

BUYING, RENTING AND PASSING ON
PROPERTY

A GUIDE
TO FAMILIES IN ARRANGING
HOUSING FOR DISABLED RELATIVES

HOUSING
OPTIONS

Nigel King and Sarah West

This publication has been written for family carers, social workers and others who want to find out more about the different housing and support options for people with learning disabilities. It explains the various choices, how to go about getting housing and what support people can find.

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Nigel King
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Chapter 1 An Overview of Options

Introduction

It is still the case that 60% of people with learning disabilities are looked after by relatives, usually parents but sometimes brothers, sisters or grand parents at home. The book is aimed at those families who want to consider the possibility of that property continuing to be the disabled person's own long term home. Sometimes families want to help their children move into their own homes. This book also covers ways families may be able to use limited assets or welfare benefits to obtain housing.

The purpose is to:

- Help families make more effective plans
- Give information on some of the alternatives
- Answer some of the most common questions

Examples have been selected to explain the key principles involved in different approaches families can take to arranging housing and support. The cases cover England, Wales and Scotland.

Organisation

This first chapter summarises the different ways a family can arrange for a relative to continue to live in the family home in the long term or buy a separate house for a relative without the family having to bear the full costs. The succeeding six chapters illustrate each of the principle ideas and fill out more detail through a case study.

Each example describes an actual situation but the names, locations and details that might reveal an individual identity have been changed.

The examples are:

- Chapter 2 - John - Continuing with a Council tenancy and obtaining a joint tenancy
- Chapter 3 - Sally - Discretionary Trust - Owning property rented to a Beneficiary
- Chapter 4 - Alison - Sale of lease in combination with a discretionary Trust
- Chapter 5 - Peter - Purchase by Discretionary Trust and income support mortgage interest payments
- Chapter 6 - Derek - Renting from a Family Member
- Chapter 7 - Simon - Tenant with a sum of money invested in a charity

The key defining feature in the situations we are concerned with is that either a close relative owns the property or is the tenant but plans to arrange for the disabled person to continue to live there, or the relatives purchase a different property for the disabled person to live in. It

should be emphasised this is not an exhaustive list of possibilities. Some mechanisms can be combined; there are different permutations of the key ideas. Some of the examples have been chosen to illustrate this.

Why plan around the family home?

The need for better information of the kind presented here is apparent in the calls from parents to Housing Options - an advice service for people with learning disabilities.

A fair proportion are from older people - some in the 80's or even 90's - who are concerned about what will happen to sons or daughters (brothers or sisters sometimes) when they are no longer able to look after them. Three out of four parents are **home owners** at retirement age and the son or daughter continuing to live at home is a possibility but how best to arrange this?

Some of the most obvious options like simply permitting a son or daughter to inherit may not be the best option. There may be other close relatives to consider. There are doubts about who will take over the caring role and how this can be organised. Legal capacity may also be introduced as an issue.

When parents are **tenants** rather than owners there are a different set of questions about whether a disabled son or daughter will be able to continue to live at home and whether a tenancy can be passed on.

Younger families may also understand the need to plan but are similarly uncertain. The situation here may be someone in their 20's returning home after a period at school or college. It may be clear that the son or daughter should be supported to become more independent, to move on. They may be increasingly frustrated at home with "mum and dad".

The social worker or care manager in Social Services (particularly those working with older people with a learning disability) similarly knows that it is better to have a credible long term plan in place than to have to react to a crisis. On the other side families fear that in the absence of a housing and support plan agreed with Social Services the only offer will be a place in whichever residential home has a vacancy when the time comes. With a bit of knowledge and planning everyone can do better.

We concentrate here on what arrangements parents (or other relatives) can put in place themselves to secure the housing. In particular we look at ensuring the family home can continue to be the disabled person's home as long as it remains suitable. This will not of course always be the best option, it is simply one option, that will suit some people.

When it is preferable, in all the circumstances, for someone who is disabled to have their own home now, or continuing to live at home is not desirable or practical, there are a number of ways families may be able to acquire another property at a modest cost.

Housing is only part of the story. For most people to be of any value a suitable support package will also be needed. This is why it is important to work with Social Services and if possible secure their agreement to funding the long term care.

A common question is "who will care"? The short answer is Social Services (or Health). They have a legal duty first to assess the care needs of a disabled person, second to provide for the assessed needs. Financial resources of course come into this - in shaping the eligibility of criteria set by a local authority. The local authority is required to take into account the person's and carer's wishes but ultimately **how** needs are met is a matter for the local authority provided that the approach chosen really does meet the assessed needs.

They **may** levy a reasonable charge where someone lives at home and receives domiciliary care. They **must** levy a charge if the person is placed in residential care. This is a first clue as to why planning around supporting someone to continue to live at home may be a good idea when there is property or other assets to pass on to a son or daughter.

- Property occupied as the principal residence does not count as an asset for the purposes of Income Support. Property is one of the very few ways of making long-term financial provision for a relative in a way that does not affect benefits
- It is "natural" to want to continue to live in the person's own, familiar home as long as it is satisfactory. In addition, for some people with learning disabilities adjusting to change is extremely difficult. To stay in a familiar property, in a familiar area, where the person is known by neighbours is valuable in itself and contributes to quality of life.
- To have more space and facilities than would be available in the likely alternatives. Particularly true if the alternative is residential care or the family home has been adapted.
- To avoid the trauma of moving at a time when the son or daughter may have lost a parent
- To give certainty about the future
- To give greater security and sometimes a level of informal support from neighbours

Reasons people give for not using the family property are:

- Too large, inappropriate, costly to run or maintain. This is particularly a concern for Social Services who fear they may be left picking up the bill
- Concerns about costs, logistics and risks of independent living. This is not an issue about the family home per se more about the concept of independent, supported living
- Sharing may be desired or proposed by Social Services for economic reasons or to combat social isolation - but there is an issue of lack of security of tenure for the sharers. (In essence the problem is that if the son or daughter owns the property directly in some way those who live with them may be treated as lodgers/licencees with little security of tenure)
- The family home may not feel the same without the family
- Problem of ongoing management and maintenance
The issue is who will organise these things and where will the money come from?

What are the options?

When it is decided that the best way forward, in all the circumstances and taking into account the disabled person's wishes, is to plan around the family home (or set up the son or daughter in a second home owned by the parents) what are the possibilities?

The best alternative depends on:

- Family circumstances
- Aspirations of the son or daughter
- Social Services (or Health) willingness or ability to fund a suitable support package
- Availability of alternative ways of providing support

The main possibilities for an **owner occupier** family are:-

- Disposal to a third party - by gift or sale
- Pass on to son or daughter who inherits directly
- Place the property in Trust

For some there is also the possibility of buying another property (rather than passing on the family home) which may in the long term be dealt with in the same way but in the short-term can be rented to a son or daughter. Rents may be eligible for housing benefit and can be used to repay a mortgage. Derek is used to outline the principles involved in this not uncommon approach.

Another option where parents cannot afford to buy a property outright is shared ownership where you buy part of a property and rent part from a housing association. So for example, if a family cannot afford £80,000 to buy a property outright they might be able to afford say half at £40,000 (Simon is an unusual example of a variant of shared ownership).

The main options for a family who **rent** their home are:

- Succession
- Joint tenancy
- Granting a new tenancy

We review each possibility in more detail in the rest of this chapter.

Options for families who own their property

When considering long term financial arrangements families are advised to prepare a will. The family home is usually the largest single asset. This can either simply be sold and the proceeds become part of the "estate" or the property can be inherited by someone else.

If the property is sold then the disabled relative may be given a share in the estate to use as they wish. The problem is that unless the money is quickly used to purchase another home the effect of the inheritance (if it is more than a few thousand pounds) will be to stop payment of income support or housing benefit and relieve the local authority of the duty to fund care (or prompt an increase in charges) until such time as the capital falls below the relevant financial threshold levels e.g £3000 for full income support.

If instead the property is inherited with the intention that it continues to be occupied by the disabled relative then the various benefits of continuing to live at home may be realised.

In addition the advantages of direct inheritance are:

- Legal capacity is not required - anyone can inherit - as no contract involved
- It avoids the trouble and expense of having to set up a Trust
- You do not have to find Trustees
- There is no doubt as to how discretion will be exercised by Trustees (see below)

The disadvantages and risks are:

- The disabled son or daughter may be unable either to carry out management and maintenance themselves or legally to contract with anyone else if legal capacity is in doubt
- Unless there are other funds held in Trust paying for major repairs may be problematic
- The property is more vulnerable to financial claims from Social Services who may seek to levy charges for services against the value of the property

Two other possibilities families enquire about are first not making a will or, second, leaving everything to other relatives on the basis that the "State will provide"

These are not recommended strategies.

- The court of protection may appoint a receiver whose decisions may not accord with family wishes if someone dies "intestate" i.e. without a will
- The Department of Works and Pension or the local authority may make a claim under the Inheritance (Provision for Family and Dependents) Act 1975 where the division of an estate excludes a disabled relative who would normally expect to share in the distribution of assets

Where an estate is divided leaving insufficient to purchase an alternative home outright then shared ownership may be an answer. Shared ownership is mainly offered by housing associations and you buy between 25% and 75% of the equity.

Discretionary Trusts

Discretionary Trusts have increasingly been seen as a key mechanism for making long-term financial provision for disabled relatives. Discretionary Trusts are a legal way of putting assets - money, shares, property - aside for a "beneficiary". Advice of a solicitor with expert knowledge of Trust law is required. To work in the way intended **Trustees** must have

discretion as to how funds are used, the beneficiary should not be the **sole beneficiary** and must not have a **right** to either the capital or income of the Trust.

Key advantages of putting property in Trust are:

- Further protection against a local authority levying a charge on an owner i.e protects the asset
- One of the few ways of holding assets that do not compromise entitlement to benefits or local authority's responsibility to provide care. This is fundamental to why Discretionary Trusts are used.
- Trustees can contract for management and maintenance on individual's behalf (also assist with other arrangements)
- May be additional funds to pay for maintenance put into Trust

Reasons for not setting up a Trust include:

- Unable to find reliable, suitable Trustees. Ideally Trustees should be comparable in age to the disabled relative - this can be difficult to arrange
- Concern that the son or daughter does not have a **right** to what is held in Trust
- Fear that Trustees will use their (legitimate) discretion to benefit people other than the son or daughter or use their discretion to withhold payments from the intended beneficiary

Although these are all real difficulties there are relatively few other ways of making financial provisions that do not have the effect of removing entitlement to welfare benefits and care.

Although none are perfect there are some safeguards that can be considered to ensure the Trust funds and property are used properly:-

- Give a letter to Trustees setting out the settlor's (relative's) wishes and intentions in establishing the Trust. Note however this is not legally binding
- Only appoint Trustees who agree to follow the guidance given in the letter
- Have at least two Trustees
- Have one Trustee who is **not** a family member
- Give a copy of the Trust deed and letter to the local authority care manager so this can be put on file and Social Services are aware of the terms and value of the Trust.
- Also give a copy to an independent organisation or advocate
- Explain the terms of the Trust to the son or daughter if possible
- Involve the son or daughter in the selection of Trustees if possible and make sure they know who they are

As the possibilities of Discretionary Trusts are not always fully appreciated three examples are included. Each case also illustrates other useful mechanisms. The cases are Sally, Alison and Peter.

Disposal

The last possibility to consider here is disposal of the property by gift or sale to a third party. Most commonly this is a housing association but it does not have to be. It could be any

relevant charitable organisation or private company or even another member of the family.
The routes are:

- Gift to Registered Social Landlord (RSL) - or other landlord who may use equity to fund management, maintenance and possibly provide support
- Sell outright to RSL (or other landlord) who then let to the son/daughter - who may be eligible for Housing Benefit
- Long lease to RSL (or other landlord) for a capital sum - the property value will be less than vacant, open market value. There are some examples where parents have moved out to enable this to happen and get sons or daughters settled alone or with others sharing while the parents have themselves moved to a different property which is now more suitable for them. Alison is an example of this decision by her parents and the careful planning involved.

Sale may in practice be difficult: few willing buyers, tenanted property only worth half vacant open market value, maybe unwilling to continue to house son/daughter, conditional on Social Services guarantee on care.

Rented Property

We turn now to how the family home can be secured for the long term when it is rented by parents rather than owned.

In order to check the legal position it is first necessary to know what kind of tenancy the family hold. This is primarily determined by the type of landlord. In broad terms landlords will usually offer these tenancies:

- Local authority - secure tenant
- Housing association - assured tenant
- Private landlord - assured shorthold tenant

The key pieces of legislation are:

- S.87-90 of the Housing Act 1985 - secure tenants
- S.17 of the Housing Act 1988 - assured tenants

Secure tenant - son or daughter who “occupies the dwelling house as his only or principal home at the time of the tenant’s death” **can** succeed **but** only one right of succession. So for example if the parents were tenants, the father dies and the mother succeeded to the tenancy there is no further right of succession

Assured tenant - right to succession by partner only **not** children. However the Housing Corporation says if another member of the family lives with the tenant for a year before their death the housing association should grant a tenancy if:

- person requested it
- it meets an appropriate housing need

Assured shorthold - children have no rights to succession. Landlord can give 2 months notice and regain possession

So what if there is no right to succeed?

- There is nothing in principle to prevent a landlord granting a new tenancy **but**
- Legal capacity is sometimes an issue - landlords differ
- In theory some forms of tenancy could be assigned. In practice secure tenancies can seldom be assigned and assured tenancies only with landlord's consent (if not already prohibited in lease)

In terms of planning, a good option, if the landlord will agree, is for the disabled person to be made a **joint tenant** giving them long term rights (John case study).

Chapter 2 John - Continuing with a Council Tenancy and Obtaining a Joint Tenancy

Introduction

This example is used to explain how a disabled person who does not have a right to succeed to a tenancy may nevertheless be able to carry on living in the family home. It uses the granting of a joint tenancy by the landlord - in this case a local authority - to secure future housing.

Personal Circumstances

John is 65 and yet still being looked after by his mother. Not only is his mother of a good age she is in poor and deteriorating health. Heart problems are forcing more frequent and extended periods in hospital.

Until these enforced absences John's mother "*did everything for him*". The extent to which John may be able to look after himself is consequently uncertain. John seldom speaks although he has made it clear he would very much like to continue living where he is. He has some difficulty in walking and using one arm so a stair lift was installed to enable John to get upstairs to his bedroom and the bathroom.

John lives in the London borough of Lambeth which, imaginatively, has a Senior Practitioner (an experienced and more senior Social Worker) dedicated to assisting families with carers over 70 to put in place long term plans for adult relatives with a learning disability. With a case load of 12 this unusual specialist has learnt that housing is central; also about wills, Trusts, benefits, legal capacity and similar topics necessary to put in place credible, secure plans.

Until the family made contact with the borough's pilot programme the family had assumed that when his mother could no longer provide care the only option would be a move to a residential home. Realisation that there were other possibilities was a considerable relief to John's mother.

Housing

John's mother is the tenant of a two bedroomed council house on an estate in Lambeth. The family have lived in the same property for over 30 years and so are well known in that community. Some of the neighbours will look out for John and help to mitigate risks that might arise if he were moved.

Local authorities issue what are termed "*secure tenancies*". Under the legislation that applies to such tenancies John might have a right to succeed to the tenancy provided there has not been a previous succession. Originally the tenancy was held by the parents jointly but on the death of her husband the mother succeeded to the tenancy. This extinguishes any rights John might otherwise have to take over the tenancy on his mother's eventual death.

The age and deteriorating health of John's mother prompted the Social Services based worker to discuss the best way of ensuring John could continue to live in the family home, having ascertained that this was the preferred option and that there were some distinct advantages to this way forward.

The main alternative considered was a residential, adult placement.

It was decided to investigate whether John could become a **joint tenant** with his mother. No questions of legal capacity were raised and this common sense approach was formalised by the housing department writing to John granting him the tenancy. This was the imaginative and very practical route to securing John's future housing.

The process essentially involves the Housing Authority (the housing department in an unitary authority) acknowledging the relatives as joint tenants. Arrangements were assisted by John's support worker. She explains the steps like this:

"First I rang housing and asked how John could be put on the Tenancy Agreement.

What was needed was a letter addressed to John at that address, to show he lived there, this was a problem as John never received post addressed to him, everything went through his mother.

I rang Glasgow where John's benefit comes from and they agreed to send a letter stating that they had always paid his benefit to that address. Unfortunately, this is where the hold up occurred, they had a backlog of work and it took several phone calls over several weeks to get an answer, but a letter eventually arrived for John (copy on file).

I then wrote a letter on behalf of John's mother to housing (letter explaining John resides with mother and requesting he "becomes an authorised occupant and that his name is placed on the tenancy agreement") and enclosed the letter from the benefit office. Within weeks they had replied by letter to John, allowing him to become an authorised occupant (copy on file)".

Support

There are in effect two care plans. First, the arrangements that exist now for both John and his mother and second the long-term plan for when John is left on his own.

At present the family get two kinds of support:-

- i. Homecare from the local authority's own team amounting to 1½ hours per day. The Homecare staff come in early in the morning to help John get up, wash and have breakfast and again in the evening to settle John at bedtime.
- ii. Mencap provide 12 hours per week to help John get his benefits, manage his money, shop and participate in some social activities.

It is an explicit part of the plan that the support agencies operate flexibly in order to adjust support according to the health of John's mother. John has occasional respite care which he dislikes. During the week John also goes to a day centre and the long-term plan assumes that this will continue.

The nature and level of care varies according to the mother's health and until recently the mother received one package of care and John another. One of the things that the specialist worker has done is rationalise the support to reduce the number of different carers and agencies involved and provide a better and more rational and economic provision.

The long term care plan provides for the following support:

- | | | |
|-------|-------------------------|--|
| i. | Meals | To help John to prepare his breakfast Monday to Sunday
To help John to prepare his supper Monday to Sunday
To help John to prepare his lunch Saturday and Sunday |
| ii. | Laundry | To help John to develop laundry skills |
| iii. | Budgeting | To help John to pay his bills and administrate his money |
| iv. | Personal care | To support John with personal care |
| v. | Shopping | To support John to buy his food for the week |
| vi. | Access to the community | To enable John to access the local community |
| vii. | Household tasks | To help John to clean his house, maintain and repair it. |
| viii. | Appointments | To help John to organise and attend his medical appointments |
| ix. | Benefit | To fill forms and to monitor his benefits |
| x. | Health | To enable John to exercise and be mobile |
| xi. | Sleep over | To be on call during the night |

The plan is to offer John:-

- 2½ hours each morning and then 7½ hours from mid afternoon until late evening during the week
- Sleep in support at night, at least initially because of uncertainties as to how John will manage alone
- On Saturday and Sunday John will have one to one support from 8am to 11 pm to assist with shopping, household tasks, supporting him to have a social life.

The plan identifies the type of support needed and who will provide it throughout a 24 hour day. It includes assistance of a support worker in the home, travel companion and sleep over cover.

Finance and care package

The cost to Social Services of John's present support package, while he lives with his mother, is £415 per week. An application is being made to the Independent Living Fund (ILF) to see if it will meet part of the cost since the local authority is contributing over £200 per week and the total cost is below the upper limit of £625.

The long term care package was costed in 2001 as follows:

Weekdays

10 hours per day at £9.05 per hour	£90.50
Sleep in	£25.00
Case management	£25.00
Central overheads	£15.00
	—————
	£155.00

The weekday cost is therefore £725 in total.

Weekends

24 hour cover is costed at £230.93 therefore the cost for Saturday and Sunday is £462.

Total care package is £1247 per week.

While this figure is high in comparison with typical residential care it reflects support to an older person who is learning disabled and physically disabled.

The cost is expected to fall over time as:-

- John learns to do more for himself. Staff have already observed John doing things his mother said he was unable to do during her periods of absence, he has just been taught to use a telephone, a *"re-kindling of old skills...."*
- The cost is based on the worst case assumptions regarding risk
- It is not clear if John actually needs sleep-in cover at night. This could be withdrawn if unnecessary
- It is possible that a dispersed alarm linked to infra-red and other monitors could play a part in ensuring John's safety.
- The house could be shared although at present there are no plans for this because it is not what John wishes. Sharing might bring costs down although it raises issues of security of tenure in relation to the person sharing.
- Central overheads and case management costs will be removed once the long-term care plan is operating satisfactorily. These alone amount to £200 per week.

The funding of support and daily living expenses is a combination of benefits and Social Services payments under contracts with care providers.

John receives the highest rate of Disability Living Allowance (DLA) both mobility and care components having just moved up from the middle rate. His mother likewise gets the equivalent Attendance Allowance. DLA is for people whose care needs are before pension age, Attendance Allowance is the equivalent for an older person. Neither benefit is means tested and receipt depends on completing a complex application form and demonstrating how

the various criteria justifying payments for support are met. His mother receives a state pension.

Housing costs in the form of "pure rent", management and maintenance are met through Housing Benefit.

Support costs are the subject of an application for Transitional Housing Benefit. A high level of support could be met in this way because a large element of cost relates to ensuring John's security and assisting him to retain his tenancy. Examples of items of support subject to a THB application are:

- Identifying and assisting with remedying minor repair in the house
- Life skills training to maintain the property
- Assistance in arranging appointments e.g. doctor, dentist, cleaner
- Arranging adaptation and enabling John to use appliances
- Assistance with budgeting and paying bills and rent
- Assistance with shopping

An application for Independent Living Fund assistance as noted above is in hand. If John were to apply when he is being supported alone in his house this would not be successful because the sums exceed those the ILF will consider.

Finally, Social Services meet the balance of any care costs.

Postscript

While this example was being completed John's mother died and the plans described were put into effect and so far are working well. The THB application was agreed so that £500 per week of support is now funded through THB. This will become Supporting People Grant after April 2003.

Evaluation

Those involved with John sum up the benefits and possible risks and weaknesses in the arrangements like this.

Benefits	Weaknesses/Risks
<p>Familiarity of property, neighbours and locality.</p> <p>No trauma of moving.</p> <p>More individual support compared to residential care.</p> <p>More certainty about the future. The plan and budget are in place.</p> <p>Necessary adaptations - a stair lift - in place</p> <p>Eventually will cut the cost of alternative accommodation to the local authority.</p> <p>Possible transfer of costs from local authority to transitional housing benefit/supporting people grant.</p> <p>The arrangement has empowered both the mother and the son who is clear what he wants.</p> <p>Social Services are working with an agency who knows the client well.</p> <p>Flexibility has been possible and sound arrangements will be put in place rather than crisis arrangements.</p> <p>It avoids residential care.</p> <p>Not moving the person out of the borough (this borough has 300 people placed outside the area)</p>	<p>Concern about the overall cost of the care package.</p> <p>Concern about risks particularly at night.</p> <p>The arrangements have involved both the elderly services team and the learning disabilities team and this has presented some difficulties and persuaded the authority that better ways of working must be found for cases such as this.</p> <p>Knowing what care to provide has been difficult because of uncertainties about John's abilities and what support is required at night.</p>

Summary

In sum, there is little doubt that John is getting the kind of service he wants in the place he would like to continue to live in. In the longer term John might not stay in this property but would be offered a smaller one-bedroom flat instead. Employing a specialist care provider has been important to get consistency and flexibility in the service so that support can be adjusted up or down according to the mother's state of health. Putting in place a costed plan now has relieved both the family and Social Services of anxiety and concern while the care provider (Mencap) has been able to plan with greater confidence and also agree to lower hourly rates than normal. The pilot project has prompted the care provider to look more closely at supported living and to respond very positively to the local authority.

Chapter 3 Sally - Discretionary Trust Owning Property rented to A Beneficiary

Introduction

This is a detailed example of how property can be held in a discretionary Trust and some of the advantages of this route. It also covers:

- Housing Benefit in relation to a discretionary Trust
- The role of Trustees in arranging support
- Some legal technical difficulties that may be encountered in a disabled group sharing a property intended for family occupation

This example is in Scotland where some of the law around capacity is different to the law in England.

Personal Circumstances

Sally is 39 and has Downs Syndrome. She can speak but others find it difficult to understand her. Her mother, who was a teacher, helped her develop a skill forming words. Sally has impaired vision and wears very thick glasses to help her sight.

Despite these limitations Sally is socially skilled and outgoing. She enjoys company.

Both her parents are now dead. Sally is the primary beneficiary of a discretionary Trust administered by Trustees. The Trust is central to her housing. The Trust was established by her late mother's will.

Discretionary Trust

A discretionary Trust is a legal mechanism by which one person can make long-term financial provision for others. Assets put into a correctly drawn discretionary Trust do not belong to the "beneficiaries". The assets are held "in Trust" administered by Trustees, named by the person creating the Trust.

Defining features of a fully discretionary Trust are:-

- a group or "class" of beneficiaries, not a sole beneficiary, must be identified
- Trustees must have discretion as to how Trust assets are used
- the beneficiary must have no right to either income or capital from the Trust

When assets are held within a discretionary Trust, only payments out (whether of capital or income) will affect the means tested welfare benefits which the beneficiary is entitled to receive.

Even some payments out of a discretionary Trust will be disregarded by the Department of Work and Pensions (DWP).

Means testing is also applied by Local Authorities when assessing how much someone should pay either for living in residential care (e.g. a Residential Care Home or Hostel) and also how much someone should pay for domiciliary care (i.e. for workers supporting a person in a flat or house). Capital and income still in the Trust will not be regarded as belonging to a beneficiary who is in residential care. The law is less clear regarding assessment for domiciliary care but usually the capital or income still in a discretionary Trust will not be regarded as belonging to a beneficiary. **Even some payments out of a discretionary Trust will be disregarded by Local Authorities.**

Housing

For the past 17 years Sally has lived in a local authority owned residential care home with 14 other residents. This is described as being warm, caring, well-run with a very stable group of staff. The local authority, at the time the Trust came into being, had a policy of moving the residents out of the home into local flats or houses but implementation of the policy was very slow and the process appeared to have ground to a halt. The reason for this was assumed by the Trustees to be lack of funds. The places in the home which had been vacated by those former residents who had moved were being used for respite care.

Knowing that there was a shortage of suitable local flats or houses available for the moving-out process the home manager suggested the Trustees consider buying a house for Sally. One

of the Trustees with a long standing interest and knowledge of disability matters felt strongly that good as the care home was, it was not able to support Sally to realise her potential or become more independent and was happy to consider this suggestion. Not all the Trustees felt the same and it was not certain what Sally really preferred.

The local authority commissioned an independent body to carry out a care assessment which said Sally would benefit from a move. It suggested a move into a house shared with other people with a learning disability. This started Trustees on the path of trying to find a house for 3 people with a learning disability to share. A newly built 4 bedroom home was identified on an estate under construction. A shortage of suitable sized properties in the locality put pressure on the Trustees who wanted to proceed with the acquisition but were unable to get the local authority to commit itself to funding the care package. The local authority had begun a review of the future of the care home and were unwilling to make any decisions until the review was complete.

In the absence of a clear decision from the local authority, fearful of losing the property and mindful of their duty to act in Sally's best interests, the Trustees took legal advice on whether it would be proper to invest the bulk of the Trust fund in a property. The legal view was that as there was no certainty the local authority would fund the necessary care it was not reasonable to put the bulk of the Trust funds into the new house but that using a percentage of the fund, would be acceptable.

In order to secure the property two of the Trustees made up the short fall investing their own money on the understanding that they would be reimbursed by the Trust if the house was ever used as Sally's home.

At this point the local authority decided to redevelop the care home dividing it into 4 units and only temporarily decanting residents who could then return after it had been re-modelled and upgraded. The local authority announced it was willing to provide Sally with a care package of support to enable her to live in the property with others with a learning disability, but only if a housing association was brought into the arrangements. It was envisaged that the housing association would lease the property from the Trustees and grant tenancies to Sally and the other sharers.

The housing association was willing to become involved only if it owned the property outright. The neighbours heard of the proposed sale of the property by the Trustees to the housing association and were very angry. They put a petition to the estate developer requesting that the developer ban such a sale. The neighbours were not against Sally living in the house on her own without the involvement of a housing association. The dilemma now became whether Sally should move in to live alone (i.e. without other sharers) with new support staff or eventually return to the care home, with the residents and support staff she knew. Sally was worried.

The process of Sally reaching a decision involved:-

- Sally making a list of all the people she knew who she wanted to help her decide
- Inviting them to a large meeting - about 40 people. This included friends of Sally's deceased parents, relatives, the three Trustees, and two of Sally's friends with a learning disability with their parents and was facilitated by an advocate provided by a charity which the Trustees had contacted for help

- Many were concerned that, as Sally was so convivial, living in the house with merely one support worker would be too quiet
- As is often the case many were concerned about safety and security of living independently. However, one of Sally's friends who also has a learning disability who had had experience of the Care Home as respite spoke out saying how "boring" the Care Home was and that Sally should "go for it".

This was the decision and the basis on which the future was planned.

Problems with the house

The above description of the sequence of events has mentioned only briefly two specific housing issues that may be faced by families replicating the process of acquiring property through a Trust.

1. Who owns the house and status of residents

The original proposal was that Sally would share with a small number of other people with a learning disability. Sally is however the intended beneficiary of a Trust which owns the property. It is not uncommon in circumstances like this for local authorities to be concerned about each resident having equal security of tenure and equal treatment.

In this case the local authority proposed that the Trustees sell the house to a particular housing association. The association would then be the landlord and grant licences or tenancies to each resident. The housing association can then take over the day to day management and maintenance of the property. Disposal to a housing association would also of course replenish the Trust funds.

The immediate neighbours had met Sally and appeared happy to have her living next door but the introduction of a housing association into the equation prompted considerable opposition to the sale. The feeling, reflected in the neighbours petition, was that the housing association would inevitably let to "undesirable" people.

2. Property Deeds

Families considering buying a property for a small group of people to share together must read the property deeds carefully. In this case they contained a clause which read:-

"Each dwelling house shall be used and occupied as a private dwelling house and each plot shall, so far as not occupied by buildings, be used as garden or amenity ground and for no other purpose whatsoever and shall remain unbuilt on in all time coming and no dwellinghouse shall be sub-divided or occupied by more than one family at a time".

It also prohibited using the property for a business. The existence of the clauses were known about before the property was purchased. However, it would be impossible in practice to persuade a developer to amend such a clause (which applied to every property on the

development) It was felt any other new build development might well contain some wording capable of giving rise to similar problems.

The neighbours used this clause, through the threat of court action, to block the sale to the housing association.

The point at issue was whether occupation by 3 or 4 unrelated people would be occupation by "more than one family at a time". Legal advice was that there has not been a relevant case that has gone to court to establish with certainty the interpretation of clauses like this.

"People with a mental handicap seldom live alone and, if able to live in the community, often share their home with others. Problems arise when there is joint occupation of a house subject to a restrictive covenant that it may only be occupied as a private residence, especially if the covenant also states "in the occupation of a single family". It is essentially a matter of interpretation, and the authorities show that it is a question of fact and degree in each case whether the arrangements for occupation constitute a breach of the covenant. Relevant factors include the number of residents and degree of performance of occupation, the relationship between them, whether any payment is made and its nature, whether the owner or tenant is in residence and if not whether other people supervise the residents."

(Mental Handicap and the Law, Ashton, G and Ward, A, Sweet and Maxwell, 1992)

There have been court cases involving people with a learning disability in supported housing where the judgement has been that three unrelated people do not constitute an ordinary family unit and the property is not being used as a private dwelling house.

There may be an issue about whether such arrangements constitute a business prohibited by the deeds. This is why the book quoted above makes reference to payments.

The Human Rights Act 1998 might have a bearing on such restrictive covenants if they prevent a small number of people, who happen to have a disability, sharing accommodation.

The Disability Discrimination Act 1995 was of no assistance in relation to the restrictive covenant problem.

The result for Sally was that the local authority concluded they would be prepared to consider Sally living independently, on her own, with the necessary support. It was decided to proceed on the basis that the house would be owned by the Trustees, who would enter into a tenancy agreement granting a tenancy of the whole house to Sally alone. Sally would receive a care package.

Support

Support for Sally in the house is provided by a care provider organisation that specialises in looking after people with learning disabilities under a contract with the local authority.

A new care plan identified what help Sally needs throughout the day, what her likes and dislikes are and alerts support workers to some of Sally's characteristics and possible reactions to certain situations or events. The care plan had been sent to the Trustees for

comment. During 4½ days in the week Sally is involved in a variety of "day opportunities" which take place outside the house - a common situation for adults under retirement age. This means that the support required is not 24 hours a day, seven days a week.

The basis of Sally's support is first a project leader allocated to Sally's house. Second a team of four support workers, all employed part-time, who provide assistance. One objective is to support Sally to be as independent as possible in her new home and another - both written into the local authority's contract with the provider - is to support Sally in forming contacts with friends and relatives and in the community to prevent any loneliness.

The Trustees have themselves researched some equipment aiding independence. As one example Sally enjoys food and company. With support she is able to make a meal and would like to invite her friends for meals. This all becomes feasible if the cooker has design features which make it simpler and safe to use and has an eye level grill. Another example is that the showers have been changed on the Occupational Therapists advice so that the temperature is always safe. RNIB advised on how to avoid glare and achieve safety on the stairs.

Sally can read signs but not more complex text but the care plan refers for example to a "written menu". Much more helpful is the use of pictures e.g. from a suitable software programme.

Getting the right support staff can make a huge difference to quality of life. The process of staff selection was careful and well thought out and was master minded by the care provider organisation. Extending over 2 days it allowed Sally, for the first time, to play a part in choosing who would support her. It involved:

- The Trustees helping to select questions and discussions suitable for the job applicants and being present at both days
- Sally and the applicants both presenting, in pictures and words, what they liked and disliked
- Sally and the Trustees and the applicants having lunch together on one of the days
- A group discussion by the applicants around for example how the applicants would make difficult, moral decisions
- Formal interview of each applicant

Tutors, support and decision making

The Scottish legal system differs from the English in that courts can decide to confer on one or more individuals power to take all kinds of decisions on behalf of somebody who has "mental incapacity". (In England courts can only give others the right to manage money as the laws stands at present). The Trustees had no right to obtain medical information about Sally and no decision making powers about the welfare of Sally. They applied to the courts to become what are termed "tutors". The court gave the tutors some general right to give support and guidance to Sally and specific decision making powers in a number of areas including:-

- Where Sally is to live - crucial in this case
- Social activities, work and training
- Health matters including diet and exercise

- Dealing with post and communications

Documentation

The documents recording the arrangements which were entered into before Sally moved into the house were:

- The contract between the local authority and the care provider organisation specifying care standards and the right of the local authority to monitor them
- The Tenancy Agreement between the Trustees and Sally
- The Care Plan describing the day to day support

These have been mentioned. In addition there was a Management Agreement between the care provider organisation and the Trustees/tutors. This not only deals with the respective landlord/tenant support duties (as is usual) but because of the Court Order it also incorporates provisions for involving the tutors/Trustees in taking decisions within the ambit of the Court Order. Neither the local authority or care provider organisations have a free hand.

A summary of the Management Agreement setting out responsibilities of the tutors/Trustees and care provider organisations in relation to the property is reproduced at the end.

Funding

There are two elements:

- Housing and associated management, maintenance and repair costs
- Care and support

The latter costs are funded in the usual way, primarily in this case, by the local authority. The package, with the number of staff involved, is not cheap. The local authority's eventual agreement to support Sally living alone partly relates to funding becoming available after a hospital closure. The place Sally would have occupied in the refurbished care home can be taken by someone being resettled from the hospital. Sally is sociable and in the longer term there is a possibility of her sharing the house (with either a learning disabled or non-learning disabled person) perhaps producing some economies.

A careful benefit check has been carried out by an experienced welfare benefits advisor. It had two objectives. The first was to ensure that as far as possible sources of income maximised non-means tested benefits rather than means tested benefits. This was in case the authorities decide that the capital or income in the discretionary Trust should be regarded as belonging to her. The second objective was to ensure that Sally had claimed all the benefits she was entitled to, and at the appropriate levels. The non-means tested benefits which Sally receives include the middle rate care component of the Disability Living Allowance and the lower rate mobility component of the Disability Living Allowance. Income Support is paid,

including the Disability Premium and the Severe Disability Premium. The total income from benefits at March 2002 was £168.85 a week.

The housing capital funding has already been explained, it came through a Trust and the assets in the Trust came from Sally's deceased parents. The Trust **may** be in a position to get an income:

- i. Sally is an assured shorthold tenant of the Trust
- ii. The Trustees as landlords charge a rent for a furnished letting which is reviewed annually in line with the Retail Price Index
- iii. Sally has submitted a claim for Housing Benefit from the local authority
- iv. She should receive 100 per cent Housing Benefit on the eligible rent
- v. The reference to "eligible rent" reflects first, that as a private letting a rent officer will be required by the Housing Benefit office to determine whether or not the rent charged is a reasonable market rent. In this case because only one person occupies the property the rent officer must take into account the fact that the accommodation is larger than perhaps strictly necessary. Second, if the rent includes the cost of items that were ineligible these would be taken out. So for example if the rent included water or sewage charge, or heating these will be deducted. The rent that the rent officer determines is the "core rent" only (i.e for the bricks and mortar aspect of the arrangement). It does not include general counselling and support costs which at the time of writing could be funded through Transitional housing Benefit and after April 2003, Supporting People Grant.

HOUSING BENEFIT AND TRUSTS

It is not always appreciated that a beneficiary **may** be able to claim Housing Benefit in respect of a property owned by a Trust. The Housing Benefit Regulations (as amended by Statutory Instrument 1998 No. 3257) do not encourage this but in practice it is possible. However:

- The letting must be on a "commercial basis" i.e. arranged as any other private sector letting with proper tenancy agreement
- The Housing Benefit administrators must be satisfied "that the liability (i.e. payment) was not intended to be a means of taking advantage of the housing benefit scheme"

Summary

One of the Trustee's files, accumulated over a 2 year period, extend to 10 feet. An indication of the difficulties that have beset trying to establish Sally in a setting that gives her more scope for self-fulfilment and independence.

Difficulties included:

- Defects in the original Trust deed - it is essential to use a solicitor who is an expert in discretionary Trusts and understands Trusts in the context of benefits and Social Care not simply in the more usual context of tax planning
- Lengthy decision making process by local authority arising partly from the fact that these situations where a private Trust provides the housing are not as common as the more usual situation where a housing association provides the housing
- Scarcity of suitable property and pressure to purchase quickly
- Court action to become tutors in order to ensure decisions could be properly taken for Sally
- Resistance of residents in a new estate to purchase of property by a housing association
- Restrictive covenants in deeds
- Problems arising from the house having to be kept safe while standing empty for 18 months.
- The Trust being liable to pay Council Tax for part of the period while the house stood empty
- Lack of certainty over entitlement to Housing Benefit

Sally moved into the house and is happy. Efforts have been made to prevent the anticipated loneliness (with success). Some of the those who were most concerned about the safety and security aspect of Sally living independently have voiced their delight with the new arrangements. Sally was accepted as eligible to receive Housing Benefit. Had she been ruled ineligible, the Trustees of the depleted Trust fund would have had problems paying for future repairs and maintenance. It would have been essential to look at other ways of obtaining some income from the house.

EXTRACT FROM MANAGEMENT AGREEMENT

SUMMARY OF RESPONSIBILITIES OF BOTH PARTIES

MANAGEMENT RESPONSIBILITIES

Summary of Management Responsibilities

The tutors will be responsible for:

1. Issuing of tenancy agreement
2. Enforcement of tenancy conditions
3. Resolving breaches of tenancy conditions
4. Liaison with the Local Authority on Housing Benefit matters

The Care Provider will be responsible for:

1. Provision of appropriate and effective care and support
2. Ensuring access to welfare advice
3. Notifying the tutors promptly of any absence of Sally from the Property
4. Sally's moving in process
5. Employment of such staff as are necessary to discharge effectively the Care Provider's responsibilities under the terms of all agreements relating to the support of Sally
6. Complying with all appropriate and necessary Health and Safety requirements in relation to the Property

FINANCIAL RESPONSIBILITIES

The tutors will be responsible for:

1. Setting and collection of rent
2. Budget for furniture replacement
3. Insuring the structure and contents of the property

The Care Provider will be responsible for:

1. Assistance with applications for Welfare Benefits in liaison with appropriate Bodies
2. Obtaining adequate employer's liability insurance, fidelity guarantees and public liability insurance
3. Assistance with Housing Benefit application forms (though liaison with the Local Authority shall be the responsibility of the tutors)

MAINTENANCE RESPONSIBILITIES

The tutors will be responsible for:

1. Maintaining the property in a tenantable and habitable condition
2. Keeping the property wind and watertight

The Care Provider will be responsible for:

1. The maintenance and repair of any appliances, fixtures or other items introduced by the Care Provider
2. Assisting Sally in maintaining the fittings and fixtures provided by the Tutors in good order and condition
3. Notifying the Tutors immediately of any repair or defect in the Property that requires to be remedied
4. Any damage, deemed excessive, to the structure, fittings or contents, including furniture, however caused by the Care Provider to the Property

Provisions for implementation of the decision making power vested in the tutors by the court order were also included in this document.

Chapter 4 Alison - Sale of Lease in Combination with a Discretionary Trust

Introduction

This is an unusual example of parents moving out of the family home allowing their daughter to establish her own life with two friends in the property. It combines:

- A lease to a housing association
- Discretionary Trust
- Significant work to the property to ensure it was suitable for three people to share

The advantages, if it can be arranged, of selling to an organisation which takes on the obligation of housing and possibly also supporting a son or daughter are:

- the family get a capital sum which can be used to increase the Trust fund or for other purposes
- when ownership transfers to another landlord the landlord can then let the property. In turn this means Housing Benefit may be claimed and management and maintenance becomes the landlord's responsibility
- if the purchaser is an RSL it may be possible to get Social Housing Grant to adapt, improve or convert the property

Selling a property outright to a third party is extremely difficult to arrange. Alison's story illustrates a variation on selling. By using a relatively short term lease some of the advantages of outright sale can still be obtained.

Personal Circumstances

Alison is 36. Born with Downs Syndrome, from the outset her parents "*were determined that she should have as an ordinary a life as possible*". Alison progressed through various schools and work preparation programmes until she got a job as a domestic assistant in a residential care home in 1986.

At a very early stage when discussions first began Alison said "*that whatever happened she wanted to live at home, to be able to keep her job and to be close to her church, the shops she used and, above all, her friends and the neighbours she knew*".

Alison and her parents considered a number of possibilities for when she left home including moving to a Camphill community and a small Social Services home.

One idea was that the family home be given to Social Services and become part of a cluster scheme. The Director of Social Services perceptively advised against this "*because models of provision change*" and in practice few Social Services will agree to take over properties. After a number of blind alleys a chance meeting eventually led to the property being transferred to a housing association on a lease for 21 years.

Housing

The elements are:

- i. **a discretionary Trust** was created under which the family property “*was to go into the settlement when we were ready to move out or on our deaths under the terms of our will*”. The Trustees were two of Alison’s brothers, a college tutor and a fourth independent person with a housing background. The two brothers are also beneficiaries and Mencap is the residual beneficiary.
- ii. **training** - a programme of 25 weeks independent living skills training was arranged in the family home. This was funded by the Cadbury Trust. It covered cooking, shopping, budgeting, cleaning, laundry, ironing. At the conclusion Alison made her own breakfast once a week and cooked a family meal once a week.
- iii. **lease** - Alison did not want to live alone but to share with two other people. The house needed substantial alterations costing £25,000. Neither the parents nor Trust could afford this. If a housing association owned the house they could apply to the Housing Corporation for Social Housing Grant to make the necessary changes. To achieve this the property was transferred to the Trust and then leased to the association for 21 years.

The association paid the Trust £20,000. This is about a third of the open market value of the house. The Trustees retain the deeds of the property.

“This arrangement was likely to give Alison less security and was one of the most difficult parts of the lease to finalise. Enormously complex issues arose, not only over Alison’s security of tenure and the position of other tenants but also over the responsibility for her care and what would happen at the expiry of the lease.”

The works were duly carried out over a period of 5 months with the family still in residence so Alison did not have to move out then move back to an altered house alone.

- iv. **care** - Social Services would not commit themselves to a care package in advance of the home being set up. As a fall back the lease contains a provision to the effect that the association “will use its best endeavours” to secure suitable care and support for the residents.

Support

To enable the parents to move out Community Service Volunteers were recruited to support the tenants during the first two years. Their term of service was the normal six months so there was a succession of volunteers of varying ability. This was unsettling for the group. The housing association was eventually able to find the funds to employ a project leader specifically for Cherry Road. The project leader provides three hours support a day to the group.

This arrangement works much better. The project leader helps with a range of practical tasks, motivates personal and house care, helps to build relationships and resolve difficulties between residents and provides emergency cover adding to security.

The group do not now need anyone sleeping in at night. The early and continuing emphasis is on intensive training in living skills and achieving independence.

Residents

One of the other residents was a school friend of Alison's, the third was awaiting a move from a Social Services hostel and moved in supported by the Social Services Outreach Team until, after six months her own separate flat was ready. In her place came Teresa whose mother had died. She needed a homely but independent, place.

Funding is based on Social Services support for Alison and one of the other residents combined with Supported Housing Management Grant (SHMG) paid to the association. The third resident gets no support from Social Services. (Under Supporting People SHMG will disappear but should be replaced by equivalent funding via the local authority).

Outcome

Her mother sums up the outcome like this:

“Alison is delighted to be living independently with her friends. The independence has given maturity to all three tenants... people with learning disabilities can live their own lives happily and safely provided they have security.”

Alison's Own Story

My parents thought I needed to live independently before they got very old and died.

I did stay at Camphill Rudolf Steiner House sometimes. They did not have a TV and I would miss my job, friends, my church and church friends, won't see much of my brothers, parents for tea, lunch and Oxfam lunch. I wanted to carry on living at Cherry Road where I was brought up.

The planning lasted 5 years. We had meetings with Bob Clayton at Calabria Housing about living skills and the past. Dick Hornby (he is the Director of Calabria Housing) looked round the house to decide about the alterations and the Trust. William, Michael and John are my Trustees. I was excited.

I needed training in living skills. My parents helped me first. Then Pamela Jones from the local college of further education came to do cooking, budgeting and ironing. The Cadbury Trust paid for this in February 1994. In 1995 before the building started, Cally and John arranged more training for me and other people at college. First day was the taster day, shopped, cooked then Peter Frail's course.

Mr Hutton the architect made plans for the house. We needed a bigger kitchen and laundry. December 1995 in the snow the building started. Mr Hartwright and his merry men came every day at 8.00 in the morning. We gave them coffee. It was noisy and dusty. They changed everything. We moved round where we ate out meals. One was in the sitting room on the tray and on the card table in the kitchen with the Mencap President. I liked the new kitchen best but the bathroom was terrible because the tank overflowed and the water boiled. It was the electrician's fault.

While this was going on, Patience and I went with Nora to a furniture shop for Patience and another tenant's bedroom and the little bedroom. Cally Bilson helped us with the curtains. Liane Walker helped us with the carpets. Chris Garvey took us to Sedgley to buy electric goods. Calabria had to

pay for it all.

Calabria helped Patience to live at Willow Road and Sue Smith came in June till January. After that Teresa Nash moved in to live with us in the summer of 1997. We are all tenants of Calabria Housing Association. We all do like to live independently. We did not like changes of volunteers and losing Val but she comes round to see us and Lucy came last Christmas. It is now better with a dedicated support worker, Ada Roston. She comes in and out nearly every day.

When my Mum and Dad moved out I was excited and I wanted to get my freedom. When the volunteers came, we had to do what we are told still. I felt nervous without mum and dad, but I am OK.

Summary

It can be difficult if not impossible to sell a property to a Trustworthy person or landlord on condition that a son or daughter will remain as a resident. There are very few suitable organisations prepared to purchase. Those that are will only be prepared to pay a value based on acquiring with a tenant in occupation. Tenanted value will only be about half the vacant possession value. A charitable organisation is obliged by charity law to pay only the market value.

Gifting rather than selling a property to a social landlord or charity on condition it is managed and maintained and the son or daughter will be supported to remain a tenant for as long as the property remains suitable is another possibility. This is done but may not be acceptable where there are other relatives who should inherit.

Alison's story provides an example of a compromise route to securing suitable long term, housing in the family home:

- Management and maintenance will be provided by the housing association who will also take a long term interest in the support and welfare of Alison and the other residents
- The Trust receives a capital sum. Alternatively the parents could use the premium paid for the lease to help purchase a different property
- The arrangement provided a means of funding adaptations at no cost to the parents or Social Services
- In the long term the reversion of the property to the Trust means that other beneficiaries or siblings can ultimately benefit/inherit.

Footnote: A version of Alison's story also appears in "*Family homes*" published by the Mental Health Foundation

All the names including that of the housing association and some details have been changed.

Chapter 5 Peter – Purchase by Discretionary Trust and Income Support Mortgage Interest

Introduction

Peter is an example of someone considered fairly severely disabled, who challenges services to some extent who has made the transition from hospital to live independently. An unusual feature is the combination of a discretionary Trust with Income Support Mortgage Interest payments (ISMI).

Personal Circumstances

Peter is 35 years old and for the last four years has lived in his own home with his own team of support staff, managed by a small care provider, Inclusion Glasgow, which specialises in person centred support in people's own homes. His home is owned by a Trust that was set up for the purpose of buying Peter a suitable home, within easy range of his family and managing the support needed to help him live there.

Prior to this, Peter had lived in Lennox Castle Hospital from the age of 13. Lennox Castle Hospital is a large long stay hospital set in its own grounds a few miles from a small village, some 20 miles outside Glasgow. It is in the process of managing a closure programme scheduled to complete in March 2003.

Peter lived in a hospital ward with 14 other people with learning difficulties, all described as having challenging behaviour, which means they might do things which are difficult for other people to deal with, for example, punch, bite, hit, shout.

After a full assessment and detailed work with Peter and his family it was agreed that he was in urgent need of resettlement from the hospital to a home of his own where an individualised package of care could be delivered and where he could develop a sense of ownership and control of his own environment. Peter has a cognitive disability and a severe visual impairment.

After moving to Lennox Castle Hospital, Peter seemed to lose a lot of his skills. For instance Peter used to sing songs, speak quite clearly, have good eating habits, put things away after himself. He used to be able to count to twenty and had begun to name things. He could set the table. He was, and is, a young man who likes peace, music, the countryside, walking, and privacy. But he lived on a crowded ward, spending only a few hours a week outside it.

Peter had acquired a 'reputation' as someone who bites. In general people have found it useful to think of Peter's biting behaviour as a form of communication. Peter used very few words and had little opportunity to express himself.

Peter requires support and prompting with eating, dressing and washing. He can and has to go to the toilet by himself but does need help afterwards. He only used one word regularly – toilet – although he used to have many more words. He does not use a formal communication system.

Housing

It was decided that in order to be successful, Peter would need the following:

- A home where Peter could be secure and not moved on if other people did not get on with him; nor should he share a home or any other environment with individuals who have unpredictable behaviour or who are noisy or unlikely to be able to appreciate Peter's need for privacy.
- Space for one or more people to live with Peter, to provide him with support and make sure he is safe.
- A home with a large space for Peter to be safely on his own, including his own toilet facilities.
- A home near the countryside, a quiet place, preferably detached with a garden.
- A location convenient for family to visit.
- Predictable life and daily routines predictable to ensure he feels secure.
- Time to develop Trust and not be supported by people he has not had time to get to know.
- Consistent supports from people who know him well and respect him.

Peter has a family who care deeply about him and his future, and Inclusion Glasgow, the care provider, wanted Peter's family to play a central role in determining his future and using their expertise to advise on the ideal home and support arrangements for Peter.

To meet Peter's needs he clearly needed a large house, in a safe area, with at least 3 bedrooms, ideally two public rooms and two bathrooms. This was needed to accommodate live in carers and meet Peter's need for space. It was felt best if Peter lived somewhere easily accessible by rail for his parents and close to his sister and her husband who live in. It was also important that Peter lives somewhere that is fairly quiet, with good access to the countryside.

Such property is very scarce within the social rented sector and it is most unlikely this could or would have delivered what was needed. Inclusion Glasgow and the family therefore looked to the owner occupied sector, where property of the size and type required was available within the cost limits of the Income Support for Mortgage Interest system.

Support

The preferred service model for Peter's support arrangements, which affected housing requirements, was

- 1 or 2 live-in carers to support Peter at home, who are there most evenings or nights and who are paid but who could also be tenants of Peter,
- 1 to 3 people who are employed to come in regularly to support Peter with activities in or outside the house.

Legal and Financial Arrangements

Peter was felt not to have sufficient capacity to contract and it was decided that the best arrangement for decision-making was to set up a Trust.

Peter's family therefore set up a Trust to act on Peter's behalf where he cannot make decisions for himself. The Trustees include family members and professionals and has the powers to:

- Recruit and employ staff
- Monitor and make key decisions about Peter's service
- Purchase and manage a house for Peter
- Take out mortgage or other loans in order to purchase a house for Peter

The Trust works in partnership with Inclusion Glasgow to manage an Individual Service Fund (ISF) for which the annual revenue is approx. £60,000. This fund is the statutory funding required to pay for the continuing support Peter requires. It is made available to Inclusion Glasgow under contract to the City of Glasgow Social Work Department. Greater Glasgow Health Board (GGHB) transferred resources to the Social Work Department for Peter's care in perpetuity. This Individual Service Fund is for care and support costs.

The Trust decided that home ownership was in the best interest of Peter and sought to enter into a mortgage on behalf of Peter. Legal title and strict liability for interest payments on the loan lies with the Trust, which considers Peter to be the beneficial owner.

Financial Issues

Peter had no private financial resources so could not provide any capital for a deposit or to cover other costs associated with house purchase. Because of the need to find alternative accommodation, Greater Glasgow Health Board offered assistance with the deposit and fees required to purchase the house.

Inclusion Glasgow worked up a proposal in partnership with The Royal Bank of Scotland whereby the Royal Bank of Scotland agreed to consider the Individual Service Fund as if it was personal income for Peter (or the Trust on his behalf) and it offered to provide an interest only mortgage in these circumstances. Inclusion entered into detailed discussions and correspondence with the local DSS about the circumstances and was advised that although the Trust and not Peter would be liable for the mortgage, Peter should be entitled to Income Support Mortgage Interest. The DSS (now DWP) did however advise that the 39-week waiting period would be applied, as Peter was not at that time in receipt of Income Support, because he was a hospital resident.

Income Support Mortgage Interest (ISMI)

Income Support can help with interest payments for a mortgage. There is an upper limit of £100,000 on the size of the mortgage that will qualify for the interest payments to be met by Income Support. A person may qualify for Income Support Mortgage Interest if they meet the following 3 criteria:

1. The person is eligible for Income Support;
2. The person is disabled, and;
3. They need to move to alternative accommodation more suited to their needs

You must have been in receipt of Income Support for a continuous period of 39 weeks or more before you can qualify for Income Support Mortgage Interest payments.

The funding equation is set out below:

Costs

House Price	£84,500
Legal fees and expenses	£ 1,484
Stamp duty	£ 845
Valuation fee	£ 175
Provision for 39 week waiting period	£ 3,948
TOTAL	£90,952

Sources of finance

Mortgage loan	£73,600
Health Board contribution	£13,404
Inclusion loan (if needed)	£ 3,948
TOTAL	£90,952

The Trust took out a mortgage loan, funded by the Royal Bank of Scotland, and on the basis that Peter would receive Income Support Mortgage Interest, this would be paid to the Trust so that it could meet the mortgage repayments. At no point were mortgage payments included as part of the costs which would be required to be met from support package, all of which was required in order to fund the care costs.

Problems

The Trust went ahead and purchased the house in October 1997 and Peter moved into his new home in January 1998 and claimed Income Support and housing costs from that date. Prior to this Inclusion Glasgow paid the mortgage payments so that no arrears would arise prior to Peter moving in. Inclusion was advised by telephone in March 1998 that the mortgage would be paid from 13 October 1998 allowing for the 39-week rule. Inclusion had made provision for this in the form of a loan to Peter that he would repay over several years as he could afford it. In April 1998 Inclusion appealed the decision regarding the 39-week waiting period. However the appeal was rejected because Inclusion was not the DSS appointee. The Appeals Service later decided that the appeal could be treated as valid.

No housing costs were received and in October 1998 (after what Inclusion Glasgow assumed was the 39 week waiting period) Inclusion wrote to the DSS enquiring about housing costs and were advised that a decision had been taken in the February that Peter was not liable for the costs and that as Inclusion had made payments prior to January 1998, Peter was not entitled under Para 2(1) (b) to receive Income Support Mortgage Interest. This decision had not been notified to Peter, the DSS appointee (Peter's sister who is also a Trustee) or to the care provider.

Income Support (General) Regulations, Sch 3 Para 2(1) (b) says that where the person liable to meet the housing costs is not meeting them, then the claimant (in this case) has to meet those costs in order to continue to live in the dwelling, and it is reasonable in all the circumstances to treat the claimant as liable to meet those costs.

This decision was further appealed in November 1998. The appeal was not heard until November 1999 and then adjourned for a further submission on specific legal arguments raised at the tribunal. These proposed that Peter should be treated as liable for the mortgage costs under Para 2 (1) (a) of Sch 3 to the 1987 regulations. The tribunal also sought medical reports on Peter's incapacity seeing this as particularly relevant in this case. A further hearing took place on 20th June 2000 and this time Inclusion Glasgow, acting as Peter's representative at the tribunal, presented Counsel's Opinion on the circumstances.

Income Support (General) Regulations, Sch 3 Para 2(1) (a) states, "A person is liable to meet housing costs where – the liability falls upon him or his partner but not where the liability is to a member of the same household as the person on whom the liability falls."

The legal arguments presented by the Welfare Rights Officer and covered in the Counsel Opinion related to Scottish Law principles and doctrines of recompense and "negotiorum gestio". Put simply these argue respectively that:

- i. The Trust is entitled to recompense from Peter because 'Where one has gained by the lawful act of another, done without any intention of donation, he is bound to recompense or indemnify the other to the extent of the gain'. It was clear from the documentation that the intention was that Peter should pay the mortgage interest via Income Support.
- ii. The Trust is acting as negotiorum gestio. Broadly speaking this is a legal term covering a situation where action is taken on behalf of someone in their absence and without their knowledge but on the basis that the person would have approved the action if they had been aware of the circumstances. The 'gestor' has to act from altruistic motives intending to benefit the absent person but must also intend to claim reimbursement of expenses – i.e. there is no presumption of an intention to donate the benefit. The Counsel's opinion was that in all the circumstances surrounding the Trust's acquisition of property and taking out a mortgage for Peter, it could be argued that this principle applied even though the Trust would also benefit from its ownership of heritable property.

The Counsel opinion pointed out that there was no case law using either of these doctrines in circumstances similar to this case but that it was arguable that the elements of these doctrines were met such that the Trust was entitled to receive from Peter the mortgage interest payments for which it is liable. Peter could be said to be liable to the Trust for the payments and for the housing costs to fall on him under Para 2(1)(a) i.e. direct liability for costs.

However the start of the Counsel opinion pointed out Para 2(1) (b) expressly provides for 'deemed liability' where the person with direct liability is not paying the costs. The Trust was not meeting the costs. Rather Inclusion Glasgow, as the care provider, had met cost prior to the original Income Support claim and was still making payments on the basis of a loan and only to prevent default on the loan that would result in repossession. Inclusion Glasgow as care provider had no liability whatsoever in relation to the mortgage and the Trust, which is liable, was not and could not make payments as it did not have the resources to do.

In the end the decision of the tribunal was that Peter was eligible under Para (2) (1) (b) and Peter received backdated housing costs, backdated to January 1998. In other words it was also held that the 39-week waiting period should not be applied. This is a decision applying only to this case on its merits and it does not set a precedent. It illustrates the complex arrangements that have sometimes to be negotiated to get the right solution for the circumstances and that sometimes a degree of risk taking is necessary to make things happen. Finally how persistent individuals and organisations can be.

Evaluation

Benefits	Weaknesses/Risks
<p>This appeared to be the only way of acquiring a suitable home for Peter quickly and with the family able to be in control of choosing the house.</p> <p>Peter has settled better than in any other accommodation in his life, has made a life for himself and after the first 6 months has not evidenced the challenging behaviour that had previously earned him such a negative reputation.</p> <p>The housing solution with sufficient space for Peter and live-in carers means that care and support can be delivered at an annual revenue cost which is considerably less than the level of support which would be required in a group or shared setting which has always previously produced challenging behaviour.</p> <p>The Trust, involving family members, controls the funding of housing and it is able to provide Peter with consistent and secure housing and support even if the Trustees need to change over time.</p> <p>The mortgage interest amount paid by the DWP at today's rates, is £383.33 a month for a large detached house. The Trust is liable for ongoing management and maintenance. This is a disadvantage from the Trust's financial position. However, if Peter was renting such a property in either public or private sectors rent and housing benefit levels would have been higher than the Income Support Mortgage Interest</p>	<p>Inadvertently this was a risky approach because although the DSS had given informal advice prior to the house purchase it had not, and could not, give more than a statement of the regulations. Inclusion did not have an easy fall back position in the event that the DSS appeal was rejected and mortgage interest costs could not be met through Income Support Mortgage Interest.</p> <p>The care provider met the mortgage interest costs for a period of almost 3 years, some £12,500. This is a big commitment from a care provider, which may not have been able to recover the advance in the event of the DSS rejecting the appeal.</p> <p>There does not appear to have been any discussion at an early stage with a housing association to explore the possibility of an individual house purchase for let. Experience in other cases does suggest that this is sometimes a frustrating experience for families and might have delayed Peter's discharge from hospital. However it does have advantages that were not considered, not least a more secure financial footing from the outset.</p> <p>The process of appeal was extremely stressful for the family who were also Trustees despite the support they received from Inclusion Glasgow as care providers.</p>

Chapter 6 Derek – Renting from a Family Member

Introduction

People with Aspergers Syndrome often find it difficult to get a support service. They do not "fit" very clearly within learning disability or mental health services and not infrequently needs are denied.

Derek is an example of someone who only needs a little bit of support provided he has a reasonable house to live in. The question of whether a family can rent a property to a close relative is a common question to Housing Options and families do not always get accurate advice on what is possible in terms of assistance via Housing Benefit to help repay a loan the family may have taken out to buy a suitable property. This case is used to set out the position.

Personal Circumstances

Derek is in his late twenties and has Asperger Syndrome; with continued support from his family he is able to live on his own.

Asperger Syndrome

Asperger Syndrome is a form of autism, it affects the way a person communicates and relates to others. People with Asperger Syndrome do not have learning disabilities often associated with autism, in fact people with Asperger Syndrome are often of average or above average intelligence.

Key characteristics of Asperger Syndrome are:

Difficulty with social relationships

People with Asperger Syndrome find it difficult to understand non-verbal signals, including facial expressions.

Difficulty with communication

People with Asperger Syndrome may speak very fluently but they may not take much notice of the reaction of people listening to them. Jokes and exaggerated language can cause problems, as they can be taken literally.

Lack of imagination

People with Asperger Syndrome may find it hard to think in abstract ways, so may be very good at learning facts and figures but have difficulty with literature or religious studies.

Special interests

People with Asperger Syndrome often develop an almost obsessive interest in a hobby or collection; usually their interest involves arranging or memorising facts about a specialist subject.

Love of routines

An unexpected change in routine can be upsetting for a person with Asperger Syndrome and they often prefer to order their day according to a set pattern.

Housing

Derek's mother invited Housing Options to speak to the support group for families who have a son or daughter with Asperger Syndrome that she leads in North London. Many of the parents in the group have difficulty in finding accommodation for their children. This is due to the lack of Housing Association schemes in the area for people with Asperger Syndrome, the high rents (and housing prices) in that part of the country, and the lack of recognition from Social Services that people with Asperger Syndrome sometimes require support.

Derek used to live in privately rented accommodation. However, the arrangements were not satisfactory, as Derek required more space and an environment better suited to his needs. Privately renting also offered no long term security.

Derek's family were keen to buy a specific property for Derek that could be rented to him. This concept was taken further as a result of this meeting and a subsequent discussion with Housing Options on the different ways of securing housing.

Capital was available from a family member to finance the purchase of a property. Derek was very involved in the choice of property, and it was bought with Derek's needs and wishes in mind.

The flat has 2 bedrooms and is on the ground floor of a converted house in North London, reasonably close to his family. Derek does not share with anyone else and now has his own garden.

How renting from a family member is possible

Housing Benefit regulations state (Statutory Instrument 1998 No. 3257) that a person can only rent from a close relative if they do not reside in the same property and the property is occupied on a commercial basis.

The Regulations state, *"A person who is liable to make payments in respect of a dwelling shall be treated as if he were not so liable where.....the tenancy or other agreement pursuant to which he occupies the dwelling is not on a commercial basis.....his liability under the agreement is to a person who also resides in the dwelling and who is a close relative of his or of his partner.....the appropriate authority is satisfied that the liability was created to take advantage of the housing benefit scheme..."*

The Regulations also state, *"In determining whether a tenancy or other agreement pursuant to which a person occupies a dwelling is not on a commercial basis regard shall be had inter alia to whether the terms upon which the person occupies the dwelling include terms which are not enforceable at law."*

What this means in effect is a family member cannot claim Housing Benefit for a relative who lives in part of the family home but may claim Housing Benefit if a separate self-contained property is acquired which can be let to a person on a commercial basis. However, the Housing Benefit department have to be fully satisfied that the arrangement has not been set up simply to take advantage of the Housing Benefit scheme.

It has been decided in the courts that when considering whether a tenancy is commercial or not, the arrangements between the landlord and tenant should be viewed as a whole. The Courts are likely to decide on the following matters:

1. Is the agreement between landlord and tenant legally enforceable?
For example, can the tenant be evicted if they break the terms?
2. The relationship between landlord and tenant. Councils are advised that there is nothing non-commercial per se about letting to a relative.

3. The amount payable – this is an important factor. The amount has to be reasonable, charging too little or too much might be an indication of a non-commercial arrangement.
4. The living arrangements should allow the tenant a “significant degree of independence”, rather than the sort of arrangements between close relatives where there would be, for example, money paid for keep and sharing of household chores.
5. In relation to foster children who reach 18, councils are advised that arrangements where the foster child now pays rent should normally be treated as commercial.

A council may decide that a tenancy is commercial but that it has been set up to take advantage of the benefit system. In one Court case it was decided that where a parent or a relation had provided accommodation to someone who then claimed Housing Benefit this in itself could not prove abuse of the system. In practice Housing Options has found where there are good reasons for parents (or other relatives) to rent a separate, self-contained property to a disabled relative Housing Benefit have not objected.

If a tenant has their claim for Housing Benefit turned down they have the right to appeal against the Housing Benefit department’s decision. A request to appeal must be made in writing and signed by the claimant or their appointee within 6 weeks of the date on the letter from the council refusing the claim. The council should then review the decision and write back again to the tenant. The tenant has the right to a further stage appeal within 4 weeks of the written reply from the council. Advice from a Citizens Advice Bureau or other welfare benefits advice agency used to appeals may be helpful.

Derek has a tenancy agreement for his new flat and claims Housing Benefit to cover the rent. The rent was set at the lowest reasonable commercial rent for the area, to appease the Housing Benefit Department and to help things go smoothly. There were some concerns that Housing Benefit would not pay, however in practice this was not a problem, although there were discussions between Housing Benefit staff and the family. A solicitor's letter was written confirming that Derek would be a tenant, that it had been arranged through the appropriate channels to satisfy the requirement that it was a commercial arrangement, and that he would not own the property.

Support

Derek receives Income Support and Disability Living Allowance, both the care and mobility components. However, he receives no support from Social Services as the Local Authority in this area do not see people with Asperger Syndrome as a priority.

Derek, although a very able person, needs some support for skills such as cooking a meal, budgeting for shopping and bills, what to do in unexpected circumstances and general emotional support and advice.

Problems

One of the few problems that they came across were due a misunderstanding with the Department of Social Security regarding the change of address. This resulted in all of Derek’s benefits being stopped, and the inconvenience and wait for them to be re-instated.

Summary

In Derek's current living situation he has good security of tenure, and is living in a property that was chosen for his needs and wishes. However, the lack of Social Services support and recognition means that he is still reliant on his family for all of his support needs. Derek's family would like, as a long term goal, Derek to be financially self-reliant.

Chapter 7 Simon - Tenant with sum of money invested in a charity to obtain a house to rent

Introduction

This example is used to illustrate the kind of imaginative thinking that some dedicated organisations are using to try and meet individual circumstances. In this case the individual concerned had access to a sum of money but not sufficient to acquire a house 'outright'. The answer was to set up a form of equity sharing under which Simon is a tenant paying a reduced rent because of his capital investment.

Personal Circumstances

Simon has a moderate learning disability and is partially deaf. The two disabilities together can make life extra hard for Simon, as due to his learning disability he is unable to use some of the coping mechanisms that are usually available to the deaf, such as sign language. However, Simon does cope well and is a good lip-reader.

Simon has a part-time job with a well-known retailer. He works 12 hours a week and claims Job Seekers Allowance. Simon receives DLA at the lower rate for care and mobility.

Background

Simon's father died when he was 13 years old and left money for him in a Trust. The money in the Trust went to Simon when he reached 18 years old. The Trust was not a discretionary Trust and this caused problems for the purposes of the benefits system as he was considered as having the assets so making him ineligible for Income Support or Housing Benefit.

Simon was advised by his family as what to do with the inheritance. Simon decided that he wanted to put it into savings for his future when he was 'old'. Simon was 29 years old when he decided he would like to move from home. An arrangement was made for him to live in an annexe/granny flat belonging to a friend of his mother. Simon lived there for 18 months and the arrangement was successful, giving Simon increased confidence and the knowledge that he was able to move on and live more independently. He used some of his savings to pay the rent.

Shared ownership for Simon was considered in order to invest the money left to him in a place of his own. Some housing associations would not assist as Simon did not have a high enough income of his own to cover the rent on the proportion of the property that would belong to the housing association.

Golden Lane Housing (subsidiary of Mencap) were approached as they were well known for helping people with learning disabilities to access housing in a more flexible way. They were very supportive and used their knowledge to help Simon to find a property. Simon has used his Trust to indirectly acquire a property by putting up part of the cost in a similar way to shared ownership.

The scheme is not however conventional Shared Ownership. Golden Lane Housing holds the money inherited by Simon in Trust. Simon is not an owner but has a tenancy issued by Golden Lane. The rent that Simon is charged by Golden Lane relates to the percentage of the property belonging to them i.e. the amount Golden Lane had to borrow to set up the scheme, spread over 25 years. Simon cannot be classified as an owner for the purposes of Housing Benefit. Legally Golden Lane Housing owns the property. A Trust deed has been recorded between Golden Lane and Simon, which is linked to the property. Simon was able to put forward 55% of the finance for the property and Golden Lane borrowed the other 45%.

If Simon wants to move out then a similar arrangement can be transferred to another property, or Golden Lane can offer to 'buy Simon out' at full market value. In this way Simon will have gained equity through the property on his share.

Simon together with an advocate and Golden Lane looked for a property. Simon was only able to look at one bedroom properties as otherwise, within the Housing Benefit regulations, he might have been considered as over provided for as a single person. Simon was able to consider properties wherever he wanted to live. Simon's mother made a conscious decision not to get involved at this stage. This gave the positive aspect of Simon choosing where he wanted, giving him a real sense of the property being *his own*. Simon chose a flat which is close to where he works and within walking distance of a good range of local amenities.

It took a while for Simon to settle into his new flat and he is gradually growing in confidence as time passes. When he first moved in, he would phone his mother very frequently during the day. This gradually reduced and was a sign of Simon's initial fears and anxieties about his flat; although he never said anything frightened him.

Simon lives in a small block of nine flats and there were concerns at first in respect of the other residents' acceptance of him. There were a few minor issues to begin with, mostly around things that Simon had not done, but as the new tenant he got the blame. A complaint was made by a neighbour. This was soon resolved and Simon has now formed his own relationships with the neighbours. The decision to allow Simon to establish his own links has worked well. One of the neighbours has Simon's mother's telephone number should it be needed.

Support

Simon's support worker is funded by the local authority through a domiciliary care provider, which provides support to people in their own homes, and helps to sustain them as a member of the community. Simon's support staff visit once a week in the morning to assist with things like shopping and budgeting, although there is also a social aspect to this arrangement. Simon chooses with the staff how he would like to spend the time.

He is given as much responsibility and choice as possible. Simon is very capable and is able to go shopping on his own and pay his own bills and check his own bank statements. Initially the paying of bills and bank statements was checked after him but now he is able to do this independently and is proud to be able to do so. Managing day-to-day finances has been very difficult for Simon as he has a tendency to overspend, at the same time becoming very anxious if he runs low on money. This problem is being overcome by Simon and his mother going to the bank once a week to withdraw money. Simon then puts the money into pots to

cover his different expenses – housekeeping, going out, clothes and savings. He likes to see the money in the pots grow and tends to spend less if they are well topped up. Every so often, if he has extra expenses Simon will talk it through with his mother and draw some money out of the bank. Alternatively he may do some ironing for his mother for which he charges an hourly rate equivalent to his usual earnings.

Simon sees his mother about twice a week, and they have a meal together at the weekend. Simon occasionally brings some washing over to put in the tumble dryer, and his mother will give him a lift if he is out late in the evening.

Simon has a good network of informal support. He has his own advocate and attends a self-advocacy group. As well as a social group they also provide ‘Life Skills’ training such as budgeting and safety in the home and when out and about. The group consists of about 50 people with moderate learning disabilities, and has been given a 3-year grant to provide this training.

For his deafness Simon uses a loop system within the home, with things like the smoke alarm, doorbell and a pager being linked into the loop.

A benefit of being a tenant of a specialist provider such as Golden Lane is that maintenance work is arranged, and when workmen are sent to the property they are vetted and approved. Another benefit is that there are wider links and resources, which can be made use of via the expert knowledge that a specialist provider has. Golden Lane has strong links with Mencap and use of the organisation's resources, which may prove useful to Simon in the future.

Problems

Housing benefit initially rejected the claim for Simon, saying that he did not qualify. They took the view that he was a homeowner and not a tenant. A 2-year appeal followed. Simon had made a claim for Housing Benefit and Transitional Housing Benefit to cover some of the support costs in preparation for the introduction of the ‘Supporting People’ grant in 2003.

Simon wasn't told of the appeal, as it was felt that he would feel insecure if he thought he might lose his home. During this time Golden Lane was very supportive of Simon's mother, helping her to pursue the appeal, if on his own, Simon's mother may have backed down. When the case finally went to court, the judge found in Simon's favour deciding he was a tenant.

Summary

Simon has been living in his own flat for the past 2-years. His mother admits that she thought she would never see her son living in such a way, and feels it is important to let other parents know this. Simon is able to invite his mum around when he chooses and that also means being assertive and telling his mum when he would rather be on his own.

Simon was offered the chance of sharing a flat with a friend, but opted to live on his own. He likes his own space and is happier not to have to consider anyone else; he eats when he wants, watches the TV programmes he likes and tidies up when he's ready. Simon's mother

is determined to allow him to live how he likes even if that means sitting on her hands sometimes if the washing up needs doing!

D:/Mydocuments/MencapCityFoundation/ReportSeptember02.doc