

# Research Report

## The health and wellbeing of spinal cord injured adults and the family: Examining lives in adapted and unadapted homes

Brett Smith, PhD and Nick Caddick, PhD

### 1. Background

#### Authors

This research was carried out by Dr Brett Smith and Dr Nick Caddick from Loughborough University, UK. The independent research reported here is supported and fortified by their expertise in spinal cord injury and health and wellbeing. Combined, the authors have 19 years of experience conducting independent research on this topic in various contexts. The research produced by them has resulted in over 100 research peer-reviewed publications, 12 research reports, and more than 200 national and international presentations. Brett was the first person to be invited as part of the 'Ask the expert' series by the founders of the Participation and Quality of Life international programme on spinal cord injury and quality of life.

#### What is a spinal cord injury?

A Spinal Cord Injury (SCI) is damage or trauma to the spinal cord that results in a loss of or impaired function causing reduced mobility or feeling. Often the spinal cord injured individual requires the use of a wheelchair. The causes of SCI include car accidents, falls, sports injuries, infection of the spinal nerve cells, and tumours pressing on the spinal cord.

SCI is of national relevance.

Every eight hours someone is paralysed by a spinal cord injury.

It is estimated that there are now over 40,000 people with a SCI living in the UK. Anyone can sustain a SCI.

Historically the majority of spinal cord

injuries have been sustained by those aged 15 to 40, with men outnumbering women. This said, in recent years there has been an increase in people over 40 sustaining a SCI.

SCI is both devastating and a serious public concern. Following SCI, the person should undergo a period of specialist inpatient rehabilitation within a spinal cord injuries centre. Here they learn how to manage the enormous physical and mental challenges that go with a SCI. For example, the individual learns how to use a wheelchair, carry out transfers (e.g., between bed and wheelchair), and care for their skin. He or she also learns how to safely manage their bowels and bladder; the damage caused to the body following SCI results in the person being unable to control them in the usual way. Learning a range of techniques to manage the bladder and bowels is necessary not just to avoid incontinence but also to avoid chronic or life threatening problems.

Rehabilitation lasts usually between three and five months, and then, when people are ready to return to 'normal' life again, they are discharged back into the community. A vital purpose of rehabilitation is to teach people how to live independently with a SCI so that

they can achieve optimum quality of life in the community. When returning to the community a *fundamental* issue for all people with SCI, *and* their family, is housing.

### The study

Housing needs when returning to the community radically change for an individual with SCI and their family. For example, for a person with SCI to access their home a ramp to the front door is often needed. Inside the home, bedrooms often need adapting. Bathrooms most frequently need adapting to fit wheelchairs. Walls also may require strengthening to install grab-bars or a hoist.

The importance of the home for people with SCI and their family is made very clear in numerous policy documents and conventions. For example, HM Government Office for Disability Issues (2012) states that:

Disabled people (including older disabled people) will have greater access to *housing*...and to participation in *family* and community life. (italics added; <http://odi.dwp.gov.uk/>)

In addition, the United Nations Convention on the Rights of Disabled People emphasises the vital role of housing for disabled people and their family through several articles.

UN Rights for Disabled people include:

- Article 9: Accessibility
- Article 19: Living independently and being included in the community.
- Article 23: Respect for the home and the family.
- Article 28: Adequate standard of living and social protection.

As evidenced above, having appropriate housing is of major importance for people with SCI and their families.

Despite this, there is great variety in the types of accommodation people live in once back into the community. One type is the *care home*.

Upon leaving rehabilitation, one out of five people with SCI live in a care home. Previous research identified that the impact on the health and wellbeing of people with SCI who live in this type of housing (average length of 3 years) is

huge. People become depressed, quality of life is significantly reduced, physical health is put at risk, relationships with friends and family break down, and thoughts of suicide are fostered. It was concluded that people with SCI should not be housed in a care home.

The alternative accommodation mainly available for people with SCI and their family are *unadapted* houses and *adapted* houses. However, we know very little about the impact of being in either one of these types of accommodation on people's health and wellbeing. Without empirical evidence it cannot be assumed the housing needs of people with SCI and the family are met.

Empirical evidence is therefore urgently needed to ensure that housing policy meets the needs of this group of people.

The purpose of this independent research was to examine people's experiences of living in adapted housing and unadapted housing. The objectives of were to:

1. Understand the *impact* and *implications* of living in an adapted or unadapted house on the health and wellbeing of spinal cord injured

adults and their families.

2. *Compare* the experiences of those who live in adapted houses with those in unadapted housing, and identify any differing *effects* on quality of life and wellbeing for spinal cord injured adults and their families.
3. Identify the *implications* for housing policy and a *hierarchy of best practice* for meeting the housing needs of spinal cord injured adults and their families.

## 2. Methodology

To meet the research objectives, a qualitative methodology was the most appropriate to use.

Whereas questionnaires or surveys restrict what can be said about a topic, qualitative methods provide the opportunity for the people that matter – people with SCI – to share what they themselves, as the experts, think is important for people to know in order to make positive changes. This methodology fits with the social model of disability.

Qualitative methods have numerous benefits that align with the social model of disability. Rather than providing superficial accounts of lives or reducing people's lives to a number, they provide rich accounts of experiences. Instead of imposing and limiting answers on people, qualitative methods enable people to express – in their own words and on their own terms – their thoughts and opinions about a certain topic.

### *Data collection:*

Data for this investigation was collected via semi-structured interviews conducted with the following participants:

- Adults with SCI living in an adapted home (n = 17). Number of people co-habiting/married (n=11). Average time in home was 1.6 years. Most of the adapted homes were Aspire properties – that is, the accommodation was not their permanent home but a temporary measure whilst a permanent solution was found to people's housing needs.

- Adults with SCI living in an unadapted home (n = 17).  
Number of people co-habiting/married (n=10).  
Average time in home was 1.7 years.
- Family members of adults with SCI living in an adapted home (n = 4). Average time in home was 1.3 years.
- Family members of adults with SCI living in an unadapted home (n = 4). Average time in home was 1.8 years.

Interviews were conducted face-to-face and lasted on average 90 minutes. An interview *guide* (see Appendix) was used flexibly throughout to encourage open-ended responses and rich descriptions of participants' experiences. The research was approved by Loughborough University Research Ethics Committee. Informed consent was obtained prior to each participant's involvement in the research.

### ***Data analysis:***

A thematic analysis (Braun & Clarke, 2006) was employed in order to identify various key factors affecting the health

and wellbeing of spinal injured adults. Thematic analysis is a process of organising and describing the data collected by identifying, interpreting and reporting patterns (themes) within the data. There are six steps to a thematic analysis which include 1) transcribing the verbal data and re-reading it for content familiarity; 2) generating initial codes or meanings by highlighting relevant segments of data; 3) searching for and identifying themes or patterns within the data; 4) reviewing the themes by considering how they fit with the data extracts; 5) defining the themes by identifying the 'essence' of what each theme is about, and; 6) writing the report. In the report, quotes from the interview transcripts are provided to illustrate each of the themes and to allow the participants to 'speak for themselves.'

### ***Validity and generalisability:***

With a total sample of 40 people, is the research valid? Yes. Are the findings generalisable? Again, yes.

Using Tracy's (2010) extensive review of what constitutes "excellent qualitative work" (p. 837), the study

used several criteria to assess the validity of results. These included: the social significance of the topic; rich rigor (e.g. weaving together appropriate concepts); a transparent audit trail (e.g. an independent researcher scrutinised sampling strategies, the data collection process, and the analysis); and credibility through member checking (e.g. participants were given their respective transcripts and later a preliminary report to test if the analysis was fair and accurate).

It is sometimes assumed that quantitative research is 'better' than qualitative research because the former is representative and the latter does not produce generalisable results. This is a misunderstanding of science because:

- 1) It falsely assumes that quantitative research produces truly representative results. Rarely does this kind of work do this because it would need to include thousands of people to take into account different ages, ethnic groups, sexual orientation, gender, religions, classes, types of impairment and so on.
- 2) It falsely assumes qualitative research cannot be generalised. The

results and stories generated through this kind of research often resonate with the wider population being studied, that is in this case, people with SCI and their families. Rather than a weakness, the strength of qualitative research lies then in that it speaks to many people who have been in the same situation.

The generalisability of the research was tested using the concept of naturalistic generalisation (Stake, 1995). This tests if the research resonates or fits with other people's understanding of a certain event, context, or experience. When it does, this means that research can be transferred across the population (e.g. to other spinal cord injured people) and topic (e.g. housing needs) being studied.

## 3 Findings

### 3.1 Housing needs

The results of the research revealed that, for all the people with SCI and their families, a main priority upon leaving rehabilitation was to ensure that they had appropriate housing in terms of meeting their new physical needs. It was also important that the transition from rehabilitation into an appropriate house

was swift.

There are a million and one things to think about when you're close to leaving rehab. A really, really big one, not just for me but my family too, was our house. Could we all live in it together? Would it be our family home again? Could I even get into it? What about the bathroom, the toilet? Where would I sleep? Which rooms could I get into? Would I be able to sit in the garden again? Would I be left alone in one room? Would I be a burden to my family? You just can't ignore your housing situation then. It's on your, and your family's mind a lot. It's so important to living well, to being happy, to having a family again. And the longer the time it takes to move into a good house the worse it is for you and your family. It's very simple, or should be. First and foremost I needed, like all people with an injury like this, a house quickly that met my needs, like a home that I can move in, wash in, sleep, cook, maybe work from, and be with family in. Not a house that isn't adapted and which I'm a prisoner in, but an adapted house that meets my needs and which I call a home. Having the right home has a massive impact on your life and it can't be underestimated. It can be the difference between living in hell or

being happy. (Carl: SCI)

My husband is a tough guy and I think as a family we can cope with most things. But of course the injury left us all in a mess, wondering how life would be. Then you think about all the practical matters. And top is housing. I recall coming home one night after visiting my husband. I just burst into tears when I walked through our front door. I couldn't stop sobbing as I walked through the house. I just had no idea how we would survive, how my husband would live in it. It was our home, our home with so many memories, and that's really when it hit me. Something needed to be done fast if as a family we were going to get through this, and my husband would have the best chance of a good life again. (Kathy: Family/Wife)

The results revealed that adapted housing was far superior to unadapted housing when it came to meeting people's physical needs. On the one hand, housing needs were met for those who moved into an *adapted* home. On the other hand, the needs of those who lived in an *unadapted* home were not met. It was also revealed that the two different types of housing had a significant impact on the health and wellbeing of both people with a SCI and

the family.

### 3.2 The impact of being in an adapted or unadapted house on health and wellbeing

Five main themes were identified that capture the diverse impact of being in an adapted or unadapted home on health and wellbeing:

- 1) Quality of life;
- 2) Physical health;
- 3) Psychological wellbeing;
- 4) Damage to relationships;
- 5) Fighting a battle against local authorities.

For ease of reference, each theme is presented separately. However, it should be noted that themes frequently overlap or influence others. For example, when living in an unadapted home, people's psychological wellbeing deteriorated further due to feeling like a burden and a lack of personal dignity.

### Quality of Life

Quality of life (QoL) refers to “an individual's overall perception of and satisfaction with how things are in their life” (Wood-Dauphinee et al. 2002). QoL is vital to having a fulfilling and enriching life (Smith et al. 2012). There was a stark contrast between the ways in which adults with SCI and family members living in adapted homes and unadapted homes appraised the quality of their lives.

People felt that living in an adapted house contributed significantly to having a good QoL.

There are basic things you need as a person with a spinal injury to ensure a basic existence as a human and a decent or good quality of life. At the top of the list is an adapted house. Without it, I'd have no quality of life.  
(Ian: SCI)

While an adapted home was fundamental to promoting QoL, living in an unadapted house resulted in a poor QoL.

It's [living in an unadapted house] had a big impact on my life. Well, it's meant no quality of life. It has taken over my life whereas I want to take



back control of my life. I want to live like a human being, not live in a house that takes away all quality of life and leaves me like living in a prison. (Lyle: SCI)

An over overarching reason why an adapted house resulted in the promotion of good QoL, whilst an unadapted house engendered poor QoL for all, was due to how much independence, physical movement, opportunities, and dignity each type of house could offer people. With regard to adapted homes:

An adapted house has made me independent. I wouldn't have had the opportunity to learn the skills I've learnt, and to be employable, rather than be seen as a drain. You can't jump in the deep end. You have to take things step by step and when everything around you is adapted it makes it all possible....My lifestyle is quite busy so in an unadapted house I don't think I'd have been able to live the sort of life I'm living at the moment. If you live in an unadapted house you don't know how you're gonna get up stairs, have a shower, go to the toilet. Here everything is a lot quicker and it takes me an hour to get

sorted then I can get on with my day. I'm 2 years into my injury but things are moving on quite quickly, especially with sport. I think the reason for that is that I've had the opportunity to get on with things that need to be done and not side tracked because you haven't got anywhere to live.... I think I've got a good quality of life because of the house. It's a taken a long while to get back to things and it's been a long process but yeah I think it's a good quality. It all comes back to independence for me and I know some people don't have that option. As I got stronger, for me it was an option that I could be independent because of the house and I think that has a lot to do with quality of life. (Harvey: SCI)

This house allows me to have a life. I can't go and jog around the block but I've still got my own space, my own front door, my own decisions. This gives me as much chance of a normal life as I possibly can...The bowel care is the most important, the dignity side of it. This place has given me a chance to get my dignity back. It's given me the chance to invite you round for a chat or just get back into life really... This place has allowed me

to live for me. It's allowed me a life that hopefully I'll be happy with. To be able to live a full a life as I can. I think what else can you ask for?

(Colin: SCI)

As a result of being in an adapted house we can go out together, we've been to the pub, we have lunch, and just the normal stuff couples do. We've been able to do all of that normal stuff. It shouldn't even be called "normal" stuff, it's just day-to-day life without any difficulties when in a house like this. Being here has had a huge difference because he's [partner] not in hospital, unadapted home or a care home. It's not stressful at all. There's no day-to-day traumas; he can get on with it, I can get on with it, and it's just homely. It's not a burden, it just feels normal.

(Jess: Family/Partner)

Our quality of life as a family has improved 100% since being in this house that's adapted...It was no life living in house that wasn't adapted. We can be a family again, my husband can be independent. (Pam: Family/Wife)

The evidence shows that adapted

housing enables SCI adults to maintain their independence by providing them with all the adaptations necessary to take care of themselves, to be able to move freely around the home, to pursue leisure and employment opportunities, and to maintain personal dignity. In enabling all this, adapted housing provided people with the resources to develop a good QoL. It also helped people with SCI feel that they were 'not a burden' and, equally, the wife/husband/partner to feel that they did not have to be responsible for everything in the house.

In contrast, unadapted housing severely prevented people from having a good QoL. This was largely because this type of housing, without adaptations, restricted independent living, leisure and employment opportunities, and where people could move. Unadapted housing also took away personal dignity and compromised personal hygiene that was crucial to having any QoL. SCI adults became reliant on others – notably the family - to assist them with daily personal bodily needs, including going to the toilet and washing.

If I had to pin point one thing that's affecting me it's loss of independence as a result of living in this house. I've

always been a very independent person. But because of the problems with the house I can't go anywhere without someone having to help me out and get me into the house again...Having the adaptations would mean I wouldn't have to camp out downstairs, I wouldn't have to have a commode or a hospital bed downstairs and be embarrassed about that. And when the standing frame arrived I just cried. I hate having it in my living room. It looks like a medieval torture device. It upset me so much to have something so ugly and it's a constant reminder of disability in my living room. I just want to make my house feel less like a hospital ward and more like my home again. (Marsha: SCI)

I've been trying to work out a plan of action for getting back into work. But I have to plan everything so much around my showering and personal hygiene it's just not possible at the moment. Living here puts me at a disadvantage in terms of getting back to work...When you really think about it, this is madness or just plain backward in thinking. If I had a house I could be independent and get work, seriously make a go of it. It's what I

want. Isn't it what the government wants, for people to work? If it is then they need to look at housing much better. (Teresa: SCI)

I need to be able to do things myself. I want to do things but I can't. Like having to ask my brother to put me on the toilet – that's embarrassing. It's no life living here, no dignity....I hate the thought of being confined to just these 3 rooms. (Don: SCI)

My flat used to be nice but now it's turned into a prison because it's not adapted. I feel really trapped. It's just a horrible feeling. (Alec: SCI)

At the Spinal Centre they have an adapted bungalow you can go to for a weekend to see how you'll cope on your own. It's brilliant but only if that's what you're going home to. And I think that's where it goes wrong. The worst thing is it's showing you something that you can have and you haven't got any of that; you're going home to reality. It needs to be adapted quicker. We have a ramp to get him [husband] in the door, that's it. They [local authorities] don't care about anything else. If there's a fire he can't even get out by himself! At

the moment we're surviving and that's all. We're not living, we're not enjoying life at all....I couldn't even rate my quality of life because it would go off any scale. I'm not too sure how much longer we can all live like this. (Jane: Family/Wife)

It's a rarity if I sit down from when I get up in the morning because I've got my son as well. We've got no care. We get no help. We're still waiting to hear about the adaptations - it would take pressure off me. We haven't got a life. I have to do everything whereas before we used to share things; cooking, cleaning, shopping, caring, taxi service, teacher, nurse, everything. If we had everything adapted Joe would be independent. (Sarah: Family/Wife)

As data above shows, whilst an adapted house supports QoL, when living in an unadapted house QoL is low. This latter type of housing, in the terms of the social model, results in people being socially oppressed. For example, possibilities to have a hobby, work, move around the house, become independent, and feel affirmative about SCI rather than a burden is severely restricted. In this regard, it is *not* SCI

that causes a low QoL. Rather, the problem lies with houses that are unadapted.

### Physical wellbeing

In addition to impacting on QoL, the type of house people lived in had a profound affect on the physical health of all.

Living in an adapted property supported SCI adults' continuing rehabilitation, allowing them to utilise and build on the physical skills necessary for good physical health. For example, bowel care, wheelchair propulsion techniques, being able to safely transfer from a wheelchair, and managing skin care so as to avoid pressure ulcers (skills all learnt in rehabilitation) could all be practiced, refined, and mastered when in an adapted house. As such, the many hours of learning how to take care of a changed body, and the vast economic cost that goes into ensuring this in rehabilitation, can be successfully transferred to the community setting.

The flat itself has been a good place to learn to be disabled. It's a well-adapted place which means I don't have any major problems getting around so it's allowed me to get used

to that lifestyle kind of thing...It's allowed me to perfect all the things I learnt in rehab, and because out here things are very different than in rehab, I had to hone what I'd learnt to take care of my body and health. Having an adapted place ensures you can do this, rather than waste all you've learnt in rehab, and probably end up back in there with a pressure sore, a bladder infection, or after a bad fall. (Lester: SCI)

In addition, because of living in an adapted house, opportunities to be physically active increased.

This is quite a spacious adapted bungalow, and can have equipment and stuff like standing frames and [exercise] bike. If it was a tiny little unadapted house I don't think I could have those and you do need those things for your rehab. (Harvey: SCI)

By contrast to adapted housing, when living in an unadapted house the physical skills learnt in rehabilitation were often very difficult to either safely or regularly practice. As a result, physical health became a concern, problems arose, and skills lost. All of which not only negatively impacts on

the health of the person with SCI and the family, but also the NHS budget.

When I was in rehab I learned to do a lot of things. As soon as I came out of there we go backwards instead of forwards. We go backwards because I get stuck basically...This is down to living here [unadapted house]. It means I'm losing what I learnt, my health is suffering, and I'm worried I'll end back in hospital. I don't want that and am doing all I can to avoid it. But the house puts a limit on how much you can do. (Hugo: SCI)

My life is completely different because of being in here, and I don't feel like anybody else. Not now. And my health is going down in here. For instance, I can't shower here so it's like me saying to you 'for a whole year you're not going to have a shower at home. You've got to go to the swimming baths and have a shower there.' Try to imagine that...Being in here is making my health worse and worse. (Teresa: SCI)

Because of the house I live in [unadapted house] I've lost all my muscle mass that I built up in rehab. I've just got nothing and I'm so weak.

I've lost it all. My health is going downhill, physically and mentally.  
(Vicky: SCI)

### Psychological wellbeing

Psychological wellbeing refers to a state of fulfilment and positive engagement with life (Keyes et al. 2002). It means a state of positive psychological health and happiness that enables one to live a fully functioning and personally meaningful life. Psychological wellbeing is not a single 'thing'; it is comprised of many components that often interact to produce a positive, meaningful, and happy life.

Living in an adapted house was associated with many components that comprise positive psychological wellbeing. For many people, this kind of house acted as a buffer against stress and worry. Because people had independence and autonomy in this type of housing, could take care of their physical health, felt they had a future worth living for, and could sustain and develop relationships, they were in a strong position to do activities that made them happy and boosted self-esteem. In addition, an adapted house opened up opportunities for people to

counter loneliness. None of this is to claim that this type of house *in and of itself* guaranteed positive psychological wellbeing for people with SCI and the family. However, an adapted house *did* create the conditions and an environment necessary for psychological wellbeing to be developed, maintained, and flourish over time.

People often think that having a spinal injury means that you're miserable and depressed all the time. That isn't the case. I'm generally a happy person and, in some ways, feel a more developed, better person since my injury. I'm absolutely certain that I would not be like this if I hadn't managed to get an adapted place. This place gives me the chance to be happy and to make something of myself, my life. (Carl: SCI)

Having everything adapted here...,it just makes life so much easier really. You probably end up doing more stuff like cooking than you would otherwise because it would be more than a struggle. I find it really positive being here. It takes the pressure off.  
(Sian: SCI)

The main point is that I don't need to worry about access, showering, going to bed, being stuck in the house. I can put all that aside and put that time into doing stuff I need to do; look for a job, playing rugby, getting out and about. (Robert: SCI)

They say that home is where the heart is. For me and my husband it's true. This is because the house is perfect for a disabled family. It has all the right things now and I tell you, it's not just given us our lives back. It's helped us put a smile back on our faces. Don't get me wrong; life isn't easy for us. It isn't easy for my husband or me sometimes. But we are happy, our hearts are more than content, they're smiling. Living here has played a big part in this. (Pam: Family/Wife)

In comparison to living in an adapted house, being in unadapted housing was extremely detrimental to the psychological wellbeing of all. The combined influence of unmet housing needs took a heavy toll on many components of psychological wellbeing. The numerous damaging psychological consequences that went with living in an unadapted house were:

- Despair and depression;
- Loss of motivation and a purpose;
- Feelings of worthlessness;
- Loneliness;
- Stress and worry
- Thoughts of suicide

For example, for many adults with SCI in unadapted housing, the misery of being kept waiting in unsuitable living conditions led to feelings of despair, anger, and struggles with depression:

It's depression. I don't want to see anyone, I don't want to talk to anyone. When people call I just give her [wife] the phone and tell her to tell them I'm sleeping....It's depressing living in here, like this, in a house that doesn't meet my basic needs. I'm, I'm at rock bottom, and feel so low, so very low. (Hugo: SCI)

The unadapted place was hard because there were carpets down, no widened doors, I could only access the kitchen, couldn't access upstairs. I was losing my temper more, I wasn't happy. (Boris: SCI)

Closely linked to depression was the eventual loss of motivation and a purpose in/for life. This dual damage to wellbeing was generated by the

perceived futility of people's struggles to live in unadapted housing.

Sometimes I don't want to get up. I just don't have the energy or the feeling of wanting to get up. That's how bad it's got. The carers come in to help me, and I just think 'why bother? Just leave me alone. I'm rotting away in here. (Don: SCI)

You need a purpose in life and now we haven't got anything because we live here. (Joe: SCI)

SCI adults' wellbeing was also often damaged by feelings of worthlessness. Without a means of contributing meaningfully to family life or work because their house lacked the adaptations necessary to become independent, feelings of worthlessness assaulted self-esteem. One person began to cry during an interview in which she spoke of feeling worthless to her family:

I feel worthless. I used to be part of a family unit. I'm not part of that unit anymore. I used to be able to contribute to daily life as a family. I can't do that anymore. I'm worthless. (Teresa: SCI)

Intense loneliness, as a result of living in an unadapted house and feeling

'trapped' in it, further damaged physical and mental wellbeing. The impact of loneliness in and on people's lives cannot be underestimated. In support of past research that focused on ageing and disability (Windle, et al. 2011), loneliness was an insidious, creeping, and penetrating attack on wellbeing that eventually leaves people more isolated and depressed.

Everything just gets taken away when you get home after leaving rehab and the loneliness is unbelievable, unbearable. Sometimes I just sit and cry. It's very, very lonely. I was watching a lady on the telly the other day and she said 'loneliness is a killer' and she's absolutely right. Unless you're put in this position you just don't understand what it feels like....Now basically I just sit here. I can get to the back door but that's as far as I go. Can't get anywhere without Ben [husband]. So that's it... Then I sit here in front of the telly. Sometimes I manage to get the plug in the socket and do some Hoovering, sometimes I don't. And then I just sit here unless anybody else calls. I just sit until Ben comes in. It's pure loneliness and it's horrible. If I sit here and I think about it too much



that's when I start panicking. That hour and a half between when Ben goes to work and the carers come in for an hour is awful; things that go through my mind is awful and I try not to think about it. And that's my day. Just sit, alone. Horrible, really horrible. I might have the excitement of changing my colostomy bag, and that is it. Loneliness is a horrible feeling. It slowly eats you up, and leaves with this deep feeling of sadness. (Vicky: SCI)

I get so bored staying at home. All day I'm at home watching a movie or surfing on the internet. That's all. That's all I can do now....I'm lonely day after day, and it's the worst feeling that takes you down even further. (Mo: SCI)

It is often a very lonely experience for my husband and me as well. Because he needs me because this damn house isn't fit for him, us, we are both often prisoners in it. And it's difficult, maybe not nice for people to visit because as you can see it's not comfortable and who really wants to pop around for a cup of tea and sit in a lounge with a commode in it, with

your husband's bed in it, and all this equipment, and smells I'm used to now. No one. Would you? (Pam: Family/Wife)

Along with depression, loss of motivation and a purpose, feelings of worthlessness and loneliness, the worry and stress of living in an unadapted house further damaged psychological wellbeing. Early on, living in an unadapted house, people with SCI worried about their future. As time progressed deep anxiety set in. This led to people avoiding contemplation about their future, giving up on hopes and dreams, spiralling further into deep loneliness and depression.

I was a positive person and was hopeful I'd get by and be a success after my injury. Now, now, because of living here, that's all gone. I can't plan, think about the future, be hopeful. Work is ruled out, it's often too difficult to meet old friends. And so I really worry now, wake up in the night worrying, stressed and can't sleep. (Colin: SCI)

One day at a time, just one day at a time is all I can think about. Because I'm so anxious and really tearful I just

can't go above one day at a time.  
(Vicky: SCI)

My life's on hold that's one of the main things. I can't start investigating my capabilities and limitations until I can get my independence, get a house that meets my needs. (Marsha: SCI)

Like all the other psychological consequences of living in an unadapted home highlighted above, worry and stress also extended to the families of SCI adults. Family members expressed constant feelings of worry about their SCI family member. The impact of worrying that began within an unadapted house eventually spread into every domain of their life, including work.

I can't concentrate on my job. I worry about getting home – I'm worried about Vicky because I know that she can't cope with the loneliness and not having anything to do. (Ben: Family: Husband)

Furthermore, as a result of what people described as, "shouldering the burden of caretaking duties" and the, "responsibility for all household chores and the running of family life", families of SCI adults quickly became exhausted

and stressed, which further damaged their own wellbeing:

I'm having to do everything and I'm totally exhausted all of the time. It's very stressful, and drags you down...I'm exhausted and can hardly function. (Jane: Family/Wife)

The damage to psychological wellbeing as a result of being in an unadapted home eventually led to over 30% of the people seriously contemplating ending their own lives.

There are days when I'm just in a black hole. I've had suicidal thoughts but where would that get me? It won't help my family. If they weren't here I'd probably end it. (Teresa: SCI)

I've had suicidal feelings...Living in an unadapted house does that to you.  
(Marsha: SCI)

I'm not sure where I can go and can't see a future for me when living here. So I think more and more, why not just end it all. Why not. My existence in these 4 walls is miserable, lonely, horrible. So why not. Living here is no better than living in a prison, but I've done nothing wrong, but I'm punished anyway, and I've contributed so much money through

my taxes so I've been a good citizen. It's an injustice. I could be again, contribute to society, I sometimes think, but not whilst in here. But I seem to be stuck in here, no one will do anything, so, so I sit here during the day or night seriously thinking, why not just end it, why not. (Dan: SCI)

The research results showed the severely damaging impact of living in an unadapted house upon the psychological wellbeing of people with SCI and the family. This was further supported by the experiences of those who had moved from an unadapted to an adapted house.

Don't get me wrong, I've had the thoughts in my head a few times that I've wanted to top myself. The thought has been there before when I lived in a house that wasn't adapted. But now I've moved here, because of this, I feel like I am moving forward, I am progressing, I am getting better. My mentality is a lot better now than what it was in the old house. My moods have been a lot better, I'm not snapping, not losing my temper. I'm happier, better quality of life. I'm absolutely loving this place. I'm enjoying my life as much as I can, and

I can get out and about...The old place was killing me and now because of moving in here I have a future.

(Boris: SCI)

### Damage to family relationships

It was evident that an adapted home not only had a positive impact on the lives of people with SCI but also their family. In addition to the themes already raised, an adapted house provided people with the chance to live as a family, care for each other, and be happy together.

The most important thing is that I'm with Jeff and it's adapted. We can have our family stay and our friends stay. It's homely to us. It's easy, there's no difficulty about anything in an adapted place....Here, we've been given the best chance to be happy together, and we are.

(Jess: Family/Wife)

In comparison, for those that lived in unadapted housing relationships with partners were put at severe risk. For example, along with the stress and exhaustion felt by family members of SCI adults living in unadapted homes, relationships were damaged by the separation created through inhabiting separate spaces and separate bedrooms.

We're not living together. We have separate lives, they come together sometimes but they're much more separate than they used to be. It's like we're in limbo. It's a huge impact. You can't have the same relationship. I look at it as if it's on hold. (Louise: Family/Wife)

It's a massive, negative impact on the family because my family shouldn't have to be disadvantaged by me being in the middle of their normal living environment. (Teresa: SCI)

Spinal injury didn't just happen to me; my family were also affected, in a major way. One of my biggest worries now is trying to keep my family together, trying to have a positive future together. I'm worried though, really stressed out, and don't know what to do, I really don't. Being in this house, with no adaptations, just living in one room, day and night, it is horrible, absolutely horrible for all of us. It's a miserable existence. I can see, feel my family being torn apart because of our housing situation. I don't know how much longer we can survive. I just hope we get a new property soon, really soon, before it's too late for us all. (Mike: SCI)

I sometimes dream what it would be like to live in a different house full of adaptations. We wouldn't just have a better quality of life. Our marriage would be stronger, or without stress, strain and being on top of each other... Being in a house that's not adapted for my husband impacts on us all, and it's put a huge strain on our relationship. It's no good for us in here, for our marriage. We need to get out if we are going to be happy. I don't want the world. I really just want the small things. I want to hold my husband in bed and to not worry about him when I leave him. These aren't big things in most people's relationships, but they are so big for us, and for me in particular. I really want our marriage to be a happy one. (Pam: Family/Wife)

Accordingly, while adapted housing took pressure off family members and allowed satisfactory relationships to continue, unadapted housing caused problems with interpersonal relationships and impacted upon the family members of SCI adults (see also below; impact and implications).

## Fighting a battle against local housing authorities

One theme, “fighting a battle”, was unique to people with SCI and their families living in unadapted homes. The participants described having to “battle” and “fight” with the local authorities to get the adaptations they needed. This was described as a constant battle to get those in positions of power to take notice and to act on their situation. The “battles”, however, were long. After each ‘unsuccessful battle’ more damage to people’s health and wellbeing was done. That is to say, the long process with local councils that people went through to seek a move from an unadapted house to an adapted one harmed them.

Mentally we’re quite strong people – and they’ve brought us down quite low, but they haven’t broke us yet – we’ve still got that little bit of fight left. But it does bring you right down – you actually lose the will to fight, and then you end up struggling. Why does this happen. Do people want to make us struggle? Our life isn’t great, it’s not. A house, with adaptions, is all we ask. That would give us the start we need and we could move forward.  
(Jane: Family/Wife)

I’ve been working since I was 15 years old, full time work all my life to give me a better quality of life. I always paid my taxes, insurance, everything into this bleeding country that I needed to pay and I’ve got nothing. It gets me down – really down and I get frustrated and angry. There’s not a lot you can do really; just hitting your head against the brick wall, one long battle that makes you heart-broken, exhausted, more sad. (Sally: SCI)

At the moment I think if I have to describe myself in one word it would be a ‘battler’ because that’s what my life has turned into; a battle in many directions. The process started as soon I came out of hospital and it’s a year and 3 months on and I’m only still at the application stage. The thing is it’s very tiring battling, it’s really exhausting. I feel really frustrated and a bit defeated by it. It’s making me more depressed. Why put me through this? Are people who work in housing trying to make my life more miserable? If they could only see how I live each day, a miserable, lonely, horrible existence, if you’d even call it an existence.  
(Marsha: SCI)

## 4. Conclusions

Living in an adapted house had a positive impact on the health and wellbeing of people with SCI and the family. It created the conditions and an environment for people to have a good quality life, to manage their physical health well, to be happy, and to sustain meaningful relationships.

In contrast, for those who lived in an unadapted house, health and wellbeing was negatively impacted on and, over time, deteriorated substantially. People with SCI and the family suffer when living in this type of home. It results in a significant reduction in quality of life. The physical health of people with a SCI is put at risk or damaged. Being in an unadapted home also damages people's psychological health, and how they recover from a traumatic injury. It results in chronic depression, loneliness, stress, feelings of worthlessness, and can lead to people to thinking about ending their own life.

Unadapted properties are not viable places to house people with SCI and their families. Rather than helping people with SCI, and their families, they actually damage all their lives, leaving people suffering in the short and long-

term. Thus, if people with SCI and their families are to live meaningful, independent, happy, and economically self-sufficient lives after rehabilitation, they should not be placed in an unadapted property for any period of time. The short-term and long-term damage done to their health and wellbeing as a result of being in this kind of home means that this environment is highly unsuitable. Placing a person in an unadapted home for any length of time is not an acceptable solution to their housing needs.

When combined with previous research that examined spinal cord injured adults' health and wellbeing whilst living in a care home, the research provides an evidence-based hierarchy of best types of accommodation for SCI people and the family. At the top, and most superior for promoting health and wellbeing, are adapted homes. Much lower down in the hierarchy, and highly inadequate for supporting people, are unadapted homes. At the very bottom of a hierarchy of accommodation, and which should be avoided at all cost, are care homes.

Adapted homes are best for people with SCI and the family. Unless it is a personal choice, placing people with SCI and their families in unadapted properties or care homes is a national scandal. This research, and past research, shows that disabled people are living in accommodation that not only does not meet their needs, but also impacts negatively on their health and wellbeing. Without change, this will continue. It will mean people spending years depressed and unhappy living in a room or two of their house, stuck downstairs completely unable to access their bedrooms, or even their children's rooms. It means having to wash at the kitchen sink every day because the bathroom isn't wheelchair friendly. It means people thinking about ending their life or actually attempting suicide. It means people needing an ambulance to come and help them when ill, and an expensive visit to a hospital. It means people ending up stuck in hospital for months on end when their physical health cannot be maintained at home – and costing the NHS tens of thousands of pounds. This is supported by a recent report on meeting the housing needs of disabled people by Habinteg Housing Association (2013). The report highlighted the significant financial cost

of failing to meet the housing needs of disabled people, to both the NHS and to local authorities. In support also of adapted housing, it was stated:

Authorities are aware that well-designed accessible housing and adaptations support independence and prevent or reduce the need for more costly services (p. 30).

To avoid not just large costs to the NHS and to local authorities but most importantly, damaging further the health and wellbeing of people with SCI and the family, more accessible housing, both in the private and social sectors, is needed. Also urgently needed is a speedier process to allow people with SCI and their families to obtain grants to adapt properties. Care needs to be designed and available so that it allows people to live independently in an adapted home. Failure to provide more accessible housing, speed up the grant process, and design care plans that do care for people with SCI will mean that their health and wellbeing will continue to be damaged. Any public housing policy that means people go into an unadapted property or care home will cause suffering and limit people's chances to work, be active, be independent, live a meaningful life, and

enjoy being part of a cherished family.

Any belief that unadapted or care homes are a viable housing solution for people with SCI and family, or any public policy position that results in this group of people living in one, means that the HM Government Office for Disability Issues Independent Living Strategy is highly unlikely to be achieved. This strategy stresses that disabled people, including those with SCI, need greater access to housing, employment, leisure and transport opportunities and to participation in family and community life. By placing people in unadapted homes, housing policy and the UK government is failing to implement the United Nations Convention on the Rights of Disabled People. This includes accessibility rights, housing rights, and family rights.

To meet these basic human rights, and to promote health and wellbeing among people with SCI and the family, all disabled people should have the choice of living in adapted housing. They should have access to independent and appropriate personal housing within the community upon leaving rehabilitation. The longer people do not have this housing the more their health and

wellbeing is damaged. Also the longer people remain in an unadapted house or care home the higher the financial costs will be for local authorities and health policy over time. It is not just the right thing to have more adapted and disabled friendly housing; it is also the smart thing.

## 5. Recommendations

The main evidence-based recommendations from this study are as follows:

- People with SCI and their families are often faced with lengthy waits to obtain council grants and/or permission to adapt their home. During these extended waiting periods, they suffer. Their lives are also placed on hold. Speedier processes are urgently needed to enable people with a SCI to obtain grants and have adaptations approved. The longer the process to obtain grants to adapt properties, the more damage is done to people's health and wellbeing. In order to prevent unnecessary suffering and the infringement of human rights, spinal cord injured people also need to be seen and respected as a person, not as simply an individual service



recipient in this process.

- If it is not structurally possible to make adaptations that would allow a spinal cord injured person and their family to live comfortably and safely in their own previous home (i.e., the home they lived in prior to their injury), they should be discharged from rehabilitation into an adapted property that meets their housing needs and supports their right to independent living. This should ideally be located close to the individual's previous home, or in a location of their own choosing. This will enable a more successful transition from rehabilitation into the community as a newly disabled person. It will also support long-term care.
- Disability friendly social housing that *truly* meets people's needs to be identified regularly by housing associations and local authorities. These associations and authorities need to work together to create and maintain an up-to-date accessible housing register so people can be offered, or themselves find truly accessible social housing more easily.
- More accessible and adapted housing is urgently needed in both the private and social sectors. This is the most viable and cost-effective solution for meeting the housing needs of people with SCI and their families and ensures that their human rights to health, rehabilitation, adequate living standards, and independent living are protected and maintained.
- To accomplish the need for more accessible homes, housing rule reforms are also urgently needed. All political parties need to commit to this. Current housing rules - including section 106 of the Town and Country Planning Act (1990), the Community Infrastructure Levy (CIL), the New Homes Bonus, and the Housing Bill (Wales) - need to increase the supply in and quality of homes nationwide that meet the needs of people with SCI and the family (see also *The Hidden Housing Crisis*, 2014).
- All new homes need to be built to Lifetime Homes Standards. At least 10% of new large developments need to be built to full wheelchair accessibility standards. This will not only be highly beneficial for disabled

people. Building more accessible homes will also benefit the increasing ageing population, as they can have similar housing needs to disabled people. Accessible and adapted housing will be an investment that will significantly help the current and future UK population.

- The damage done to the lives of spinal cord injured people as a result of being in a care home cannot continue. Action and policy change is urgently needed. The priority of these changes should be focused on providing more accessible housing so that people with SCI can lead, with their family, fulfilling and independent lives.

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## Appendix - Interview Guide

### ‘Grand tour questions’

Can you tell me something about your life?

What does the notion of home mean to you?

### Home life pre injury

Can you tell me about your life before your injury?

Probe: quality of life, well-being, identity

Can you tell me about where you lived?

Probe: who, quality of life, well-being, belonging

Can you tell me about your home life?

How did you feel about living in your house?

Probe: how important was it and, if so why / if not why not

### Life post injury (rehabilitation)

Can you tell me about your life in rehabilitation?

In rehabilitation, did you think about your future?

If so, probe for what they thought about, including housing, and if plans had  
been put in place to envisage that future

If not, why not?

What do you think could have been improved in rehabilitation?

Probe: information about transfer and housing

With what you now know now, what advice would you give to someone in rehabilitation in terms to thinking about housing?

### **Life post injury (home)**

Can you tell me about your life in your home?

What impact does being in your house have on your life?

Probe: family, friends, employment

How does being in your house make you feel?

What is the impact of being in your house on everyday family life?

What is the impact of being in your house on your quality of life?

What is the impact of being in your house on your well-being and happiness?

Do you have hopes about your future?

Probe: If yes, probe for what. If no, why not?

### **Closing**

Is there anything else that you would like to tell me about your housing experiences?

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