

FOREWORD

The following stories have been collected from different households throughout Scotland. Each person featured in this booklet has faced a housing problem that needed a creative solution. These personal accounts reveal how standard housing and care practices have not addressed or met individual needs and aspirations. The stories are narrated from the individual's perspective, and there is no author analysis because the problems and solutions they discuss are very clear. However, the final chapter is written by the editors to highlight issues that the stories have in common and offers suggestions for new strategies and joint working practices for finding person centred housing solutions.

The booklet is not intended to be an information guide about the owner occupied sector and disabled people. The personal accounts are intended to offer insights to disabled people, professionals, families and supporters engaged in the process of finding suitable housing and to enable and inspire creative solutions to housing difficulties. For reasons of anonymity some names and places have been changed, but the experiences and stories are true. The people interviewed were given the opportunity to contribute to the writing and editing of their story. Therefore each contributor is author of their own story and we are grateful for the hard work which Mo Simpson, Tommy Morrison and The Smith family have undertaken during the compilation of this booklet.

Tommy is a man who uses few words to speak but he is very clear about what he wants and what he means. Tommy was supported by his flatmate Adrian to narrate his own story.

CHAPTER 1 TOMMY'S STORY

Before I owned my current house I lived in Lennox Castle hospital- an old, large institution. I lived there for a long time. In fact it was for 40 years, because I went to Lennox Castle when I was 3 and left when I was 43 years old. I had to leave because the hospital was shutting and I'm not in contact with any close family so I had to think about where I wanted to live. My friend Andy, who worked at the hospital, and Jean and Neil, who both worked for Inclusion Glasgow, helped me think about moving from Lennox Castle. I was quite reluctant to move out of the hospital at first because I was worried that I wouldn't be able to see Andy. Jean spent a lot of time with me and talked to me, explaining that I would still see Andy. They spent a year talking with me and building my confidence to leave the hospital. After some time I made my decision and said 'I'll leave the hospital but I'm going to live near Andy.'

Andy lives in a small town near Lennox Castle called Kirkintilloch. At first we spoke about the possibility that I could live with Andy and his family, but we decided that it would probably be too much because he's got a busy family life with kids. So I decided that the next best thing was to look for a house nearby. I looked for rented property from the local council, private landlords and housing associations but there wasn't anything. I had to be near Andy, but Kirkintilloch doesn't have many houses for rent. I also needed a three bedroomed house because I needed a room for myself, a flatmate and a place for support workers to sleep. There are many families who are on council waiting lists who need three bedroomed houses so I didn't have any

luck. Jean, Neil and the hospital assessment team got in touch with Ownership Options to help me get a house to live in. Ownership Options were really good, 100%. All of these people and Ownership Options helped me, but Gerry my advocate did most of the paperwork for me.

It was a long time between knowing I was going to leave Lennox Castle, buying my house and living in it. It was about 14 months before I was living in my house. I tried different options in that time. I looked at me living with Andy, but that fell through. I looked at houses to rent but there weren't any suitable for me. I looked at a house and Gerry, Inclusion and Ownership Options began to start the buying process but that fell through too. It fell through because everyone was too slow and the process seemed too big. Jean, Neil, Gerry and myself had to liaise with Ownership Options; they had to liaise with Scottish Homes and then back through the chain to us. Even to get a survey, we had to tell

Ownership Options we'd seen a property and they would arrange the survey. The surveyor would give his report to Ownership Options, and they would talk me and Gerry through the report so that we could make a decision. By the time I had a survey carried out on the property it was almost sold and by the time it had all come together for us we'd missed the bus so to speak. It takes a lot of time to go backwards and forwards between the different people but I don't know how the process could be shortened.

Ownership Options helped me to find the money to buy a house, get a mortgage and work out the amount that I had to spend on a house. I was quite stuck to find somewhere within my budget. In effect, I was made homeless by the hospital closure, and because there were no suitable rented houses for me, Scottish Homes gave a grant to Ownership Options to help me buy a house. This was enough for me to put a deposit on a house and the Bank of Scotland gave me the rest of the money. I get some help with my mortgage interest payments in my income support, from a benefit called Income Support Mortgage Interest. Without this, I would not have been able to buy my house. I chose the house and my bedroom in it. I'm a complete Celtic fan and the house had a green garage- but I was really keen on the house generally, so everyone jumped to help me buy it. We had all had some practice and the process the second time around was



“ I’m a complete Celtic fan and the house had a green garage ”

much smoother and came together better. I was worried it would fall through again at the last minute and if it had, I think I would have begun to doubt whether I would ever have my house. Inclusion, my support provider, didn't want this to happen and so they loaned me and my flatmate £2,000 to secure the house. Inclusion has a contingency pot of money, which isn't a lot, but is available for use when needed. They used this money to help me get my house. So it was the fourth attempt at getting me a house which succeeded. Looking back, it does seem a lengthy process, but I got there eventually.

When buying my house I needed help with all the decisions that had to be made and to understand the complicated processes. I gave my Power of Attorney to Gerry my advocate, so that he could act in my best interest to buy the house. I still signed the papers, but I needed Gerry to explain to me what I was signing. I didn't have any problems, but it helped a lot that Ownership Options knew all about the legal things. I imagine it would have taken much longer without them. I didn't have any problems from solicitors or mortgage lenders. But I wasn't the first person on a benefit income, with an attorney that the bank had lent money to. I don't know if the first person in my situation to buy a house was up against all kinds of problems or not. I think the people who helped me buy my house had to think

creatively and use back ways to ensure I got my house.

I had to find all the furniture, so me, my flatmate and some of the people from Inclusion went shopping. I chose everything and we haggled over the prices to try and get things cheaper. I had lots of fun doing that, and we did get things cheaper! I got the money to buy furniture from my support service. For the first few years of leaving hospital you can get an amount of money for additional support, materials, housing costs, furniture or whatever. It was about £4,500. It seems a lot but I had to furnish a three bedroomed house and after we had bought the electrical goods and beds it didn't go far - so we had to haggle. I bought the best that I could afford for all the big things, like my oven, and then bought cheaply for little things. The smaller stuff can be replaced over time. At first, it seemed like "four and a half grand, way hey", but it didn't go far. ... I had a good time shopping though!

My flatmate helps me with house management stuff, like meals, shopping and maintaining the house. We've just had our living room and dining area redecorated because we had a flood - our cold water tank burst and the ceiling came down. We've decorated it green - I've chosen everything in green. I've got green curtains, green furnishings, green toaster and

everything. It is very hard though on a benefit income to find the money for house maintenance. Even if you manage to save some money, you can't save over a certain amount because your income support will get stopped. I do have some earnings. I have therapeutic earnings through working at Lennox Hospital social work administration department. My support team are looking for other work opportunities for me once the hospital closes. But there is a problem. Income support is an all or nothing benefit. I cannot earn more than about £60 a week before I lose some benefit. That means I need to find a very well paid job to pay my mortgage, or I can't earn much at all and I'm stuck on a benefit income. Apparently, housing benefit tops up low incomes if you rent your house but income support mortgage interest doesn't work like that. I find money management quite difficult so I have appointed my flatmate as my benefit appointee. The benefits agency has a policy that states if you have a Power of Attorney they must be your appointee. But that is silly because, for me, Gerry is on the sidelines of my day-to-day life and he couldn't have been my appointee. It would affect my relationship with him as my advocate and I don't want that. It makes sense for me to have my flatmate as my appointee.

So that's how I got my home. I'm very proud of my house and I love showing people round it. The thing that I really like best is having my own bedroom. I love '60s and '70s music and have all the compilation albums going. I also have all my Celtic memorabilia in my bedroom, so I just feel completely happy there. For 40 years I never had my own bedroom or even my own space. Although I lived in different wards during my life at Lennox Castle I always shared a room with four other men. I had a curtain around my area that was meant to give me some privacy. But it is excellent having my own space and bedroom. I spend a lot of my time now unsupported. For two nights a week I'm in my house alone. And for another three nights my flatmate's about - but he's not working, he's my flatmate and lives here. So five nights a week I don't need any support. I like to do things for myself and I've become dead confident within the house. My flatmate does support me to get out and about. We do all kinds of things, but I especially like to go to art exhibitions- as much for the free wine and peanuts as the art! I am an avid painter. I made a chair sculpture which I sold and is now in a town in France. I also have a painting in Celtic Park.



CHAPTER 2 MO'S STORY

'I'm afraid you can't stay here any longer, we need the beds!' So in October 1989, after spending nearly a year living in hospital, I was finally discharged. Before leaving I had a two-week trial in Red Cross House, but I didn't get on very well and went back to the hospital at the end of the first week! I could've gone home to live with my parents, but they were getting older, had medical problems of their own and their house would need to be adapted for a wheelchair. My only other option was to go into a nursing home, so I went to live in Fairburn House, a private nursing home four miles from Muir of Ord. There was no proper rehabilitation set up there, probably because no one was expected to leave! They did have four ground floor flats for patients who might benefit from rehabilitation, but they weren't wheelchair accessible, so I couldn't go and try out living alone.

In 1994 I started wheelchair racing although I had to stop through injury. Unknown to me at the time a trip to Glenrothes for a road-race was to have a strong influence on my future. It was to be THE turning point in my life. The physiotherapist from the nursing home took me down to Glenrothes and while there we went to the Cheshire Home where she had worked while doing her training. She introduced me to one of her former patients who was still living there. She was a woman with very limited movement, who controlled everything using a special touch sensitive collar round her neck. She invited us to her flat- it was in a complex but it was her flat. I thought 'boy, she's living here on her own'. Her quality of life seemed absolutely fantastic - much, much better than mine was. She still needed physical support even though she had special adaptations to compensate for her impairment, but she was independent



in her own flat; and I was in a nursing home!! That didn't seem right and it made me seriously think what I was missing out on, because I wasn't in control of my life. I made my decision. If this woman could do it, then so could I. After speaking to some fellow wheelchair racers who were also living on their own, my decision was clear. There was so much I couldn't do because I lived in the nursing home and I knew that I needed to get out, because this was not where I should be living.

As my medical condition had improved I decided to learn to drive. When I passed, this helped me realise exactly what I wanted out of life- my independence. When I said I wanted to leave the nursing home there were loads of discussions as to whether I was making the right decision. I got a social worker and her first priority was to get my name on the council housing list, and I got 45 medical points as I was living in the nursing home. When a house came up in Muir of Ord, I jumped at the chance. It was in a sheltered housing complex, and everyone thought this was great, including myself at that stage. There would be security and support to help me regain the confidence to live independently in the big wide world.

When I first moved into sheltered accommodation I had a full-time carer to help me cook my meals and things like that.

Obviously cooking wasn't new to me but it had been a long time since I actually made a meal for myself. Being in a nursing home you get everything done for you and you get lazy, and as I hadn't done things for a while, my confidence had dropped. There was nobody else in my age group within the scheme. My next-door-neighbour was 90 and never came out of her house because she didn't keep well; so I never got to know her. The warden kept me informed on how she was, so when she had a bad day I would keep the noise to a minimum. I could have gone into the village on those days but as most of the local services weren't accessible, I was pretty isolated.

Then at the end of 1997 I had a blackout and lost my driving licence for a year on medical grounds. I was so stuck- it was terrible. Money was the biggest problem. People tend to forget that although you get mobility money it's not enough, especially when there's no accessible transport. Taxis are so expensive it was costing me a fortune; a trip to Inverness and back was about £24. Often I couldn't afford it, and had to plan my day to get the maximum benefit of spending all that money. I didn't want to be stuck out there in the middle of winter, and not be able to get out of my house for weeks on end. I had to go back to Inverness; I couldn't cope with the isolation and the worry that it might happen again, so I frequently stayed at my mother's. Most of

my family were in Inverness, although my brother and his wife live in Muir of Ord. They did give me support over the telephone but they couldn't give me any physical support as they both worked full-time. If I went back to Inverness, I could get the family support I needed, particularly from my sister. She still helps me with physical things, like mopping my floors, and other things that are difficult for wheelchair users. The other problem I had was that there was no room in my kitchen for a washing machine. My carer said she would do my washing for me but I used to do it in my mum's machine. I'm not against carers but some seem to think 'we're here so we'll do it for you', even though you can do it. By doing this they are taking away a little bit of your independence. This could be something as simple as throwing a towel into the washing machine. I suppose it's what you call 'caring instinct"! I wanted to move because I didn't need or want sheltered housing

anymore. I got quite a lot of support when I decided I wanted to move and my social worker helped me think about my housing options. These options were with Local Authority Housing, Albyn Housing and Margaret Blackwood; ownership had not even crossed my mind at that point. When I contacted Highland Council Housing Department they said 'We can do an exchange for you- to another sheltered housing scheme.' But I didn't want to move there; I wanted my own house, to be independent in. They gave me eight non-medical points and told me it would be four to five years before I would get a house! I went to Albyn Housing Association but they couldn't help me for at least two years, as I wasn't a priority case. I did get 2 points for relative support though, but I needed 17 points to move to Inverness. Houses are currently allocated using a points system, and even though I was eligible for an exchange to sheltered housing, I didn't have enough points for an ordinary rented house. A far cry from the 45 points that I had before! While they all tried their best to sort my housing situation, the biggest barrier was the fact that they had no wheelchair accessible housing. They had housing suitable for somebody with mobility difficulties, but not for someone who uses a wheelchair full-time. Fully accessible houses are few and far between, which is ridiculous. I had also applied to Margaret Blackwood Housing Association and when their Director

“ Try and get involved in the project from day one. Say you want to be part of this consultation and ensure that you are included in every single decision that will have an impact on you. ”

Richard Gregory had to come up North, he arranged to meet with me to discuss housing options. He said, 'I don't think that you would be suitable for the individual house purchase that Margaret Blackwood offer, but we work with a sister company called Ownership Options in Scotland. They are helping disabled people to purchase their own house". I was interested, so he put my name forward and that's where it all started. Julia at Ownership Options was very, very supportive. Before I left the nursing home I had had to think about my future because I didn't want to spend another five years there. I wanted my independence. And when I first spoke to Julia I was trying to think 'What do I want and where do I want to be in five or even ten years time?" Julia went through everything with me, with a fine tooth comb. She told me that I would need some savings to pay for solicitor's fees because that was something they could not help me with. I went into ownership because there was no accessible housing available for rent. If you have got confidence, even if it's been suppressed, and this housing option suits your needs, go for it!

Before going any further I had to get life insurance to cover a mortgage, which wasn't easy considering my medical problems, but Standard Life eventually accepted me. To help pay for my house I got a grant from Highland Council of about £9000. Scottish Homes also provided grant funding and I got

a mortgage from the Bank of Scotland. The reason for the Scottish Homes and Council grants was to build a house to wheelchair accessible standards. I couldn't have afforded it without their help. Ownership Options did the correspondence and co-ordinating work and I had to pay my own solicitor £1000 to do the whole transaction. So even with the grants I needed at least £1500 savings or access to that amount of money to go down the ownership route. I also had to think about what furniture I would need. The social fund from the DSS will give or lend you money to purchase furnishings, depending on your circumstances. Sometimes it is a one off payment and sometimes a loan. I got over £1000 from the social fund for things I needed, like my washing machine, dining table, curtains and flooring.

I have a benefit in my income support called Income Support Mortgage Interest relief, or ISMI, which pays for the interest on a mortgage. Until recently, my mortgage was at a discounted interest rate. First of all it was about £164 a month, then it went up to £178 and now it's £260. The DSS pay £240 so I pay the excess myself. I know how it works, but it's complicated trying to explain it. The DSS takes an average of interest rates that isn't necessarily the same as the interest rate you've got. So the interest rate I pay at the moment is actually higher than the current DSS average. Sometimes if your interest rate



is down, and the DSS are working on an average, you receive more in ISMI than the interest you have to pay for. So it sort of balances out eventually. I also had to think about what happens to my income support and my mortgage if I had another blackout. That was the only frightening bit for me as I know my benefit would stop. I've managed to save two months worth of mortgage interest, so I've got some slack if it happens and by doing this I feel secure and in control of paying my mortgage.

I think it's important that people do some forward planning before going down the ownership route. Budgeting in particular is very important. I'm not saying that I can't manage my money, but because it's a new situation, you realise that things like household bills become a priority. When you're on a low income you've got to work out what is luxury for you and what is essential. I had to sit down and work out what I got in benefits and income generally, and then work out how much everything costs. I then budgeted for maintenance like getting my boiler serviced, or my washing machine fixed if it went wrong. It's a safeguard, but something you HAVE to do, especially if you've not got a lot of money or savings; you've got to balance your books. I've also got a garden, so I had to think, 'Who's going to look after it and how much will it cost?' I'm sorry now that I never asked for more money when I got my mortgage. I

don't know if I would've got more or not but it would have helped me get my garden the way I wanted it. I'm just getting parts of it finished off now as I haven't had the money to do it, and the builders only put topsoil on the gardens. Most builders grass-seed these areas, but I had to get somebody in to grass-seed. It just finishes a house off. If you are thinking of ownership you need to take everything into consideration, especially outside the house. Note everything you need to buy, and get some quotes on any work that needs done. Then try to get it all incorporated into your mortgage so you don't have to fork out six months later for somebody to come and lay a patio or whatever.

Try and get involved in the project from day one. Say you want to be part of this consultation and ensure that you are included in every single decision that will have an impact on you. After all you are the one who will be living in the house and it's a matter of choice - your choice. I got all the plans and told the builders what I wanted. They asked me if I wanted an en-suite toilet, but I didn't. I wanted two bedrooms, and a combined lounge /dining area because I didn't want to eat in my kitchen. I also asked for a hatch in the wall so that if I'm entertaining I'm not taking through hot plates on my lap. It is also important when anybody is getting a house built to make sure that the measurements for your toilets,

handrails and other things are exact. Make sure you stress the height you want your kitchen units at, the height you need your toilet for transferring, where you want your shower seat and all the other things, so that they're suitable for your needs. If you sell the house in about ten years time it might not be exactly suitable for the next person's needs but they will be able to change things. When I went looking for a house, I wanted one with two bedrooms. I'm living on my own so one bedroom should be sufficient, but what happens if I have a fall, break an arm and can't get myself in and out of bed? If I ever need somebody with me 24 hours a day I don't want to go into hospital or back into a nursing home to get that support - I want to stay in my own house. With a spare room I can be at home and have the help I required for as long as I needed it.

I got laminate flooring put down which is much better than carpet, especially for a wheelchair user. I had to be very practical about all my needs and wrote them down so I could tell the housing people. By doing this I could think about what my dream house would be like and what I would have in it. Everyone should do that because although it might be a dream, one day it could be a reality.

My biggest problem was that I couldn't move in immediately because the toilet and the shower had been fixed in the wrong

place. As several of my friends use wheelchairs I wanted the toilet to be accessible from either side, but the plumber got it wrong. He installed it in a different place and to top it all, the toilet was at the wrong height. I practically had to get on my knees to get on the toilet it was that small. They ordered another one, which was a proper accessible toilet system, but they couldn't fit it immediately. And as the following week was the Easter fortnight, it sat in my front room for three weeks. A long time to keep your legs crossed! When it came to the shower, I wanted the seat on one wall and the showerhead on another. This was also in the plans, but the plumber did it again! He installed them in the wrong positions so I had to get him back and sort it out even though he insisted he was right. Professionals should not just see involvement of disabled people as a nice gesture, I know what I need and they need to realise that they can't always get it right.

Now I've moved in, I feel as if I'm part of the scheme here but I've still got problems. I can't get into any of my neighbours' houses - they've all got three steps up to them. But that's not my fault - it's the builders, because they never thought that I might want to see my neighbours, borrow a cup of sugar or even have Christmas dinner with one of them. Everybody's got to come here because I can't go to them and I'm not cooking a turkey for the whole street!

Disabled people will still be excluded, and buildings will still be inaccessible unless architects and builders start listening to us. It doesn't take an ounce of sense to know that if you make everything accessible everybody can move around. The more they build houses with three steps up to them, the less accessible it's going to be for future generations and for me - steps should be a thing of the past, after all this is the 21st century.

At the last election none of the manifestos had disability high up there on the agenda. Why not? Disability is a civil rights issue. If disabled people are to be treated as equal citizens, attitudes need to change. And although we have a Disability Discrimination Act - discrimination will still happen unless we have fully enforced civil rights. Generally people don't think about how they treat other people, and they don't like to think about what could happen to them in the future. No one thinks they might become wheelchair users and have to deal with the discrimination that disabled people currently face. We all need to realise that attitude begins with the person, and affects everyone we come in contact with. Unfortunately there are a lot of negative attitudes out there. So if disabled people are to have any value in society then these attitudes must change, including their own! I believe change CAN happen, but it needs to start with each and every one of us, taking

responsibility for our own attitudes that contribute to the inequality that exists in the world today.

The government also has a part to play. They are ploughing money into joint working to modernise community care but it won't remedy the situation. I can guarantee that somebody will be going through experiences similar to mine. Maybe they're stuck in hospital or a nursing home because they can't get any accessible accommodation. Real change is where all homes are totally barrier free so everybody can live in them. Until real barrier free design principles are accepted as minimum standards in the same way as health and safety regulations or building structural standards, disabled people's housing experiences will be the same in ten years as they are now. Architecture students have got the opportunity not to repeat previous mistakes. But mistakes are still happening because disability and equality issues are not part of their training. To create lasting change these issues need to be included as standard in the school curriculum.

Getting my house hasn't been simple because of all the particulars that came with it. I don't think I would relish going through the whole process again. More than anything else it's such a stressful time. People who are going into ownership must know that it's not plain sailing. It's not just a case

of signing on the dotted line and the house being yours. There's so much more to the process, especially if you are disabled. But when I think about it, I'm glad I've done it. This is MY house and I'm very happy here. I often wonder what my circumstances would be like if this hadn't happened? I don't think anybody ever stops learning, and I have learnt an awful lot not only about the process, but also about myself.

Some of my pals jokingly say, 'Of course, we don't really know you now, because you're a home owner!' And I've also learnt to put up with occasional sarcastic comments from people about being able to own my home while on benefit. I haven't got loads of

money, because I get income support but thanks to joint working by a number of agencies I am a homeowner. I am very grateful for the assistance I had from Ownership Options in Scotland, the Bank of Scotland, Scottish Homes, Highland Council, and Margaret Blackwood Housing Association.

For a disabled person having your own house is important. I can vouch for that because before I had limited options regarding where and how I could live. I used to dream about it and never thought it would come true. But it has - I've got my own house! So don't ever give up on your dream. As dreams really can come true!



The person at the centre of this story is David, but housing and support affect the whole household, so this story is the story of the Smith family, narrated by David's mother.

David was born with a severe heart condition and was dying, so we took him to America where he had major heart surgery, but he got brain damage at the operation. At about the age of four David was labelled as being hyperactive, hypotonic and having a learning difficulty. Children with similar health difficulties mostly die, so nobody really knew what things were going to turn out like for David.

CHAPTER 3 THE SMITH'S STORY

David went to play groups and nursery schools, but his first five schools found his behaviour difficult and he was put out of them all. His sixth school said he could stay until he was 11, so we moved nearer the school to reduce the travelling. After 6 weeks they decided they couldn't support him so he went to residential school- all before he was 7. He enjoyed the school and stayed there until he was 16. That was a period of stability for all of us, but David had to leave when he was 16 and he was sent to another place, which was a disaster. David was in a bedroom with five other people and he knew that they were taking his things. At times he seemed happy, but often he was miserable. He was there from age 16 until he about 22. One day we were called to a meeting by the social work department. We knew there were difficulties but were quite unprepared for what was said. They told us that he had to leave because his behaviour was dreadful, he was violent and too difficult. We asked if they could suggest where he could go and were told that they were too busy supporting the people there to be able to advise and help the parents of those that they felt couldn't fit into their set up.

He came to live with us at home in the city's suburbs, but he was offered a bed in the local geriatric hospital if we couldn't cope. He tried all the adult training centres but was put out of them because they said he caused mayhem. We got a lot of help from the social worker, with support at home because David needed a lot of physical support. We decided to move back to our previous town and bought a house with a couple of acres to give David the space he likes. All the day placements offered to David were in small rooms completely unsuited for him because he's a man who likes space. One organisation offered David a day placement and a bit later on offered him a place in one of their residential houses as well. He went to live in a big double fronted villa in a posh area of the city, but he was sharing his bedroom with another young man and tension developed between them. The other thing was that the carers weren't looking after David physically. He would often be wearing the same clothes from Monday to Friday and come home for the weekend unshaved. His skin just broke down because he wasn't being washed, even though the staff said he was bathed daily. It was just awful.

It was a disastrous time for us all. One of my daughters was very ill with a mental illness and the social workers just kept saying 'You really can't cope with David at home, he's got to stay there and it is the best place for

him'. David was moved from sharing a bedroom to having his own room in a basement, with a stone wall less than 6ft from his window. When his behaviour was difficult, they put him to bed in the basement. I said, 'Why are you doing this? You know if he's upset like that put on his hiking boots and take him out on the hills and let him walk and get space.' But that seldom happened. They did offer him a new day placement working outside making compost, tending to the garden and going out on the hills. The project developed so he went out in a work group laying paths and planting trees. He really liked it, still goes there and is very proud of his work.

With no notice, we got a phone call saying they wanted David admitted to the Mental Health Hospital because they'd had to start him on Melerril, an anti-psychotic drug, but we were never informed when he started this medication. He was locked in a secure unit there for 6 weeks. David settled down and the psychiatrist said he didn't need Melerril anymore, although they might start it again if his behaviour became bad. I was very unhappy about it. He was on Tegretol as well which they use for fits, but he's not an epileptic. The hospital said 'He's a manic depressive, he's got mood swings. It's called bi-polar affective disorder. He needs Tegretol to even out his mood swings' but I doubt that very much. I think he was just very badly misunderstood. There was a great meeting at the hospital about David with the hospital

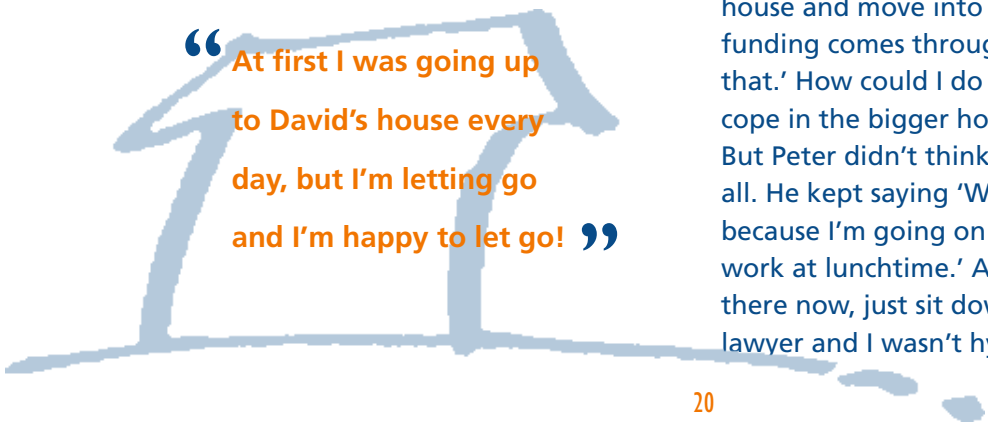
staff and the staff from his residency in the villa house. The staff had meetings with the doctors and we were informed about the decisions - they were saying terrible things about David. The staff at the residential place said they needed two to one support for David, which the social work agreed to, which we estimated to cost about £78, 000 in 1998. Honestly, you would think he had horns or something! Everyone felt it would be too much for us if David lived with us. We did think about providing an institution ourselves. We hadn't thought of him having a house for him alone because we were so brainwashed into hearing that he needed 'institutional care'.

We went on holiday and when we returned David went back to the residential house. He walked straight into the kitchen and punched somebody! It was agreed immediately that there was no point in David living there, so he came home with us, but there was no support set up for him. Although we lived in a different local authority area, the city social work department did their best for us and agreed to help. We found a local agency to provide carers for us. It was very intrusive on our life - they were coming in to our home at 7 in the morning to support David to get up and go to his day placement and then he was back in the evening and they were there to help. I hadn't been very well with high blood pressure and my family weren't well. David

was exceptionally happy at home and although he still challenged us sometimes, you could see he was beginning to settle. His skin healed too, because he was getting clean clothes and washed.

My husband became seriously ill, and he was in and out the hospital and it wasn't practical for David to live with us. We were desperately searching for somewhere for him to live. We went furthest North, into Wales, and were in touch with people even further away! He was offered one place, on a trial basis, in Wales. He was offered another place in the North, which he would've loved, but they couldn't guarantee a permanent residency because he was at the top of their age limit. We very reluctantly withdrew from it but its set-up got us thinking. The houses were built around a central farm and college, and the residents were supported to live alone in their own house. We also thought about moving nearer his day placement. In the meantime, we turned the old dairy in the garden into a wee cottage for my husband and I, leaving the house free for David and his carers. But it ended up with everyone in the cottage so we came back to the house. The cottage wasn't big enough for David and a carer, and we couldn't afford to do anything more to it, so we were all back in the house. We started looking for country cottages to rent, but as soon as we mentioned 'learning difficulty' nobody

would rent to us. The local care and housing providers could not offer David anything. We realised that maybe we could sell our big house and buy two completely separate small houses- one for David and one for us. I asked the social worker, Peter, about it and he said 'Brilliant idea'. I asked him about the funding, and he said that it wouldn't be a problem because the only extras to his current support package would be the sleepovers. We looked at many houses, discussed options with Peter and generally kept him informed. He never once said there would be a problem with the extra finance. We found this wee house which fitted all our criteria so I told Peter about it and he said 'That's fine, that's fine.' We put an offer in and it was accepted. I was in regular contact with Peter and we agreed that the day I got the keys he would come and see the house. Everybody got very excited. We started asking David if he would like to stay in his own house near us and have his supporters stay with him. To try and minimise the amount we would pay in



“ At first I was going up to David's house every day, but I'm letting go and I'm happy to let go! ”

bridging loans we put our house up for sale a week before we were due to get the keys for David's new house. Some people wanted to buy our house on the first day it was on the market. We explained that we wouldn't be accepting offers for a week because we didn't want to risk being without a house and they were happy to wait.

Then our lawyer phoned saying there was a slight hiccup with the conveyancing. It was nothing to worry about but the settlement and getting the keys was likely to be on the Monday rather than the agreed Friday. I phoned Peter because he was due to see the new house. He said 'Oh well, it doesn't matter but I'm going on holiday tomorrow. I'll come and see you anyway though because I want to talk to you.' He never said there was a problem. He visited us at about 11.20 and came out with the fact that he hadn't got the funding for the care in place as it had never been passed by the finance committee. He was out of order.

He said 'What you should do is take the house and move into it with David until the funding comes through.' I said 'I can't do that.' How could I do that? I could hardly cope in the bigger house with all its space. But Peter didn't think that was a problem at all. He kept saying 'Well I need to go because I'm going on holiday, and finishing work at lunchtime.' And I said, 'You sit down there now, just sit down.' I phoned my lawyer and I wasn't hysterical but I felt

hysterical. I've never felt like that in my life. My lawyer said 'Well it's 11.20 and they haven't faxed me the document I have asked them for, but they have said they will get it to me today. The settlement time is at 12. If I can get a letter typed and faxed to them before their one is faxed to us I can get you out of this.' ... and that's what happened. We gave the sellers a short explanation and it was left that if the care funding got sorted in the next day or two we'd get back to them. We were very upset because it put the sellers in an awful position. Peter seemed quite happy with himself and went on his holidays, not thinking he had done anything wrong.

I waited on the Monday for the social work department to ring, but they didn't. I phoned them on the Tuesday, asking to speak to Peter's line manager and I got a very stiff response. He said, what was I making all this fuss about, this money had never been passed and I'd no right to buy a house without care being in place.... What a nerve he had. As if we would be daft enough to go buying houses, as if we were ignorant fools. I had a terrible row with him. His comments were followed up with a letter. I wrote back to Peter's line manager and involved other people by sending them copies of these letters. My lawyer wrote to the department, our GP wrote a letter stressing the effect this was having upon our health, and I wrote to my district councillor

who wrote a stiff letter to them. I had phoned Enable to ask them for advice and they offered to take over the legal affairs from our lawyer if we were being charged a lot. Our lawyer never charged us for the botched conveyancing, he was a wonderful, supportive man and we couldn't have got through without him and his staff. I was prepared to write to my MP and The Scotsman. I felt it was not right the way that this was being dealt with.

I withdrew myself, curled up for 2 days and ate! I was just so fed up. And then I got angry and my husband was very depressed. I thought 'I'm never again going to have anything to do with the social work department unless I've got copies and unless I have minutes taken at meetings'. I still insist on that. Never again will I trust anybody in that capacity.

I phoned a place in the South of England that has had David's name on their list since he was 16. Although they were supportive they didn't have anything suitable. They suggested we tried one of their ex-workers who had moved to Scotland to work with a care and housing provider. We rang him, and although he couldn't help, he gave us the names of two other organisations. I phoned them and they put me in touch with Ownership Options. Their adviser was great. She was on our side, and I almost didn't have to explain to her what I'd been through with

the social work. She agreed it was time all this messing around stopped. She encouraged us to think that the local authorities had an obligation to get David somewhere suitable to live. She was the person who really picked us up. We had this very stressful meeting with the social work department. My husband wouldn't go because he was so upset. My two daughters came, the Ownership Options adviser and the Welfare Rights adviser. At that time we had just got a firm offer of a trial in Wales which my husband was very worried about. We're a very close family, and although we weren't coping living with David it didn't mean we didn't love him and didn't want to see him. It was in Wales, so we'd never see him. We had this meeting and the Welfare Adviser said 'Wales? Wales? It's not even his own country! How could you think of sending him to Wales?' And that reinforced our concerns. Peter shut up and there was no more talk of David going anywhere. After all the carry on about the house Peter was still our social worker, but very nervous. Shortly after this meeting the social work agreed to, and passed, the amount of money needed for David to have sleepover carers in addition to his day to day support. I said I wanted it in writing before I did anything because I didn't believe them. Once we had it in writing, we started looking again for smaller houses that would suit David. The house we had looked at was gone.

We were driving past his current house as they were putting the board up and went and had a look around it. It fitted all the criteria and we told the owners we would be very interested in it. I phoned our lawyer to put in an offer and kept Peter informed. We bought some of the occupants' furniture because they were moving abroad. The people who had seen our big house the first time had been continuing to wait. We told them that once we had the keys to David's house we wouldn't put our house back in the paper as long as they gave us a fair offer. We had the keys, they offered and we accepted. We then needed a small house for ourselves to live in, which had to be near David's house. We saw our current house for sale, which is 5 minutes walk from David's house and we bought it the first day it was on the market.

To introduce David to the idea of his new house we started talking about how his sisters don't stay at home because they've got their own houses and asking whether he would like to have his own house. We progressed onto saying 'when you get your own house we will do so and so. You will be able to have your own garden and your things.' We bought presents for him, which were things that he likes or associated with things that he likes like a chip pan fryer, and some nice mugs. We carried that on occasionally over many months. Once we had the house we were saying 'You will be

getting your new house soon'. It could have been a time of great stress for David. We almost had the keys before we said anything to him about 'When you move in...' We took David up to the house with all his presents so he could see it. He was very quiet and didn't seem to understand, so we just took him to his house each day, letting him help and choose and just be involved as much as possible.

David has an assured tenancy and pays rent to us, which is used to upgrade the property and saved for future maintenance. Ownership Options told us David could claim housing benefit, not the social work. We had no hassle from the housing benefit department. We filled the forms in and a very nice housing officer came to visit us to confirm that we satisfied the regulations and had not created a contrived tenancy. We referred him to the social work department who told him about the difficulties we had had finding somewhere for David to live. The social work department use a local agency for his care, and only intervene if there is a problem. David goes to his different day placements during the week and has a team of eight carers. He's very quick to let people know or let us know if he doesn't like somebody. David and his supporters must like each other. With a few people it was very obvious that things would not work out, and there have been people who have not liked working with David.

We had one hiccup with the service providers. Initially we had an hourly contract and we were to give 3 weeks notice if David didn't need their care- like when on holiday with us. There were other occasions when he was with us, like when he was dreadfully upset and we took him out with us because we knew what would relax him, or when one of his carers was ill and I said he could visit us rather than have a complete stranger in his house. The service provider had complained to the social work department saying we had been cancelling hours at short notice. They were billing the social work department for these cancelled hours. The social work department told us this in a letter and sent the bill to us because we had broken the contract. There was over £600 to pay! I wrote a letter and then I started bombarding the social work department and care agency to let them know when we were going away. But you can't live your life three weeks in advance! I was seeing our new social worker and one of his colleagues and mentioned this bill to them. Our social worker was very sympathetic and his colleague was outraged because it's wrong that people with disabilities are not allowed to be flexible and go out because it's a super day. He also said it was important to keep family links, so the bill was cancelled and it's all changed now. But that caused a bit of a problem because of bad feeling. We stayed with the providers though, because the team were good and our problems were with the

administration and they did get it all sorted out.

At first I was going up to David's house every day, but I'm letting go and I'm happy to let go! It's been difficult for me because he has had a lot of physical illness in the past and all this rejection by people. He visits us for tea or coffee but sometimes doesn't stay for very long. He tidies up our cupboards if he thinks it needs doing and then stands up and clears his throat to tell you that he's had enough and it's time to go. It can be just ten minutes and he goes away up to his own house. Well, he's so proud of it. It's lovely for us. It's really lovely. The thing David likes best is having his own key and his own space. He's never had that in his life. He really enjoyed being able to have his sister and brother-in-law to stay with him over Christmas.

We're all really happy, it's felt great! David's violent behaviour has all but stopped. He has gained continence. His skin is all clear, he's got a smile on his face and he's just so very, very happy. He used to have many obsessive patterns of behaviour, but it's all diminishing as he's got more secure. All these people were wrong and I just wished they'd listened to us from the beginning. If we had got the support we should have had, we would all

have lived so very differently because he could have stayed with us. By the time he was in his early 20's we would have found him his own house but we had never been given that option. Parents generally know what's best and we should've said 'no more' sooner. We both felt terribly guilty. Just because we couldn't cope with living with David- but we did cope because we had to- didn't mean we didn't love him and didn't want him around. He is our son. We just listened to the experts and were brain washed into thinking that they know best and they didn't.

We had a meeting yesterday- a personal plan- and all the people at it were involved with David. One of them has recently come back to work with him after 3 years and he said, 'I couldn't believe it. There David was, in his own house, opening the door and welcoming me, shaking my hand and walking me in.' David's very proud of his own house. I don't always get in now, sometimes I've had an interview at the door. It's wonderful because he's too busy doing something else and doesn't want to be interrupted. The carers, family and everybody who's involved in his care have all been a part of this wonderful movement out into the community and independence.



CHAPTER 4 MODELS AND STRATEGIES FOR PERSON CENTRED HOUSING SOLUTIONS

Although their circumstances are unique, these three stories detail experiences which are familiar to many disabled people. Rather than lament the difficulties faced by Tommy, Mo and David, this final chapter uses their stories to identify and suggest good practices and positive strategies for supporting disabled people to access suitable housing in the owner occupied sector.

Process and funding models

Table 1 summarises the financial and legal models which Tommy, Mo and the Smith family used to secure their homes. It offers comparisons of the different processes and advisory roles, and identifies some good practice indicators. This booklet does not aim to analyse or evaluate the cost effectiveness of these funding models and housing solutions. However, where public sector funding support had been provided, people who could not have otherwise accessed the owner-occupier sector have been ensured a long term sustainable future. Legal arrangements ensure value for money and grant claw back on property resale. These models could be applied to assist other disabled people and families living in unsuitable housing who have little or no prospect of securing suitable housing within the social rented sector in the right place and in a reasonable timescale.

The Roles of Different Sectors

Grants Awarding Agencies

Mo and Tommy purchased their houses with the assistance of grants from Scottish Homes and a local authority. As most of the agencies involved were pioneering a new approach it is not surprising that their experiences illustrate

where improvements could be made in replicating the models. Both needed the detailed approval of grant funders for the type and design of their potential homes before purchase could be concluded. For Tommy, this process took too long and so he lost the opportunity to secure the first suitable house. Mo describes how she needed two bedrooms and a lounge diner, which she had to justify to the funders. It is important that funders recognise that disabled people and families know their own needs and avoid inadvertently removing the choice and control of the disabled person by imposing standard conditions on process and outcomes. More work is required at a strategic level to address these issues, and to further the use and development of these models into the mainstream of funding support for housing for disabled people.

The Benefits system

Tommy and Mo talk about maintenance costs and budgeting, with some reference to the difficulties that are present within the current benefit regulations. Income support is reduced if a person has savings of more than £3000, regardless of that individual's circumstances. This provides a disincentive to save for maintenance. As Tommy explains, the benefit system is not tenure neutral. While the housing benefit system for low income working tenants is less than ideal, nevertheless some financial support for housing costs is possible. For working home owners on a low income there is none, and this can act as a disincentive to employment.

Statutory and Voluntary Bodies

Table 1's section detailing key players in the process of securing housing notes the role of Scottish Homes in two cases and Highland Council in one. However at the earlier stage of advising and assessing options, with the exception of Tommy, there was remarkably little input from statutory bodies, such as social work or housing departments. Yet in all cases these were the agencies to whom the people turned first for advice and support. Mo and David mention how their social workers looked only to the social rented sector for housing solutions, even though this sector is limited in many geographical areas and localities.

For Mo, neither local authorities or housing associations, (with the exception of Margaret Blackwood Housing Association) looked beyond their standard housing allocations points system when considering the needs and circumstances of the applicants and did not offer any alternative housing advice as part of that process. Mo found out about ownership possibilities once she spoke to Margaret Blackwood Housing Association and was fortunate that the council recognised the limitation of its own stock and systems and was prepared to consider supporting an alternative route. David's parents found a way to secure a home for David, but not to finance its running costs, including maintenance. They needed a rental income. However, it was Ownership Options and not their social worker that provided advice on David's eligibility for housing benefit. Tommy had a number of agencies involved in securing him a suitable home, and although long, the process was smooth. All of the agencies supporting Tommy ensured his lifestyle and social networks were not compromised in the search for a suitable house and they were committed to exploring all the possible options.

Access to a range of housing options and to good quality, comprehensive housing advice should not be a hit or miss affair. We need to build on some of the good practice identified particularly in Tommy's story, where different agencies worked together, with Tommy, and remained involved until a final solution was achieved.

The Private Sector

It is notable that Mo and Tommy found the process of getting a mortgage to be straightforward whilst the rest of the process was quite complex. Without the willingness of the lender to explore a potential new mortgage market and work with Ownership Options to understand the benefit system these stories may have had very different outcomes. All three stories highlight the role of the solicitor. Although pivotal in most house purchases, the legal and financial transactions were more complex in these cases in part because of the number of agencies involved. Tommy's solicitor was willing to find a legal approach

that would enable his client to be supported in complex decisions and the Smith's solicitor extended his role to the extent that the family felt supported by him.

Mo required detailed technical input to ensure her home would be accessible and meet her physical needs so she worked with the developer's sales manager and architect on the layout of her house. The developer was willing to stretch usual timescales, to listen, to make suggestions for design and to carry out work on an 'at risk' basis, while the grant funding was secured. Without this understanding, the whole project could have failed.

These are all examples of good practice by particular firms or companies within the private sector. For disabled people to have the mainstream housing option of the owner occupied sector, this good practice must become the rule and not the exception.

Inter-Agency Working

Table 1 shows Tommy had a number of advisers and supporters, which necessitated a high level of joint working and communication with all parties working to the same agenda. David's parents only had to liaise with their solicitor in terms of the house purchase. However the housing and support arrangements were so interdependent that the role and support of the social work department was critical. Yet David's parents really had to work alone with little system support and at times system failure. Mo experienced considerable anxiety throughout the process of achieving her home, despite being at the heart of the process. A significant part of this was caused by processes implicit in a grant system that is not designed for individual house purchases and yet is the only mechanism currently available for supporting individual house purchase for disabled people.

People who do not use services find buying a house a stressful experience. With the extra input of funders, care providers, benefits agency and sometimes technical advisers, effective interagency working

is essential to avoid the experience of people like Mo, Tommy or the Smith's being confusing and prolonged. Ownership Options played a key role in co-ordinating the different agency contributions. However we need to work towards a position where systems of advice, support and funding are streamlined and co-ordination and advice is available in the mainstream.

Person centred housing solutions and quality of life

Table 1 details the type, size and location of housing which Mo, Tommy and David wanted- ordinary homes in ordinary places, but this was beyond their reach in the existing housing systems. The standardised services, such as residential care, group homes and sheltered housing that Mo, Tommy and David had been offered could not enable them to fulfil their potential or aspirations because these services defined suitable housing in terms of support or ignored lifestyle choices and social networks which people who do not use services take for granted. Tommy, Mo and David's stories clearly illustrate the importance of house location, space, size and even colour to their quality of life. The transformation in their lives as a consequence of being able to make a positive and personal housing choice is clearly evident. For such experiences to become more common, national and local policy makers and planners must look beyond the limited current availability of housing in the rented sector to develop alternative routes for meeting individual requirements.

These housing choices have also been fundamental to enabling the individuals to choose their supporters. Mo needed to be in Inverness to receive support from her sister - which she prefers to support from a paid sheltered housing warden. Tommy's supporters listened to his housing choice, which means he chose his flatmate and now chooses how and when he receives support. David's care providers ensured that he liked his support workers and that they liked him. Often, people who use support services are expected to like everyone whereas people who do not use services routinely choose who enters their home and if they employ help they ensure that they get on with the person and trust them.

TABLE 1: SUMMARY OF PROCESSES AND MODELS

	TOMMY
Method of obtaining suitable housing	Purchase of existing property on open market.
Tenure status at end	Owner.
Housing position at start of process	Hospital resident –rehousing required, hospital closing. On rented housing waiting lists.
Assessing options: Type and location of housing required	Near Andy. 3 bedrooms. Options in rented sector scarce/not available.
Legal position	Appointed Power of Attorney to assist with decision making. Mortgage loan and Grant secured in property.
Assessing options: Financial position	Eligible for ISMI + benefits. Access to set up grants. Scottish Homes grant for initial purchase and future affordability. Health Board resource transfer funding for care and support.
Capital cost of purchase	£76,850 including legal fees and money for essential repairs.
Sources of capital finance	Bank of Scotland Interest only mortgage, £48,750. Scottish Homes Special Needs Capital Grant, £26,100. Inclusion Glasgow Interest free loan, £ 2,000.
Responsibility for eventual capital repayment, buildings insurance, management and future maintenance	Tommy, with assistance of care provider and network of friends and supporters. Paid for from personal income (benefits + therapeutic earnings).
Support arrangements	Supportive flatmate, paid support team, friends.
Key players in process of securing housing in owner occupied sector	Tommy, Advocate, Inclusion Glasgow, Bank of Scotland, Scottish Homes, Ownership Options, Solicitor.
Role of Ownership Options	Vehicle for Scottish Homes grant, Funds and process co-ordination, Supporter and adviser, Assessment of options, Appraisal of affordability.
Good practice indicators	Person centred working. Choice and control by Tommy. Good communication network. Inclusive outcome. Cost effective and sustainable.

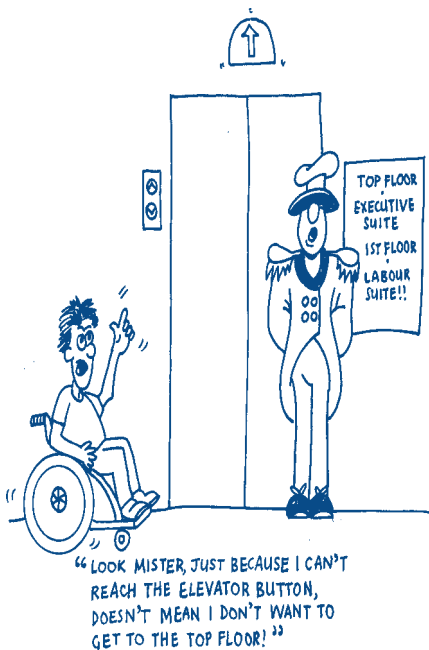
TABLE 1: SUMMARY OF PROCESSES AND MODELS

	MO	DAVID
Method of obtaining suitable housing	New build adaptation to standard plan within developer's site.	Purchase of existing property on open market - buy to let by parents.
Tenure status at end	Owner.	Tenant
Housing position at start of process	Council tenant in sheltered housing for older people - on rented housing waiting lists.	Living with parents - crisis point for whole family. On waiting lists for rented housing and residential care.
Assessing Options: Type and location of housing required	In Inverness. Independent, not sheltered. 2 bedrooms Designed/ adaptable to full wheelchair user standard. Rented sector options v. scarce	Near sea in quiet area with space. Short walk from Mum + Dad. 2 bedrooms. Detached, semi or end terrace. Options in rented sector unavailable No sustainable residential options.
Legal position	Appointed and fully instructed own solicitor. Mortgage loan and Grants secured in property	Incapable of instructing solicitor/ appointing a Power of Attorney. Will incorporates future ownership and Trust managing the property.
Assessing options: Financial position	Eligible for ISMI + benefits. Sufficient small savings Possibility of grants for initial purchase and future affordability.	Parental capital/savings for initial purchase. On Income Support - eligible for Housing Benefit for rent costs. Social Work funding care and support.
Capital cost of purchase	£67,222 including legal fees	Figure not available.
Sources of capital finance	Bank of Scotland. Interest only mortgage, £42,000. Scottish Homes Special Needs Capital Grant, £15,972. Highland Council Grant, £ 9,450.	Capital provided by parents from combination of equity and savings.
Responsibility for eventual capital repayment, buildings insurance, management and future maintenance	Mo, Standard Life endowment policy, other costs met from personal income - benefits or earnings.	Parents as landlords responsible for insurance, management, current and future maintenance, improvements. Met from rental income.
Support arrangements	Informal family support	Paid support team, parents and extended family support.
Key players in process of securing housing in owner occupied sector	Mo, Macrae builders, Bank of Scotland, Scottish Homes, Highland Council, Ownership Options, Solicitor	Parents, Solicitor, Ownership Options, Welfare Benefits Advisor
Role of Ownership Options	Vehicle for grants, Funds and process co-ordination, Supporter and adviser, Assessment of options, Appraisal of affordability	Supporter and housing benefit advice.
Good practice indicators	Person centred approach, Choice and control by Mo, Inter-agency co-operation, Cost effective and sustainable, Inclusive outcome (constrained by access to neighbouring houses).	Choice and control by family acting on behalf of David. Involvement of David in process and pace of change. Support for family networks. Cost effective and sustainable. Inclusive outcome

Conclusions

More than 116,000 disabled people in Scotland are unsuitably housed. 65% of the suitable housing for physically disabled people is in the owner occupied sector and 63% (and growing) of Scotland's housing stock is in this sector. We need a pragmatic response to meet the scale of housing need and to create equality in housing choice for disabled people. This response requires more opportunities and strategies to enable disabled people to access housing in the owner occupied sector, to buy or to rent as David does.

Tommy and Mo were supported to access the owner occupied sector by a number of agencies that were willing to pilot new approaches for meeting housing need in a person centred way. Individuals and agencies have been satisfied that it has secured cost effective and inclusive housing solutions. These models therefore need to be developed from pilots to provide mainstream approaches within local and national housing strategies aiming to provide equality of housing opportunity.



The Culture of Ownership

In 1961, 26% of the Scottish population owned their home; in 1981, 41% of the population owned their home and today 63% of the Scottish population own their home. We live in a culture that values ownership and choice, a culture where 80% of the population aspires to own their home. However, only 38% of physically disabled people and a tiny number of people with learning difficulties are home owners. If social inclusion means access to culturally valued social norms, the under representation of disabled people in the owner occupied sector needs to be considered and addressed.