing Association in order to develop supported living options for adults with learning difficulties.
2007	• Opened a weekend café in nearby county – run by adults with learning difficulties and located in a nature reserve popular with the general public.

Table 3.3   Diagrammatic Representation of External Partners in Relation

To Involve Housing Association

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┌─────────────────────────────┐        ┌─────────────────────────────┐
│ Partners with Commissioners │        │  Partners with Other        │
│      and Regulators         │        │  Voluntary Organisations    │
│                             │        │                             │
│ AB County Council (esp      │        │ Centre for Integrated Living│
│ Supporting People Team)     │        │ ABC Parents Group           │
│ CD County Council           │        │ Local Village Centre        │
│ EF Borough Council          │        │ Local charity               │
│ GH County Council           │        │ Head Injuries Trust (1997)  │
│ IJ County Council           │        │ Local Law Centre (1997)     │
│ Primary Care Trust(s)       │        │ Local advocacy project (1996)│
│ Learning Skills Council     │        │ Voluntary Action (1998)     │
│ (Second Base) 2005          │        │ HODIS (2000)                │
│ Rose Project (2007)         │        │ Homeless Project (2001)     │
│ Inspection Unites (pre 2002)│        │ Learning Equals (2004)      │
│ Care Standards Commission   │        │ NIACE                       │
│ then Commission for Social  │        │ Friends of the Adult        │
│ Care Inspection now Care    │        │ Training Centre (Europe)    │
│ Quality Commission          │        │                             │
│ General Social Care Council │        │                             │
└─────────────────────────────┘        └─────────────────────────────┘
                    ┌──────────────────────────────┐
                    │ Involve Housing Association   │
                    └──────────────────────────────┘
┌─────────────────────────────┐        ┌─────────────────────────────┐
│      Is recognised by:      │        │  Partners with Other Housing│
│                             │        │    Associations (ongoing)   │
│ One Borough Council Housing │        │ Middle England Housing      │
│ Association Forum           │        │ Association                 │
│ AB University Social Work   │        │ Mountain Housing Association│
│ Department                  │        │ River Housing Association   │
│ CD University Social Work   │        └─────────────────────────────┘
│ Department                  │
│ City & Guilds (2005)        │        ┌─────────────────────────────┐
│ Investors in People (2000   │        │    Affiliation to Other     │
│ onwards)                    │        │       Organisations         │
│ AB University Housing Degree│        │                             │
│ Valuing People Support Team │        │ National Housing Federation │
│ (2002 onwards)              │        │ (since 1993)                │
│                             │        │ Chartered Institute of      │
│                             │        │ Housing (since 1998)        │
│                             │        │ SITRA (since 1997)          │
│                             │        │ Association of Supported    │
│                             │        │ Living (since 2002)         │
└─────────────────────────────┘        └─────────────────────────────┘
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3. Strengthening the Organisation

The examples illustrated by the documentary analysis refer to decisions taken which improved the infrastructure of the organisation. These included staffing and equipment as well as policy changes.

Table 3.4   Examples of Strengthening the Organisation

1996/97	• Involve Housing Association purchased its own premises in 1996 and first computer system in 1997. • Youth worker appointed to work with young people (separate function to the tenancy related support.)
1998	• First tenant representative appointed to Involve Housing Association Board • Employment of Supported Housing Manager • Executive Officer appointed as Non Executive Director on Primary Care Trust. In particular to offer experience from the voluntary sector.
2001	• Tenant Participation strategy written • Strategy Committee set up by Board to look at Registered Social Landlords and other options. • Social work student explores service user involvement strategy • Welfare Rights Worker appointed.
2002	• CD moved from the local Village Centre to carry out tenant participation role with service users. • Service User Forum established • Joint Chief Executive Officer appointed. • Group accounts produced for Involve Housing Association and the Involve Charity. • Team building visit to Dublin, for Involve Group staff. • Idea of becoming a Registered Social Landlord abandoned Involve Housing Association to concentrate on its own internal group structure. • Shared use of office premises. • First Tenant Participation Worker appointed by Involve Housing Association • Welfare Rights worker funded to provide sessions as part of Coalfields Regeneration Project.
2003	• 3 service user representatives appointed to Involve Housing Association Committee – 5 year term accountable to the Service User Forum. • Official name change of the Charity and known collectively as the Involve Group. • Quality Assurance Officer and separate Head of Property Services appointed to Involve Housing Association. • In-house Decorator and apprentice with learning difficulties appointed.
2004	• Maintenance Department Involve Housing Association restructured – gardener appointed by Involve Housing Association to support service users and maintain limited number of gardens. • Lifetime Homes Committee set up involving service user representatives (as experts by experience) • Opened an in-house training venue after capital investment. Important to provide training to 600 plus staff who needed accessible facilities with car parking.
2005	• Housing Options Group (HOG) set up with service users to promote supported living. • Supporting People leaflets devised by Involve Housing Association tenants. • Head of Human Resources appointed across the 2 organisations.
2006	• Health and Safety Officer appointed • New website launched • Head of Information Technology appointed • Sub-office in north of county opened

4. Innovation

During the period in question examples of innovation emerged from the data analysis. By this I mean something that is unusual (not routine), ground-breaking (in a particular area of work or location) or responsive to an individual situation (in an exceptional way).

H has Aspergers Syndrome and wanted to live with her boyfriend. As social housing is difficult to access in that area, Involve Housing Association decided to support H to buy a 25% share in a Do It Yourself Shared Ownership Scheme (DIYSO) via Middle England Housing Association, one of its partner housing associations. The Board offered H a loan of £12,500 to purchase her share. This was ground breaking at the time (1998). She lived there for several years until her circumstances changed and she moved away. Involve Housing Association then sold her share to Middle England Housing Association and the property is still rented to an adult with learning difficulties and managed by Involve Housing Association.

Table 3.5 lists examples of innovation identified from the Board minutes. Some of them are specific developments mentioned previously but are nonetheless examples of innovation and give 'thick' description of Involve Housing Association. There is an argument that most of the specific examples are ones of innovation but I have identified it as a separate category in order to reinforce the uniqueness of some of the developments at the particular time thereby creating a new distinct category.

Table 3.5   Examples of Innovation

1997	• Creation of Acorn Project as a housing and care advice service for disabled people – first in the area and one of only a few nationally.
1998	• Tenant goes to Alaska to showcase Involve Housing Association's participation in People First conference in Alaska. Service user told his life story. • Purchase of a bed and breakfast hostel to provide a specific service for adults with learning difficulties (entirely funded out of Housing Benefit) • Use of charity loan raised by Involve Housing Association to fund mortgage facilities to adults with learning difficulties who were unable to borrow from elsewhere.
2001	• Link established leading to twinning project abroad. • Registration of a council house as a children's home to comply with CSCi (Commission for Social Care Inspectorate) regulations and meet the needs of a young woman with learning difficulties who was under 18 and needed accommodation.
2002	• First official exchange visit to Mediterranean island.
2003	• Opened sandwich shop and run by adults with learning difficulties. • Set up Shoestring Smart Cars as part of a day services project and at the request of service users.
2004	• Supporting People Review with service users input results in a four star report. • Attended conference in Budapest as part of European Disabled People's Movement and celebrating work in the European Union. • Set up the JT Project in memory of former Chair, (who died suddenly in 2007). First of its kind in the area providing work and training opportunities for adults with learning difficulties. Premises part of a builder's yard rented from the builder who is sympathetic to the organisation. • Executive Officer becomes one of the founder Directors of the Association for Supported Living – a national body promoting the needs of adults with learning difficulties in supported housing.
2005	• Involve Housing Association tenants participated in the Learning Equals project funded for three years 2004-2007 involving other housing associations and based in the East Midlands Region. • Established Second Base an apprentice scheme for young people who may wish to work in supported housing/care provided placements for 50 young people over 2 years. Employed 17 within the Involve Group. Only project of its kind funded by the Learning Skills Council in the region,
2006	• Local Directory of accessible Facilities and Friendly Service produced by service users. • 2 social work students on placement as part of the European Project. • Agreed to fund Brokerage Project 1 day per week (predates focus on personalisation post – 2008 Act).
2007	• Service users with learning difficulties participated in research regarding their own experience of social workers. • Involve Resource centre identified as a beacon site and part of multi-disciplinary learning project.

5.   Withdrawal or exiting from a particular service

The final category which emerged from my analysis of the minutes over the ten year period 1997-2007 includes examples of withdrawing from service delivery and Table 3.6 shows the reasons for withdrawal. The overall effect of activities in this category was to sharpen the raison d'être of Involve Housing Association in relation to working exclusively with adults with learning difficulties. The emphasis on a single client group was ratified by the Board in 2002 at the same time of the creation of the Joint Executive Officer post. It was also evident that national changes, for example, the advent of the Supporting People regime would have a negative impact on some of the areas of work, for example, working with young homeless people. The required notice was given to certain projects in order to concentrate the business activities and focus on working to, with and for adults with learning difficulties.

Table 3.6 - Examples of Withdrawal for Service/Ideas

1997	Conversion of sheltered housing project	Local authority decided to work with other partners elsewhere
1998	Use of local Hostel	Involve Housing Association decided not to partner with private landlord
2000	House in local town rented from Middle England Housing Association.	Transferred to existing tenant.
	Proposed new offices.	Decided to move to elsewhere as it offered better facilities.
2001	Two houses in local town	Houses not suited for young homeless project
2002	Two houses for people with poor mental health	Mental Health projects – not in experience/expertise of Involve Housing Association.
	Local Village Centre	Lottery funding ran out Involve Housing Association could not justify using reserves for non-housing purposes.
	Wood Yard Project	Linked to Intensive Support Service deemed not fit for purpose and project was closed. Limited social enterprise experience.
	Registered Social Landlord Application	Decided to create alternative in-house group structure.
2003	Young homeless people's projects	The Board decided that Involve Housing Association not suited to service delivery in this complicated area. – Supporting People changes allowed transfer to 3rd party who had more expertise.
	Local sheltered scheme for older people	Older peoples service project – run by another housing association who decided to continue alone and not work in partnership.
2005	Dispersal of Intensive Support Service	Newly agreed strategy and more integrated support provided in the community by Involve Housing Association.
	Change of arrangements at a flat scheme transferred back to ownership of Involve Housing Association.	Better rental income and maintenance service achieved by terminating lease with another housing association and bringing it back to Involve Housing Association.
2006	Withdrew Resident Warden at flats providing instead a peripatetic service.	Better use of resources Better outcome for service users and release of an additional flat for a service user.
2007	Drop in service for young people.	Following the decision not to run young homelessness projects the lease for the drop in was handed over to the Youth Service.
	Drop In/Offices	Unfortunately Involve Housing Association did not win the local Day Services tender and therefore could not afford premises – relocated to another rented venue which proved more cost effective.

The documentary analysis of the records of Involve Housing Association illustrates the growth and direction of the organisation over the period in question. Examples in each of the five categories help to capture the rapid development over the ten year period in question 1997 – 2007.

In 1997 Involve Housing Association had twenty-four tenants. During the financial year 1997/1998 alone, thirty new tenancies were created. Generally, the referrals for new service users moving into accommodation came via the social services department but the demand was high and often people referred themselves. Since 1993 and the advent of the care management assessment process, there has been an increasing emphasis on independent living. However, the funding of this was problematic primarily due to lack of an identified budget for community care. Following the change of government, after the general election in 1997, this began to improve. In addition, the training of care managers to better assess people for independence (together with the introduction of the Direct Payments Act 1996) proved to be a positive impetus to increasing the available range of housing options.

Involve Housing Association began to concentrate on wider partnership working in order to deliver appropriate housing. For example, the Acorn Project, set up in 1997, worked with the local centre for integrated living to provide housing and welfare rights advice to potential service users. It became one of the first national disabled person's advisory services concentrating on adults with learning difficulties and was involved in the national co-ordinating body for housing disabled people.

In September, 1997 at the Annual General Meeting, the charity and Involve Housing Association came together in order to explore joint board membership. This was the impetus for structural change and wider Board membership. Although the two distinct legal entities remained, reflecting housing and care, as separate but mutually compatible functions.

Between 2000 and 2002, the documents show that there was a degree of rationalisation, both in property stock and personnel. In particular, houses that were no longer deemed fit for purpose, were handed back to their owners (for example, a council property and four properties on the site of a local hospital). The latter were deemed to be institutional models of housing and alternatives in the wider community were identified. Similarly, the charity transferred four of its smaller properties to Involve Housing Association in order to increase its portfolio and asset base prior its application for recognition as a registered social landlord.

Regarding personnel, two senior staff were seconded from the charity to the Association in order to develop day activities (1999) and supported living (2002). This added further impetus and energy to the development of Involve Housing Association. In addition to property development in new areas, for example, there was an expansion into alternative day activities in two areas.

All the developments were needs-led, that is, based on the identification of 'gaps' in provision or responding to requests from individual service users (or more often at that time, their carers). Similar rationalisation occurred regarding

the concentration on services to and for adults with learning difficulties. In particular the withdrawal from the local Village Centre which had proved successful to that community but was only funded for three years by the national lottery fund. Although extended for one further year by the use of Involve Housing Association's own reserves, it was an expensive and time consuming activity. The provision of services to the former mining community was much needed but it was disconnected from the rest of the organisation. The surpluses generated by the Association came from working with adults with learning difficulties and there were no service users resident in the mining village. Arguably they would not be particularly accepted given both the insular and inward looking nature of the community and the difficulties often experienced by adults with learning difficulties living in similar communities highlighted in the Pilkington Report (2011).

The redeployment of the co-ordinator of this project into the role of Tenant Participation Officer at Involve Housing Association in 2002 would appear to have provided the essential catalyst for an emphasis on tenants' involvement. The worker at the local Village Centre had previously trained with Involve Housing Association as a Housing Manager. I had supervised her placement and knew her strengths and commitment to tenants' participation. Her redeployment was an opportunity to develop the service user 'voice' within the organisation. She set up the Tenants' (now known as the Service Users') Forum. Two additional representatives joined the Board following the Annual General Meeting in 2003. Having the right philosophy as well as the necessary staffing level was critical in terms of service delivery. The organisation was able

to move forward 'with' adults with learning difficulties and develop appropriate and responsive services not just 'to' and 'for' them.

There were structural changes external to the organisation, particularly between the period 1999-2003. In particular, the development of Primary Care Trusts, within the Health Service, encouraged changes at Board level as it was not deemed appropriate for representatives from Health to serve as board members of essentially a provider agency. There was a general split between commissioners and providers which led to the need for the recruitment of new board members. Given the problems of recruiting trustees to the charity highlighted earlier, it was an opportune time to review membership. Involve Housing Association offered a strengthening of the membership and given its constitution allowed for the active and full participation of its participants, that is, tenants or service users. This occurred at the same time as the Valuing People White Paper (2001). This further encouraged service user involvement following its introduction after the 'Nothing about Us, Without Us' Report (1998).

Similarly, the development of the Supporting People arrangements in 2003 actively encouraged and welcomed tenant involvement. As the largest Supporting People provider at that time in the locality, a prime example of tenants or service user involvement was developed. It had emerged both from the ideological roots of the organisation and its practical application over the five years between1998-2003.

Main changes 1997 – 2003

The documents show that by April 2003, Involve Housing Association had:

- Decided to concentrate exclusively on services to, for and increasingly with adults with learning difficulties

- Increased the number of elected Service User Representatives on the Board from one to three.

- Developed a stronger Board membership reflecting the changes in Health and Social Care

- Appointed a Joint Chief Executive Officer (between the Charity and the Association)

- Developed an integrated executive team to deliver housing with care

- Withdrawn from certain schemes (for example, young homeless peoples' project)

- Expanded person centred services particularly in supported living and day services. Developments from 2003 onwards reflected the new emphasis of the organisation. In particular, service user involvement led to a number of 'home grown' initiatives which were requested or suggested by service users on the Board. For example, the start of the car valeting service and the move from the rented sandwich shop to larger premises which were purchased by the Association in order that a cafe service could also be provided. Individual property purchases reflected the needs of named individuals identified within the

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organisation or referred from outside the organisation (particularly by carers).

- Developed an increasing emphasis on empowering service users. For example, as (unpaid) volunteers working in the shop it was necessary for service users to undertake training, for example, in food hygiene. Service users became involved with the Lifetimes Homes Committee which discussed design issues relating to properties, often offering practical and cost-effective solutions to meet increasing physical needs. Following the accreditation with City & Guilds in 2005 new training courses were introduced in order for service users to gain formal recognition for their achievements. As advocates for the wider Service User Forum to whom the three service user representatives are accountable, additional courses were developed. The initial courses concentrated on 'softer' areas, for example, confidence building. These courses extended into other areas, for example, equality training, disability awareness, or raising understanding of the wider social –political context. Involvement in external training, for example, Equal Partners, in association with the National Housing Federation developed out of this core approach.

- Produced a Directory of Accessible Facilities in the local area after local research by the Service User Forum. This was received positively by other agencies. The Domiciliary Care Inspection by the Care Standards Inspectorate in the same year achieved an overall three star rating with an additional comment that Involve Housing Association warranted a four star award for its service user involvement strategy and practice.

The diagram below (Table 3.7) summarises the descriptors for Involve Housing Association identified through the analysis of documents that is, minutes which chart the development of the association over the given period.

Table 3.7   Descriptors for Involve Housing Association generated from the data

Independent

Part of voluntary sector – working with like-minded organisations

Set up with backing from Health and Local Authority

Person centred 'People First' since1991

Working in partnership with commissioners/ regulators and other housing associations

Value driven (based on assessment of need)

Local to area

Working with education, eg university, NIACE and local colleges

Descriptors for the organic growth of Involve Housing Association

Creating community based solutions

Involving service users and their families

Innovative

Radical

Opportunistic

Social enterprise (that is, surplus ploughed back into organisation)

Positive approach to risk taking

Chapter 4

The Findings: Presentation of the analysis of the group interviews

> Cresswell states:
>
> *"We [re]present our data partly based on participants'*
> *perspectives and partly based on our own interpretation,*
> *never clearly escaping our own personal stamp on a*
> *study"* (2007:43)

In Chapter 2, there was an explicit acknowledgement of the researcher as an actor in the organisation under study. The insider-researcher perspective continues on the presentation of the interview findings due to the researcher's intimate connections with the organisation and its key participants.

Note regarding names of actors

To protect confidentiality all names have been changed. However, in order to help the reader, I have used the same letter of the alphabet to categorise each group of interviewees as follows:

Founder Members

- Frank
- Fred

Long-standing Members

- Larry

- Len

- Leslie

Service User Members

- Sam

- Sarah

- Sid

Executive Team Members

- Ernie

- Eve

- Ewan

The four sets of interviews were carried out in order to capture participants'

views on certain aspects of the organisation.

In particular:

- Motivation and reasons for being involved in the organisation

- Significant events – good or bad identified by individual Board Members

- Governance and in particular issues relating to service user involvement

- Future challenges or opportunities over a five year period until 2014

The interviews provided additional data to the documentary analysis. They enhanced description and deepened the understanding of the organisation offering thick description as well as the ability to generate themes for later discussion.

There were three sets of Board member interview, namely and in order of interview over a four week period:

- Service user Board members (three)
- Long standing Board members who had served on the Board since 1995 (three)
- Founder Board members (two) both had been involved from the outset

In addition and during the same interview timescale, three members of the senior management team were interviewed. All three members of staff had been involved in the organisation since the early 1990s and therefore could add weight to the case study.

The Board is responsible for setting the business strategy and policy whereas the executive team, including myself, is responsible for day to day operational management and implementation of that strategy. I am employed by and report to the Board. My line manager is the Chair of the Board. The Board meetings are held bi-monthly and prior to each meeting there is a Finance and Strategy meeting known as the F&S Group. This consists of four Board Members – Chair, Deputy-Chair, Treasurer and another Board member as well as the

Company Secretary (an officer), the Head of Finance and myself. The F&S

meeting is not a formal sub-committee of the Board: rather it is an opportunity to

explore financial and strategic matters in a more detailed manner. It

recommends items to the Board but in itself has no decision making

responsibility. It is wholly accountable to the Board. It was established in 2006

in order to explore matters which could not always be aired at Board meetings

due to the lengthy agenda or need for further detailed information. There are no

service user representatives on the F&S group which is a reflection of their

potential beneficiary status in order to avoid a conflict of interest.

> *"I think you can legitimately* [do this] *because it is their way of*
>
> *considering questions of policy that they are direct beneficiaries of"*
>
> (Frank – one of the Founder Board Members).

The executive team (at 2007) was highlighted in Table 1.5. Members of the

executive team not only send regular reports pertaining to their departmental

responsibility but they often attend Board meetings in order to report on their

particular area of concern. In Chapter 2, I referred to the nature of the

conversational interviews together with an outline of the questions posed to

each group (Appendix 5). Basically, several areas were explored.

1.   Motivation (or reasons for getting involved in the organisation)

The first set of questions explored members' involvement and reasons for being

on the Board. In terms of service user involvement, Sid talked first as he has

been involved for 12 years and was the first Tenant Board Member recruited in 1998. When asked how he first got involved he said:

"With having the house and stuff like that and with being in a self-advocacy group."

When asked why he was still involved Sid replied:

"Because I am so happy with what Involve do for us...in the way of the care and the support and how people listen to you."

He also explained his involvement at a Board member's away day in 2002 when he was asked by the late Chair of Involve Housing Association how many people with learning difficulties should be on the Board.

"And this is where another two Board members come in.....so in other words it was giving us a chance......and including people [with learning difficulties]."

Sam, a service user, joined the Board in 2003:

"When I got involved it was like we had a meeting at this day centre and er......we got all out together to set up a Tenant's Service User Forum. I went and I thought it was a good idea and then got voted on, you know as Chairperson."

Sam stated that he was still the Chair of the Service Users Forum:

> *"I am representing people with learning disabilities as well who can't speak and that."*

When asked why he was personally involved in Involve Housing Association he added:

> *"It opens more doors...it broadens my horizons...it builds my confidence up and I do presentations and they listen to you."*

Sarah, another service user from an adjacent shire county (an area of expansion for the organisation after 1999), also joined the Board in 2003:

> *"I was asked by the local charity Chair Person if I would like to become a member of the Board...It is a good thing for me because I work with people who are profoundly disabled...and haven't got a voice because they can't speak, so I am their voice basically. I help the parents to have a voice."*

Again her motivation is that:

> *"It just gives me more confidence. I like the people I meet within Involve. They are all very good to me, they look after me. My staff team where I*

live are brilliant that I have got...whatever I give, I give back to what they give to me."

The issue of representation was critical. All the service users stated that they were nominated by the Service User Forum and their commitment to ensuring that issues were raised involved attending several other meetings as well as the Board. A written report – prepared in a simplified one side of A4 format – was always presented at each Board, highlighting key requests or concerns. This mandate was acknowledged, particularly by Frank who regarded this as an example of the service user's democratic accountability. His own political belief and years of active involvement in local politics underlined this.

The role of ambassador (on behalf of the organisation) was also explored. All three service user Board members had visited the Mediterranean island which Involve twinned with as part of an exchange programme and had taken part in meetings with adults with learning difficulties on the island. There was recognition of the importance of this for the organisation and their role as representatives on behalf of other service users (over 20 other service users have been part of the twinning programme not just Board members).

The three long-standing members – Leslie, Larry and Len had all been involved during the ten year period 1997-2007. Leslie joined the Board in 1995 as a parent-carer with the intention:

"primarily just to give the Board that extra bit of spectrum." (Leslie)

Leslie had met me in my role as the then Director of Involve Housing Association at a meeting in 1991 when he was involved as an interested parent in the setting up of an independent living project for young people with learning difficulties in partnership with Involve Housing Association. Although personally involved in promoting opportunities for young people with learning difficulties, his daughter only became a tenant of Involve Housing Association in 2007. This is an example of a carer being involved in developing something 'for the future', wanting to know that options were available but not necessarily wanting to access the service immediately. In terms of his involvement as a Board Member, Leslie said:

> "I retired in 1995 and it has given me a sense of purpose...knowing how much good it is doing for service users."

Larry used to work for many years with adults with learning difficulties for a national charity. Larry joined in 1996 when he was:

> "Invalided out of my job and not able to go back to work. About that time I joined the Board of Involve and was very happy to do so." (Larry)

He had observed the development of Involve Housing Association from its inception and:

> "When I was.....retired and had the time I was glad to have a part in the developing organisation......"

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"I have always found debates and discussions that we have had on the Board ......interesting to me. I have a continuing interest in social care developments generally and some of the debates and discussions that we have had on the Board have been of very high quality and I found this both interesting and satisfying to be part of the ongoing developments in social care and the service generally. I have enjoyed that very much. I have never felt I have been a bit of a country cousin come to town being from the south of the county where until now we have not been very active...I haven't felt that I have contributed very much but I have certainly greatly enjoyed and been interested in the discussions over the years; certainly well worth the task of getting a bus to get me here."

However, Larry added:

"It would be even more interesting if one was able to be more directly involved."

Although he did not elaborate at this stage Larry later wrote to me about his wish to be more involved. This is understandable given his own extensive background in managing social care at an operational level and his early retirement due to ill-health. Letting go in the caring profession can be as difficult as for parents of adults with learning difficulties.

Len, a longstanding board member, became involved in Involve Housing Association in 1995 as two of his colleagues from the University were founder members and on the Board. Again he became actively involved once he retired:

> "First... I don't believe in retirement. A second reason is that I have always been a joiner and an active kind of person and of course what Involve fits in with my social and political beliefs." (Len)

He stated that he felt involved:

> "It is very much a sort of a job. I feel that we have done things generally speaking very well in the past...and I find that very pleasing and enjoyable. Not saying we are perfect but I think we do things well and that is good."

He did not give any specific indication of what he felt was not so good: rather his comments were more akin to the desire for continuous improvement and awareness of being too complacent.

The two founder members of Involve Housing Association who were interviewed as part of my research have been involved since its inception in 1991. Indeed the Chair, Fred, promoted the idea of a 'not for profit' alternative strategy when working in his former role as assistant Director of Social Services. Asked why he was involved in Involve Housing Association, Fred

recalled his childhood involvement with adults with learning difficulties:

> *"It became part of my being...that I grew up with the idea that these were people who had what we would now call rights...so it was important to me that ultimately I followed a path that improved their lives, gave them power. I get considerable satisfaction from the point of view of seeing people empowered and being integrated into the communities in which they were born."* (Fred)

Frank agreed:

> *"I came initially for political reasons...I see myself as a socialist and I think making a contribution in this way is not just doing something on a voluntary basis but is part of your total life experiences and you need to do things that relate to what your philosophy of life is about."*

Given his strong political belief and his focus on educational issues throughout his personal and working life, this ideological position was explicit and a strong *raison d'être* for Frank's involvement on the Board. In terms of feeling involved, valued and respected as a Board Member both felt positive about this:

> *"It's an enjoyable experience"* (Frank)
>
> *"It's a vital part of my life."* (Fred)

The three senior members of staff had their own motivational reasons for being involved in the organisation. When asked why she was involved in Involve (as a member of staff) Eve replied:

"I love the value base of ours which is very service user focused...the people you work with are phenomenally motivated – the service users are brilliant...I wanted to give back to the people that I had supported right early on in my career – there are sixty service users from the long-stay hospital...it's about giving them something back as well."

As Eve had been a Board Member I was able to ask what she felt was good or not so good about being on the Board:

"I felt that my contribution was valued as a Board Member in terms of my wealth of knowledge and what I was able to bring nationally and locally in terms of service development elsewhere to inform some of the decision making for the Board. I think some of the challenges were around the TUPE[1] transfer and getting it right."

Eric's involvement has been in every aspect of the organisation from its early days. He joined Involve Housing Association as a temporary, part-time member of staff in 1994 and in his words stayed because he "never found the door".

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[1] The TUPE transfer refers to a transfer of National Health Service staff to the Charity. The matter was discussed over 6 years and eventually happened in October 2009. Although outside the period of research it had a major impact in terms of time spent at Board meetings during the period studied.

"I suppose in the voluntary sector you have to be a bit of a jack of all trades...you have to be...flexible. That's what makes it interesting."

He stated that he felt valued and respected especially by his colleagues:

"It has always given me as much back really."

Ewan transferred to the employment of Involve as a day services worker from the social services department in 1995. His role has developed over the years to Head of Day Services and since his employment in the voluntary sector he has trained as a qualified social worker and is now a practice teacher for social work students. He chairs the organisation's Training Committee as well as:

"being involved in various matters that could be grievances, disciplinaries and general troubleshooting"

When asked about whether he felt valued and respected, Ewan was clear:

"I feel very valued – yourself and John (previous General Manager who retired in 2002) *have been excellent managers which has an impact on why people stay."*

2. Significant (or Key) Events

These linked to the Milestones identified as part of the documentary analysis. The interviewees recalled a number of key events.

a.   *Service Users' Recollection*

Each service user had a different 'key' event often memorable because it impacted greatly on their own life. Kate described leaving a day service she disliked to move into a catering service run by Involve:

> *"I like going out and meeting new customers and...that.....I promote it all the time to friends and family whoever I meet – Involve's Occasions do catering every day."*

Sam talked about his own personal development:

> *"I remember when I started... I didn't have any confidence, would not say boo to a goose. I went to a meeting...about setting up Shoestring Snacks...and I thought to myself I could get something out of this...It built my confidence up meeting people and I haven't looked back since."*

He talked positively about moving from the sandwich shop to the charity shop (both run by Involve) and being part of the exchange project.

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Tangible events which impacted on service users lives were recalled as significant. For example, the purchase of disco equipment so that Sam could be the disc jockey at service users' parties. Sarah mentioned the buffet service of which she is a key member of staff (in an unpaid capacity).

Sid – the oldest of the Board members, both in terms of age and active involvement, recalled the opening of the sandwich shop as a key event. As a Board member:

> *"I opened...and I got is going and actually could remember...helping and supporting Sam on the bus to the sandwich shop...he actually got his confidence from me helping him on the bus."*

Not all experiences were viewed in a positive way Sid could remember the young homelessness projects.

> *"It kept coming back as an item on the Board...some very, very, very bad issues...I knew one of the tenants, but not naming anybody, started a fire in one of the flats and he actually disrupted my support day with it."*

In summary, the service user responses were as follows:

GOOD	NOT SO GOOD
• Christmas lunch for Board Members • Getting together • Feeling respected • Making a difference • Changing things • Training opportunities • Choosing staff	• Disciplinary Matters (*"It makes you feel on edge"* [Sarah]). • Experience of young homelessness project • Unsuccessful Tenders (for example, for day services) • Losing TRI (the in-house day service funded for three years as a pilot project)

KEY ISSUES RECALLED BY SERVICE USER BOARD MEMBERS AS SIGNIFICANT
• Snack shop, Involve's Buffet Service. Sarah and Sam worked together. 'Different every day' • Involve's exchange project with the Mediterranean island – all have visited the island. • Move-on accommodation for young homeless people – the latter had been a negative experience particularly for Sid who was a victim of crime. • King Project – emergency accommodation for young homeless people – the perspective was less personal. • Renting office to an advocacy project of which Sid is a member • Regional Training (residential course for voluntary Board members) • Buying disco equipment (Sam is resident DJ) • Choosing own staff (all had been involved in recruitment). • Second Base Project – young people working in health and social care (several students had been on placement with Tenant Board Members).

From long-standing Members:

GOOD	NOT SO GOOD
• Rewarding to see the development of the charity • Debates and discussions at Board level • Continuing success of the organisation • TUPE transfer (finally achieved in 2009 outside 10 year period but discussed for over 6 years before it actually happened.	• Getting used to being slightly removed from what is happening operationally • Quite long intervals between meetings (which are held every 2 months) • *"Can't think of anything negative at all"* (Leslie)

b.   Key issues recalled by the long-serving members as significant

Long- standing members emphasised different areas as significant:

- Opening of local Resource Centre (1995). The first day service run by a voluntary organisation.

- Opening of outreach day service in nearby town (1999). This was an extension of the Resource Centre.

- Opening of Involve Resource Centre (2001). This focused on the needs of people with profound and multiple learning difficulties.

- The changes in governance and management structure in 2002 following the appointment of the joint Chief Executive Officer.

- Expansion to other geographical areas, for example.

- The purchase of the new office headquarters was deemed to be: *"fundamental to the kind of organisation we are and the values from which we started."*

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- Developing new schemes – *"I think both the property, the infrastructure and communications have developed with a beautiful balance between caution and necessity."* (Leslie)

- Consistent expertise – *"The presence in the organisation over that entire period...of certain constant figures...people who came with enormous experience...knowledge and wisdom to guide the organisation through."* (Larry)

Both founder members emphasised the concentration of services to, for and with adults with learning difficulties as a significant step-forward. They recalled the withdrawal from running the local village centre.

> *"We just weren't up to it...it was a diversion from what we were really about."*
>
> (Fred)

c.   *Key issues recalled by both Founder Members as significant*

- The local Resource Centre which opened in 1995 as the first day service in Derbyshire run by a voluntary organisation. Further it was unique due to supported accommodation (8 flats) which was developed above the Resource Centre in partnership with Middle England Housing Association.

- Local service delivery was a key factor. For example, the history of the Resource Centre was discussed at length including the resistance

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from the local community who publicly opposed the idea of providing a day service in the area. This was a negative experience involving adverse press coverage based on 'NIMBYISM' and the fear of the unknown.

> *"We spent a lot of time in negotiations with the local people...arguing like stink and I have to say that I think it was only when they tasted what we had to offer that their whole attitude changed...and they wanted it."* (Fred)

- Housing developments generally, as moving people out of institutional care requires alternative accommodation and for that housing to be part of local communities, that is, integrated not segregated.

> *"Without housing, without bricks and mortar, the thing doesn't work"* (Frank)

- Underpinning this was deemed to be the general philosophy of the organisation.

> *"Moving towards (proper) care in the community we have developed ......in a way which no other organisation that I have ever seen or visited."* (Fred)

- Both commented on visionary management which included the Board and the executive team.

> *"I don't think it could work unless you have got a management structure led by someone who, and Board Members, who have got some sociological imagination."* (Frank)

- Both founder members regarded it as vital to have a strong moral value base at Board level and within the management infra-structure.

It only works if you have got people who are involved for personal and political reasons." (Frank)

All the participants mentioned the impact of the local Resource Centre which was the first not-for-profit day service for adults with learning difficulties in the shire county. Appendix 8 highlights the importance of this service, not only ground-breaking at the time but in subsequent developments in day services. The block grant which secured and funded the service was 'stretched' to encompass newer developments, responsive to unmet needs for example, a nearby market town and a village. This is a further example of organic growth. There is an argument for this to be explored as a case study within the overall case study analysis of the organisation. The significance of this in terms of the organic nature of the main case study will be explored in the discussion chapter.

3.   Governance

The questions concentrated on the effectiveness of the Board in terms of governance as well as its skill-mix and membership. Comments included the age profile (and the associated difficulties in recruiting people of working age). However the three long-standing Board Members felt that the Board was "very strong" (Larry) with "age and sage" (Leslie): that the Board "has had a very definite influence on the way the organisation has developed" and about which although developments often arise from management initiatives (the Board) "has made...a very valuable and good contribution." (Frank)

The significant involvement of the Chair, Fred, was acknowledged by all three. He has been a constant influence having been involved from the beginning as former Assistant Director of Social Services. He had appointed me to the role of Principal Development officer for Adults with Mental Handicap (as it was then known) in 1988 and encouraged my secondment to set up the not for profit organisation in 1990.

> *"I was attracted to joining the Board in the first place because Fred was there...I had an enormous respect for him. It was a great pleasure to join any organisation that Fred...was part of."* (Larry)

This area highlights the influence of 'key people' or significant others and their relevance in terms of growth and development of the organisation.

In terms of governance at Board level, Frank felt that:

> *"The Board has been very effective...if you look at the success of Involve whatever is down to management it's also down to the policy determined at Board level."* (Frank)

Fred queried the mix of the Board:

> *"What I do not understand quite honestly is why we hang together...but my judgement is...we all come from similar backgrounds...I know people joined us due to contact with existing Board members."* (Fred)

The two debated the fact that decisions were generally unanimous and that there had never been a "punch up" (Fred) or strong disagreement. Frank suggested that:

"There is no punch up because there is no bottom line...you have not got a stake in it in an economic sense. There is an emotional commitment, there is an ideological commitment, there is an intellectual commitment but there is no economic." (commitment) (Frank)

Frank acknowledged that although "we have had very effective management" this was challenged by a difficult period during an industrial relations issue. He felt that lessons could be transferred to other voluntary organisations although Fred felt that Involve was unique in the voluntary sector.

"We are not as well organised and structured as many organisations are – I think there is a benefit in some...looseness." (Fred)

There is by definition a uniqueness of the organisation. However there are also strong emergent themes which will be discussed later. These may have transferability or generalisability to other voluntary sector or 'prototype' organisations as described by Mulally (1993).

The members of the executive team who were interviewed included the former Company Secretary who stated that the birth of the internal group structure had significantly strengthened governance.

"That was quite a change of direction...The two organisations (Involve Housing Association and the Involve charity), *a bit like a speed boat and an oil tanker so it provided interesting times when it was decided to get closer together."* (Eric)

As Company Secretary of Involve Housing Association between 1994-2006, Eric had seen the changes at close range, as he had also been in attendance at each Board meeting throughout most of the ten year period covered by my documentary analysis so had a valuable insight into the impact of change within the organisation. There was a significant change in 2002 with the creation of a joint Chief Executive post.

"John (the previous General Manager of the Charity) *retired so that in a way forced the issue...we needed to find a vehicle that could push into the future."*

Eric had witnessed the changes at Board level:

"Some people grasped the nettle earlier than others...understood quicker the reasons for forming a group structure."

The Board's skill mix was identified as a key issue:

"The Board were always aware they needed to widen the skill mix...and there have been times when action has been taken to reinforce the

Board." (Eric)

Significantly, the service user group of Board members did not have any views on governance. This may be due to a limited understanding of the term governance as a distinct concept. It may be better explored by a consideration of service user involvement which is both more accessible and relates to a wider social movement promoted by People First and the Valuing People agenda.

Service user involvement

In summary the issues raised concern:

- Respect for service user views and a positive approach to their involvement.
- Tokenism
- Language used and accessibility
- Legal duties and levels of competence and understanding
- Limited representation from the Service User Forum ('the usual suspects')
- Potential conflicts of interest

I will outline these from the data collected during the interviews.

a. Respect

In relation to service user involvement on the Board Leslie said:

> *"I think it has been wonderful because...they give you the insight of actually being in the situation...they find themselves as valued and I personally value them greatly for their additions."*

This was widely accepted by the other two Board members in the long-standing Board member group.

> *"Yes, they often do make very pertinent comments...and one enjoys their being there."* (Larry)

The Service User representatives felt included by other Board Members.

> *"Yes we do – they give us a chance."* (Sam)
>
> *"They make us feel welcome."* (Sam)
>
> *"They are great"* (Sarah)
>
> *"It's called respecting each other"* (Sid)

An example of being respected was being involved in the residential course in Leicester with other voluntary Board members.

Sam commented:

> *"It opened their horizons as well to see a person with a learning disability."*

They described the format of the meeting at the monthly Service User Forum and meet as a sub group prior to Board meetings where they are able to discuss minutes of meetings and papers for the agenda:

> *"We just like write a report out and.....say what the Service User Forum is doing."*

Eric from the executive group acts as a link person with service user Board members in between meetings.

Being acknowledged and involved featured highly in this area. Service User Representatives regarded other Board members as 'friends' and rated, for example, the annual Board Members Christmas lunch as a memorable event. The significance of this perception will be discussed later in terms of professional boundaries and dialogical relationships. Eve, a senior member of staff, recalled a significant event that which happened in 1993 whilst she was on secondment with the organisation and predating the period of the research. It is relevant because the impact was profound and is still a major influence on her working life.

"We went to the People First conference in Canada and we had taken two service users with us and it was just the impact the whole event had on them personally and how much more you got to know about them as individuals...but also seeing the shift that empowerment agenda it gave to the service users and that never left me."

When asked generally about any potential challenges regarding involvement of service users on the Board, the Service User Representatives struggled to answer this. After a significant pause to think (approximately 15 seconds) Sid said:

"We have got mixed age"

And Sarah remarked:

"Parent involvement as well – It's a positive thing."

b.   Tokenism

Turning to the representation of service users on the Board, Frank raised concerns about tokenism as "the great danger" but both founder members regarded their involvement as extremely positive. Non-disabled Board Members referred to tokenism as a danger but this was not mentioned by the service user representatives. This may be due to the fact that they felt fully engaged or it

may be due to their lack of detachment or ability to identify with the abstract concept of tokenism.

> *"I think it's not just them being on the Board that allows them to make a positive contribution, I think it is at the stage before then – how the service users' group meetings...when they send their delegates to the Board...is as important as them being user members...it is clear that they are involved in a lot of collective service users' activities they bring to the Board and I think it has been done in a sensitive way and I have got as much from it as the service users have got from it."* (Frank)

Fred raised the issue of "a very clear educational context" but "I do get concerned about the stress some of them are under for clear reasons, (for example) when they have to read" (out loud). The Service User Representatives always have an item on the agenda regarding the Service User Forum business and each Board Member reads out an item. This is rehearsed before the meeting with support from Eric as the Head of Learning and Development. He helps the service user representatives to put their report together. Fred felt uneasy about this: (reading out loud).

> *"I have talked to Sam about it...why don't you just talk about it rather than writing it down?"*

However Frank thought it was a:

"Positive thing...they are at the Board in a delegated capacity and I think having the written report is...they feel that they have a link back to the service users."

Both felt that in regard to financial issues, "there is a bit of tokenism" (Fred) "it's a constant threat." (Frank) Concerns were also expressed about the implicit power relationships:

"We are the landlords, we are the management of the care packages...we have to demonstrate....that our service users' organisation is the best possible we can have to develop that sense of independence in an advocacy sense...you need to satisfy the external critic." (Frank)

In terms of involving service users on the Board, Eve stated that it had made the Board and organisation more accountable to service users. This involves not just taking time to explain complex matters but strength in numbers.

"I don't believe in tokenism in any way, shape or form. This organisation doesn't subscribe to that either. Having more that one service user representative was part of that approach and ensuring their presence throughout Board meetings." (Eve)

Ideas of coaching, mentoring or buddying from support staff were discussed:

"I am concerned that there is real engagement maybe it can never be achieved...but I just think it could go a step further...than it is at the moment." (Fred)

c.   Language used and accessibility

Ewan, a senior member of staff, expressed concerns that service users were still in an overall minority on the Board:

"The challenge...is [to] *ensure that the information that is shared with them is at a pace that they can...relate to...We might just need to talk a bit slower or plainer English and check that the service users understand what we are saying."* (Ewan)

Ewan admitted that other Board members may also need training to understand the needs of service users:

"Maybe we assume everybody will understand the needs of people with learning difficulties because that is the kind of organisation we are."
(Ewan)

Eric suggested a mentoring role or buddying system between Board members:

"It's a two way thing increasing understanding on both sides." (Eric)

Concerns about service users' understanding were raised by non-disabled Board members although there was an overwhelming agreement that the involvement of service users was both desirable and positive. The suggestion of simplified reports and accessible materials came from the senior executive team who displayed more practical knowledge regarding remedies for redressing any imbalance. This is understandable given that the senior staff are regularly engaged in day to day working with adults with learning difficulties. They are aware of the importance of accessibility in order to enhance understanding. In addition there are various tools and technologies available to support this, for example, Symbolwrite, Picture bank, Via Voice and Dragon Naturally Speaking. In addition staff are often involved in supporting service users at meetings external to the organisation which stress the necessity to avoid jargon and present reports in an easier to read or understand format.

Eve raised the issue of accessible minutes and written information, although all agreed that it was difficult to achieve in a consistent manner whilst ensuring compliance, for example, in terms of the translation of legal documents. The main obstacle was speed of discussion and taking time to understand issues. Pre-meetings were seen to be helpful in ensuring that tokenism could be avoided or at least reduced. This also allowed for time to be spent on agenda

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items. The recognition of the issues concerned helped to encourage further debate and allowed possible alternatives to be explored.

She noted that for service user Board members:

"Their confidence has blossomed since being involved...on the Board."

The service user representatives meet with the wider Forum of service users and regard themselves as its representation at Board level although they remain as individual Board members in their own right. Eric recognised the clarity amongst service users about their representation of issues from the wider Service User Forum.

"They are always interested or concerned that the content of the service user report gets delivered and we go through that and decide who wants to do which bit and work that out and....people keep ownership and that pleases people-gives people more motivation...they...see it is very important. They...are champions for the rest of the Service User Forum."
(Eric)

d.   Legal duties and the levels of competence and understanding

Larry raised the issue of legal liability for decisions taken under the Companies

Act 2006 and:

"Whether it was reasonable to assume that those Board members (with learning difficulties) were able to discharge those legal responsibilities..."

In another :

"organisation the agreement has been that Board members who were service users might become observers on the Board – welcomed, valued but not obliged to take the legal responsibility." (Larry)

Leslie queried whether this re-classified service users as consultants and advisors, but:

"we must make it clear that they are not there on our Board just for lip service...and we listen to their views." (Leslie)

The three long-standing Board Members in this group acknowledged the personal development and growing confidence of the service user Board members "developing potential" (Leslie) but Larry was concerned that:

"doesn't, of course, answer the problem about what to do if it is a situation where they are equally responsible for complex financial decisions which let's face it, they cannot possibly make."

Len pointed out that there was not a competency test *per se* for any Board member. As well as the understanding of complicated matters, for example, the presentation of accounts can be difficult,

"not simply for service users but for ourselves." (Len)

Leslie raised the issue of welfare or the overall duty of care. He recalled a separate meeting (of the local Partnership Board) when somebody with a learning difficulty became distressed and the meeting had to be adjourned:

"I can say categorically I have never sensed any stress or strain on our members...it does not matter that they are not getting 100% of exactly what is happening, nobody manages 100% concentration for a start. I consider that they (service users on the Board) *are important."* (Leslie)

Whilst serving as a Board member herself in 2007, Eve recalls a particularly difficult Board meeting which was discussing a serious employment matter.

"I remember getting really frustrated one day when somebody [another Board member] *said to me perhaps we need this conversation* [but] *not with service users present because they will not understand it."* (Eve)

She had addressed this issue by taking time to explain the complicated and confidential issue to service users.

"They did grasp the concept and did grasp the complexities of what was happening but it was the time factor of doing that and...it was putting my money where my mouth was really, demonstrating by example – this is how it should be done and this can be done...it is about transformational leadership and that is the appeal about the organisation...I think it also educated some of the Board members...I think...most people did change their viewpoint [about service users not being able to understand complicated matters and their significance]. (Eve)

This highlighted the key area of mental capacity, that is, the intellectual understanding of adults with learning difficulties of matters discussed at Board level. This raised the issue of being a Board member for Involve Housing Association and the implications of this in relation to company and charitable law in the wider setting that is the framework of charitable companies in England and Wales. There are specific legal duties in being a Board member in addition to the assumed liabilities inherent in the job description, although limited for the company in respect of any decision taken in good faith. In addition, for all Board Members there are issues relating to ethical standards, code of conduct and performance at a Board level. These apply equally to adults with learning difficulties and although their needs may be different this did not appear to detract from their rights and responsibilities as a full and active Board member.

e. Limited representation from the wider Service User Forum

One Board member queried their representation of others:

> *"Their contributions are useful and interesting, no doubt about that. I do worry a little about whether there are other service users...you whether we have a very restricted pool of people who are perhaps able to come onto the Board and whether there is a wider pool that we should occasionally be looking at."* (Len)

There is a clear mandate from the Service User Forum which meets regularly. It holds its own annual general meeting each year and reappoints the representatives to serve on the Board. This is not necessary in law as each Board member serves on a 5 year basis (which under the constitution can be renewed if the person agrees to stand and is re-elected). However it is ideologically significant as it reminds Service User Representatives that they are part of a wider Forum and that they represent other people, not just themselves.

In terms of opportunities for others to stand, this is always a possibility. However, there are few service users who are both 'active' committee people or have the ability to contribute without a substantial amount of support. This may not be impossible but it would considerably change the conduct and format of the Board meetings. Further, there is an argument for continuity of individual contribution by the existing Board members. All three have 'grown into' the role

and understand the inner workings of the organisation. This takes time for any Board member to develop. However the knowledge and expertise that has been developed is an essential element in ensuring that the service user voice is heard and included.

f.   Potential conflicts of interest and issues of confidentiality

(i)   Conflicts of interest

Conflicts of interest were discussed and Ewan felt that service users:

> *"Could sometimes be representing their own personal needs which might sometimes override the fact that are there to represent service users generally."*

Eric was quick to point out that Service User Representatives do declare their interest if it affects them directly. As an observer at the Board he had witnessed this on many occasions:

> *"If you were going for your own property you couldn't vote for it because you are declaring your interest to that item."* (Sid – service user)

When asked why this was an important thing to do, he stated:

> *"because they think you are wanting more than them."* (Sid)

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Other Board members clearly stated that they observed service user declarations of interest and these are recorded in the documents (minutes of meeting). Thus their interest is transparent and verifiable. Hence declarations of interest from service users were acknowledged and appreciated:

> *"And if this is the case there is no conflict of interest by definition."* (Larry)

(ii)   Confidentiality

In relation to the issue of confidentiality Ewan and Eric felt that this was a risk but:

> *"Service User Representatives tend to take it extremely seriously but they sometimes slip up – but everybody does that."* (Eric – staff member)

It was suggested that prompting or a reminder from the Chair at the end of each meeting may ensure that people kept confidential business as confidential outside the meeting. This would apply equally to all Board members not just those with learning difficulties. Issues of confidentiality were discussed and understood:

> *"If it is something that is really private and confidential you have to be careful what you say...you just treat that person as I would be treated myself."* (Sarah)

The Service User Forum has developed its own ground rules for meetings. The most important one is "What is said in this room stays in this room". This has helped the Forum discuss matters affecting individual members which may include personal matters or indeed staff employed to support them. Adults with learning difficulties may over-disclose their personal details partly out of dis-inhibition but sometimes due to a lack of understanding regarding the official protocol or procedure, for example, of making a complaint. The experienced tenant participation member of staff who is present at the Forum meetings is able to clarify procedures or refer matters elsewhere if needed. There is a tension between maintaining confidentiality and ensuring that matters of safeguarding, whistleblowing or health and safety are managed appropriately. This is a tension which exists elsewhere in social work and is not particular to the area of learning difficulties.

4. Future challenges or opportunities until 2014

The four sets of interviews indicated a range of challenges and opportunities over the next few years. I have collated them as follows:

- Internal strengthening of the organisation
- Proposed areas of development
- Working in partnership (with external voluntary organisations)
- The Personalisation agenda

1.   **Internal strengthening of the organisation**

- Getting more people involved in the Service User Forum

- Succession plan for Board members considering in particular the age, skill mix

- Succession plan for senior management. Frank highlighted my role as the Executive Officer.

  "I think...an important role that you have played is not only managing but also in developing ideas and bringing to the Board visions about what we are doing, the direction we are moving in and since the outset this constant issue of the Board has been about releasing you from day to day repetitive grind issues to take more time on development work." (Frank)

Succession planning can take time not simply in terms of recruitment but in building up the knowledge of the inner workings of the organisation following the loss of key people and organisational memory.

"Replacement is going to be a major problem and we are going to have to think very carefully about how we go about planning for it." (Fred)

- Strengthening the internal management structure. At the time of the interviews in (2010) three posts of Assistant Director had been created. Larry referred to how the new operational role of the three Assistant Directors would impact on the development of the

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organisation in terms of operational matters and future succession
planning.

> *"In a young-newly established...organisation it is natural to rely on*
> *the central figure but as the organisation develops and grows then*
> *more people become involved...and it is a good thing we have the*
> *opportunity to meet and listen to that whole group of people."*

(Larry)

- Planning more away days in order to develop the business strategy
  for the organisation. In particular this would involve internal
  stakeholders, that is, staff and service users from across the
  organisation.

- More in-house training especially for service users. This was
  requested by the Service User representatives who have benefitted
  from the extensive training offered by the organisation. In particular,
  Involve Speak-Up (confidence building), INDEVA (pre-employment
  training) and INACT (training the trainers).

- More staff training. This was highlighted by the executive team and in
  a sense is outside the area of research. The interview timetable was
  2010 but the area of research covered the period up to 2007. The
  executive team mentioned the integration of former National Health
  Service staff into the organisation. Although this happened in October
  2009, it was discussed for five years before and therefore forms part
  of the research period. The need for Values training formed a
  substantial part of the discussion pre- transfer. The integration and
  embedding of the 182 former National Health Service staff post-

transfer is ongoing (and post the research period). However, there was general agreement for more staff training concerning change management (for example, in respect of the personalisation agenda).

- Selling training as a way of promoting the organisation and generating additional income.

2. Proposed areas of development

- More individualised day activities.

- Offering real employment opportunities to adults with learning difficulties (that is, not just training which whilst important may be linked to pre-employment).

- Developing respite care or short breaks

- More services for young people in transition from school to adult services (the next generation of service users).

- More apprenticeships for young people (the next generation of carers).

- More social work training (the next generation of social care managers)

- Information and advice for carers (for example, in relation to welfare rights and housing options).

- More publicity and promotion of the organisation including the use of presentations, video diaries, personal stories and talking to schools about the organisation.

- Use and recruitment of volunteers particularly in the light of government policy (at the time of the interviews, notions of the 'Big Society' were topical. This may have prompted this topic).

  "We need to be more aware of where potential support is coming from in the future." (Frank)

- Maintaining the pooled mobility transport offered by the organisation. This provides 110 vehicles for use by all the service users and is funded by an individual's contribution of the mobility component of Disability Living Allowance (DLA). Over the years this has ensured transport for everyone regardless of where they live or their individual contribution. At the time of writing this was under threat. During the interview stage, Frank had stressed the importance of maintaining the service as:

  "It's much better to operate a collective system and the cost of operating outside of a collective system would be prohibitive for many individuals." (Frank)

- More services to meet the needs of older people with learning difficulties. In particular, dementia care given the general increase in this area as well as the predisposition of some adults with learning difficulties to pre-senile dementia.

- Specific services for parents who themselves have learning difficulties.

3.   **Working in partnership**

- Working with other like-minded voluntary organisations (for example, housing associations). However , Eric stressed the need for Enable to remain independent :

    "We have always had a kind of wariness when we sign up with different people. I think we always need to...keep that streak of independence...that is worth preserving." (Eric)

- Working with other training providers

- Working with general health providers particularly at the primary and secondary level not just learning difficulty specialists.

- Working with advocacy groups in the area. Ewan highlighted the need to work with more service users led organisations.

- Working with families and carers:

    "to make them aware that change is afoot." (Fred)

- Working with local authorities and other housing providers to ensure access to affordable housing. This was particularly related to planning for future developments and the shortage of housing especially in rural areas.

4.   **Personalisation**

The 2008 Health and Social Care Act 'Putting People First' promoted the increased use of personal budgets in order for people to purchase self-directed support. This change in the funding, but more importantly the control of social

care is significant. It was promoted by the last government and since May 2010 there has been a substantial change in the overall policy. In particular, the reassessment of people requiring support has led to some people not receiving enough funding to purchase their own care or indeed any funding at all due to the increased threshold for receiving support. The financial reductions in local authority budgets have compounded this. Although these events are post the research period, I have outlined them here in order to place the personalisation agenda in its current context. Questions were asked about the future (up to 2014). Therefore, the interviews noted the impact of personalisation and in particular whether there would be enough money to meet identified needs.

> *"The ideas of personalisation are so obviously right and in accordance with everything this organisation stands for...Yet one knows perfectly well...that the simple basic question about whether there will be in fact enough money to pay for that are enormous worries and so personalisation is the challenge not only for the future but for the present"*
> (Larry)

Len queried whether the infrastructure of Involve could cope with the increased financial complexity of personalisation. This led to the exploration of formal partnership in relation to other organisations as part of a larger group structure. This could potentially offer a larger infrastructure and some economies of scale in relation to backroom functions, for example, finance and human resources.

> *"Perhaps it is a question that is still there and something which we ought*

to be thinking about." (Larry)

"Personalisation is a new buzz word but I think we have a lot of these elements and have done for a number of years involving service users in recruitment isn't new." (Ewan)

"Given the current political climate...shackled by thoughts that you can't do anything...and it stops that innovation...I don't think as an organisation we will stop being innovative." (Eve)

Eve did however raise a concern about personalisation in registered care homes, given the block contract funding and the requirements of regulators, for example, the Care Quality Commission. Ewan stressed the importance of training staff to understand the issues raised by the personalisation agenda. This was understandable in terms of his role as Chair of the Training Committee but also as the lead practitioner for social work training within the organisation.

"One of the biggest challenges is going to be working positively with the staff to ensure we can make [the] change."

Despite the challenges ahead, the respondents remained optimistic. This was particularly noticeable in relation to the senior staff who were interviewed.

"Involve has always been flexible and adaptable...If anybody is going to do it Involve...will." (Eric)

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"Involve has always been ahead of the game when it comes to changes – philosophy...the history of Involve has put us in a right good position for the future." (Eve)

"Our mission statement 'Putting People First'...is seen as a new term but we have been using it for...20 years..." (Ewan)

The four groups identified similar issues although significantly only the service user representatives mentioned the need to get more people involved in the Service User Forum. They indicated that they wanted to include more people who accessed only part of Involve's service, for example, day activities (not just tenants or residents). This showed great insight into the range of activities and the equal value of people using the range of services. It links into the personalisation agenda above as this would allow people to choose from a range of services including different providers, as well as the case in question.

Having described the data collected as part of the research, I want now to explore the significance of this. Chapter 5 discusses the broad themes generated by the data.

Chapter 5

Discussion: Themes from the Research

Introduction

The data relates to the period 1997-2007 but is set in the broad historical and socio-political context of health and social care post 1971 and its relationship with adults with a learning difficulty. This chapter generates five broad themes from the findings identified in Chapters 3 and 4. The themes are drawn from both sets of data.

Namely:

- Telling the story of the organisation.

- Effective pragmatism.

- The practical impact of the collective board.

- Embedded value base.

- Future implications (up to 2014).

The research concerns the period surrounding the move from hospital to community living. In telling the story of the organisation in question the importance of opportunism, effective pragmatism and adapting to being part of a wider national context are explored. Alongside this the practical and interactive governance involving service users as equal participants is

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discussed and related to Braye's (2000) checklist , as well as the roles of significant others in the overall picture.

1.   **Telling the story of the organisation**

(a)   **De-institutionalisation**

The story of the organisation is one of dynamism and a changing emphasis from institutional to community based models of care over time.   This is evidenced by the data. During the research period 1997-2007 there was a definite move away from the registered care model which had been the preferred model of community care funding pre-1993, with registered care beds reduced by one third.

This was in line with the changing emphasis of community care from care homes to supported living as well as promoted by the introduction of care management and 'spot' contracting following the full implementation of the NHS and Community Care Act (1990) post-1993 and the rise of commissioning. (Shepherd, 1995)

In theory, 'spot' (or individual) contracting allowed for more innovation, choice and control but was still managed by the local authority. Nevertheless, the combination of housing benefit, community care funding, the Independent Living Fund and from 2003, Supporting People funding, actively encouraged innovation and access to alternative funding streams. During the research period there was certainly a wider movement nationally which encouraged the

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development of alternatives in community living. This included the rise of the People First movement and an emphasis on the hospital population of adults with learning difficulties leading to a new White Paper, Valuing People (2001).

However, the development of a range of options described in the findings predates the concentration on tenancies and home ownership advocated by Valuing People (2001). Indeed by that time, Involve Housing Association supported 176 tenants, mostly adults with learning difficulties. Several tenants had been supported to become home owners, which was at that time extremely rare for adults with learning difficulties. The documentary analysis illustrates the specific concentration of resources and working in partnership with others (particularly other progressive voluntary organisations and housing providers) in order to achieve meaningful solutions for service users and their families.

This was partly driven by knowledge of housing options but more significantly, by requests from service users and their families. The eventual closure of the hospital in 1996 meant that alternatives had to be developed. The option of moving into or indeed back into the institution had been removed. As the organisation had been operational for at least six years by this time, it was possible to re-invest its annual surpluses into community based alternatives. Funding was a key driver but the availability of an organisational structure which was ideologically committed to community living was also important, in terms of responding to individual need.

The move out of the institution also prompted the need to develop alternative

day care. As hospital patients, the residents had not accessed day activities

outside the institution. Once discharged and dispersed to smaller homes, they

needed meaningful activities during the day in order to maintain friendship

networks. This development was a consequence of de-institutionalised

thinking, a commitment to making a difference in people's lives, but it was also

driven by the fact that access to local authority day care was unavailable to the

vast majority of former patients who were seen as the responsibility of the

health authority rather than social services. The organisation developed its own

alternatives partly in response to this barrier. Arguably, the 'new' day services

at that time still involved segregated activity based on people of similar needs

being brought together in an intentional way. However, the model was located

in the local community rather than all in one place as identified by care villages

or intentional communities (Collins, 2000). The findings show a move from

separate to more integrated services over the research period, notably the

move from a separate 'buildings based' service to the use of a room in a local

community centre as a hub or drop-in facility.

(b) **Strengthening the organisation**

Over the period 1997-2007 the documents plot a steady growth in terms of the

organisation. This was not only in terms of annual turnover as a result of

increased activity but in terms of a changing structure in order to improve

service delivery.

In 1997, the annual turnover was £4.4 million: this had increased in 2007 to

£10.1 million.

This was largely due to two factors:

(i)   The 'merger' with the care charity in 2002 which increased turnover and brought the housing and care functions together in an holistic way being two sides of the same coin in terms of integrated community care.

(ii)   Increased business due to 'spot' contracts, new developments in another shire county, expansion into day activities and the opportunity to increase rental income with the introduction of the Supporting People (SP) regime in April 2003. In the financial year 2003/2004 Involve Housing Association was the largest SP provider in the county and received £1.3 million in 'new' income. This allowed for some re-investment and growth.

In addition, the new group structure in 2003 led to the creation of a joint Chief Executive Officer post and subsequently a new operational management team. Changes also occurred in respect of governance and the strengthening of service user involvement at Board level from one representative to three by the end of 2003. Their influence on the Board led to further developments post 2003 which are reported in Chapters 3 and 4. This further strengthened the organisation, for example, the service user voice became louder by involving more people. This was recognised by external bodies. For example, in terms of Supporting People, a top rating in outcomes monitoring was achieved for service user involvement. However, the potentially negative impact of tokenism will be discussed later in this chapter.

(c)   **Increasing specialisation**

2003 was in effect a watershed year for the organisation. The decision to withdraw from certain client groups, for example, young homeless people, was taken as a consequence of national changes in funding introduced as Supporting People. The documents illustrate this change which was discussed at Board level, and prompted by the negative experiences of tenant Board members in terms of bullying and so-called 'mate' crime. One direct experience (which was discussed at length at Board level) led to a collective decision to withdraw from the young homelessness projects Involve Housing Association had managed up until that time. The introduction of Supporting People and the review of existing stock allowed for this to be implemented quickly and without a loss of service to young people. The projects (and buildings) were transferred to another provider who concentrated solely on providing services to homeless young people.

Transfers of responsibility to other providers led to an initial loss of income but the resultant increased concentration on adults with learning difficulties led to an overall specialisation within the organisation. Parallel withdrawal from other areas of activity highlighted in Table 3.6 further enhanced this specialisation.

There is a wider debate in social work concerning generic versus specialist services delivery (Seebohm, 1968). As a voluntary organisation not directly affected by statutory re-organisation, the decision to concentrate exclusively on one client group was regarded by Board members to be both positive and

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deliberate. It further increased the service user voice and their 'expertise by experience' was valued as part of the overall raison d'être of the organisation.

During the research period (1997-2007) there were parallel specialist, multi-disciplinary learning difficulty teams operating within the local health and social care environment. Gradually these developed into commissioning agencies. As a provider agency, Involve Housing Association offered complementary, yet essential, services including housing, care, support, registered care and day activities. The emphasis on people with learning difficulties allowed for an holistic approach to person centred planning (Sanderson, 2006) as well as the consolidation and development of knowledge about service delivery to and for that particular client group. This helped to develop a strong information base which further reinforced and developed the specialist expertise within the organisation. The influence of learning from each other will be explored later.

Finally, the concentration allowed all the surpluses generated each year to be spent exclusively on services for adults with learning disabilities, emphasising this specialism and expanding the scope of the organisation as well as investing heavily into the local infrastructure. The data shows examples of investment into new and often innovative services. This apparent golden era of investment will be discussed later in relation to the future direction of services for adults with learning difficulties within health and social care.

2. Effective Pragmatism

(a) 'Being in the right place at the right time'

The organisational structure enabled the transfer of funding and staffing under section 23(b) of NHS Act (1977). This had already been utilised in the earlier hospital discharge programme. In 1993, the implementation of the NHS & Community Care Act (1990) allowed for grants to be given to voluntary organisations over a limited period.[2] Being 'available' as well as 'ready and able' and fit for purpose allowed for the injection of over £400,000 of capital funding to facilitate the closure of a 20 bed hostel for adults with learning difficulties. The availability of funds, the structure of the organisation plus the willingness of the Board to engage involved a serendipitous opportunity to expand the business and meet particular needs. Three properties were purchased and ten people with learning difficulties were re-housed. The opportunity was an unanticipated consequence of the organisation's development: an example of organic or ad hoc development as it had not been predicted or part of the overall business plan. Rather it was based on a commitment to continuous improvement and taking advantage of an opportunity. This is often the experience of voluntary organisations which have developed in response to unmet need, gaps in provision or seizing opportunity. Their flexible structures allow for adaptability and innovation which, once a need is proven can be a precursor to mainstream funding and development. This 'can do' approach is often the essence of not for profit organisations not impeded by bureaucratic structures or cultural inertia (Osborne, 1998) and

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[2] Special Transitional Grant was introduced by central government to promote the implementation of the NHS Community Care Act (1990)

(Chew & Lyon, 2012). The findings clearly show that this was evident in the case study.

(b)   Seizing opportunity: an example of community based day care (Appendix 8)

Hargreaves (2001) refers to examples of creative or "blue sky" thinking. This innovation in day activities was recognised by all the interviewees as well as the wider service user and carer forums. When service users with learning difficulties leave children's services, day services are often their first experience of adult social care as day activities offer a degree of respite to adult carers. Developing alternatives in partnership with service users has not only strengthened the organisation but has also delivered tangible examples of innovation and new development. The day services environment can offer service users the opportunity to develop their own ideas and for example, run their own meetings (often with staff support). This can be a new and exciting experience for service users. Earlier day services offered by the organisation were more protective and offered a safe space for people to meet. This was seen as a 'stepping stone' to more community based models which were developed during the research period 1997-2007. For example, the opening of the sandwich shop offered an opportunity to offer a service to a local community but it also exposed service users to potential risks based on negative community attitudes to adults with learning difficulties. This challenged the organisation to assess risk in a positive way whilst maintaining necessary support to ensure the maximum benefit to service users. These risks were

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openly discussed at both the Service User Forum and at Board level as part of a philosophy committed to improved participatory power. For example, training courses in learning difficulty awareness were devised and contact was made with the local school to challenge prejudice based on ignorance. This led to an improved situation in the community as well as an increase in the self esteem of the service users involved.

Similarly, the funding for care and support was further aided by the introduction of direct payments following the Direct Payments Act (1996) which in itself was a precursor to the more recent emphasis on personalisation (Putting People First 2008). This enabled support to be provided in a more person-centred way allowing for the individual to develop new skills, vary his or her role and increase their contribution.

(c)   **Adapting to change at both a local and national level**

Throughout the research period, national changes were taking place in health and social care. (Health Act 1999) In particular, the move from health authorities to primary care trusts (PCTs), and from block grants to spot contracts, and an increasing differentiation between commissioners (usually PCTs or Local Authorities) and providers. Underlying this, provision for adult social care was largely the domain of the private sector which in turn was divided into the profit and non-profit (usually known as the voluntary or third) sectors.

The findings of interviews with Board members highlighted the organisation's flexibility, responsiveness, commitment and development of creative solutions in partnership with service user representatives.

3.   Managing the Organisation

a)   The overall impact of the Collective Board

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The term "Board" or management committee has been used throughout to mean the organisation's governing body. It is the body with overall responsibility for governing the organisation, overseeing and controlling its management. The legal structure may be a company (limited by guarantee), which may also be a charity or an industrial and provident society. Its governance structure or the rules of engagement will be sent out in a rule book or memorandum and articles. The structure will be externally monitored by Companies House, the Charity Commission, the Registrar of Friendly Societies (or combination).

Ideally Boards of management provide leadership through six key principles identified in Chapter 1. I have devised a framework describing the board based on eight C's namely clarity, composition, commitment, continuity, co-production, culture, communication and consumerism.

(i)   Clarity of Purpose

Frank, as a political activist but also a founder member, was clear about the

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necessary split in function between Board and employed staff. He acknowledged the inherent difficulties in managing 'industrial relations' but was clear about the necessity of satisfying the external critic and being open to scrutiny in all aspects of service delivery. *"It was very difficult for us and the support issue was to insist on the independence of an assessment.....it was not an abandonment of responsibility.....it's a taking of responsibility because board members don't have an economic stake...they are there in a policy making sense."* (Frank). Within the organisational structure there is a clear separation of executive (operational) from the Board (strategic) function. This is seen as important in terms of managerial relationships and running the overall business.

In 2005, a Finance and Strategy sub-committee was created in order to separate some of the day to day operational details relating to finance and other strategic matters from the wider Board. Although items would need to be approved at Board level it could be argued that this is 'rubber stamping' or approving a certain direction after a decision has been taken in principle. Frank clarified the non-involvement of service users on the Finance and Strategy Sub-Committee as this could lead to a potential conflict of interest. As direct beneficiaries of potential services it was deemed better to separate some of the detailed matters concerning staffing and finance from the overall strategic intention of the Board.

(ii)   Composition of the Board

All the non-disabled Board members who were interviewed were white, retired

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males. Their average age is 72. This reflects the demography of the geographical area in question. Being retired from work allows them time to focus on the voluntary organisation which might not be easy for Board members who are in employment. The service user Board members were all younger adults, that is pre-retirement age but none were in paid employment. This is typical of the profile of voluntary board members outlined in a recent report by the Charity Commission (2010). There are women serving on the Board but with the exception of one former member (who could not be interviewed due to illness) they have been appointed since the period covered in this study. Fred noted that the non-disabled Board members came from a similar background which concurs with the national survey on volunteers (2008).

(iii)   **Commitment of Board Members**

The combination of age and experience (referred to as "age and sage" by Leslie) allows for people to give their time in a positive and meaningful way. Meetings are held during the daytime: this helps to meet the needs of carer representatives in particular who may not have been able to meet after the working day due to lack of, for example, day care support for their son or daughter.

Commitment of time to attend regular Board meetings and sub-committees is a strong feature of voluntary Board members who give their time freely (only out of pocket expenses are claimed). There is a national debate about payment for Board members and some housing associations pay approximately £5,000 per

year to each member with added allowances for special responsibilities. This has never been proposed for the organisation and it could be a particular challenge in relation to an individual's welfare benefit status whether as a service user or retired person. People who are employed, however, are already being paid by a third party and therefore payment as a Board member is not an issue. The individual commitment to attend meetings was acknowledged in the interviews. Overall participants felt committed, valued and engaged. For example, Larry remarked that he enjoyed the debates so much – it was well worth getting three buses to attend meetings!

Frank stated that there was no economic investment as Board members, although there were other levels of emotional, ideological and intellectual commitment. Arguably, this is not the case for service user Board members. Their housing or care and support may be potentially at risk, mainly due to external factors for example, reductions in contract funding or changes in housing benefit. The economic impact on their lives would therefore be profound and direct. This would appear to confirm the view that service users do have an economic stake in decisions taken. There is a definite tension between the rhetoric and reality. The impact on service users lives is more directly affected although arguably this can be mitigated by their voice being heard at Board level: their direct experience is crucial to other Board members' wider educational understanding. In terms of human dynamics it is harder to ignore someone's views if they are present than if matters are discussed elsewhere and without effective participation. It also allows for 'group think' in relation to the identification of areas of concern or improvement: the opportunity

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to generate solutions to problems.

Some Board members had an intellectual or reified understanding of the lived experience of service users whilst others, particularly service users themselves or carers, had a more direct or personal insight. For example, Leslie, as a carer of a daughter with learning difficulties, understood the need for supported housing and became involved in the organisation 15 years before his daughter became a tenant. He was involved as a concerned individual and interested in the 'common good' not just his own 'personal gain'. This was described earlier in relation to service users.

All the Board members – including service users – mentioned being involved to 'make a difference' or 'give something back'. This example of philanthropy underlies the composition of many charitable boards in the United Kingdom. It has two facets. First it is part of the value base of the third sector or not for profit organisations and second it is part of an individual board member's motivation to be involved in the first place. The two facets reinforce each other. Individual motivation is often a product of upbringing (as in Fred's case), educational experience (as in Len's case) and political belief (as in Frank's case) or lived experience generally (as in Sid's, Sam's and Sarah's case). The last three are 'experts by experience', whereas other Board members are involved due to an intellectual interpretation and awareness of the lives of service users together with a desire to change the status quo in relation to service delivery. For example, Frank said he became involved from his housing background 'without bricks and mortar (community care) does not work'. Conversely, the lack of

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transferrable experience could be a barrier to the involvement of people employed in unrelated activities.

(iv)   Continuity of Board Members

At the time of the interview the eight non-disabled Board members had collectively, 85 years of service (taking account of the years 1991-2007). This may be rare in other organisations depending on the demography and turnover of trustees which is often enshrined in the governing rules, if there is a fixed term for Board membership. The organisation's rules allow for re-appointment subject to rolling reappointment and there is no overall fixed term. This was designed to ensure that service users did not have to stand down when they had acquired a level of engagement and knowledge at Board level.

The composition of the Board has remained fairly constant over the years. In general this can be seen as a strength rather than a perceived weakness. It provides continuity of input which is consistent and builds on the knowledge, skills and experience which comprises the Board as a whole. Rapid turnover could lead to a loss of organisational memory which can in turn have a negative impact on organisations. It can lead to delayed decision making, poor planning and weak direction.

It can take time to understand the complexities of voluntary organisations, given the increasing professionalism and managerial shift in order to meet external regulation. A multi-million pound turnover means it is not possible to have a

part-time (or even volunteer) treasurer, as it was in the early days of the organisation. Since 1996 there has been a finance team of three qualified accountants and support staff to manage the day to day transactions, serving 350 service users and 650 staff and to meet external audit requirements. There are, however, potentially some negative effects of continuity. First there are problems of self-perpetuating 'cliques' which can be intimidating for new Board members. Being strong as a group can lead to a feeling of being an outsider for new members. Second, it can limit new ideas. There can be a tendency to avoid new ventures as 'it has been tried before', for example, following the negative experience of working with young homeless people and trying to provide integrated housing, the Board has been reluctant to work in partnership with other organisations with a diverse client group. Third, while a strong board with years of collective knowledge may be stabilising, it can easily be de-stabilised by for example, the sudden death of the Chairman in 2007. Succession planning is an ongoing debate at Board level. However, on balance, the research participants stated that continuity was a positive influence at Board level.

(iv)   **Co-Production: Working as a Board**

Overall Tyson (2011) urges the recognition of innovation from passionate and committed organisations who have striven to put people they support in control of their lives. The blend of Board members and the element of co-production between service users and allies and supporters has resulted in practical examples of creativity, for example, innovation in day activities or the purchase

of individual properties.

Within the organisation an alliance was developed between disabled and non-disabled people working together with a common value base and sense of purpose. User-led organisations are defined as those where service users are in the majority on the governance structure. They tend to involve people with physical (rather than learning) disabilities. However, Gross (2011) notes the low participation rate of disabled people on Boards. This may be due to other factors, for example, disabled people working elsewhere (often as consultants doing disability equality training), or be due to societal restrictions caused by the nature of the disability. This is even more noticeable in the involvement of adults with learning difficulties. The organisation is clearly not user-led but the degree of user-influence is strong. For example, service users are not in a majority on the Board but, arguably, their influence and impact has been great. This is illustrated by the examples of user-influenced or user-initiated services. It is vital to the essential philosophy of doing things with people rather than doing things for people.

The interaction of the two distinct groups at Board level is regarded as beneficial and based on mutual respect not tokenism. The non-disabled Board members understood the meaning behind the question of service user involvement and its contribution to the Board. To them, their input was invaluable and kept the focus sharp. Indeed it was the raison d'être for their being involved. However, the service user representatives could not grasp the implicit meaning behind the question, stating "they give us a chance" after a

considerable pause to think about the question. They were not aware of any barriers to their involvement and did not suggest any practical or reasonable adjustments to improve their engagement. They appeared to be satisfied with their contribution at Board level, although this could be due to a limited understanding of the particular question or its reason for being asked.

Although there was an overwhelming agreement that their involvement was both desirable and positive concerns about service users' understanding were raised by non-disabled Board members. The increase in numbers was regarded as a positive move both in terms of avoiding tokenism and allowing for different perspectives to be raised. The quality of debates regarding health and social care at Board level were recognised by non-disabled Board members and in particular, the vital contribution of service user input at Board level was acknowledged as one of 'lived' experience. There was concern raised by Len about whether other service user representatives (from the wider service user group) should be sought. How feasible this would be is debatable given the increasing emphasis on services for people who achieve a care assessment at "substantial" or "critical" and who would, by this definition, be less able to participate at a board level due to perhaps limited verbal communication. As there is a need to avoid acquiescence and tokenism described earlier (Finlay and Lyons, 2002), these factors indicate that there will be a limited pool of potential service users who could serve as Board members in future. This has been an important element in determining the future succession strategy for the Board.

Non-disabled Board members tended to mention development which affected the structure of the organisation or the staff as a whole. For example, Len described the computerised finance system being *"worth its weight in gold"* (he is also the treasurer so financial matters are his priority concern). Larry mentioned the move to the new headquarters which has brought the staff teams together. In his view this has helped to improve communication between staff.

All shared a discrete sense of value in the development in alternative day services. Experiencing the difference in day services from the more traditional services on offer elsewhere appeared to be a positive element in defining significance and positive impact on service users' lives. Service users, in particular, expressed the value in terms of maintaining friendships and having a more exciting experience. As discussed earlier developments in day services were initiated directly by service users (or their carers defined as secondary service users). Their success in terms of more positive alternatives to traditional day care and service user involvement (often as instigators of the new service) was acknowledged by all the Board members. It is the case that Board members have had more exposure to the available day services than to the accommodation based services. Clearly service users have participated and Board meetings have sometimes been held at day centres, allowing other Board members to see the service in action. This could explain their enthusiasm for day services as they are less likely to have visited the accommodation based services as the organisation does not encourage 'official openings' and intrusion into people's personal space as this would be an invasion of their privacy.

(vi)   Culture

This relates to the overall value base which is encapsulated at both the strategic or board level and the operational or management level of the organisation. The culture of the board assumes equality of opportunity and access for all its members, based on mutual respect.

At every level of activity and decision making within the Board it is assumed that service user representatives have the necessary individual mental capacity to participate fully. They are equal members. However, issues of legal liability were raised by one of the non-disabled Board members. Larry wondered whether service users properly understood their responsibilities and questioned their ability within company law. However, there is no "test" for directors of any company, other than one of solvency and not having been in custody for criminal activity. Codes of Practice presume that directors will always act in a legal and ethical manner (Part 10 of Companies Act, 2006).

In reality, within limited liability, directors are protected as long as decisions are taken in 'good faith'. With the legal parameters clarified, I would suggest that any issues at Board level would be more to do with conduct (including breaches of confidentiality), unethical behaviour or the avoidance of conflicts of interest.

In summary, the implications for service users with learning difficulties being "on board" are different but equal to other board members' liability. The particularisation of this issue is embedded in the overall functioning and value

base of the organisation as a whole which will be discussed below.

(vii) **Communication**

Previously, I have referred to communication matters. The conversational style of interview allowed service users to discuss matters freely. There did not appear to be a sense of repetition or acquiescence referred to earlier. Each example given was one of verifiable fact and had clearly had an impact on each individual's life experience. During the interviews there was a palpable sense of pride and achievement amongst service users both in terms of their own personal growth and development and through obtaining certification for certain courses, for example, food handling or first aid. The recognition that service users had not formally obtained any form of educational qualification before must be acknowledged. There was also a sense of belonging: of being part of a family including other Board members and staff as well as the wider service user community. Anecdotal stories or examples of relevance to service users are communicated at Board level against the ground rules of 'what is said in the room stays in the room'. This again reinforces the internal culture of the organisation of which they are a part: a culture based on mutual trust and respect and honest communication.

In terms of written communication, the service user representatives produce their own report for each Board meeting (with paid support) and read it out aloud at the Board meeting. This has proved to be powerful. The requests from the Service User Forum are clearly stated in writing (and therefore a

matter of record): reading out loud reinforces the key item. While some of the non-disabled Board members queried the necessity to read aloud and found this a source of embarrassment (to themselves), it has improved the confidence and literacy of the service user representatives. This experience appears to allow service users to redefine the boundaries of the essential communication: it redresses the overt power relationships by slowing down the discussion process. The dialogue is different as it involves active listening and a particular presentation style.

The participation of service users at Board level together with active listening has led to positive outcomes. Whilst not user- led, there is user-influence on the direction of new services, for example, in day activities. The concept of independent living goes beyond housing and social care: its development puts service users at the heart of influencing decisions in the sense that without their invaluable contribution based on a need-led approach, new services would not have been instigated. The generation of surplus which is in turn re-invested into the business allows for service users at Board level to influence the overall business plan. It is not only a process of **em**powerment but one of **ec**powerment (Salisbury 1991) whereby economic decisions regarding investment are made by service users thereby conferring both power and control by targeting resources based on identified need. Essentially this makes a positive difference to the lives of service users and gives them a sense of purpose.

(viii) **Consumerism**

The specialisation (concentrating on learning difficulties) and move to community living were largely encouraged by the increased emphasis on service user involvement. The ideological reasons for this will be explored below.

This structure and overall context of the case study was built around the practice of tenant participation and their active involvement. Initially there was only one service user (tenant) representative, 1998-2003. With the advent of the Supporting People programme and following a residential workshop involving some tenants and Board members in 2003, the Board invited a total of three service user representatives to serve on its committee. The documents show that this was a deliberate decision initiated by the Chairperson and ratified at Board level. Thus listening to the service user or consumer voice was a proven part of the ethos and structure of the organisation.

Earlier service user involvement is also evident. However, this was largely carer involvement and generally it is acknowledged that carers and their sons and daughters may have differing perspectives in relation to their view of the world and approach to, for example, risk (Styring, 2003). I prefer to acknowledge the different knowledge and skills service users and their families can bring to the discussion whilst also stressing that service users (or adults with learning difficulties) are 'primary' and their carers are 'secondary' consumers. Overall carer involvement in the organisation has been at an individual rather than

collective level. This can be due to lack of time (caring duties by definition restrict availability) or lack of experience in terms of being involved in group activity (many carers report feeling isolated or overburdened by their caring responsibilities and may be unused to meeting together).

Conversely, the service user forum has blossomed within the organisation. It has enabled service users to meet together socially and share experiences, leading to less isolation and the development of friendship networks. This has been supported and actively promoted by the organisation which has invested in necessary paid support staff, transport, hire of venues, funding and training. There is a wider and current debate concerning 'paid support' and 'artificial friendships' (Duffy, 2006). However, the identification with the Involve 'brand' is a key theme reinforcing both customer satisfaction and a sense of belonging which was evident from the interviews with service users.

(b)   The Role of Significant Others

Although there is a sense in which everyone has a role to play in the overall running of the organisation, there are particular roles or individuals who contribute in a more significant way. Goffman (1959) uses the term 'significant others' in his phenomenological analysis of key actors in everyday life.

(i)   Fred

The Chair of the Board (as an instigator and catalyst for the setting up of the

organisation in 1990) is fundamental. In 1988, a former Assistant Director of

Development in Social Services, appointed me to the role of Principal

Development Officer (Mental Handicap). Fred was the lynchpin in terms of the

intricate partnership between Health and Social Services. His charismatic

personality, knowledge of both services and positive working relationships with

colleagues was critical in 'making things happen'. He negotiated political

access to the Leader of the Council in order to ensure that the creation of the

separate legal entity was supported at this key level. To ensure political support

he suggested that the original subscribers to the charitable company were the

Chair and Vice Chair of the Social Services Committee. When he took early

retirement, he himself joined the trustees. His knowledge and expertise proved

invaluable and he still continues to be actively involved over 20 years later. His

passion and vision as well as his obvious caring approach is ingrained into the

overall value base. He is respected and was acknowledged by the other Board

members in the research. In terms of stability, turnover in the membership of

management committees can be negative or detrimental: in the case of Involve

Housing Association, the continued presence of a strong and effective leader

has been a great strength.

(ii)   **Frank**

The Vice Chair was also a founder member. His background as a District

Councillor serving on the local authority housing committee as well as his strong

political understanding has been beneficial to the development of the

organisation. His previous career as the local co-ordinator of the Workers

Educational Association (WEA) and extra-mural provision on behalf of a university has been critical in terms of his approach to being on the Board. He has regarded the board meetings as part of a lifelong educational journey for everyone involved, not just the service user representatives.

(iii)   **Service User Board Members**

Though clearly individual representatives, I refer to them collectively as this is their own perceived identity as Board members. They see themselves as mandated by the service user forum and accountable to this group which meets monthly. This consists of over 40 regular attendees, largely from supported living and day services rather than registered care. This reflects both their ability and historical factors. Most adults with learning difficulties in registered care are now elderly (having left the hospital over 20 years ago). Emerson & Hatton (2008) noted that people with more severe learning disabilities were more likely to live in registered care homes. In addition the culture of the staff who support them is not always aligned to the value base of the larger population within the organisation. There is a resistance to change or trying new things and reluctance to engage in, for example, external meetings. This is changing over time largely due to training, the fact that registered care is an increasingly smaller part of the organisation and the recruitment of dually qualified nursing and social work staff who are trained more recently and have a commitment to integrated approaches to health and social care.

Service user involvement at Board level has been vital to the development of

the organisation. First, increasing from one to three representatives in 2003 helped to create a lobby or interest group on the Board. It avoided the isolation that one service user could experience and was a genuine attempt to avoid tokenism ('the constant threat' noted by one of the founder Board members during the interviews). Sid had been the lone voice on the board and because of his involvement in other advocacy projects he had been asked to join several other committees both local and national. This had led to him feeling somewhat 'overloaded' and requiring additional support.

Second, the ways in which they are involved is a significant factor. In order to serve on the Board it is necessary to be in receipt of services from the organisation. This acknowledges the consumer dimension as well as the individual's knowledge, contribution or 'expertise by experience'. Individually and collectively, the service user Board members are able to speak about their own experiences as a vital part of the organisation as well as views of other service users. Monthly meetings of the Service User Forum allow for the ideas to be discussed. Pre-meetings take place before the Board and there is a specific agenda item from service users. This is not designed to prevent comments on other Board items or marginalise service user representatives. Their involvement at Board level is inclusive, regarded as important and treated as equal. Their participation as experts by experience is acknowledged by other Board members. However, having a specific agenda item ensures that any matters of concern to the service user group can be brought to the attention of all Board members.

The fact that service user Board members are elected from the wider Service User Forum is a strong indicator of the degree of recognition both by other service users and by other (non-disabled) Board members. The Service User Forum represents a collective response to a common interest. The monthly meetings help to formulate ideas and policies in relation to the group's ontological experience. For Leonard (1984) this has psychological benefits: it promotes self-esteem for the service user and moves them away from the cult of individualism which dominates western society. Bewley and Glendinning (1994) noted in their study of voluntary organisations the apparent lack of accountability of disabled people who participated. They did note, however, that where disabled people represented groups of disabled people they appeared to be more representative because they were accountable to a group of other disabled people and came prepared following previous discussion.

Underpinning service user involvement is the wider debate about user-influence within rather than user-led organisations. As adults with learning difficulties constitute three out of twelve members at Board level, this clearly amounts to influence rather than overall control. A sole member would constitute a lone voice at Board level and the individual service user may feel intimidated, lack confidence or feel unable or unwilling to speak at meetings. Service User Board Members stated that financial and human resources matters were particularly difficult for them to understand or created tension if in relation to their own support needs. This was acknowledged in the findings. Finance can be a complex area for any lay person. Following the intricacies of a balance sheet or income and expenditure report can be daunting. Equally matters

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concerning human resources (or staffing) can be acrimonious or indeed personal to the service user by involving people who may support them directly or of whom they have some working knowledge. It is understandable that individuals may feel discomfort when dealing with personal staffing matters (for example, stating that they do not want certain people to work with them on a day to day basis). Support staff become friends of service users albeit in a paid capacity. In reality, there is more of a personal risk and investment in the overall service delivery for the service users as consumers or recipients of services. They have an economic interest and more to lose. Despite their involvement at Board level influencing the power dynamics there may have a direct impact on their day to day life. The consequences of things going wrong are higher. Conversely there is a stronger imperative to get it right. These are fundamentally important elements of each individual's life. Personal involvement can also lead to a more emotional (or heartfelt) response to change. For example, Sid talked about his experience at Eden House (where he once lived and the negative experiences he had with other younger tenants). Emotion was sometimes displayed by service users but was not exclusive to them. For example, the Chairman described the organisation as being *"a vital part of my life",* (Fred) when interviewed as part of the research and was visibly moved by his involvement.

The personal impact on service users came across strongly in the interviews. Service users outlined areas of improvement in their own lives when asked about key events of the organisation. Declarations of interest were acknowledged by service users in particular, for example, when discussing the

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purchase of a block of flats one of which may be offered to a service user representative. Sid in particular understood the reasoning behind this *"because they think you are wanting more than them."* Other Board members clearly stated that they had observed service user declarations of interest and these are recorded in the documents (minutes of meetings). Thus their interest is transparent and verifiable.

'Speaking out' for other service users was a strong theme. Sarah felt that she represented the area where she lived and as the most articulate tenant living there she stated that she was the *"voice"* for other local tenants. This ambassadorial role was evident in the findings and is portrayed at Board level, thus conveying purpose and reinforcing a sense of belonging.

Assessing the quality of service user involvement

Braye (2000) warns against tokenism or involving people in meetings where decisions have already been taken, using "agency jargon" and often denying training or financial recompense for service user involvement. She identified eight key areas which assess the quality of service user involvement and I have assessed my findings in the light of Braye's criteria.

1.   *Too little time for meaningful discussion*

None of the participants in the research indicated that this posed a problem. On the contrary they claimed to feel fully engaged in the

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discussion, to feel listened to and respected for their views. They did, however, identify certain factors which created anxiety, for example, discussing staffing issues, particularly in relation to their own team and potential disciplinary matters. They may acquiesce in terms of not understanding the complexity of employment law and it has been necessary to implement policies and changes in job descriptions in order to reflect service users being able to choose staff or request for someone to be transferred.

2.   *Low access to senior staff*

The structure of the organisation is based on horizontal or dialogical relationships: it therefore allowed access to senior staff and indeed members of the executive team attend Board meetings. For example, all Board members have access to the home telephone numbers of senior staff. Social events, for example, birthday parties involve invitations from both service users and senior staff. This can be seen as a blurring of professional boundaries but it is an essential part of being treated as an equal.

3.   *The need for preparatory training of service users (preferably by disabled people)*

This was recognised from the beginning. Advocates were involved in pre-meetings of service users which take place prior to each meeting and

are co-ordinated by the Head of Learning and Development. This is for two reasons. To allow greater discussion or explanation around agenda items and to prepare the Service User Forum report which is always presented at the Board meeting by the tenant service user representatives. Additional training is provided, sometimes by disabled people who are themselves trainers but training needs to apply to **all** Board members. This has taken place but only to a limited extent. For example, there was a residential conference attended by all Board members in 2003. This lasted two days and led to the increase in number of service user representatives as members from the Service User Forum also attended the conference. Away Days for Board members take place annually and these have been regarded as training events. Finally, the Annual General meetings always involve a presentation from the Service User Forum and guest speakers who raise areas of debate relating to current learning difficulty. Training covers encouraging speaking up at meetings and cascading confidence aimed at promoting well-being and improved self-esteem) as well as bespoke training (for example, around the personalisation agenda, or changes in welfare benefits which have a direct impact on service users' lives). Other specific training has taken place, for example, Sarah and Sam have qualified in food hygiene so they can work at the catering project. Training has been accredited in accordance with City and Guilds standard setting and is externally verified. Service users have achieved certification and this in turn has had a positive impact on active

involvement at Board level. Training is not an 'event' but an ongoing process of empowerment and confidence building.

4.   *The need for clear guidelines of confidentiality*

There is a clear policy of confidentiality based on the ground rules devised by the Service User Forum itself *"what is said in the room, stays in the room."* This has proved efficient and has withstood the test of time. These ground rules were used in the research process. (Appendix 3)

Service User Representatives are clear about any necessary declarations of interest in matters pertaining to their own personal situation (for example, the purchase of a property for their own individual occupation).

5.   *Codes of practice on conducting business*

Over the years of service user involvement there has been discussion about the presentation of reports, the format of papers and their accessibility. The emphasis is on verbal presentations sometimes involving visual input (for example, PowerPoint), photographs, plans and drawings. This is in accordance with best practice for ease of communication. However, it has not proved possible to translate Board minutes and reports into a symbolised version largely due to the lack of

suitable software and symbols (including technical vocabulary). There is also a general lack of time or key personnel to do this specialist work. The emphasis has therefore concentrated on pre-meetings, verbal explanations and use of visual aids as described in order to mitigate this problem area. The Service User Forum members present their own written report (usually one side of A4 sized paper) which is read out in turn by the Tenant Board members. This practice has developed over time and provides a useful focus for the service user priorities as well as a specific item on the agenda. Business is conducted in relation to the rules of the Association: the minutes reflect the topics discussed and the decisions taken. They are not a verbatim record of the discussion which often can be protracted and lengthy. Service users are also actively involved in discussion and are usually eager to second resolutions for decision making.

6. *Need to focus on monitoring outcomes*

The documents show that service users have often generated the idea for a particular service, for example, to open and run a charity shop or make an individual property purchase. This then becomes the objective resulting often in a positive outcome. Focus on outcomes is now more prevalent in person centred planning. (Sanderson 2006) It is particularly relevant to adults with learning difficulties in terms of recording milestones or achievements which may be seemingly minimal but can identify a significant impact in relation to a service user's life.

7.   *Too much focus on service user representatives by managers*

Service users represent themselves not managers. Sometimes ideas

from members of staff may be discussed at Board level but they are

introduced by service users therefore mitigating any potential power

relationship in favour of staff. Service User Board members clearly see

themselves as part of the wider social milieu within the Service User

Forum. They feel that they are mandated to raise issues or ideas on its

behalf.

8.   *Devaluing assumptions about the capacity of some disabled groups to*
        participate linked to a reluctance to accept self-advocacy

One or two Board members, who have joined the organisation at a later

date, have struggled with the degree of service user involvement. This

can reflect a lack of understanding or a wider prejudice about an

individual's capacity. However, the strength of the Board (including

service users) has been able to challenge this perception in a positive

and meaningful way. None of the Board members are tokens and overall

there is evidence that Involve Housing Association has embraced the

idea of self-advocacy by increasing the service user representation from

one to three members. This degree of user-influence is significant,

avoiding isolation of one "token" representative and (by being linked to

the Service User Forum), providing a clear mandate for service user

views to be aired. This value base does not imply an assumption about

capacity: rather the opposite is evident. There is a genuine attempt to listen to service users: to value their contribution and accept their proposals and recommendations at Board level. In addition contacts are maintained with independent advocacy groups (two in particular). At any point service users can involve the use of independent advocates. This is particularly useful in relation to issues regarding personal legal matters, complaints or political campaigning.

There is a potential conflict of interest in funding independent advocacy. There is an on-going debate nationally about the funding of independent advocacy especially in a climate of reducing public expenditure. Many advocacy projects are reliant on grant funding which is becoming increasingly difficult to obtain. Fundamentally, how "independent" can citizen advocates be when their very existence is fragile or dependent on limited state funding? In order to overcome these issues, there has been a local recognition of the value and purpose of independent advocacy thus recognising the differing positions that may need to be taken by the parties involved. The Association has access to two local advocacy groups. Any funding given to the organisations has been explicitly for non-Association related activity in order to maintain a clear boundary of roles and offer uncompromised representation which is funded out of other independent grant-aid.

In summary, the experience of service user Board members (as stated during the research and tested against the criteria of issues as outlined) appears to be

one of active involvement and meaningful participation. It is outcome focused and achieves a level of involvement commensurable with the overall Board agenda. The contributions and personality of each Board member has had a direct impact on the shape of the Board. The strength of working together as part of an educational experience is vital and based on effective communication.

This study does however reveal potential threats to effective service user involvement not least of which is the fragility of funding. This will be explored in the final chapter.

(iv)   Executive Team

Eric

Eric (as Company Secretary and part of the executive team) had witnessed the impact of several reorganisations over the period in question (2002, 2006/7). He recognised the strength of Involve Housing Association in terms of delivery, better governance involving the mixing of Board members and promoting the inclusion of service users. This had greatly impacted on the charitable body within the group described by him as an 'oil tanker' as opposed to the 'speed boat', Association (the case in question). The impact of the bringing together of the two into the group structure overall was to improve governance, accountability and Board representation (including the active involvement of service users). This resulted in better operational management and service

delivery. The growth of the organisation is demonstrated by the documentary analysis: the voices of the voluntary Board members help to articulate this by adding meaning and purpose.

Eve

Eve had recently been employed by the organisation as an Assistant Director. Previously she had been involved with the service users as a Community Nurse (working at the former hospital) and had served as a Board member (2003-08). She recalled attending an International People First Conference on behalf of the organisation in Toronto in 1993. Although outside the period covered I have included this as part of the philosophical commitment to service user engagement by the organisation. It predates the Valuing People agenda: The People First movement was seen as 'ground breaking' in relation to adults with learning difficulties in a way that Centres for Integrated Living were seen as radical in relation to disabled people in the 1980s.

This philosophical commitment to service user involvement was utilised when she became a Board member. She challenged another voluntary Board member who felt that service users should not discuss a confidential matter regarding a Human Resources issue "as they will not understand it". Eve argued against this exclusion and took time to explain the matter to the service user representatives. This was both an educational experience but also demonstrates her personal commitment to valuing and respecting service users' contribution.

Ewan

Appendix 8 highlights the discussion with him about the development of day activities. As an unregulated area of service delivery, that is, not inspected by external bodies, there had been a significant opportunity to develop alternatives which were more responsive to requests from adults with learning difficulties. There was a clear emphasis on organic development in response to an antithesis to more traditional day care. In addition, this included new service users, for example, often older carers. It was often an introduction to other potential services in the future and arguably, allowed a gentler engagement than a crisis referral made by a newly allocated social worker once a crisis occurred and action was needed to place an individual in accommodation and care. Ewan is a significant actor as the principal social worker within the organisation, Chair of the Training Committee and lead trainer for social work students on placement within Involve.

Myself as Executive Director

My role has been instrumental in developing the organisation. However, rather than it being a subjective entity there is a dynamic to the organisation: a sense of it having a life of its own: an objective reality which exists independently from its founders - the whole being greater than the sum of its parts. Rather than regarding my role as an insider researcher as a negative influence I recognised my commitment to being a structural social worker, of engaging in praxis which Mulally (and others) celebrate. Withorn (1984) states that socially committed

social workers will need to achieve some harmony among their politics, their work and their personal lives which Mulally suggests involves 24-hour effort, a commitment to a dedicated way of life.

Mulally contends that one of the ways for structural social workers to contribute to social change or transformation is to "create, develop and/or support alternative social service organisations." (1993:183)   As an alternative service Involve Housing Association was "cutting edge" in an effort to achieve "comprehensive change".

The fusion of strategy and practice is an example of dialogical or horizontal relationships promoted by Mulally, and for me it continues to inform my practice.

4.   **Embedded value base**

The understanding of the educational impact of critical theory (Dominelli & McLeod, 1989) which informs the social model of disability and underlines the role of oppression in respect of marginalised groups, for example, adults with learning difficulties. Conscientization (Friere, 1970) is an illustration of this process moving towards empowerment.

In the Involve organisation this is underpinned by a value base which celebrates difference and service user involvement. This is illustrated by the existence of dialogical relationships at all levels. These are based on mutual respect and learning together.

A dialogical relationship is exchanging, comparing and communicating. The overall aim is to initiate new forms of working based on a different view of the world: one of co-operation, mutual trust and respect often challenging the prevailing ideology of the overall socio-economic context as discussed by Mulally (1993).

Examples of dialogical practice were illustrated by the findings and ultimately based on mutual respect and recognition.

Brandon's work (1983) in relation to mutual respect could be applied to the organisation and its underlying value base.

"Professional" Approach	"Gentle" Approach
Cold calculated response	Warm, spontaneous
Ideological approach	response
Crude techniques to control	Love
Complicated language	Easy giving of self
Distance – professional	Closeness
boundary	Solidarity recognising mutual
Objectivity	humanity

Bazeley (1977) identified personal or group development through decision making which led to increased competence and power amongst people with poor mental health. These elements are evident in the interaction both at Board level and within the context of relationships between the executive team and service users. For example, getting together with Board members for a Christmas lunch or taking part in away days. Direct contact – often "hands on" support to attend meetings, go on holiday or participate in conferences – is ensured with the executive team thereby reducing any barriers and achieving

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the desired horizontal exchange. The common experiences of participation and governing the organisation are enshrined in the value base, a shared sense of purpose and identity which characterise a prototype organisation or "glimpse of the future". (Mulally, 1993) For Mulally, the social worker is constantly engaged in an educational journey with service users with no particular group holding all the answers. This involves reviewing and updating knowledge of the service user group and the socio-economic impact on their lives. This is illustrated at Board level in terms of policy formulation and adaptation in relation to changes at both a national and local level: a constant re-interpretation of the impact of change on the lives of service users. For example, this was evident in the discussion regarding the withdrawal of providing services to young homeless people in 2003.

Between Board members, the dialogue is based on mutual sharing and learning as well as an acute understanding of disability issues particularly in relation to the society's marginalisation of adults with learning difficulties. The representation of three service users at Board level operates as both an internal and external lobby group, raising consciousness and awareness of issues affecting people's lives. The mutual trust and respect that has developed over the years is an essential element in terms of good governance outlined earlier and underpinned by the embedded value base. Service user Board members have been actively involved in social work education: examples include recruiting students onto courses, helping to evaluate students on placement and being interviewed by Doel and Best (2008) as part of their research relating to the lived experience of social work.

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For Mulally the role of structural social work is to promote.... *"a climate, a relationship, resources and procedural means through which people can enhance their own lives."* (1993:162)

The case study has demonstrated that the Board operates as a means of empowering service users: of making a difference in their lives and as a powerful educational experience connecting people to the wider socio-political environment. This can be done individually (as in 1:1 casework) or collectively (as in group work). At Board level, individual experiences are aired as examples but the group discussion about possible solutions, are part of a wider educational journey.

Whilst not user-led, there is a clear evidence base of user-influence and direction of new innovatory services, for example, developments in alternative day services. The concept of independent living goes beyond social care: its development puts service users at the heart of decision making in the sense that without their valuable contribution and need-led approach, new services would not have been instigated.

5.   **Future Implications (up to 2014)**

Chapter 4 identified key areas noted by the group interviewees including the internal strengthening of the organisation, proposed new areas of development, working in partnership and a concern about the impact of personalisation. In terms of strengthening the organisation, service users listed more service user

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training, promoting the Service User Forum and the wider organisation as well as involvement with social work training as key areas for future development. It could be argued there was a vested interest but in reality, this is how they 'connect' with the organisation in a practical and real sense: the important items for the future were closer to their own lived experience. Similarly, the executive staff team noted the need for new job descriptions with flexible and adaptable staffing for the future: again this recognised the day to day experience of their largely operational role.

Succession planning was a key area for the interviewees, particularly the older Board members. Securing the future was an area of concern and this linked to the notion of forming closer alliances with like-minded voluntary organisations (or working in partnership), maintaining strong leadership and strengthening the organisation through difficult times which were all highlighted. Facing the future and challenges ahead are common concerns to most voluntary organisations and the implications for the organisation are huge. In particular, the potential loss of leadership and organisational memory were key factors and the value base of the organisation, were paramount. There was an acknowledged and recognised steady growth over the research period and concerns about whether this pace could be maintained in the new age of austerity despite increasing need.

In terms of proposed development there was also an understanding of the increasing expectations and greater say of adults with learning difficulties and their families. As Jones (2011) notes that *"as people with learning disabilities*

have a greater say in how they want to be supported, their aspirations are likely

to change, to increase and providers need to be in a position to respond.”

(2011:143) These concerns are frequently raised at board level because

service users (primary actors) and their carers (secondary actors) are involved

in the organisation over a distinct period of time.

Proposed new areas of development involved more of the same thereby

reinforcing the success and value of the organisation.

Maintaining existing services which worked for individuals, for example, the

pooled transport system within the organisation were also indicated. At the time

of writing the threat to remove the mobility component of disability living

allowance (to those living in registered care homes) had been withdrawn due to

the successful lobbying, in part by the organisation. Steering a course to the

future was a key theme amongst interviewees.

The impact of personalisation would require further exploration as this is a key

influence on the future direction of services at the present time (although at the

time of the research it was not yet in force). Boxall *et al* (2009) explores the

influence of individual budgets.

Conclusion

The degree of user influence evidenced by the research is significant and

participatory. I would argue the wider board has genuinely embraced the

service user voice. This has taken place over time and is embedded in the

nature and values of the Board. In addition, there are examples of real

reciprocity between Board members and the Executive. Loss of key individuals

could seriously erode this holistic approach as could the impact of creeping

bureaucracy in order to satisfy external regulators. The effect of commissioning

and the one size fits all approach decisions could lead to further fragmentation

as well as piecemeal service delivery, which in turn could undermine the overall

quality and dilute the organisation's raison d'être in terms of service user

involvement. Chapter 6 considers the influence and impact for the future.

Chapter 6

Conclusion: Influence and Impact for the Future

"Overall transformational change can still be possible as it does not happen from the top down because government says it should. Most often, it happens through a.......combination of showing local leadership, the tireless work of inspirational individuals and community groups and the willingness of people and organisations to do things differently because of a shared vision or conviction that it is the right thing to do."
(Bennett, 2011:195)

This study has explored and analysed the development of an organisation working in partnership and involving, as directors, people with learning difficulties who have historically been denied a voice.

The study covers a specific period, 1997-2007, which in terms of UK developments in health and social care could be described as a 'golden era' of service development. The creation of the organisation predates this 'golden era' and will need to continue into the future in order to meet the needs of service users and their families. Huge strides were made, during the research period at a national level with above-inflation real growth in terms of investment and opportunity. Parallel developments in services to and for service users with learning difficulties between 2001-2007 followed the creation of the Valuing People Support Team and a national agenda for improving lives outlined in the Valuing People White Paper (2001). The documentary analysis of the

organisation clearly demonstrates its support for the value base enshrined in that new agenda.

Through the research I have identified key events and themes relating to the development of the case study as a prototype organisation (Mulally, 1993) over the period. In particular, I have argued that the development of an alternative to the former institutional model of community care stimulated innovation and creative solutions. These were encouraged by the direct involvement of the service users who not only served on the Board in equal capacity but were (and remain) part of a larger body of service users involved in the day to day experience of the organisation. This has provided them with a strong mandate and sense of involvement. Their journey has been part of the overall educational influence and development of a learning organisation. This has been mutually beneficial to both disabled and non-disabled participants and is characterised by horizontal (or dialogical) rather than hierarchical (or top-down) relationships.

Alongside innovations, the period in question demonstrated decisions to withdraw from certain projects, for example, working with young homeless people due largely to a lack of expertise to tackle the issues presented. Interviews with Board members supported the evidence gathered in the documentary analysis.

All the people interviewed as part of the research discussed the need to develop new partnerships based on the stated aims and objectives and strong

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value base which underpins the organisation. Working as equals, based on mutual respect and a shared understanding, was seen as critical in giving real voice (Elbow, 1981) to service users and their families. Telling the story of the organisation based on its rapid growth over 20 years and offers a hopeful or optimistic story of change and improvement in the lived experience of people with learning difficulties.

Transformational change involves both being heard and finding a willing listener. Being there (through prolonged engagement) at Board level is at the heart of this case study. It is embedded in the praxis and day to day operational detail as well as part of its overall and deliberate strategy from its inception. The strong value base is the raison d'être of the organisation.

This study has demonstrated how this has happened at the micro level, illustrating the impact of Board members as well as significant others. However, this has not occurred in isolation. The micro level of activity has been grounded in its socio-political context and historical time frame as described by Layder (1993).

Campbell (2008) states that there are three key areas of debate for social care for the 21st Century. These are paying for long term care for older people, support for carers (for example, respite care) and promoting independent living for disabled people. Together these inform the nature of service delivery:

"And whilst each fights for a slice of the cake, we are failing together to

fight for the bigger and different flavoured cake we all need." Speech at the Disability Conference (2008)

To achieve independent living the main ingredient of the organisation it is necessary to engage in interdependent living, forging alliances with carers, other service users and other allies or supporters who may or may not be non-disabled people. This has been the story of the organisation from its genesis.

Facing the Future

At the time of writing the organisation is about to embark on a more formal and legal partnership with a like-minded organisation. The basis of this decision was the need to secure a future succession plan and business strategy highlighted in Appendix 9 (SWOT analysis with Middle England Housing Association). It was also a consequence for the need to forge an alliance with others in order to face the challenges at a macro level and avoid isolation.

Between the end of the research period (2007) and the time of writing (2011/12) there was a paradigmatic shift in terms of the economic climate as well as a move away nationally from user involvement in a meaningful sense, for example, the withdrawal of funding for training with service users. Changes in policy direction, reductions in public expenditure, the redefinition of assessed need for social care and a move towards generic service delivery (rather than specialist services) have all occurred since the election of the coalition government in 2010. Further, the dismantling of the Valuing People Support

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Team and the 'watering down' of the philosophy of personalisation have all served to move away from an emphasis on service users and their families being in control (Duffy, 2012). This further reinforces the notion of a previous 'golden era', not just from a vision through 'rose-tinted' spectacles but as a fundamental change in direction post-2010. The narrowing of definition in terms of eligibility for social care is likely only to serve to reinforce this change and could impact adversely on the lives of service users within the organisation. Pressure on budgets for adult social care may result in less money being available for adults with learning difficulties generally as services compete with the increasing demand from older people given the demographic change in the population.

There is a tension between the ideology (or perhaps rhetoric) of the Valuing People agenda, with its emphasis on rights, choices, inclusion and independence and the practice (or perceived reality) of service delivery based on compromise, reduced funding and the promotion of more risk averse models of service delivery. These factors could result in a negative shift in terms of values and attitudes towards adults with learning difficulties. Rather than promoting rights and choice, the 'new' model of community care may well involve a retraction from what has been regarded as good social work practice and innovatory service delivery in the recent past. This could have further adverse consequences. The Pilkington Report (2011) highlighted the negative experience of a family living in the wider community without necessary support. This may become more common in the ideological shift based on an arguably vacuous notion of a Big Society. There is an assumption that the community

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cares for its most vulnerable but this may not be the reality. The recent increase in hate crime towards adults with learning difficulties and a general antipathy towards disabled people encouraged by 'scroungerphobia' and a moral panic about benefit entitlement would indicate that the situation for people with learning difficulties is no longer improving. With the danger of going backwards it is important to have recent historical data which can point to an alternative or empowering agenda for the future. This has been demonstrated by the study of the organisation and the critical role of service users and their families as part of that.

Lessons need to be understood in terms of the wider socio-political context. There could be a dis-integration of services to and for adults with learning difficulties. In the local authority largely relevant to the case study, the dismantling of learning disability teams has led to de-specialisation or conversely, a generic approach to service delivery. Single (or common) assessments lead to a loss of specialist application to care assessments, a general reduction to a lower common denominator and a 'one size fits all' approach to health and social care. This moves away from a pro-active or positive emphasis on the differential needs of adults with learning difficulties and an undermining of the previous allocation of resources. In addition voluntary organisations, for example, the organisation in question, are left to argue from a position of weakness due to tendering, loss of contracts, unequal power relationships and limited finance. Further, there is evidence of creeping re-institutionalisation as cost cutting leads to larger economies of scale and the move to larger units of accommodation similar to the hospital environment

which was closed in the 1990s. There is evidence of a move from supported living to registered care homes following the changes in Independent Living Funds assessment criteria which have left some disabled people ineligible due to new criteria or unable to afford to live independently. The situation is likely to worsen with the introduction of changes to benefits in 2013 (Welfare Reform Act 2011) as the changes are disproportionately bound to affect disabled people. (Duffy, 2012)

There are further 'drag' factors operating in respect of sometimes onerous regulation in health and safety law, the complexity of employment law and the (often bureaucratic) requirements of the Care Quality Commission. This level of control is contrary to the ideology of co-production within the participatory or emancipatory paradigm as it tends to offer a negative (or risk averse) rather than a positive approach to risk taking.

A fuller analysis of the changes post-1997 could form the basis of future research which although outside the scope of this study, could have a serious impact on both the future of the organisation and the service user experience. In particular, research topics could include matters raised above as well as issues of vulnerability and safeguarding. Mental capacity is another area of concern. Labelling adults with learning difficulties may well lead to a diminution of citizenship and their potential involvement as co-producers in the future or as instigators, investigators and enablers. This would reverse some of the proven success of the organisation in seeking to involve service users in the co-production of services to meet their stated or perceived need.

However, writing this study has led me to remain largely optimistic about the future given the strength and wealth of evidence of service user involvement. Changes will be inevitable but adaptation to the challenges ahead will lead to further opportunities for innovation. The evidence has demonstrated the degree of evolutionary change, creative solutions, seizing opportunities, a sense of ownership and involvement of service users which has been significant rather than tokenistic. The strength in numbers as well as a structure based on co-education and meaningful communication has endorsed the involvement of service users despite their disability. Indeed because of their disability, structures have changed and their role has been recognised as different but equal: as a powerful force to be recognised. The concept of being differentially able supports the ideological position of the organisation. The 'great danger' of tokenism stated by Frank has been addressed directly by being acknowledged as a possible 'elephant in the room'. The emphasis on mutual learning has resulted in a seamless approach to service delivery, reflecting social work values and leading to innovatory praxis. Lessons may well need to be learned going forward. In particular, there is the challenge of maintaining service user involvement from a potentially limited number of service users who are able to use words to communicate and understand the complexities of meetings and their protocol. The use of advocates, carer representatives or other means of ascertaining service users' views may need to be further explored and utilised. Size may prove a challenge as expansion into other geographical areas as part of the new group structure could lead to logistical problems and a move away from the grass roots. New enabling structures will need to be developed in

order to keep the faith alive. Overall the preservation of the value base is paramount and this offers the best defence for the future despite all the challenges described above.

In addition, there are clear lessons in relation to social work practice, and as part of its commitment and learning the organisation, continues to offer placements to over 20 social work students each year. Actively listening to service users and making a difference to people's lives is the essence of best social work practice. (Doel & Best 2008)   The social work profession is going through major changes at the present time. The role and importance of the voluntary sector is part of that landscape and this unique study may offer some insight into its contribution albeit from the perspective of a single case study.

This study has given me the chance to appraise the historical development of this voluntary organisation through both the analysis of documents and interviews with Board members and key staff. As the Chief Executive Officer who needs to not only oversee the day to day management of the organisation on behalf of the Board, but also recommend to the Board the necessary direction of travel for the future, I have been able to draw meaning and new learning from the research.

Overall I believe that it has been a story worth telling as it provides a unique insight into the inner workings and impact of a voluntary sector organisation operating in the complex world of health and social care in the UK in the 21st Century. Most of all, I have described the unique contribution of adults with

learning difficulties in the running of the organisation which can only reinforce the importance of such involvement in the future. It is a classic example of evidence-based research which must inform practice in health and social care.

The journey has been challenging but exhilarating: exhausting yet refreshing. I would like to thank all those who took part in the research and more importantly acknowledge the special journey which has been taken together, down a long and winding road. Their contribution has helped not only to develop the study but offer pointers (and hope) for the future. Indeed, there are factors which will resonate with other like-minded organisations offering the possibility of further research particularly in relation to the contribution of the voluntary sector to health and social care, the impact of macro forces on services to and for adults with learning difficulties and active service user involvement in governance.

54,012 words

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18 February 2010

Dear

Research Project

As part of my research studies at Sheffield Hallam University, I am undertaking a review of Involve Housing Association as a single case study. I am writing to ask you to take part in a group interview in relation to my research project.

So far, I have looked at the minutes over a 10 year period 1997-2007 and this has produced milestones which I have grouped into key themes. I would like to meet with 3 groups of Board members (founder members, more recent recruits and service user representatives) in order to explore the key areas and your views as an active board member.

The aim would be to meet for 1-2 hours at Involve House at a convenient time to suit each group of Board members. With your approval I would like to tape record the interview and I have asked Violet (my PA) to take notes by shorthand. This will provide a detailed record of the meeting which I will then be able to analyse. I have obtained approval to proceed with my research from the University and the County Council (known as ethical approval). I will also need to obtain individual consent forms from yourself as a participant (see attached form which I have prepared in a symbolised format). In respect of service user representatives, I am asking for independent staff support to be available and Alan and June have both agreed to do this. This will enable me to concentrate on the research angle but allow for support (or explanation) to be offered by other staff.

If you do not wish to take part in this research, it is perfectly okay. However, your involvement would be most appreciated as you have been identified as a key "driver" in terms of the organisation and its development over the period in question.

This project is seen as a unique opportunity to analyse the story of Involve Housing Association: the untold story which has been referred to on many occasions. I understand Violet has contacted you and has arranged your interview to take place on **Tuesday, 2nd March, 1.00pm to 3pm at Involve House.**

If you have any questions in respect of the content or purpose of this letter, please contact me directly.

I look forward to completing this piece of work in the near future and thank you in anticipation for your commitment to help me do so.
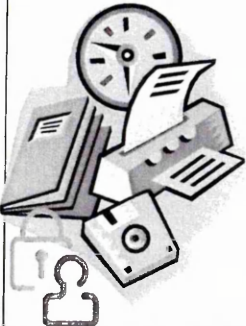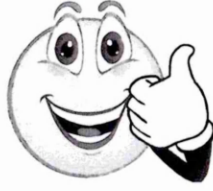
Best wishes.

Jackie King-Owen

ACCESSIBLE CONSENT FORM (used for everyone)

**Involve Housing Association: A Single Case Study**

Please ✓ Yes or No

		YES	NO
	1. I have read and understood the letter for the above study.		
	2. I understand that it is my choice to take part and I am able to stop at any time, without my rights being affected		
	3. I understand that information collected will be used to help the study		
	4. I understand that all the information that I give will be confidential and my name will not be used in reports or publications without my agreement		

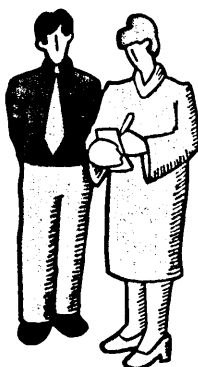|			
	5. (where needed) I agree to my support team being told that I am taking part in this study		
	6. I want to take part in this study		
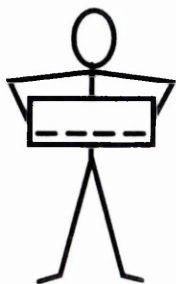
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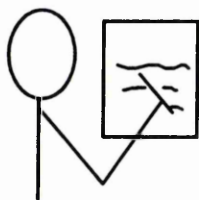
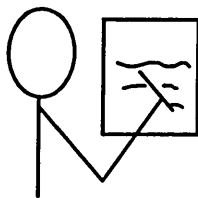My signature / mark of agreement :

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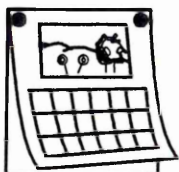
Date :

_____

Witnessed by :

Name :

_____

Signature

_____

Date:

_____

Researcher Name : _____

Signature : _____

Date : _____

GROUND RULES (for group interviews)

A.   Please switch off mobile phones (Do not put on silent)

B.   Speak freely and honestly but:

C.   Please do not speak across each other

D.   Listen to each other and try to develop a conversational approach

E.   Keep the focus on the questions asked as far as possible

F.   Commitment to confidentiality – "What is said within the room stays in the room" – This is the agreed philosophy of the Service User Forum

G.   Enjoy! And thank you for taking part.

Limited Capacity?

Capacity is a wider legal issue. The assumption of mental capacity underlines the legal status of adults with learning difficulties to be, for example, self-advocates or Board members. The Mental Capacity Act (MCA) 2005 has recently been introduced. In a sense it is early days in terms of its implementation and the building of case law to support tribunal decisions. However, there are five statutory principles which act as a benchmark in terms of acts or decisions taken in relation to someone who lacks capacity.

Principle 1: A presumption of capacity

Each adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise. This means that you cannot assume that someone cannot make a decision for themselves just because they have a particular medical condition or disability.

Principle 2: Individuals being supported to make their own decisions

A person must be given all practicable help before anyone treats them as not being able to make their own decisions. This means you should make every effort to encourage and support people to make the decision for themselves. If lack of capacity it established it is still important that you involve the person as far as possible in making decisions.

Principle 3: Unwise decisions

People have the right to make what others might regard as an unwise or eccentric decision. Everyone has their own values, beliefs and preferences which may not be the same as those of other people. You cannot treat them as lacking capacity for that reason.

Principle 4: Best interests

If a person has been assessed as lacking capacity then any action taken, or any decisions made for, or on behalf of that person, must be made in his or her own best interests.

Principle 5: Less restrictive option

Someone making a decision or acting on behalf of a person who lacks capacity must consider whether it is possible to decide or act in a way that would interfere less with the person's rights and freedoms of action, or whether there is a need to decide or act at all. In essence, any intervention should be proportional to the particular circumstances of the case.

Source: SCIE Website (downloaded 30/3/2011)

CONVERSATIONAL STYLE INTERVIEW

QUESTIONS ASKED

A.   How long have you been on the Board?

A1.   What is your role and involvement? Ask individually (for the record and in order to identify key actors).

A2.   Why are you personally involved in Involve Housing Association?

A3.   Do you feel valued, involved, respected?

A4.   What is good/bad about being a Board Member?

B1.   What were the most significant events/milestones from your perspective?

B2.   What was the single most significant decision?

B3.   What were the key challenges?

C1.   How effective is the Board?

C2.   What are the key issues/challenges of being a Board Member?

C3.   What are the current issues for Involve Housing Association?

D1.   What are the challenges of involving service users on the Board?

D2.   Has the involvement of service users on the Board made a difference? In what ways?

D3.   What are the potential conflicts of interest in engaging service users on the Board?

E1.   What are the key challenges for the future (say to 2014)? What if anything needs to change?

E2.   How can Involve Housing Association best meet the challenges ahead and adapt to the future?

E3.   Is the structure of Involve Housing Association fit for that purpose?

E4.   What services would you like to see Involve Housing Association develop?

E5. Do you think Involve Housing Association should strengthen its partnership with others? In what ways? With whom?

E6. Finally, the emphasis on personalisation (or transformational services) focuses on co-production with service users and their families. What do you think of this agenda? How can Involve Housing Association meet this challenge? What, if anything, needs to change?

Ethics Approval

Initially I wanted to interview service users who are part of the organisation in terms of their experience of community living, however, this had a number of ethical issues regarding power and control and possibly influence regarding their housing, care and support. I debated the ethical dimension with my supervisor and it was agreed that I would be able to proceed if I reversed the relationship and interviewed members of the board instead. This in effect produced the same results in telling the story from a service user perspective as there are three tenant representatives on the board as well as carer representatives. It overcame the issues regarding power and control as effectively they are the management committee of the organisation. I am employed and accountable to them on a day to day basis.

The title has changed in so far as I wanted to focus on the journey that had been taken collectively by the board and as I regarded this as a single case study with some degree of generalisation for similar organisations, it was felt more appropriate to emphasise the partnership approach within the housing organisation. I also captured the period 1997-2007 which with hindsight, especially in times of austerity and a different direction for health and social care, could be referred to as a "Golden Age".

May 2013

Centre for Health and Social Care Research

Faculty of Health and Wellbeing Research Ethics Committee
Health & Social Care Research Ethics Review Group

Report Form

Title: Listening to Service Users' Stories: What is Their Experience of Community Living?

Principal Investigator: Jackie King-Owen

Recommendation:

Acceptable: ✓

Not acceptable, see comments:

Acceptable, but see comments:

Comments:

You may now proceed with your research.

Signature : ~~Peter Almark~~   Date: ..23 February 2010

Peter Almark,
Chair
HSC Research Ethics Review Group

Please remember that an up-to-date project file must be maintained for the duration of the project and afterwards. The project file might be inspected at any time.

Note: Approval applies until the anticipated date of completion unless there are changes to the procedures, in which case another application should be made.

Working with Middle England Housing Association

The relationship with Middle England Housing Association started prior to the Executive Officer's move to the shire county. When Involve was established in 1990, Middle England Housing Association was offered a position on the Board as one of the two partner housing associations due to the existing knowledge of the officer. Throughout the early nineties, support was given freely. In particular, the conversion of the first independent living project for young people with learning difficulties in a local town and the alteration of two former wards at the long-stay hospital into temporary nursing home accommodation prior to the cessation of the Residential Homes Allowance in 1993. Middle England Housing Association co-ordinated the renovation of the local Resource Centre in 1995. In addition Middle England Housing Association obtained funding via the Housing Corporation for eight flats to be created above the Resource Centre in a lease-back scheme managed by Involve Housing Association.

In relation to the period in question, 1997-2007, the involvement of Middle England Housing Association in the work of Involve Housing Association has been crucial. In particular, Middle England Housing Association has:

- Used its capital via the Housing Corporation to provide two wheelchair accessible bungalows (1997).
- Converted a house for young people leaving care. (2000)

- Purchased and renovated a shared house for three women with learning difficulties. (2002)
- Building a two four bed wheelchair accessible bungalow in an adjacent county and added a third house as part of that project. (2003)
- Organised three schemes known as Do It Yourself Shared Ownership (DIYSO) in order for adults with learning difficulties to become part-owners in an area of scarce social housing.
- Provided substantial funding for furniture and equipment.
- Provided support with day to day maintenance of properties until the Maintenance Officer moved to work directly for Involve Housing Association in 2002.

Seizing Opportunity: an example of community based day care

Researcher What were the most significant events or milestones from your

perspective?

Ewan For me I would say it has to probably be Golden Resource Centre

because it is from Golden Resource Centre which was developed

by Involve Housing Association, which is really where everything

else, particularly for me, has sort of developed, a really key

milestone that one particular service which we got off the ground

and it has had such a knock on effect in the way day services in

particular have developed and offshoots.

Researcher Could you give some examples of what you have developed from

Golden House?

Ewan From the Resource Centre which was set up in 1995, in 1999 a

Community Centre in a nearby town was developed which was

based on the same sort of philosophy – community based day

services but we took that to another level of actually providing

those services from a community centre run by the people of a

local town which actually has included service users that use

Involve's day service there. That was a significant offshoot and

then another significant offshoot was another Resource Centre

which was set up in 2003, which again that was a specialist day

service for adults with and is still a specialist day service for adults

with profound needs and in particular nursing needs and learning difficulties and again that has proved to be very popular and successful for the service users who are in Involve tenancies and nursing and registered care homes as well as by the people that purchase the service particularly the County Council who really value that type of service and say that we are particularly good at that. Other developments have also included small sorts of social enterprise or little businesses with a work ethic for service users. Again those sorts of seeds were sown at the Resource Centre with Shoestring Plants, an offshoot work type activity which people did and still continue to do. Then from that we got initially Shoestring Snacks which was around 2002-2003 – a little sandwich shop in a local town run with service users with learning difficulties which proved very popular and then the AB Project which was developed around 2004-2005 which again was a very large work based project and again that was quite opportunistic because there was a need for some sort of base for the Property Services for all the equipment, and a workshop for the joiner to do work, so they needed builders premises, some sort of workshop. I think we got really good value because the idea of developing it as a day service as well meant people could go there as well and do day activities and be part of property services doing jobs for the homes, gardening, landscaping, deliveries, and basic vehicle checks. That has proved again very popular with service users

and it has also increased our day services with other authorities, particularly in this case a nearby county council.

Researcher Can you tell me a bit about how you funded those and stretched the resources of the Resource Centre – that seemed to be the starting point – how did it work?

Ewan At the Resource Centre I kind of supervised and trained up staff to sort of effectively take over from my role. I was a manager and got people in as Assistant Manager or at senior organiser activity level. I supervised and got them trained up in that role. I then worked with one of those individuals who was Robert and gave him the responsibility to develop the Community Centre. This was pump primed for want of a better word by Involve Housing Association to basically fund Robert's post. We got a little bit of surplus so we knew from the Resource Centre that if Robert was working out there we could actually fund it within the Resource Centre remit without going into any particular debt and could fund the rental of the rooms. We could certainly do it for a year and see how it takes off. So effectively Involve Housing Association put in the money to support it and make it happen. Robert and I linked in with the then social workers and service managers who then started to refer people. Starting with one particular individual who lived in a local town and then it gradually took off and developed and established itself. We built up and as we started getting more service users we actually took on more staff to meet the needs. So everything worked well there financially and then

with the Involve Resource Centre I again had got a member of staff who, a number of staff – I knew I had got people there ready to go to the next level, to the senior level so Involve Housing Association backed up by them. I had staff working at the Resource Centre who I knew would be interested in working there so we set on a manager there again who was well trained and I worked alongside this particular manager, Louise for probably about a year and I was actually based up there myself. That was the time I moved from the Resource Centre to Involve Resource Centre.

Researcher You came on secondment for about two days a week.

Ewan That's right and started developing that service and worked alongside Louise to give her the support she needed to get that service up and running as a senior. Then again we started to get people to be referred particularly in a couple of properties but also private referrals. Then again a bit like the Resource Centre model we started as we increased the number of staff. I was then able to back off and leave Louise to run that herself. At that time I was also involved in helping to set up the Shoestring Snack shop. Then again the staff came from the Resource Centre initially so they are all people we have grown and trained and then moved into these other positions, those that wanted to develop a career. Followed then by the AB Project where Simon again took over. I trained him up. He was as senior at the Resource Centre, so promoted to senior and then he was ready for the next move. We

have kind of done it over the ten years but it has probably been gradual. Nicely kind of coached staff up, got them trained up into roles they could achieve – stayed with them until I knew they felt they were okay, then I backed off and let them fly and worked on another project.

Researcher So it is a kind of mentor and leadership model which has grown and developed the organisational structure.

Ewan A good thing about this organisation is that I have been able to do that and yes there are obviously lots of other things to do as well but I have been able to do that and grown along with the staff. More recently we ran a care at the weekend, Gooseberry Fayre, and again at that stage we didn't have a particular structure for that to fit in, so I actually personally worked there at the weekends with the service users to get that up and running but as soon as I got a member of staff appointed which was Caroline. Caroline worked alongside me for an intensive 4-5 weeks working together to get her on the right track and then around that we built a structure with Simon – it was a work project so I felt that would fit well with the AB Project. We quickly developed a structure having given it some thought on how it would work best. Then Simon took over the management of Caroline so it has grown like that, grown very well.

Researcher What are you most proud of?

Ewan	(Ewan gave some thought to his answer at this point). I think it is hard to separate. I think probably I would go back to my original, Golden Resource Centre. I see that as a lot of the offshoot, a lot of what we have got has come from the Resource Centre. Without the Resource Centre I am not saying none of the stuff would have been here but that really was I think the catalyst and I worked there for a good few years, probably 7-8 as an operational manager. I do believe I had quite an influence on the staff there. In some ways some of the practices happening there rather than the projects are probably in the large part due to the way I practised there and had a lasting effect on the other projects – perhaps a bigger impact than one realises. I think for me that is the key one, almost the Rolls Royce one. Ten years, fifteen years on it is still, touch wood, getting good and highly commended. It was recently inspected by the Advocacy Service, by the County Council within the last six months. It has had Environmental Health going in checking out all the catering. We have awards in all those things. It is hard to set up any service but trying to maintain and keep things up to that standard consistently, not just a one or two year hit, I think that has been very good. In fairness the other projects have followed in a similar vein.

SWOT Analysis of Involve Group (in relation to entering a formal partnership with Middle England Housing Association)

STRENGTHS	WEAKNESSES
1. Value Driven 2. Strong reputation since 1990 3. Service user focused 4. Financially sound – reserves 5. Property portfolio 6. Well trained staff 7. Social work/nursing experience 8. Committed Board Members 9. 'Stable' staff teams (low turnover) 10. Up to date on rapid changes in health and social care	1. Over dependent on one shire county 2. Contracts under threat by cost cutting and tendering 3. Succession plan needed for both Board and senior management 4. Future uncertain
OPPORTUNITIES	THREATS
1. To diversify both geographically (area) and into other client groups (but retain specialism for each one) 2. Be part of a bigger organisation with a good reputation 3. Reduced overheads for example, in the Human Resources and Finance departments 4. Access to development programme and stock for the future 5. Secure succession plan for Board, senior managers and myself	1. Loss of power/control (need to retain continuity of membership at least 1/3rd of new Care & Support Board) 2. Bureaucratisation – this can lead to delays in decision making and lack of closeness to our service user base (need to be clear about our future business plan and strengthen the service user forum) 3. Dilution of value base over time? (Need to be clear about our intentions and retain name of 'Involve' 4. Erosion of assets, eg property and reserves (need to retain property base in charitable organisation and earmark reserves for specific 'projects') 5. Changes over time, for example CEO role at group level. This can lead to changing emphasis in the wider organisation – need Memorandum of Understanding to include exit strategy